PEDIATRIC AIDS HEARING

HEARING

BEFORE THE

SELECT COMMITTEE ON NARCOTICS ABUSE AND CONTROL HOUSE OF REPRESENTATIVES

ONE HUNDREDTH CONGRESS

FIRST SESSION

JULY 27, 1987

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(100th Congress)

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SELECT COMMITTEE ON NARCOTICS ABUSE AND CONTROL PEDIATRIC AIDS HEARING

MONDAY, JULY 27, 1987

HOUSE OF REPRESENTATIVES,
Washington, DC.

The Select Committee met pursuant to call at 9:40 a.m., at Harlem Hospital, 135th Street and Lenox Avenue, New York, NY.

Present: Charles B. Rangel (presiding), Representatives Benjamin A. Gilman, Edolphus Towns, Bill Green, Ted Weiss; Senator Alfonse D'Amato.

Staff present: Elliott A. Brown, minority staff director; George Gilbert, counsel; Barbara Stolz, professional staff; and Robert Weiner, press secretary.

Mr. RANGEL. I want to thank Harlem Hospital for the reception it has given to this member and to this Committee, to allow us to hold hearings on this very sensitive subject.

We have with us the ranking minority member of the Select Narcotics Committee, Benjamin Gilman. From Brooklyn we have Congressman Ed Towns. From Manhattan, though not a member of the Committee, very supportive of all the work we do, no matter where we go, Bill Green. And, of course, one of the outstanding leaders that we have in the U.S. Senate, Senator Al D'Amato.

One might question why a Select Narcotics Committee would be coming to Harlem Hospital to deal with the problem of children, especially boarder children, but the reason for it is that the spread, the epidemic of narcotics has caused a crises in our nation and, indeed, in the world, and there is no end to how much agony and pain that can be caused, especially when you see a child that you try to hold in your arms that no one wants to have, a child that has been born of addicted parents, a child that is unwanted.

If we are going to see where our nation is going, where our world is going, I think it all starts by looking at where our children are going. I was moved in the pediatric ward of Harlem Hospital, as a father, as a politician, and as an elected official. It seems to me that whether we go to our prison system to see the spread of homosexuality and the spread of AIDS that are there—things that people don't like to talk about either in the churches or in the synagogues—it seems to me that if we go in our schools and see the number of kids that are being forced to drop out of school because of their habits, it seems to me that wherever we go where there is a crisis, that we find that who's being killed are our youngsters in criminal activity or in fights that they're having; that all of this is related to the spread of drugs.

So, as we look for the year 2000, let's see how many people are not going to be around for the year 2000, even the children that are being born today may not be around. We have an obligation as those who perhaps want to leave some type of a legacy, as parents, as Americans, as members of Congress, as members of this Committee. It is tragic that we have to be involved in AIDS, but it is something that we cannot avoid. Perhaps we can see what the federal government should be doing and see whether people like Mother Hale cannot only be inspired, but that perhaps we can get other people to realize that these are not just Mother Hale's children, these are our children and that they should not have to be warehoused in a hospital, as caring as the hospital is.

I call, at this time, on my colleague, Benjamin Gilman.

[The prepared statement of Congressman Rangel appears on p. 80.]

OPENING STATEMENT OF HON. BENJAMIN GILMAN, U.S. CONGRESS

Mr. GILMAN. Thank you, Mr. Chairman.

I want to commend you, Mr. Chairman, for bringing us to Harlem Hospital to conduct this very important hearing, one that has an impact not only on the metropolitan area, but across the nation, and we look forward to our distinguished panelists who will be testifying over the course of the morning.

Over the past decade our Committee has taken testimony from a host of individuals, individuals who have first-hand knowledge of the tragedy of drug abuse. Yet today's hearing at Harlem Hospital is going to focus on the innocent children, children who have become known as AIDS' babies and for whom early death is a certainty, a real tragedy that we must try to find a resolution for. Most of these tiny babies contracted the AIDS virus while still in their Mother's womb. Their Mother's abuse illicit drugs intravenously or themselves were infected with the virus by a sexual act. Giving birth should evoke joy, instead for a growing number, the joy soon turns to anguish.

The problem of abandoned babies and need for specialized social services, targeted prevention efforts, and a myriad of other considerations are what we hope for from our distinguished witnesses who are going to be addressing us this morning.

I am particularly pleased that our Surgeon General, Dr. C. Everett Koop, has been able to take time to be with us this morning. His dedication to the public's health and his many years of commitment to our nation's children cannot be questioned. Dr. Koop has approached the serious problem of AIDS head on and I am certain will be of great assistance to this Committee in responding to this most recent crisis.

I am pleased too that the President has recently appointed a distinguished panel to work on the AIDS problem and we look forward to an early report from that panel, and I know Dr. Koop will be monitoring the work of that panel very assiduously.

Our former colleague in Congress, Mayor Ed Koch, is also welcomed this morning. He has never swayed from discussing any serious issues and has always provided our Committee with the benefit

of unique expertise and perspective. As New York City confronts special problems, it also manages to devise special solutions, pragmatic solutions.

The problem of pediatric AIDS requires a special approach since it is expected that the number of pediatric AIDS cases will rise. I have heard statistics of as much as five to ten percent of the births in the hospitals today in the metropolitan area have some positive sign of AIDS. Congress has responded with additional funding for research this year, but many more, unfortunately, are going to die before a cure or any effective treatment is found. We are going, therefore, to have to comprehensively assess the way the many applications of pediatric AIDS in the HIV virus affects our population. Ultimately, the AIDS virus affects all of us since it affects a non-abusing, heterosexual population through sexual contact with abusers of intravenous drugs or with their partners.

When our Committee first addressed the issue of AIDS and drug abuse, we realized that this nation was being confronted with an epidemic of monumental proportions that knows no socio-economic status, race or religious origin. Yet the problem of pediatric AIDS is one primarily affecting black and Hispanic women. A chilling statistic, but one that is most telling, is that the HIV virus is now the leading cause of death for women in New York City between the ages of 25 and 34. And of the 199 pediatric AIDS cases reported in New York City since 1979, fully 73 percent of those have already passed away. We are going to have to reach out to these women and to their children. And our response must be coordinated and it must be comprehensive, and I hope our witnesses this morning are going to provide us with some of the answers to the many crucial questions surrounding this highly complex and deadly issue. We look forward to a candid assessment from each of them.

Thank you, Mr. Chairman.

[The prepared statement of Congressman Gilman appears on p. 87.]

Mr. RANGEL. Thank you for your sensitive statement.

Congressman Towns of Brooklyn.

OPENING STATEMENT OF HON. ED TOWNS, U.S. CONGRESS

Mr. TOWNS. Thank you very much, Mr. Chairman.

Mr. Chairman, I am delighted to join you and the other members of the Select Committee at this most timely hearing to discuss the phenomenon of pediatric AIDS.

Mr. Chairman, as I was studying the briefing materials regarding this issue, I couldn't help but be struck by the seriousness of the situation. I must tell you, I was simply overwhelmed. One hundred and nineteen AIDS cases reported since January of this year. Five hundred and twenty-seven cases overall. The tragedy of this situation is that 80 percent of these babies are the children of IV drug users. These babies are the real victims of our war on drugs. These children, as well as the countless numbers of men and women whose use of IV drugs make them susceptible to AIDS, should serve as constant reminders of the mounting urgency of our fight against drugs.

For too long, too many of us have thought of AIDS as a disease that only affects male homosexuals. But it's not. It affects women. It affects children. How long are we going to wait before we take this disease seriously? We've seen it take one of our colleagues from us; it has taken the lives of unending numbers of men and women; not it is taking our future, our children.

We've got to get our heads out of the sand, and wake up and smell the coffee. We've got to get serious. We've got to commit all of the resources at our disposal—time, money, expertise, everything we have—to fighting this war on AIDS and the connected war on drugs.

Mr. Chairman, I certainly want to thank you for leading the way and insuring that these issues don't get pushed to the back burner. But rather that they stay in the forefront of our minds and our activities.

I would like to close at this time because I am anxiously awaiting the testimony of the witnesses. Thank you very much.

Mr. RANGEL. Thank you, Mr. Towns.

Congressman Green.

OPENING STATEMENT OF HON. WILLIAM GREEN, U.S. CONGRESS

Mr. GREEN. Thank you, Mr. Chairman. Dr. Koop, I want to join my colleagues in welcoming you here today. We appreciate the leadership you have shown on the issue of AIDS and we look forward to your remarks.

Up to now it appears that most of the education we have been giving the public on AIDS has been oriented towards the sexual transmission of the disease. And even though you, Dr. Koop, have repeatedly stated your opposition to premarital and extramarital sex, nevertheless you have felt that it was important, as a physician and as our leader on public health issues, to educate the public about condoms. And so we have ads about condoms running on our TV and in the papers and in all our media. But in New York City drug abuse is rapidly overtaking sexual activity as the major transmitter of AIDS, and I think your statement and the other things we are going to hear this morning will make it very clear that a major part of the problem of children with AIDS is essentially that the mother was an addict or had sexual intercourse with an addict. I wonder why we are not giving the same emphasis to teaching people how to sterilize the needles that are used by intravenous drug abusers?

I have here a bottle, it is a sample of what is used by a group in San Francisco. And they distribute this bottle filled with a household bleach. It is technically sodium hypochlorite, five-and-a-quarter percent, but it is household bleach; you can buy it anywhere in a store. And on that bottle are very specific instructions as to how to fill your syringe with the household bleach, to flush it twice, then to flush the needle twice with water. There are very explicit instructions about not drinking the bleach and about not injecting yourself with the bleach. And I am told that in San Fransisco this program is enormously successful in making clear to addicts how, before they pass along the needle, they can sterilize it with a readily available, easy to buy, cheap disinfectant.

So I guess my question this morning is, if we can do the advertising about condoms, even though we may dislike the conduct of those for whom we are recommending their use, why, even though we don't want people to be intravenous drug users, why can't we do the same type of effective campaign to them? If condoms, why not disinfecting needles?

Mr. RANGEL. Thank you, Congressman Green. I hope that at the appropriate time you might share that information you have with this Committee and we will be glad to look into it and perhaps would be able to join with you in your statement.

Senator D'Amato certainly has been in the front of fighting this war on drugs, and it has taken us to different countries, to our own borders, to our communities and certainly to Central Harlem where he is no new friend to the problems that have faced the boarder children and especially to Mother Hale, and I am glad that you were able to take the time out of your Washington schedule to share time with us this morning.

OPENING STATEMENT OF HON. ALFONSE D'AMATO, U.S. SENATE

Senator D'AMATO. Congressman Rangel, let me thank you, number one, for inviting me—more importantly for having this hearing—and our Surgeon General who has been second to none in attempting to galvanize legislative initiatives and other initiatives that are so desperately needed.

I think, number one, that I would ask that my full statement be included in the record as if read in its entirety so that we can save the Committee time and hear from our Surgeon General. But let me commend Surgeon General Koop.

Second, I think we had better wake up to the fact that the drug epidemic is not on the wane, it is increasing. Our commitment to the drug war is almost frivolous in terms of the severity and the impact. When we stop to think of the four to 500,000 heavy drug abusers in the New York Metropolitan area, when we think of the 200,000 heroin addicts, with as many of 90 percent of them carrying the AIDS antibodies, no wonder why we have 30 percent now of the AIDS transmission plus that is taking place as a result of those in the heterosexual community who are drug abusers. No wonder why we see and will begin hearing about the tragic incidences of babies who are born, not only as drug addicts, but with the dual affliction of drug addicts carrying the AIDS virus as well.

We say we are fighting the war. We have thousands and thousands who are waiting for slots in drug-free treatment centers, and we do little in terms of our educational efforts, and we do tragically little as it relates to rehabilitation. Maybe it is going to take some of the shocking testimony, and I hope they lay it right out and let the people know, and if it is somewhat frightening, let it be. Wake up as to just what is taking place. And the tragic impact on our health facilities and in health care. We are going to have hospitals that treat no one but AIDS cases because they either don't have any other facilities or because people just will be afraid to go to those hospitals. What are we doing to prepare ourselves as it relates to alternative methods of care and the billions upon billions

of dollars that are going to come down on our cities and on our states and the federal government?

This is certainly an area, Congressman, that maybe people are afraid to move into, but I commend you, Congressman Rangel for beginning to focus on this tragic situation and the connection between AIDS and its spread as it relates to intravenous drug us.

So, again, thank you for calling this hearing and I look forward to the testimony of our Surgeon General.

[The prepared statement of Senator D'Amato appears on p. 90.]

Mr. RANGEL. Thank you, Senator, and without objection your statement will be entered in its entirety in the record. And I would like at this time, if there is no objection, to enter the statement of Senator Moynihan into the record, where he indicates that a conflict has prevented him from joining with us, but outlines the comprehensive legislation bill which he has introduced and to let us know that he joins with us in this fight.

[The prepared statement of Senator Moynihan appears on p. 94.]

Mr. RANGEL. This time it is a great honor to be on record in introducing, for the purpose of accepting testimony, a truly great hero, a fearless hero, and someone who has done it with the respect of our Congress and respect for the constitution. As Senator D'Amato has pointed out, these are very serious waters and troubled waters that we are walking, and the fear that AIDS has brought to the minds of people to such an extent that parents, mothers, can walk away from their children, that people are fearful of coming into hospitals or into wards where these children are, I think perhaps shows, as the Senator has said, that in the area of drug abuse our great nation has really not faced up to the problem. It is because of you and the courage that you have had, that have allowed unknown people, ignorant people, to join in the fight against those things that allow Americans to kill themselves, whether it is tobacco or whether it is AIDS. And we hope that you know that the Congress doesn't want to stand behind you, we want to stand beside you as you point out what can truly improve our national security, and that is that we fight the right things, not necessarily with bombs and guns, but certainly with education and weapons that would allow people not to be born as victims of this terrible disease.

So, indirectly, we know that we list you in our war against drugs and that "Just Say No" applies to many other activities to preserve our health. And I can tell you that I speak on behalf of the Congress, and more specifically the members of this Committee, that you make us proud to be in government and I want to thank you for adjusting your calendar so many times to meet that of our legislative calendar so that once again we can be here.

Thank you, Dr. Koop, we are anxiously awaiting your testimony. If there is no objection from the Committee it will be entered in its entirety into the record, and you proceed as you feel most comfortable.

[Applause.]

TESTIMONY OF C. EVERETT KOOP, M.D., SC.D., SURGEON GENERAL, U.S. PUBLIC HEALTH SERVICE, AND DEPUTY ASSISTANT SECRETARY FOR HEALTH, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Dr. KOOP. Thank you, Mr. Chairman.

Mr. RANGEL. The Chair waited until the appropriate time to say that applause will not be taken at these hearings.

Dr. KOOP. Thank you for those kind words, Mr. Chairman.

Members of the Committee and I guess I should say Fellow Brooklynites, I am C. Everett Koop, Medical Doctor, the Surgeon General of the United States Public Health Service, and I am pleased to be able to be appear today to discuss with you the serious and extremely complex problem of AIDS in children. This is a problem that is all the more devastating because it affects the most defenseless of us and because its cause, its impact, and its solutions lie not only in our health system, but also in our fundamental social and moral underpinnings.

In the few minutes available I will mention some of the highlights from the 13-page comprehensive summary of Pediatric AIDS provided for the record.

AIDS in children was first described in 1982. Just over 500 cases in children under the age of 13 have been reported; that is 1.4 percent of AIDS patients are children. Two to three times that number of children have been diagnosed with human immunodeficiency virus infection but do not meet the current definition of AIDS by the Centers for Disease Control.

The majority of children acquired the virus in the perinatal period and were born to mothers who either have been intravenous drug users themselves or are the sexual partners of men who are intravenous drug users. Eighty-one percent of the cases I have mentioned have been reported since 1985. A small number acquired AIDS through blood transfusions or through treatment of hemophilia before blood and blood products were safe.

Just over 2,000 cases of AIDS have been reported in women, 95 percent of whom are of child-bearing age. We expect over 20,000 cases in women of child-bearing age by the end of 1991. In 73 percent of the perinatally acquired cases, the mothers are either intravenous drug abusers or the sex partners of those who use IV drugs. Fourteen percent of the children were born to women from Haiti and Central Africa where heterosexual transmission of AIDS is the major mode of transmission. Seventy percent of the children I have mentioned with perinatally acquired AIDS are from New York, New Jersey, and Florida, reflecting once again IV drug use. The proportion of children from other states has increased over time, from 24 percent in 1982–84 to 34 percent in 1985–86.

Cities with large populations of intravenous drug abusers can expect increases in the number of perinatally acquired AIDS cases. With the majority of these cases are linked to IV drug abusers, 88 percent of these children are black or of Hispanic ethnicity. The prevalence of AIDS in black and Hispanic children is 15 and 9 times that in white, non-Hispanic children.

Over 85 percent of the children I have talked about were diagnosed in the first three years of life. Half were diagnosed by the

age of nine months. Over 60 percent of the children have died. Half of them died within 11 months following their diagnosis.

There have been two hospital-based studies here in New York City of all women who gave birth in the hospital. Over a several month period, two percent of the women were infected in one hospital, and 3.5 percent in the other. If these results are extrapolated even to the New York City Metropolitan area, this forecasts a staggering number of pediatric AIDS cases in the future.

Transmission of the virus can occur during pregnancy in several ways: through passage of the virus through the placenta; during labor and delivery, through exposure to maternal blood and vaginal secretions; or after birth, through breast feeding. This latter route is probably quite rare in the United States. IV drug abusers have not been using breast feeding as the method of taking care of their youngsters.

Studies have not enabled us to predict which mothers are likely to pass the virus to their infants. Studies in different places show that between 30 and 80 percent of mothers do indeed pass the virus on. Many infectious diseases are, as you know, more severe in pregnant women, but in one ongoing prospective study, none of the women progressed in their stage of HIV disease during pregnancy.

Now, our ultimate goal is the prevention of perinatal infection. This requires prevention of infection among women first, and then prevention of pregnancy among HIV-infected women. We must reach out aggressively to the following groups of women: both IV drug abusers who are in treatment and those who should be not in treatment; partners of IV drug users; and prostitutes. One-third of the prostitutes are also IV drug users. Special attention must be paid to teenage prostitutes; in a recent survey, 52 percent of a sample of teenage prostitutes thought they were at little or no risk for developing AIDS.

Several major challenges face us. First, many women, due to lack of disclosure by their partners, do not know that they are at risk and are, thus, a hidden and difficult to reach population. Second, the majority of women with AIDS come from ethnic minority groups. The greatest challenge is that knowledge about AIDS transmission and risk may have little impact on behavior. The behavior changes required to prevent heterosexual and in-utero transmission require disruption of sexual relationships and, in some cases, decisions not to have children.

One's ability to utilize health education information and to make changes in one's behavior largely depends on socioeconomic status, educational level, sense of power and control, and vocation. The women we need to reach, unfortunately, have low socioeconomic status, a low educational level, and a sense of powerlessness and helplessness and are either unemployed or work as prostitutes.

In conclusion, Mr. Chairman, this epidemic is bound up within the broader social problems of poverty and ignorance. These problems are manifested in IV drug abuse, promiscuity, and poor self-image. The consequences of drug abusing parents, parental bi-sexuality, and low socioeconomic status are visited upon the children. Many will not survive until school age.

In the Surgeon General's report of October 1986, I called upon communities to set up task forces to anticipate every phase of com-

munity life and the social fabric to be affected by the AIDS epidemic. Many sections of the nation have not yet encountered the problem of pediatric AIDS. In these States, governmental and professional leaders in medicine, public health, education, and human services must begin immediately to plan for what they are going to do when their cities do have a number of HIV-infected children. I will facilitate this process where possible by providing consultation through our well-established network of State, territorial, and municipal health offices as soon as possible.

In this brief time, sir, I have tried to give you a sense of the problem and some beginning steps. I certainly do not have all the answers. We are talking about major behavioral changes for individuals and for society. The enemies are the old enemies, fear and ignorance, poverty, racism, death and suffering. AIDS has certainly raised the stakes. The battle must be enjoined at a higher level of commitment and concern.

I will be pleased to answer your questions, sir.

[The prepared statement of Dr. Koop appears on p. 96.]

Mr. RANGEL. Surgeon General, thank you for your testimony. We certainly go into this phase of the battle feeling a lot more secure, knowing that you are with us.

This Committee has primarily concerned itself with the area of drug control education, prevention, treatment, rehabilitation, production, and interdiction. This tragic problem has taken us into areas that we would rather not be in, and it is almost tragic that the Chairman of the Committees yield to us in allowing us to get involved in this area because they would rather not be in it. And so we are in the school educational systems, we are in our clinics and in our hospitals. We are involved with the armed forces, with sports figures, with entertainers, with our court system, with our prison systems, which certainly have not been given the attention that it deserves as we warehouse people and turn them out in worse condition than when they went in. And now we find that we are involved in this AIDS epidemic as we are seeing it being spread between intravenous drug abusers.

Certainly we appreciate the recommendations that you have given nationally and to this Committee today, but as it relates to IV drug abuse, is it possible that your office could find time to lend itself to be involved in establishing a national policy that would allow us to get our heroes overtly and covertly to be involved in this war on drugs so that you would be satisfied that even if you were ignorant and poor, that your country had prevented this poison from coming in the United States in the first place. Do you feel comfortable as a partner in government, in knowing that on our foreign policy we have a mission to destroy the fields and to prevent the production, and that we as partners in government will be protecting our borders against this coming in. As a doctor, as a humanitarian, do these types of issues find its way on your agenda as you educate and try to prevent the spread of this disease.

Dr. KOOP. I think you know, sir, that my life-long professional occupation has been with children. I was involved in this for 40 years before joining the government as Surgeon General. My commitment to children went beyond that, and primarily to handicapped

children; certainly the children we are talking about today are handicapped.

In addition to that, since being Surgeon General I have certainly done all that I can to lend the voice of moral persuasion that goes with my office to my colleagues at the Alcohol, Drug Abuse, and Mental Health Administration, in promoting the kinds of messages that our young people need in reference to drug abuse. But, as you have so eloquently stated, this is not just a problem of drugs on the street. We are dealing with the importation of drugs by illegal means. It is associated with crime. It is into prisons, where it cannot be controlled. But the problem that I see, sir, that is most difficult in a city like New York, is the difficulty of reaching the people we want to reach with a message. Because many times drug abusers are not as alert to the things that are being said to them as other people are. Many of them are functionally illiterate, and the Centers for Disease Control, which has the lead in AIDS educational programs, is even as I speak trying to find ways innovatively and creatively to reach the target population we are talking about. For some it might have to be in the form of comic books. In other cases, we may need to find places where the audience is captive and they can see progressively educational films on AIDS. But basic to this whole problem is that if we do not turn drug abuse around, we are not going to turn around the spread of AIDS in the black and Hispanic populations, and we certainly are going to look forward to increasing numbers of children being born to these people.

I think we should also say at this juncture that if you could stop it tomorrow, there are still so many people in the pipeline that this AIDS problem is going to go right on through the end of this century, with increasing disease, disability, and death and all the social implications that we are all well aware of. So it is a monumental problem that needs everyone's attention.

The office of the Surgeon General, Mr. Chairman, is not set to do this sort of thing. But I am available to any of the agencies in the Public Health Service, to lend the role of the Surgeon General, the authority that goes with the office, and the moral suasion that I am able to bring to this particular problem.

Mr. RANGEL. Well, you have already given us the moral support, Surgeon General, and I am trying to get a different type of support. Let me reframe the question.

Our government has no problem in reaching the poor and the ignorant during times of national emergency and recruiting them into service to fight the wars, to educate them and to be prepared to do what is necessary, especially in terms of ground combat. But yet, in getting the message out, this member is yet to hear any statement coming from the Secretary of State publicly where it makes the internationally trafficking of drugs as serious a threat to our national security as terrorism and communism. Do you believe that the threat of international drug trafficking, as it relates to Americans, is a threat to our national security?

Dr. KOOP. I don't know that I know enough about all of the innuendos in that statement, sir, to give an answer. I certainly know what drug abuse does to individuals. What it does to aggregates of individuals is a scourge on our country; and the government has, in

the various aspects where I relate with different divisions, mounted major efforts to interdict the smuggling of drugs. The Coast Guard, as you know, has changed its function from purely search and rescue missions to interdicting drug traffickers. I know a little bit about that because one of my responsibilities is to provide the health care for the Coast Guard and I know that they have indeed changed their mission. And I think that some changes have been made, but certainly not enough.

Whether it threatens our national security, I don't know, but it certainly threatens our national health.

Mr. RANGEL. Well, President Reagan has indicated that he thought it was a national security question, but you cannot refresh my recollection of any statement you have heard from the Secretary of State.

Let me say this: I know that a part of health care is prevention. And you have just said a great part of that is education. We've had the Secretary of Education before this Committee many times. We have not identified any national educational program that concerns itself with the prevention of drugs, with the exception of that that has been created by the First Lady. As the Surgeon General of the United States, could you identify in the Department of Education any program that we have that might reach the ignorant and the poor as it relates to drug prevention?

Dr. KOOP. There are demonstration projects trying to come to some common denominator that might be used both in education and in the Public Health Service. The National Institute on Drug Abuse, for example, will soon begin funding a 3-year project that we talked about this morning, which will specifically target, among other groups, the female sex partners of IV drug abusers and prostitutes. This work is being done in several cities and it will make use of community institutions and resources and design strategies to find these high-risk women and to reach them with the message about how they have to change their lives. And I think this is a major step forward because we have not had that level of contact with the people involved. If we can provide some guidance from our experience in these three cities to use elsewhere, we will have accomplished a lot.

The National Institute on Drug Abuse [NIDA] will be funding community-based outreach demonstration projects designed to reach three high-risk groups—intravenous drug abusers, sexual partners of drug abusers, and prostitutes who are intravenous drug abusers or are sexual partners of drug abusers. Comprehensive programs specifically focused on intravenous drug abusers not in treatment are planned for implementation in five large cities with the highest prevalence of intravenous drug abuse and AIDS. In addition, smaller highly targeted projects will be implemented in 15 cities and communities that have been identified as "hot spots" of intravenous drug abuse and AIDS although their incidence of AIDS is still relatively low. Through these programs, a combination of outreach methods proven to be effective will be used to reach high-risk women and communicate AIDS information including how they must change their behaviors. NIDA will be testing outreach strategies that utilize indigenous workers and community institu-

tions such as emergency rooms, health care agencies, drug abuse treatment programs, and the criminal justice system.

Unfortunately, it takes a long time to implement and evaluate a project like that and come up with recommendations and time is very essential for the needs we have.

Mr. RANGEL. I think you are suggesting that we are just getting started in some projects that could identify the connection between AIDS and IV drug abuse, but certainly for the last two or three decades, our communities have been hit with IV heroin drug abuse and the estimate that we have from 500,000 to 750,000 IV drug abusers, and I am certain that you would agree that each one of these people are potential AIDS distributors. That being the case, with the exception of three projects that are targeting IV drug abusers who are women who are sexually active, could you direct this Committee's attention to any national program that concerns itself with educating and causing our children and our adults to know the dangers of drugs, which certainly would include the dangers of IV drug abuse?

Dr. KOOP. I don't know the intricacies of all of them, but I do know that all of the agencies of the Public Health Service, and particularly the National Institute of Drug Abuse [NIDA], do have and have had programs about drug abuse throughout all of the communities in all the regions where we operate. It is not a part of my particular assignment in government to monitor those things, so that I can't give you specific and exact information about them, sir.

Mr. RANGEL. Well, Mr. Surgeon General, as you fight with us against this epidemic that is creeping around the world, we tell you that there is no national educational program. And we know that we will be able to count on your support. That if we are going to stop the AIDS epidemic, we have to do something to control the drug abuse use and you would have to agree that if we can't get a handle on it abroad, that we owe it to our country and our children to at least have an educational system which makes information available to their children, their teachers and their parents as to the dangers of AIDS and the dangers of drug abuse.

I am afraid that this administration believes that the major responsibility for this type of thing should be with local and state governments, but your presence here reaffirms my faith that this is more than just a national problem. This is an international problem and it concerns taking the type of steps that would protect us against this intrusion against our health and our security. And so we will be sending information to your office, Dr. Koop, so that you will know that we need your help in making certain that this administration provides the information that would be necessary so that meetings like this and hearings like this would not be necessary.

As I said before, you are one of our heroes, with or without medals and we are going to be depending on your to fight the rest of this battle.

Mr. Gilman.

Mr. GILMAN. Thank you, Mr. Chairman, and Surgeon General Koop, we certainly welcome your thoughts on this very critical issue.

Do you see some need for a mandatory program, something that the Congress should be adopting to mandate, for example, mandatory testing of pregnant women?

Dr. KOOP. I think that we do still have a problem, sir, with the stigma that goes with this diagnosis, but certainly the great majority of women who are reporting to prenatal clinics in this country are now being tested.

Mr. GILMAN. That is all on a voluntary basis?

Dr. KOOP. It is on a voluntary basis, but the response is pretty near a hundred percent.

Mr. GILMAN. And you do not see any need for imposing any mandate?

Dr. KOOP. I think to impose a mandate, sir, would put a tremendous burden on our monitoring system, would be very expensive, would not improve the results very much, and might indeed keep certain people away from the very prenatal care that they need.

Mr. GILMAN. What about the testing of babies? I understand that some of the pediatric centers are reluctant to test because they don't know what they are going to have to be confronted with after they find positive signs.

Dr. KOOP. You know, I had a workshop in Philadelphia in April on pediatric AIDS and we will be providing all of you with the published book that resulted from that by the end of this month. And certainly one of the things that was included in the recommendations made to me was that all newborns in areas where high-risk behavior is common, and it might be expected that there is a significant level of HIV positivity in the community, be tested.

Pediatric AIDS, as you know, is a little peculiar. The disease does not manifest itself in babies the way it does in adults and we are just now shifting gears to get the pediatric diagnosis on a more sensible level. I think you will see some changes in the way pediatric patients are managed very shortly.

Mr. GILMAN. Well, then, are you recommending testing of pediatric patients?

Dr. KOOP. I would certainly recommend the testing of pediatric patients who are born in areas where there is a significant level of HIV positivity.

Mr. GILMAN. And how should the hospital be responding to a positive test of pediatric cases?

Dr. KOOP. Then they need to trace back to the women.

I think most of the problems are picked up before the babies are born because transmission is either *in utero* or through the birth canal and very seldom through postnatal contacts.

Mr. GILMAN. I think what I am trying to focus on is how does the hospital, the pediatric section of the hospital respond to taking care of that pediatric baby? Do they then become boarder babies? What do we do about that problem?

Dr. KOOP. That is not usually the decision made by the hospital. Babies who are born HIV positive may be babies who indeed are infected with the virus and are HIV positive for, that reason or they may be babies who merely carry their mother's antibodies and do not have the disease itself. Time will sort this out or you, can do tests for the virus itself, which is time consuming and expensive.

The babies who are true AIDS babies do have serious problems that require acute and chronic medical care. As I have testified, an unfortunately large number of them succumb in the first year of life. The difficulty that has been alluded to by several of you is that because many of the parents of these youngsters are already drug addicts, the babies are abandoned. And one of the things that the workshop in Philadelphia called for, and which Dr. Hale has done so well here in New York, is to provide community cradles, if you will, to care for these youngsters who have been abandoned, because the myths and misinformation about AIDS rampant in the community make it very difficult to put these babies in the ordinary types of foster homes.

Mr. GILMAN. Do we have a program to help finance things such as the cradle program, the Hale cradle program, that you are talking about?

Dr. KOOP. That is one of the things that I would be very hopeful, sir, would come out of the President's Commission—a recommendation that this is necessary.

Mr. GILMAN. Is there a need for a revision of the Medicaid system? Because it is my understanding that Medicaid presently does not take into account the severe economic impact on the hospitals with regard to treatment of AIDS pediatric patients.

Dr. KOOP. I think that that is largely true, sir, and I am doing all that I can from where I sit to move in direction of relief for that situation.

Mr. GILMAN. Then there is some need for Congressional attention in that area; is that correct?

Dr. KOOP. If there are not changes in the manner in which the program functions at present, yes, sir.

Mr. GILMAN. I think, according to Dr. Margaret Heagarty, the Chief of Pediatrics here at Harlem, the cost can run as much as $800 per day, and perhaps $60,000 per year per patient?

Dr. KOOP. That is correct.

Mr. GILMAN. An enormous burden for any hospital to try to absorb. It is my understanding that there's are least five or six AIDS pediatric patients in their pediatric unit currently. That's a standard patient enrollment for the past year or two.

Dr. KOOP. Yes, sir, I understand that.

Mr. GILMAN. I would hope that your office would make some recommendations to the Congress with regard to this. We certainly would be willing to help.

I hope you have had an opportunity to look at the measure that Mr. Rangel referred to that some of us in our Committee had introduced—it is a $200 million measure—to amend the Public Health Service Act to provide for a comprehensive program of education, information and risk reduction, also training, prevention, treatment care and research concerning the acquired immune deficiency syndrome. And we certainly would welcome, if you have an opportunity, any thoughts you might have with regard to this proposal.

Dr. KOOP. I will do that, sir. And every member of Congress will get a copy of the report on that Surgeon General's Workshop and will be able to see the recommendations that were made to me and which I endorsed.

Mr. GILMAN. Do you take part in the Blue Ribbon Commission established by the President?

Dr. KOOP. No, sir, I do not.

Mr. GILMAN. Will you be sitting in on it? Will you be monitoring it? Will you be assisting them?

Dr. KOOP. I will certainly be monitoring it. I don't know whether they will be asking me to provide testimony or not, sir.

Mr. GILMAN. Well, I would hope so, and we hope that you would prod them into quick action.

Dr. KOOP. Thank you.

Mr. GILMAN. Thank you, General.

Mr. RANGEL. Congressman Towns.

Mr. TOWNS. Thank you very much, Mr. Chairman.

Mr. Surgeon General, you mentioned three demonstration projects. Could you tell me what cities they are located in?

Dr. KOOP. No, I don't know where they are, sir, but I think they are in high-risk areas and I think New York is one of them.

Mr. TOWNS. Could you expound on the kinds of things the demonstration projects are doing?

Dr. KOOP. No, I can't, because I don't know the details. These are projects that are funded or will be funded by the National Institute on Drug Abuse. Once the awards are made information about them can be obtained from NIDA. I don't have it, sir.

Mr. TOWNS. Let me ask you this, sir: In the demonstration projects, would you know whether or not they are doing any studies surrounding the use of disposable syringes?

Dr. KOOP. No, I do not know that, but I might be able to add a word about that and tell you some of the information that I have picked up.

We have never done a study in this country about disposable needles, but some of our Western European allies have done this. I represent you, as you may know, every year, as the chief delegate to the World Health Assembly and have the opportunity to talk to ministers of health from countries that have done short-term projects on the use of needles.

The concerns were two: Will the use of free needles provide opportunity for people not involved in IV drugs to use them? Secondly, will having clean needles cut down on the transmission of AIDS? And the answer seems to be no to both of those questions. They had no evidence—this is anecdotal, not statistically significant—that the provision of clean needles increased the abuse of IV drugs, but unfortunately neither did it seem to do anything about the transmission of AIDS.

I think one of the problems that people are not aware of is some of the cultish practices that go with IV drugs. Even when clean needles and syringes are available, IV drug abusers tell me that they prefer to share needles with a companion. They enjoy knowing that one or two drops of A's blood is mingled with B's blood. You and I may not understand that. I have to confess that I don't. But it is part of the cult that goes with this type of drug abuse. So that I am not sure that providing free clean needles is going to do anything.

The use of bleach was spoken about this morning, I have watched that in action in San Fransisco, and I think one of the

most important parts about is that the bleach is being given out by ex-drug addicts walking around the communities, who are counseling about where you are going on the down-hill path of drug abuse. This is probably more important in that effort than the bleach itself.

Mr. TOWNS. Well, can't we employ the same tactic with disposable syringes? Can't we have ex-drug addicts walking around distributing them? I think that any kind of demonstration project has to explore different kinds of options. In as much as the virus can be transferred from one person to another through IV drug use, the use of disposable syringes might help reduce the incidence of transmission. I just find it very strange that this has not been tried even in a pilot kind of way.

Dr. KOOP. You can understand why it hasn't been tried because there are so many people who are afraid that it will increase the problem of drug abuse and that you would be defeating your purpose. The little information I have given you from Europe would tend to contradict that. But I think you have to take into account that even when such things are available, there are those addicts who do not take advantage of them.

Mr. TOWNS. I think that we would have difficulty saying that until we actually tried on a pilot basis. So maybe that is something we need to begin to think about. I am hoping that this demonstration project would include some kind of information along those lines as well. I am not saying we should do it on a massive basis because we don't know enough about it. But I think that once we have something as serious as this, I think we should try a lot of things at the same time.

The other question I would like to raise with you: Mr. James Butler, President of Local 420 (Hospital Workers Union), is going to testify later on today. In your opinion are these workers at special risk?

Dr. KOOP. I think that health workers obviously would be at special risk, but the great majority of health workers are not at any terrible risk if they follow the guidelines that have been promulgated by the Centers for Disease Control.

Now I would separate from hospital workers two other categories: those who work in emergency rooms, and those who work in operating rooms. In emergency rooms I think people have to be especially careful because there is not time to do testing on patients and you have to, therefore, assume that any patient that you deal with who is bleeding profusely, or where you have to get involved with his blood, is positive. You should, therefore, take precautions not to become contaminated with that blood. The times we are particularly concerned about blood would be when you are touching it with your bare hands, particularly if you have cuts on your fingers or chapped hands, or when there is long-term contact with blood. It would be possible, for example, for an emergency room worker to be leaning over a patient who was profusely bleeding, as I have done many times, and to get the whole front of his suit saturated with blood. There are now operating room gowns that are impervious to blood, and I think those should be worn in any situation where there is that type of contamination.

When you get to the operating room, there are several things that are going on across the country now that are public health problems and about which I am concerned. One is that doctors are refusing to operate on patients. Secondly, nurses are saying, "I'd rather work in another part of the hospital," and there is a tension in the operating room that is making it difficult for people to work. Actually, across the country, only one and one-half people in a thousand are serpositive, but operating room personnel are acting as though they all are positive and the tension runs high. Therefore, today, the Centers for Disease Control is meeting in Atlanta with public health officials and others to update existing guidelines and discuss the testing of surgical patients in hospitals; those three problems that I have told you about will be addressed by that group.

Dr. HALE. Thank you very much, Mr. Chairman.

Mr. RANGEL. Mr. Green.

Mr. GREEN. Thank you, Mr. Chairman.

Surgeon General Koop, I have been in public life now for a quarter of a century and during most of that time the drug situation has been a very serious problem. I started as a legislative counsel in the State Legislature in 1961, and I was elected to the legislature in the 1964 election. I can remember in the early 1960's the Methadone Maintenance Program was developed and everyone had high hopes that that was the way to solve our problem. And then when, although it proved useful it didn't prove to be a total answer, here in New York State we had Governor Rockefeller's first "War on Drugs", which consisted of mandatory in-patient treatment of addicts. That didn't work. We had the second Rockefeller "War on Drugs", which consisted of mandatory prison sentences for those distributing drugs. That obviously didn't end the plague either. As I have looked over the years at the statistics on treatment centers, if you really look at them with a hard look, what percentage of those who walk in the door initially seeking help ultimately walk out and stay cured? We are evidently stuck with intravenous drug users who are probably going to stay intravenous drug users, at least until they get older and perhaps they age out or die out of the situation. And I guess that is why I have gotten concerned about the whole question of bleach or whatever it is to disinfect the needles.

You are certainly right, from everything I understand, that there is the culture of sharing needles among drug users, and the question is if you can't end that, can you impact on it in some way so that they at least flush the needles between use with some sort of antiseptic? I am glad that you have taken a look at the San Fransisco experience, and is that a possible model, with all the counseling by former addicts, that we should be introducing here in New York?

Dr. KOOP. I know that everything you have said is true, and I know that it is very discouraging. I guess that part of what you are saying is a statement on the human condition. But we have to take that as a given, unfortunately, and I am in favor of doing anything that can be done to stop the spread of AIDS. Right now, it seems that in places such as this city, the best place to put your attention is on drug abuse.

What I think we need, and I don't know all the answers, is to find newer ways of reaching people that we have not yet tried. Whether this is a reachable population, I don't know. As I talk to drug addicts, when they are coming up or going down, what you and I are saying makes very good sense to them, but when they want a fix, they are not going to remember what we said.

Mr. GREEN. Let me turn to the cost issue that Congressman Gilman raised. And all of us who are concerned for the condition of our hospitals and health system here in New York City are, of course, frightened at the costs that we see down the line. At present, for example, under the DRG program, there is no diagnostic review group for AIDS. One goes in with pneumonia or whatever and that is the diagnostic review group that is attached, assuming that the person has lived long enough to qualify for Medicare under the disability program, which we hope will be an increasing number, particularly with the availability of the AZT treatment. Invariably the AIDS cases are on the upside in cost and the system really is not dealing with them. And that is probably true of all the third-party payer systems that we turn to in terms of the AIDS patient. Doesn't the federal government have to face up to this and either create another DRG for AIDS, for those who are going to be in the Medicare system, and perhaps accelerate the time of eligibility for Medicare under the disability insurance systems; don't we need some payment mechanism that specifically addresses the AIDS problem?

Dr. KOOP. Well, Mr. Green, I have been on public platforms and television and radio shows around the country. For the last four months, I have been calling for consultations at the federal, state, and local levels on three major issues, all of which you have touched on, which are absolutely essential, and which I would hope that the President's Commission would address early on. One of those is the cost.

Who is going to pay for AIDS? Who should pay for it? You and I know that certain cities are bearing a tremendous burden now. They can lean on the state just so long, but at some point costs may have to be shared by the federal government. Very much a part of the whole cost issue, which, again, you alluded to, is the question of where insurance fits into this picture? We do not yet have any national policy about risk sharing or any kind of system that would get the best for the greatest number of people. Finally, what we are using this money for in the final analysis is for the care of the patients. And right now, as has been mentioned at this hearing, babies are being treated for $800 a day, some adults are being treated for $1,200 a day. That is all fitting and proper and good if it is going to do something for the patient in question. But we are also using acute-care beds for terminal patients; we need a hospice-type system where AIDS victims can maintain their independence as long as possible. Give them home care, but when the time comes for their final illness they do not require intensive-care beds, and they could be in a hospice-type setting where they have food and warmth and loving care.

Mr. GREEN. Of course, we have had a federal demonstration program on hospices since even before AIDS burst on our consciousness. Are we at a point now where we can look at that demonstra-

tion and say, "Here is a model that is worth our while to reproduce, and if it is shouldn't the federal government be sharing in the cost of reproducing it?"

Dr. KOOP. I have implied that, yes.

Mr. GREEN. Thank you, Mr. Chairman.

Mr. RANGEL. Senator D'Amato.

Senator D'AMATO. Mr. Chairman, let me make an observation, if I might. I certainly concur with the suggestion and thought that the President's Commission on AIDS certainly, at the very least, make as an ex-officio member——

Mr. RANGEL. Exactly.

Senator D'AMATO [continuing]. The Surgeon General of the United States. I would hope that maybe this distinguished Select Committee would make a request, make a recommendation to the President that Dr. Koop be included as an ad hoc member.

Mr. RANGEL. If the Senator would yield on this point, it just seemed to us that it would be incredible to have a national commission and not to include the Surgeon General, but you can bet your life that we will write in no uncertain terms that we believe that is in our national interest.

Senator D'AMATO. Let me say I am pleased to undertake action, legislative and otherwise, in the Senate, at least attempting to get a sense of the Senate, supporting inclusion of the Surgeon General to this Commission. I don't know whether the Surgeon General will appreciate our movement in that direct.

Dr. KOOP. I wish I hadn't come this morning. [Laughter.]

Senator D'AMATO. Mr. Surgeon General, I would like to touch briefly on three areas. One of them relates to testing. And only to the extent that you have indicated, and others, that in some of our hospitals there is literally pandemonium or, to put it mildly, a highly charged atmosphere in the operating rooms where surgeons and attendants, et cetera, are taking extraordinary procedures as it relates to protecting themselves, and devote a disproportionate amount of their energies to their own care as it relates to the procedures, due to this fear of AIDS and possibly contracting it. Would you be prepared to make a recommendation—you indicated a study is taking place now—that would call for the testing of people who are coming in for surgical procedures so that the medical community would not have to face as highly a charged situation and could perform their operations with a greater degree of reliance on their own safety and spending more of their energies on the patient's care, as opposed to the tensions that are gripping more and more of our hospitals?

Dr. KOOP. I have already come to grips with that, sir, and I am on record recommending just that. What is happening in Atlanta today is the group is putting what we have been talking about into words.

Senator D'AMATO. So that there may shortly be guidelines that would recommend the testing——

Dr. KOOP. Of surgical patients.

Senator D'AMATO [continuing]. Of surgical patients.

In your view, because this will be viewed by many as rather controversial, what will that do? Will that be of greater benefit to the patients in general?

Dr. KOOP. Well, first of all, what it would do from a public health point of view, which is my concern, would relieve that tension you mentioned in the operating room. Instead of being that tense for every patient, you would only take special precautions for, say, somewhere between 1 and 5 percent of the patients.

Senator D'AMATO. What are some of the special precautions, Doctor, and how does that affect patient care when the situation arises?

Dr. KOOP. Well, the special precautions that I would take if I were, say, doing open heart surgery, where there is a tremendous volume of blood and so forth that is lost, are the following. I would wear a type of protective operating gown that is impervious to blood. I would wear glasses, which I do anyway. I would wear double gloves, not because it is more difficult for a needle to go through two gloves than one, but because, just like condoms are not 100 percent safe, neither are rubber gloves 100 percent without holes. And having been a surgeon for 40 years, I can tell you that in about every sixth or seventh operation, and knowing you had not stuck your finger, you would take your glove off and there would be blood around one finger nail. I would take these precautions, and I would also insist that in those procedures the most experienced hospital personnel be on hand.

I speak with some authority on this because I have an aneurysm of my radial artery on my hand; I punctured myself with a needle and got hepatitis. So I know that no matter how careful you are, accidents happen. They are less likely to happen with a well-trained team that has been through the same thing over and over again. I think there are really very simple precautions that can be taken; to do what I have described takes a little longer, but this is small price to pay for safety.

Senator D'AMATO. Doctor, I said three questions, I am going to cut it down to two.

It seems to me that in some of our private discussions, and in some of your public statements, and others that have been made by medical personnel at this hospital and other hospitals, we find increasingly a significant number of beds for pediatric and in other areas being utilized for caring for AIDS' patients when they should not really be in those beds. Two things take place: A tremendous cost to the hospital, the institution itself, nonreimbursement in many cases; and, second, the development of an attitude by the general public, and the very facilities that are reaching out and meeting these needs, are then rejected by the general public and also by the health care workers, as facilities that they do not care to work in or people don't care to go there for treatment. It seems that we desperately need the kinds of programs that Mother Hale, the cradle program for infants, the hospice programs for others, and that this nation faces a medical crisis and also a tremendous financial crisis.

Would you care to comment on that?

Dr. KOOP. Everything you have said is true. We do face a real impact of this epidemic on the health care delivery system. You have to be careful that what you said, Senator, is not misinterpreted to mean that all patients with AIDS should be out of hospitals. Many of them are being treated there properly. Remember—some-

times people forget—AIDS is incurable, but it is not nontreatable, and you can add to the quality of life and the weeks, months, and years of life significantly by treatment. Often that has to be done in acute care institutions. But when a patient does not require that kind of care, then there is the alternative hospice system, and I certainly have been on record for almost a year now urging people to come to grips with this and provide for it in their communities.

Senator D'AMATO. Are there any models that you could suggest or any roles that you think we could suggest in developing the kind of hospice treatment?

Dr. KOOP. I think that any of the hospices that are functioning around this country are good models, because the hospice is not a building, it is a program and a concept. You are dealing with a terminally ill patient and, therefore, you treat that patient a little differently than if you were trying to save his life for next year. Any of the existing models are good.

One of the problems with long-term care institutions in this country is that, in general, they have been catering, because of the demand, to elderly, female patients. Now the demand would be for young male patients. Many of these institutions are not equipped to mingle those groups yet. Something has to happen about that.

Senator D'AMATO. Thank you, Mr. Chairman.

Mr. RANGEL. Thank you.

Dr. Koop, is it safe to say that this AIDS crises is an epidemic?

Dr. KOOP. Oh, it is more than that, it is a pandemic. It involves every continent on this globe.

Mr. RANGEL. Okay. If you can take the word of this Committee that heroin production will be going up, or certainly not decreasing in any of the production countries, if you can take the word of this Committee and the State Department, and DEA and Customs and the Coast Guard that if they had maximum efficiency that they don't expect that they could cut down by more than 20 percent or interdict the amount the drugs coming into this country; if we know that the tonnage that is coming in now is going to be increased, I am certain that you would agree that we have to concentrate on demand reduction.

Dr. KOOP. The way you have phrased it, I would have to agree too.

Mr. RANGEL. Now, having said that, whether it is H.R. 2626, that this Committee is supporting, don't you believe that it is essential, as a part of this fight, to have a national education prevention program that you would know everything about?

Dr. KOOP. I certainly couldn't oppose such a program, sir.

Mr. RANGEL. No, that is not my question, Doctor.

Has Secretary of Education Bennett ever come to you to ask your support for a program?

Dr. KOOP. No, sir.

Mr. RANGEL. Has he ever consulted with you for the need of such a program?

Dr. KOOP. No, but that is really not a line of consultation that has been operative.

Mr. RANGEL. Has the First Lady ever shared her concern about drugs and asked you to support an educational program?

Dr. KOOP. No, but she has talked to Ian Macdonald, who is the Assistant Surgeon General.

Mr. RANGEL. Has Dr. Macdonald ever come to you with a national educational program?

Dr. KOOP. Yes, we have discussed that.

Mr. RANGEL. Now, would you tell me what that program is?

Dr. KOOP. No, I can't tell you, sir, because as I have said, this is not one of my assignments and I do not know the details.

Mr. RANGEL. Well, Doctor, the reason why you cannot tell me is because we can tell you that there is no national education program that deals with the prevention and decrease in appetite for these drugs, with the exception of the First Lady's program, which is "Just Say No."

We hope that we can get you as a Doctor, a Doctor for the nation, to do what we think we were able to do in our own state, to tell our health commissioner, Commission of Health, that health is education. Education is a part of health. Would you not agree?

Dr. KOOP. That is what I spend my time doing.

Mr. RANGEL. So that if indeed we are going to fight a war with all of the other things that are necessary for war, you have to be equipped as a part of a health program to be identified—I hope you would agree—with a health educational program that deals with this crises. I would hope you would agree that that is important.

Dr. KOOP. I agree with you.

Mr. RANGEL. Then you have just volunteered to support some type of a national education program and we are going to consult with you to see as to whether or not what we have drafted would be in line with that that you would suggest to our nation.

Dr. KOOP. Your consultation is welcome. I have never been backward about my opposition to drugs, and I have aided any other agencies of this government in the fight against drugs whenever I have been asked to.

Mr. RANGEL. I know that and that is why you are a hero in our books and we thank you for sharing your views with us and we look forward to working with you. If you cannot personally participate in the President's Commission on AIDS, we are certain that arrangements could be made for someone of your outstanding qualification to have a staff member to be there. But you can see that in our appreciation of your ability, that we would feel more secure in knowing that a person of your stature would be on the Commission.

Dr. KOOP. Thank you.

Mr. RANGEL. Thank you.

Our next witness is the Mayor of the City of New York. And we will be brief because he has to leave by 11:30.

Mr. Mayor, we welcome you to the Committee.

The people responsible for Health and Hospitals will be introduced by the Mayor and we welcome him, and I just want to say and make public that recently, last year, that Congress was able to pass an omnibus bill dealing with this crisis in drugs of some $2.7 billion. That there is no question in my mind that had not the mayors of the various cities that have been hit the hardest by drugs come together and politically and legislatively support this legislation, it would have not been enacted. I might say, however,

that Mayor Koch initiated the leadership in pulling them together after an exchange that he and I and other members of this Committee had at a hearing, right here in the City of New York, and more specifically in the borough of Manhattan.

I hope, Mr. Mayor, that as short as the time is that you would allow for such an exchange to see whether or not we will have to put that same type of effort behind our educational program, and in addition to this, to see that wherever AIDS go, as a result of our collective fight against drugs, that we make certain that the federal government is there on the front line and not hiding behind the mayors and the governors.

Thank you, if there is no statement from the members of this Committee, we welcome your testimony. We want you to know that your full statement as is will be put into the record; that you can speak as you feel most comfortable and we ask you to identify the co-panelists that you have with you.

TESTIMONY OF HON. EDWARD I. KOCH, MAYOR, CITY OF NEW YORK

Mayor KOCH. Thank you very much, Mr. Chairman.

Mr. Chairman, I will stay as long as you would like me to stay because I think this hearing is extremely important, and whatever it is I am scheduled to do, it will simply wait.

The people who are with me are the President of Health and Hospitals Corporation, Jo Boufford, and the Administrator of the Human Resources Administration, William Grinker. And what I would like to do—and also Dr. Pauline Thomas of the Department of Health is with us as well. I am sorry, Doctor, I didn't see you there. When you get into the Q and A, I am happy that they respond based on their expertise if you would like them to.

What I would like to do in a very brief way so we can get to the Q and A quickly is to outline the concerns that I have. I am not going to repeat what the Surgeon General said.

Normally I don't come to a hearing in advance of the time I am scheduled to go on, because time is so precious. But I knew that he was going to be here and I wanted to hear his statement because I think that we are indeed very lucky to have as Surgeon General, C. Everett Koop. He is a very brave person whose life actually has been in danger in some cities in this country—he told me that personally—as a result of his positions, which are not supported by some parts of our community who simply don't want to face facts and who allow their ideology to supercede medical matters as opposed to having medical matters be pre-eminent. So we are very lucky to have him.

Now, in the City of New York, since the first detection of AIDS in children, we have had 199 children who have been identified as having AIDS. We expect that this year there will be as many as 1,000 children who will be infected with the AIDS virus. That is the information that we have. It is obviously a matter of extraordinary concern. Three-quarters of the children who have been identified as having AIDS, of that 199 group, have already died, and they die within two to three years. It is an enormous tragedy when

anyone dies, but when an innocent child dies within two to three years of their birth, it is an especially grotesque situation.

What is it that the City of New York is trying to do in a general way as it relates to AIDS? We are engaged in seeking to educate people; and there are two major groups that get AIDS, as we all know: The homosexual population and the IV drug user.

With respect to the homosexual population and also heterosexual where they are IV drug users and can transmit it to someone who doesn't already have the virus, we are engaged in sponsoring a program that will spend $6 million for buying ad space on TV. We don't want to have the public service ads that appear at 3 in the morning. We want to have public service ads that are paid for, that appear during prime time. We have raised 6 million dollars in the private sector, and we cannot get these television stations to carry the ads. To date, to the best of my knowledge, of these extraordinary ads on the use of condoms, only one of the ads has been carried that I have seen. Most of the stations don't even carry that one; some do, and they don't carry the others. The only one that they carry that I have seen is of a woman talking about her son. But the other ads talk about women carrying condoms with them for their own protection and they won't carry those ads, nor do the newspapers carry those ads. Now, I don't know how we can deal with that, but it is a fact.

As it relates to the IV drug user, we have tried on two occasions to get the State of New York to accept a proposal for the distribution of clean needles. Now, one has to understand that a minority of states in the union require a prescription to get a hypodermic needle. New York happens to be in that minority group. In my understanding, the majority of states say you can go to a drug store, if you are an insulin user and need to buy a hypodermic, you go right to the drug store and you can buy a hypodermic needle. You cannot in the State of New York. That is the law.

When Dr. David Sensor, who is our former health commissioner, and noted in the field (Steve Joseph, our current health commissioner is likewise noted in the field) proposed that there be the elimination of the prescription or that free needles be distributed, every law enforcement official that I asked said, "Absolutely not." They have their reasons. Those reasons have already been stated by members of the Committee and by Surgeon General Koop: they think that it will spread the addiction, the use of heroin, et cetera. But my own feeling is we don't know that, and we do know that people are dying and you have to try something. So we couldn't get what Dr. David Sensor wanted, which was simply distribution of the needles. A clean needle costs 19 cents; when you buy it through a prescription it costs $2.50.

Now, Steve Joseph came up with an alternate plan, which was that we try a sample, and take people who are waiting to get into a drug treatment center and who have been tested as free of the virus, and give them free needles while we are waiting to get them into the drug center, and then monitor and see whether there is a difference in terms of their getting AIDS as opposed to some control group. And he submitted that proposal to Dr. David Axelrod because as a laboratory experiment, the State Health Commissioner can authorize it without legislation, and Dr. David Axelrod re-

jected it on the basis that the sample wasn't large enough. So we are going to try to get an even larger sample. But in the meanwhile time goes by and people are dying and there doesn't seem to be the sense of urgency, and that is what is distressing.

In the City of New York there is a constant battle: Are we doing as much as San Fransisco, or are we doing less? And the AIDS advocates will always say we are doing less, but everybody who looks at the matter and compares the programs says we are doing more. I have to rely on Steve Joseph, our current Health Commissioner, who says that we are doing more than any other city in the country, notwithstanding the attacks upon our programs, and that we have programs that other cities simply don't have, and the numbers that are involved are astronomical. My recollection is, and I am using memory now, is that in San Fransisco, in the hospitals, they have 60 patients. We have hundreds of patients, hundreds of patients, and there is simply no comparison with the money we are spending, not only per capita, but percentagewise we spend much more than any other city on the patients. And we had AZT available in our hospitals before the federal government said that it would pay any part of it. We said that we would pay for any patient who fit the profile to get AZT out of City funds. Now, fortunately, the federal government has said it would come in and pick up some of that cost.

The one area that I cannot figure out, and I am just throwing it on the table because nobody has ever talked about it, and I solicit your help: Until we get a cure, until we get a vaccine, we have to treat the patient and extend their lives, but we know that they are going to die, and they are going to die early. Two, three, four years and there comes a point when they are going to die. They cannot die in dignity in the State of New York in large numbers and I will tell you why. Because the federal government, I am told, does not provide reimbursement for the hospice which everybody says is necessary. What is a hospice? A hospice is where at the end of your life, when there is an acceptance that you are not going to be able to be saved, and you want to die in dignity without massive medical treatment being given to you, that you can go there and die in dignity. We do not have that in the State of New York for AIDS patients because of the federal government's rule—now, I am just repeating what the Doctor said to me, and if she is wrong, I am happy.

Mr. RANGEL. Would you check that with the Doctor in terms of Medicare reimbursement?

Mayor KOCH. Yes, I am going to tell you what they say. That you are not eligible as a hospice unless you spend 80 percent of your time out of the hospice.

Have I stated it correctly?

Dr. BOUFFORD. Out of an institutional setting.

Mayor KOCH. The hospice meaning the physical setting. In other words, while you and I, as reasonable, rational people, believe that a hospice is a place that you go to die, the federal government's position is that you should spend only 20 percent of your time in that physical setting, otherwise it is not eligible for reimbursement. Have you ever heard of anything so stupid? I have not.

What I am simply saying is, that is the reason, the major reason why governments, local governments, can't set up hospices. So what do we set up? We set up facilities for chronic care, for major medical attention, not necessarily acute-care facilities, but that is not what is our major need. We have that and will need more of that, but our major need at this point is the true hospice, the kind of hospice that they have for cancer patients at Calvary in the Bronx where you go to die and to die in dignity.

I am going to stop, Mr. Chairman, and I am happy to take any questions you have.

Mr. RANGEL. Well, I am shocked. We are writing up a health bill now, as Dr. Boufford knows. Has that been brought to the right—when I leave here I am going to Ways and Means to mark up a Medicaid bill, and I have never heard of anything this ridiculous.

Dr. BOUFFORD. Our understanding is that there is a 2-month limit on in-patient institutional reimbursement, and that the reimbursement in general for AIDS patients is not adequate to cover the cost of their care because they are a very special group who needs more care than the average patient who is eligible for hospice. And there is an inadequacy of reimbursement and a two-month limit on the institutional setting.

Mr. GREEN. Will the gentleman yield?

I know there has been a long-standing controversy about the adequacy of the reimbursement rates for hospices, going back to some questions of statutory interpretation when that was first written into the law. On the other hand, I think it should be understood that a hospice is not intended to be an extended care facility or a nursing home. The hope is that a majority of hospice patients can, in fact, be cared for most of the time on an out-patient basis. Therefore, the mechanism set up to finance it—though, as I said, there are real controversies on its adequacy—does look toward the patient having to be in the hospice as little as possible.

Mayor KOCH. Bill, that is the conundrum. We are not talking about people who can be in their own homes. We are talking about people who are at the end of their lives and who will die in the hospice, and if the information given to me is correct, if they spend more than 20 percent of their time in that physical facility, the facility is not eligible for reimbursement. That is what I understand the case to be.

Mr. RANGEL. Well, it seems to be that if we are paying $500 and $600 a day and up to $1,200 a day for adults in reimbursement, that we are talking about $60,000 to $120,000 a day in reimbursement for terminal cases in our public and private hospitals. So let me say this: I hope that you will notify your New York City representative to contact us this afternoon so that we can make certain that if there is any controversy, at least the issue is discussed.

Mayor KOCH. I will.

Mr. RANGEL. Mr. Mayor, you have had the courage to talk about things that have been unpleasant and that have involved controversy; certainly this idea of clean needles is one that should be looked into. I have hoped, without any professional understanding, that as we see the homosexuality activities kind of being restrained as a result of the fear of AIDS, that perhaps common sense and good judgment might affect the heroin user to understand that he

is dealing with AIDS and dealing with death, but as you said I don't have any unique reason to believe that this would deter their behavior.

In any event, there has been a lot of talk about condom use and whether it should be in the classrooms and what not. I wonder whether, in looking at the spread of AIDS as it involves the IV drug users and those that they are having sexual activities with, whether or not political and church leaders have looked into sexual activities in the prisons? This is something that of course people don't like talking about, and we got chaplains in the prison, so if you get into any trouble over this one, you can charge it up to me. We have got Jewish Chaplains, Christian Chaplains, right there where this type of behavior goes on. We have guards that understand it. We have inmates that are subjected to this type of activity against their will. We have brutality. We have assaults, but now I would think we are having attempted murder if indeed one of these people have AIDS. These people are discharged, they are rotated. They come back to the general community and they are involved in sexual activity.

First, do you believe that there should be mandatory testing for those people who have been convicted and will be put away in penal institutions, and after, or if you find that the virus is available, is there anything that you have suggested or to your knowledge is being done to eliminate or contain the problem?

Mayor KOCH. OK. As it relates to the prisons—I will take the second question first and then I will go into the mandatory testing in a minute.

Mr. RANGEL. Sure.

Mayor KOCH. We actually have made available in the prison system, in the City prison system—it is not available in the State prison system—condoms. And we have done it in a particular area, but they will also be available for those who ask for them outside of that area. When a prisoner comes into our City jail system, and about 70 percent of them have not been convicted, they are awaiting trial and the other 30 percent are sentenced for misdemeanors. We have about 15,000 people in our jail system today, twice what we had 5 years ago. We have a special area where someone who identifies himself as homosexual and is in fear of being assaulted in the regular prison population, may get condoms in a homosexual section of the prison for their protection. And we have made this available because we know that consensual sodomy takes place in prison. And anybody who doesn't believe that has their head in the sand. We are not talking about assaults. That takes place regrettably too, but not as often as people think. Consensual does take place regularly, we are sure.

We have made available condoms in the homosexual section of the prison on a regular basis. That was done with the consent of the Board of Health. It is very important in all of these matters. You know, here the Mayor says "Distribute clean needles if you can." If the law says you can't, then you can't. The Mayor says—because none of this can happen unless I agree to it. The Commissioners are not going to go out and do something as controversial as that knowing that immediately upon their doing it the people are going to come and ask me what's my position on it? Therefore,

these controversial matters are done with my agreement, but never against the decision of the Commissioner. The Commissioner broaches it first.

So, with respect to the condoms, notwithstanding the attacks made by a whole host of people, religious and not so religious, on the distribution of the condoms, we are distributing them. Notwithstanding the attacks made on the ads, we are providing some dollars and raising other dollars in the private sector. Notwithstanding the attacks made with respect to the distribution of needles, I am supportive of them. That is my position on that.

Now with respect to mandatory testing. Major problem: My position is that there should not be mandatory testing for anyone. That you should encourage under many situations voluntary testing. The reason that you don't insist on mandatory testing, at least in my judgment and the judgment of the experts who have given me this information is that after you have mandatorily tested, what have you got? You can't do anything for these people. You have branded them. You have said, "For the rest of your life, short or long as it may be, you are going to be in danger of losing your job or losing your apartment or being scorned and being perceived as a pariah." Because once you have put that on their record, no matter what anybody tells you, there will always be the risk, and the risk will occur in different situations, that that information will become public.

Mr. RANGEL. What about treatment?

Mayor KOCH. Well there is no treatment for AIDS. There is treatment for the symptoms or the sequela, which would be the pneumonia or the cancer, and when you get the pneumonia and you get the cancer, you go into the hospital and we treat you. But the fact that you have the AIDS virus in your blood stream, there is not a thing they can do about it.

Mr. RANGEL. But could not the person who has AIDS condition their conduct accordingly?

Mayor KOCH. Well, one would hope that high-risk groups who have—what is interesting is this, and it raises an additional problem: AIDS is not spreading into the heterosexual community. Two percent of the people in the City of New York who have AIDS are in the heterosexual community, outside of IV drug users, outside of that group. And maybe around the country—they sometimes use the figure four percent, but most people say it is closer to two percent, and in New York City that is the figure that we use. Therefore, AIDS is still restricted to very limited groups: Homosexual, unsafe sexual practices, IV drug users, and hemophiliacs.

Mr. RANGEL. Well, how about mandatory testing for homosexual, addicted prisoners?

Mayor KOCH. And the answer is that after you have made that test, you have branded them. Sooner or later they are going to get out.

Mr. RANGEL. After you are an addicted gay prisoner there is not too much branding to be done. [Laughter.]

Mayor KOCH. Well, you are mistaken about that, Mr. Chairman. Seventy percent of the people in our jail system have not been convicted of any crime.

Mr. RANGEL. I was talking about our convicts. That's all I am talking about.

Mayor KOCH. Okay, so now you are talking basically about the state prisons where you send people who have been sentenced for felonies.

Mr. RANGEL. Yes.

Mayor KOCH. Let us assume that you tested everybody there. Let's take your assumption. And you find that "A" has the virus. What are you going to do about it? Sooner or later he is going to get out, what are you going to do about it?

Mr. RANGEL. All I am saying, and again, just as you had ideas, it was some idea that I had that if a person being discharged from a prison finds out that he or she has AIDS, that they might be able to govern themselves in such a way that they would not spread the virus. In addition to that, it would appear to me that even those who are in prison having been identified as having the virus, would too, restrict their conduct.

It would seem to me that everybody, every person in the world, would want to know whether or not they are carrying the virus, and I appreciate the constitutional questions of mandatory testing, but I would not think that anyone who is sexually active would not want to know whether or not they are carrying the virus.

Mayor KOCH. Every drug user today, IV drug user, knows—I think the figure was—more than 60 percent of them right now have the AIDS virus. They can just assume it, and the others are going to get it. They are going to get it, so they don't need the confirmation, and having the confirmation——

Mr. RANGEL. What would clean needles do then? If they already know they've got it then clean needles are not going to do much.

Mayor KOCH. The difference is that there are people who are being addicted every day and those are the people who you would want to be able to save with clean needles, or those who don't have the virus now. But what I am simply saying is that more than 60 percent of IV drug users today have the virus and most of them will get it over the next several years.

Mr. RANGEL. Well, I hope that with your health specialist we might be able to have an informal meeting to see whether or not we could have joint hearings that would include City Council and state legislators and members of Congress, to bring witnesses to actually see whether there is any preventative, whether it is needles, whether it is condoms, but I think that if enough of us talk about these things that we can shatter the culture that we live in that "it is just unpleasant and so let's forget it."

And, Dr. Boufford, we are going to listen from the hospital workers this afternoon, and I assume you believe that we are doing everything that we can to protect the doctors and the nurses and the workers that find themselves providing treatment to AIDS' patients?

Dr. BOUFFORD. As a matter of fact we have been very pleased with the cooperation with the unions. We have been working with District Council 37, Local 420 and other unions in our system, in the public hospital system, for over four years now. They have worked with us in designing the training, on organizing it, and

making sure that every new employee and existing employees are constantly trained and retrained.

Every time there is a new piece of information that comes out, like the CDC cases the last few weeks, that seem to indicate there might be additional risk, we have worked with the unions to implement new training programs, and I think our workers have been very supportive and have really been very committed to patient care, even in the face of initial anxieties.

Mr. RANGEL. We will allow the record to remain open so that if there are questions that are raised before the hearing is over, we will forward it to your office and that of the Mayor.

Dr. BOUFFORD. Fine.

Senator D'AMATO. Mr. Chairman?

Mr. RANGEL. Yes, Senator?

Senator D'AMATO. Would you yield for a question on that point?

Mr. RANGEL. Sure.

Senator D'AMATO. Dr. Boufford, I have had a conversation with Dr. Koop; he has testified or given information just last week to about 25 Senators, and the question you may have heard us talk about, as it relates to operating room problems is—to characterize the Doctor—he said the tension and anxiety levels are great. They are tremendous. There is very real concern in those surgical rooms. And you have heard the Doctor make mention of the fact that he has supported the concept of tests for those patients who are about to undergo surgery so that we could reduce the tension in these rooms greatly. He has indicated that 95 percent of the anxiety, the tensions, are now being directed to prevention of the possible acquiring of AIDS or coming into contact in such a way that might bring about that.

Would you support testing for those patients who are going in for surgery so that we could eliminate that fear and concern that now is prevalent in many of our institutions, on behalf of the surgeons and their assistants?

Dr. BOUFFORD. It is interesting but we have not seen increased evidence of that tension in our system. We have recently, as I said since the recent CDC cases brought in representatives from surgery, from our emergency services and others, and have involved them in the process of looking at additional precautions, and the feeling is that in many instances in our hospitals—especially high-risk workers like surgeons and dentists—have been taking extra precautions, such as had been recommended by the CDC before—in some instances double gloving, protection of eyes, masks—that these steps had already been in process. We have not seen evidence of this additional tension.

Senator D'AMATO. Well let me put it another way.

Dr. BOUFFORD. Essentially the normal precautions in an OR are the ones you would be taking.

Senator D'AMATO. Doctor, I hear you, but let me put it another way: A person is going in for critical heart surgery. Now he has got a hospital staff that is going in with double gloves, where they really aren't necessary because he is not carrying that virus; masks and what not, tension in that room. Maybe it is not a person with open heart surgery, maybe it is someone else, but those kinds of situations. So what about the relationship as it relates to patient

care and those people who do not represent a threat? So don't you see a reason for considering, certainly to keep and improve the quality of medical care which is suffering today?

You don't believe that medical care is suffering as a result of that concern? I am not suggesting to what extent, but if you don't believe it I am going to make a suggestion to you that as the numbers of AIDS' patients begin to increase, you are going to begin to see the general medical care beginning to suffer. That's a fact.

Dr. BOUFFORD. I don't think that there is any question that the additional burden of AIDS has added a burden to institutions. I would hope that the quality of medical care is not suffering because I think people are really trying to give the best care they can to all patients throughout.

Our position generally, I think patients who are at risk clinically, who have been identified as at risk or have clinical indications of HIV infection or AIDS, are already being tested in the course of their hospitalization as one of a number of clinical tests that are conducted. Should they go to surgery they would be known. That has been the policy of CDC up to now, and that has been the policy we have been following. If they change their policy, we will have to look at it and deal with the implementation in our institutions.

Senator D'AMATO. Okay.

Mayor KOCH. Mr. Chairman, could I give a little addendum, because I want to be clear on why I am opposed to the mandatory testing because I think it is very, very important.

It is a slippery slope. I think that is really the major problem. And while it would be, you know, something that we could agree upon normally—people have been convicted of crimes; we know substantial numbers particularly who were IV drug users who are now behind bars, that they have the virus. And so people would say, "Why not?" But the next group is even easier; and then the third and fourth group become easier still.

So before we reach the point of mandatory testing, we want to be sure that it has some medical value that would overcome the other aspects of it, and that would be the major reason why I would oppose it even for that group. That does not mean that at some point, particularly if you get a vaccine or get a cure you are able to do something, that you wouldn't do something in that area, but it is the slippery slope aspect. That is number one.

There are just a couple of points on which I wanted to have the record totally clear.

I mentioned earlier that when I do any of these things that are really very controversial, I try as hard as I can to get medical support for what I am doing. We have been blessed in a way with a Health Department medical board—the Board of Health—very brave people. Kevin Cahill is on it and a number of others. And they have said that we should be doing these very controversial matters, and that is helpful. When you are attacked you can say, "It is a medical matter. You are not a doctor, I am not a doctor, we are going to listen to the doctors on a medical matter."

Then the third thing I wanted to mention is this, and I have mentioned it a number of times and I am very concerned about it: As the country recognizes that one of the major group involved here is IV drug users, and that is becoming the largest group in

the City, not yet, but it is the largest increasing group; it is now about 35 percent of the total number of patients that have been identified, but it is becoming a larger and larger percentage because the homosexual group is getting smaller and smaller because of changes in their sexual practices, and so the increase is not as large with new cases coming on. You will, therefore, have two groups that are not held in universal esteem: homosexuals and IV drug users. Probably the IV drug user is held in the least esteem or lesser esteem because it is a criminal act as opposed to religious sanction with respect to the homosexual activity. And it is that IV drug user, overwhelmingly minority, that we have got to worry about protecting their rights, to care, because when we reach the point that the rest of the country suddenly no longer fears AIDS spreading into the heterosexual population, which is why we are getting a lot of attention here. People are saying, "It can happen to me. It can happen to my child. And, therefore, let the government do more," even though the government isn't doing as much as it should, regrettably, but nevertheless there is that pressing for it. You go to a dinner table and it is always a subject of discussion. I fear for those categories, the homosexual and IV drug user, that support is not going to be there, and that is what we have to worry about, and that is why we constantly have to talk about the fact that every one of these people, child or male or female—it is not an appeal for religious support—but they are God's children, every one of them, and they need medical help and it has always got to be there.

And then, finally, and here I would like to commend you and Congressman Gilman as leaders of the Committee dealing with drugs, and we have worked so closely together—and of course the Senator on the Senate side—what is to me an outrage is that we are not able to get the federal government to do the two things that you all want and that I certainly want, which is the interdiction by the military of drugs before they get into the country. And the other is cutting off economic and military aid to the four countries in Latin America that supply most of the cocaine that comes into this country: Mexico, Peru, Bolivia, and Columbia. And you, Mr. Chairman, were responsible years and years ago for giving that authority to the President. The President declines to use it, and Senator D'Amato pointed out at another hearing that we held, that when he brought a motion to the floor of the Senate to impose sanctions on one of those countries, when the President said that he would not—even though there is the admission that that particular country is allowing drugs to be grown and to be brought into the United States—the sanction which he had brought to the Senate floor, was defeated by a vote of 48 to 39, as my recollection of what happened.

That is the outrage. That there isn't an understanding of what it is that we are allowing our so-called friends to do to us. They are killing us and we are paying them while they are doing it.

Mr. RANGEL. Mr. Gilman.

Mr. GILMAN. Thank you, Mr. Chairman, and Mayor as usual you have underscored some very important aspects of this whole problem.

Roughly what is the City allocating for doing something about AIDS?

Mayor KOCH. Two hundred and fifty million dollars out of a billion dollar law enforcement budget is going solely to the interdiction of drugs in this City, and that is outside of our budget relating to dealing with AIDS. That is just law enforcement.

Mr. GILMAN. And how much is being allocated for the AIDS program, Mayor?

Mayor KOCH. We are spending $385 million on dealing with AIDS in this budget, of which a little bit less than $100 million comes from City tax levy funds.

Mr. GILMAN. And a portion then comes from the federal government?

Mayor KOCH. The balance would be split in some form between the federal government and the state government, mostly Medicaid.

Mr. GILMAN. Mayor, you talked about a five-year program to combat AIDS. What are the major bases of that program? What is the basic concept?

Mayor KOCH. The basic concept is that we can only hold the line until the federal government comes up with a cure or a vaccine, and that our job is education and treatment. Those are the two things that we can do. We are trying desperately to do that. I have told you about the television. We are spending more money in our school system. It was your Committee that identified 2 years ago that the federal government was spending $3 million nationwide on education. They disputed it. They said $20 million nationwide. It wouldn't make any difference, 3 or 20, neither is acceptable. We are spending, last year and probably more this year, $7 million and I don't even think that is enough in terms of our education system.

We are showing what I suppose is known as explicit material in our classrooms, and I am urging the Board of Education to bring it down to the lower classes as well. It is silly to think that in our modern day and age that youngsters 11, 12 and 13 and 14 don't know about sex. Regrettably many of them are participating in sex. I remember the Surgeon General giving me a figure which was that more than 50 percent of the high school students in this country engage in sexual intercourse. And that figure is skewed because the figure for males is about 70 percent, and the figure for females is below the 50 percent. So it comes out to a little bit over 50 percent. Our message to high school students, to juveniles, to delinquents is abstinence, absolutely. And that is the message we are going to keep promoting, but we also know that 37,000 teenagers in our school system last year were pregnant. So we know that some of them are not engaging in abstinence. And we have to get out the message that if you are not going to abstain and you are going to do what we perceive to be terrible for a youngster, for a juvenile, for an adolescent, then we think they have to know about condoms.

Mr. GILMAN. Mayor, is there an AIDS prevention curriculum that the City has adopted?

Mayor KOCH. Well, I can't answer that question directly. The Board of Education does have a curriculum. Our curriculum relates to the commercials, the handing out of—and it was embarrassing to begin with, but now it is no longer embarrassing. All of these

things become embarrassing the first time. We were handing out, and still are, condoms in some of the special bars that have been identified as places where you can expect high-risk sex to occur.

Mr. GILMAN. What about the educational program in the City? Is there a mandated curriculum?

Mayor KOCH. There is a curriculum. There is a Board of Education curriculum. A film. The original film was found not to have mentioned abstinence as much as it should have, and so it was corrected and now it has an abstinence factor and it is being shown.

Mr. GILMAN. Is that the whole curriculum, a film?

Mayor KOCH. What?

Mr. GILMAN. Is that the whole curriculum, a film?

Mayor KOCH. No, discussion as well, but you would really have to get it from the Board of Education.

Bill, do you know?

Mr. GRINKER. There is a classroom discussion that accompanies the film.

Mr. GILMAN. Do you know whether there is a state mandated program on AIDS education?

Mr. GRINKER. State mandated? I don't know whether there is.

Mayor KOCH. I don't know either.

You are talking about in the education field, I just don't know.

Mr. GILMAN. Yes, prevention amongst our young people.

Mayor KOCH. We will get that information for you.

Mr. GILMAN. Are there some areas that you would like to stress for congressional assistance in this program?

Mayor KOCH. Yes.

At the current time, if you are eligible for SSD, you have to wait two years before you get this disability insurance. Most AIDS patients die before they become eligible in that two-year wait. That should be changed so that it is equal to the SSD given for those who have kidney disease where you are immediately eligible from the day of diagnosis, that's number one.

The second is that AIDS now has been expanded by way of definition, and it is no longer those few diseases of a special form of pneumonia and a special form of cancer, they have also identified dementia and what they refer to as "wasting away." Neither of those two have been declared, so far as I understand it, as making you eligible. Even after the two-year wait, you don't have AIDS if you are wasting away or you have dementia as the sequela of the disease. That should be changed.

Mr. GILMAN. Well, Mayor, I recognize that that is a salutatory suggestion.

Mayor KOCH. Medicare not Medicaid.

Mr. GILMAN. Yes.

Wouldn't that then change your position somewhat in identifying those patients or those people who have AIDS? Shouldn't they be identified as early as possible?

Mayor KOCH. They want to be identified. We have clinics.

Mr. GILMAN. I'm talking about testing now.

Mayor KOCH. Mandatory testing?

Mr. GILMAN. Yes.

Mayor KOCH. There is a difference between voluntary testing and mandatory testing.

We have clinics in the City of New York where you walk in anonymously, not by name, you are able to have your blood tested. If you went to a private doctor the three tests involved would cost you $250 with the counseling. We provide it free, the tests and the counseling. I don't know how many thousands of such tests have been given, but we encourage people to take the test. The difference, I think, in our approach is that we don't believe that you should mandatorily require people because who will you require? The vast majority of people don't have the AIDS virus. Probably in the country it might be one percent. And if you took large groups of people and said, "You will mandatorily be given the test," it will run into billions of dollars and an enormous waste of money.

Mr. RANGEL. Will the Gentleman yield?

Mr. GILMAN. Just a moment, Mr. Chairman.

I am looking at a New York Times article of July 8, 1987, that says, "City officials estimate that up to 500,000 city residents are infected with the AIDS virus."

Mayor KOCH. Correct.

Mr. GILMAN. With that substantial segment of your population being affected with the virus, wouldn't it then be beneficial to try to determine who the carriers are?

Mayor KOCH. Ben, if I can do that—Congressman Gilman.

Mr. GILMAN. We have known each other long enough.

Mayor KOCH. Right.

Think about what you just said. Shall we then say, in New York City because we very honestly say—it is an estimate, nobody really knows. You just extrapolate from other figures—that there are 500,000 people who carry the virus in them. So what does that mean? We don't know who the 500,000 are. Shall we then require that every New Yorker on the 1st day of January come in and take a test? Seven-and-a-half million of them? How are you going to identify them?

Mr. GILMAN. What about the high-risk people?

Mayor KOCH. Let's assume high risk, what does that mean? Do you go out and every drug user that you bring into the prison system, let's say, that would be where you would get them. Homosexuals haven't violated any criminal sanction. I don't know where you would identify them. You go to a gay bar and close the door and say, "You can't get out unless you take the test?"

What we are saying is that mandatory testing is a slippery slope. At some point you are going to require whole groups, and then it becomes a problem of identifying those groups and maybe they don't want to be identified, and maybe you have ruined their lives, their jobs, their apartments, et cetera, and where will it stop? We have 240 million people in this country. Shall we test every one of them? That runs into billions of dollars. What we are doing is encouraging testing. We are saying to people, "We have these free clinics. Come on in." And high-risk groups are coming in.

Mr. GILMAN. And is their attitude going to be the same if this escalating figure continues in this manner? How then do we prevent it from affecting the entire population?

Mayor KOCH. Well, again, it will not affect the entire population, and that is one of the things that I mentioned. The heterosexual population of this country appears not at any substantial risk.

Only two percent of those having AIDS in the City of New York, I am told by our experts, who are not participants with IV drug users or bi-sexuals in their sex lives, if they are women, only two percent would be heterosexuals leading a heterosexual life. Therefore, it is not spreading into the vast numbers of our population. Now it may change, but that is the scientific fact today.

Mr. GILMAN. Do we have mandatory testing for any disease in our population? For example, in the schools didn't we test for TB mandatorily at one time?

Dr. BOUFFORD. There are certain precautions, certain things that are taken. There are decisions that are made for children, for example, they have to be immunized——

Mayor KOCH. Immunized, they are not tested.

Dr. BOUFFORD [continuing]. Immunized as a state law, to get in, or tested for TB to get into the school. But those are regulations that are developed to prevent infectious diseases that have treatment.

Mayor KOCH. If I could go a little bit further. I think the easiest thing for every one of us would be to say sure, why not? But the consequences are enormous for mandatory testing. You will stigmatize large numbers of people and you will not have helped their medical treatment, not at all. You may say that if someone is tested and they are not part of a high-risk group or they are part of a high-risk group and they suddenly know that they have the AIDS virus, that that is going to in some way or other cut down or eliminate their sexual activity. That is a possibility.

Do you believe it? Do you believe that if those 500,000 people that we estimate, just on projections, that if we were to identify those 500,000 people, that in fact the vast majority, substantial numbers, will end their sexual activity for the balance of their lives? Do you believe that?

Mr. GILMAN. I would think that it would have some benefit to those 500,000 and to the population as a whole.

Mayor KOCH. I agree that simply knowing that the virus is out there, that there are, we know, amongst homosexuals, far greater precautions taken. How do we know that? I am told we know it because of the reduction of regular venereal disease and, therefore, we know that they are using condoms. That is what I think comes from this.

Mr. GILMAN. I will be pleased to yield, Mr. Chairman.

Mr. RANGEL. Should a child that was born to an addicted mother be tested for AIDS?

Mayor KOCH. Okay, let me tell you what we are doing about that, and maybe Jo—I have just been told that she can define it better than I, but I have just been told by Bill Grinker that over 70,000 people have voluntarily been tested in the City of New York at our anonymous clinics.

Mr. RANGEL. No, we encourage that. And I am not firm in my mind so we have no confrontation here that we should have any type of mandatory testing.

Following the line of Ben Gilman, do you believe that a child born to an addicted mother should be tested?

Mayor KOCH. Okay. I am going to tell you what happened, because it will interest you. It happened in this hospital.

We had a meeting with 10 Harlem ministers on foster care because we had at that time close to 300 so-called boarder babies. Everybody should know what a boarder baby is, you probably do. A boarder baby is born in the hospital and stays here past the point where they need medical treatment. It's at that point they become a boarder baby. Prior to that they are just a regular patient.

We had about 300 so-called boarder babies because it was difficult to find foster parents in sufficient numbers to adopt them—or not adopt them, to take them by way of foster care. And at the table one of the ministers said, "Well, one of the reasons that we may have problems in finding parents is that isn't there the problem of AIDS and do we know whether or not a child who is given in foster care has AIDS?" We went around the table, and the policy at that time was, "No, we didn't test them." We did not tell the foster parents. And the policy has now been changed as a result of the meeting in Harlem Hospital.

Tell them what the policy is, Jo.

Dr. BOUFFORD. All right. The policy will be that the foster parent who is considering adoption of or taking into their home as a foster child, a child who is at risk—and there are some definitions for the high-risk child—at the request of the parent, the child will be tested and the results given to that potential foster parent in the context of counseling. And the criteria that are being used is if the child has shown clinical indications of having AIDS or an AIDS-related type of syndrome, which would be swollen glands or some kind of immune problem or chronic diarrhea or other problems like that.

If the child comes from a family in which other children, other siblings, have been shown to be HIV positive, if the parents have a history of being drug users or if there is a bisexual father or a hemophiliac parent who may have been infected through the blood supply previously, those kids will be defined as high risk, and if a foster parent is considering adopting one of those children they will be tested at the request of the foster parent and the results given them in the context of counseling.

Mr. RANGEL. Well, suppose it is not high risk, with your voluntary system, why would this group have to be targeted? Could not any foster care parent say, "Test the kid before I care for him?"

Mayor KOCH. Yes, they can.

Mr. RANGEL. So what difference does it make whether a child is high risk?

Dr. BOUFFORD. Because essentially, again, as the Mayor was saying, we are trying to deal with the clinical indications for these tests in a medical issue. The important thing about children to realize is that up to 60 percent of children who could test positive at birth may convert to negative, but it may be as long as 14 months after their birth because they could be carrying the antibody from their mother that they got during the pregnancy, but that does not mean that they are necessarily infected. So you have to be very careful about the testing and about counseling the potential foster parents.

Mr. RANGEL. So we have a lot of children that are being born right now that are not even tested for AIDS, even if they come from high-risk families.

Mr. GRINKER. The test is very inaccurate for the first 9 months and you wouldn't really get an accurate picture of whether a child had AIDS or not.

Mr. RANGEL. I don't care for how long, you are saying that right now, no matter how high the risk, that no child is being tested for AIDS unless the foster parent requests it?

Dr. BOUFFORD. No. In some instances already in the hospitals children are being tested because the physicians determine that there is a clinical indication for testing them.

Mr. RANGEL. Well, if I have a clinical indication that an inmate in a prison should have AIDS, why wouldn't that be mandatory?

Dr. BOUFFORD. The parent may have AIDS; the parent may be a drug abuser; the child may show symptoms of having a compromised immune system when they are born.

Mr. RANGEL. Well, if there is no treatment for AIDS, as the Mayor would say, why would you have this mandatory testing on infants?

Mayor KOCH. Okay, I will tell you the difference, Mr. Chairman. There is a difference between an adult whose informed consent you can get and an infant who has been placed in our care for foster care where the City becomes, in effect, the parent.

Mr. RANGEL. I am not talking about the foster care population.

Mayor KOCH. Then who are you talking about?

Mr. RANGEL. Just kids in the maternity ward.

Mayor KOCH. You mean every infant that's born in the hospital?

Mr. RANGEL. I am not asking that. I am saying that if, indeed, the mother is an addict, a heroin addict, and the child is born, would you have a mandatory testing there, even the mother or potential foster parent——

Mayor KOCH. The answer is no.

Mr. RANGEL. Okay.

Mayor KOCH. The medical practice——

Mr. RANGEL. Then it is consistent.

Mr. GILMAN. I think I have overextended my time.

I thank you, Mr. Chairman. I do take issue with the Mayor's reluctance to test some segments of the population. I would hope the Mayor would rethink——

Mayor KOCH. Mandatory. I am for voluntary testing. Mandatory.

Mr. GILMAN. I am talking about mandatory testing. I hope you would rethink that.

Mayor KOCH. I am always willing to think on any subject that you think is worth thinking about. I mean that.

Mr. RANGEL. Well, I disagree, but I think you raised enough serious questions that we have to have staff to go to the table to see whether or not any good could come out of it.

Mayor KOCH. Correct.

Mr. RANGEL. I would agree that if there could be no good coming out of it there is no need to identify that population.

Mayor KOCH. For a balance of interest. It is always a balancing of interest.

Mr. RANGEL. Exactly.

Mayor KOCH. Okay.

Mr. RANGEL. We will bring you what we have and I think it is open for discussion.

Mr. Towns.

Mr. TOWNS. Thank you very much, Mr. Chairman.

Let me say at the outset, Mr. Mayor, I agree with you on the issue of clean needles and I am happy to hear your position on that. One concern that I have is that the radio and television are not carrying your ads.

Mayor KOCH. Correct.

Mr. TOWNS. What are you doing then, to of get the message out, recognizing there is a tremendous need to educate the general public?

Mayor KOCH. Well, wherever I go and, for example, yesterday I was in a church and I said to the Minister, "I'd like to talk about AIDS and I would like to talk about it very explicitly, and I would like to mention things that are not normally mentioned in a church, and he knew what I was talking about, and he said, "Go right ahead." And what was interesting, at the end of my comments I always like to take a little show of hands, and I talked about clean needles and I talked about condoms, and what was interesting in that church which had about 500 people in it, that they were absolutely against the issuance of needles, and absolutely for the distribution of condoms, which was interesting to me.

In some cases I get people who are just absolutely against both. In some other cases they are for both. I think it is an educational operation. If you explain that you are going to save a life—that is the way I always put it—I say, "Assume for a moment that you are going to save a life or lives by giving out the clean needles, would you do it?" Well, you get more people, but there is such anger at what the drug traffic has done to this country, that I think it clouds their minds as it relates to the medical aspects, whereas with condoms there is no such anger.

Mr. TOWNS. Have you thought about an AIDS information van?

Mayor KOCH. I haven't, but I will think about it now.

Mr. TOWNS. Particularly targeting the communities that are considered high risk.

Mayor KOCH. It is a good idea. Good.

We do have outreach workers, but I don't know that we have a van, but it is a nice idea.

Mr. TOWNS. You mentioned a budget of $385 million for AIDS?

Mayor KOCH. Yes, sir.

Mr. TOWNS. How is that money being distributed?

Mayor KOCH. Well, the vast majority would be in Medicaid. You know, it costs, on the average reimbursement, about $500 a day is the reimbursement rate. It costs $800 a day to treat an AIDS patient. So in addition to our paying 25 percent of the Medicaid costs, and the Feds paying 50 and the State paying 25, the other 300 is eaten by us. So that would be a large segment.

Then we have AZT which the City, up until recently, was going to pay for totally by itself, but now the federal government is paying, and we can give you a schedule on how the 385 is broken down, unless somebody has it here, I don't know.

Mr. TOWNS. Are you funding any community based organization?

Mayor KOCH. Yes. The one group that I mentioned on a prior occasion objected when I included them because they didn't think we should include them as a City-funded group. That was the Gay

Men's Health Crisis. We gave them, I think it was something like $350,000 to help. It is obviously very small. We also are very involved in home health care. We provide services to people in their homes.

Mr. GRINKER. For the Visiting Nurses' Society we have a program for home care aid, as the Mayor has indicated. We also have a program with the AIDS Resource Center for a program at the Bailey House.

Mayor KOCH. Oh, let me tell you about Bailey House.

Bailey House is a hotel that we have purchased, which has—my recollection is 44 rooms, and every patient gets his own room. Bill Green was instrumental because the Feds had eliminated their SSI payments because they are in a building that the City owns. And he was instrumental in getting them to back off and to give them their SSI or their SSD payments. We keep that population somewhat balanced between those who are homosexual and have AIDS, and those who are drug addicts and have AIDS. The homosexual population is more affluent, more knowledgeable. They have more resources, for the most part, than the drug addicts, and, therefore, we make a special effort for the drug addicts, but we don't want to leave out that part of the homosexual population that also needs apartments. So we try to have a balance.

Mr. TOWNS. Have you explored the possibility of establishing a public hospital for AIDS patients?

Dr. BOUFFORD. Yes. At this point we have essentially had the policy that there was no medical indication for a separate facility, and so the AIDS' patients have been involved in the mainstream of our medical services. The State in its proposal to have AIDS' centers, have AIDS' designated centers in hospitals, requires that the AIDS' patients be placed in particular nursing unit for purposes of consolidating the resources available to those patients. And as our hospitals have applied for AIDS designation, we will be moving patients together, although we may not always be able to keep all the AIDS' patients in an AIDS' unit. But, again, it is not a medical indication, it is a programmatic indication.

In terms of long term, as we look towards the numbers, we are exploring the idea of an AIDS hospital, but we have some real concerns as to whether it is feasible to staff it and support it and whether it is really a better decision medically, and ultimately we will make the decision based on the medical indications.

Mayor KOCH. Can I give you an anecdotal aspect that bears upon this?

A good friend who happens to be a doctor at one of the major voluntary hospitals told me the other day of the following: They have patients with AIDS and other medical conditions, and when an AIDS patient goes into the bathtub, the special room that they have to bathe them in, they put up a sign, and the sign, which I have never seen, but it is sort of caution, but the caution is for the AIDS patient who is vulnerable to diseases that might be in the water or bathtub left by a patient who had used the bathtub before him who had some other disease. But that is not the way the patients who don't have AIDS on that floor respond. They think the sign is related to the AIDS patient and their fears go up. So what I am really trying to convey is that there is a huge problem.

When you have patients on the same floor, for the reasons that Dr. Boufford has given, it is good medical practice thus far, and very few hospitals ever want to be known as an AIDS hospital. St. Clair's basically is and it is to the credit of the Arch Diocese that they did that. Most people don't give them the credit; they deserve the credit. But there is the feeling that you are causing enormous emotional problems to some of the other patients on the same floor because the signs that are there for caution are to help the AIDS patient who is susceptible to other diseases, not the other way, but that is not the way the other patients view it.

Mr. TOWNS. How many AIDS patients are there in New York City hospitals today?

Dr. BOUFFORD. On any given day in public hospitals we have about 400 patients, in-patients.

Mayor KOCH. That is only ours. We have 37 percent of the patients.

Dr. BOUFFORD. There are probably about 900, 1,000 on any given day.

Mayor KOCH. Right.

Mr. TOWNS. Well, I think that it points out that it is a very severe and growing problem; particularly as you look down the road, the area specialization could be developed much faster if you had an AIDS hospital.

Mayor KOCH. We are not ruling that out. I want to tell you that we originally had clinics. So there was a big discussion and we went to the gay community to get their input, which I think is the thing to do. And they said that they wanted the clinics in the regular hospitals. They did not want a special clinic because they did not want to be segregated in that sense. Then, later on, they changed their mind, and they said in addition to the clinics in the regular hospitals, they also want to have special clinics that are devoted only to AIDS, and we have done both.

Mr. TOWNS. Thank you very much, Mr. Mayor. I think that you are aware of the problem and you are moving——

Mayor KOCH. We are trying very hard.

Mr. TOWNS. No question about it.

Thank you very much for your testimony.

Mr. RANGEL. Congressman Green?

Mr. GREEN. Let me return to an issue that I raised previously.

Mayor KOCH. You have no stock interest in bleach, I assume.

Mr. GREEN. No stock interest in bleach.

I really offer it as an alternative to the clean needles, if you are stymied and frustrated.

Mayor KOCH. We are going to work with that.

Let me tell you, we are absolutely going to look and see whether that is a feasible thing to do. I promise you, today I am going to ask our people to let me know before the end of the week whether it is pragmatic, responsible medically, and I am going to get back to every member of the Committee and tell you what their advice to me was.

Mr. GREEN. Dr. Koop indicated that he thought the program had been effective in San Fransisco primarily because it was administered by ex-addicts and that their counseling was a key part of the program. It doesn't seem to me important whether it is the bleach

that lures the addict in to get the counseling or whether it is the bleach itself that actually solves the problem. If it works, it works.

Mayor KOCH. I agree. I am going to get back to you no later than Friday with the best information in the City on that, and if the best information is to do it, we are going to do it.

Mr. GREEN. Thank you, Mr. Chairman.

Mr. RANGEL. Senator D'Amato.

Senator D'AMATO. Well, Mr. Chairman, first of all, let me thank the Mayor for bringing to our attention the question I know that you will be looking into, and I intend to work with you as it relates to reimbursement for the hospices. That is an incredible situation where one must be outside——

Mayor KOCH. Eighty percent of the time.

Senator D'AMATO [continuing]. Of the hospice 80 percent of the time.

I think that our efforts in the drug area just must be intensified if we are going to have any effect because the IV community is spreading the virus into the heterosexual community. People aren't as aware as they should be of the potential danger. I would also ask you to ask the Doctor to keep an open mind and to watch this situation as it relates to what is going on in the hospital rooms, not only in the hospitals that come under your jurisdiction, but to quote Dr. Koop: "There are tensions in the operating room with doctors refusing to operate, nurses quitting the operating room. Medical professionals have expressed significant concern about the potential risk of contacting AIDS during the performance of surgical procedures." And then he went on to characterize this as saying that in some cases 95 percent of the tensions in that room are with regard to the question of AIDS and their possibly contracting it.

It would seem to me given the Mayor's observation, and I agree with him, he says vast majorities of the people don't have the virus. That is why you should have testing for certain segments where you can eliminate them as people who potentially would contract this, and relieve the tensions in that operating room so that those vast majorities will get the kind of excellent care that they are entitled to and not have people double gloving when they shouldn't to perform sensitive surgery, and all kinds of other procedures.

So I hope you just keep that in mind.

Mayor KOCH. I don't rule that out at all. I think medical advice is what is required. What is medically sensible to do in a balancing of interests. I don't rule that out and I am going to ask the Board of Health, as it relates to that particular aspect, which is very limited, relating to people who are going to be operated on. Because I have heard some doctors on television say that they won't operate unless the test is given. I have heard some doctors on TV say that. So that is a factor.

Senator D'AMATO. Thank you very much, Mr. Chairman.

Mr. RANGEL. Thank you, Senator.

We are very pleased to have with us Congressman Ted Weiss who, I think it goes without saying, has been the leader in providing education and support for AIDS victims.

Congressman Weiss, thank you for joining the Committee.

Mr. WEISS. Thank you very much, Mr. Chairman, and I will ask now to have my opening statement entered into the record.

Mr. RANGEL. Without objection.

[The prepared statement of Mayor Koch appears on p. 110.]

STATEMENT OF HON. TED WEISS, U.S. CONGRESS

Mr. WEISS. Let me express my appreciation to you, Mr. Chairman, for bringing the Committee here to New York to deal with this important problem.

In the course of the hearings my Subcommittee has held over the past 4 years, what strikes me as remarkable is that there has not been more panic or hysteria stemming from ignorance: The federal government has done precious little to provide education to the American public at large. So discussions, such as the one that I just walked in on on testing, offer a broad exchange, which is crucial and familiarizes everyone with the issues.

I know that many think, at first blush that mandatory testing is a panacea. However, I know the Mayor's experience has been that mandatory testing may in fact drive underground the very people who may most need to come forward for testing.

Mayor, I read an interesting article in today's Newsday on the issue of testing infants. This offers an additional reason why infants might be tested. There have been some cases where foster parents find out that their foster child has AIDS, after they have accepted the child into their family. In such cases, they ofter tend to turn the child back. It is to the child's interest and the family's interest to prevent that kind of trauma.

Is that the experience that you have had?

Mayor KOCH. I believe that that is a fair statement. But what was interesting to me was, if you read that article, the reporter by her language was conveying distress that we were providing for such testing in the case of children that are being provided foster care.

I personally believe, but I am going to be guided by the medical factor, the medical factor does not go as far as I think, from a lay point of view, it should go. Because the medical factors, which we related a little while ago and we are happy to give you the exact aspects of it, do not require the testing of every child going into foster care, even at the request of the foster care parent, the putative foster care parent, as explained to me. As explained to me, they are only going to do it for high-risk children and we have already seen what that means: A mother who has been on drugs, or whatever else would be involved. I believe—but, again, it is a layman's point of view and, therefore, I am not going to impose it; I am going to listen to the medical people—but I believe that every foster parent, putative foster parent, should have the right to say, "I would like the child tested before the child comes into my home," because you have to deal with that child in a very special way. A child is different than an adult. An adult has to give informed consent; the City can give informed consent for a child because it is in our care. But I want to just put it right on the table, the current procedure, as explained to me by Dr. Boufford—and if I am wrong you just jump in and tell me I am wrong—is that if the

child is not one of these high-risk cases, and a putative foster parent requests testing, we simply will look for another foster parent.

That is what you said to me. That is what this procedure says. I don't happen to like that. I believe that we don't have enough foster parents, and if a foster parent, a putative foster parent says, "Well, can't you test the child before," then we ought to do that as opposed to saying, "Well, if you are insisting on this child being tested, then we don't want you as a foster parent because this child isn't in a high-risk group." I think that that foster parent is entitled to that certainty.

Mr. GRINKER. I would just add, Mr. Mayor, that over 75 percent of the children who would be entering in the boarder baby classification who would be entering into foster care, are in that high-risk classification.

Mayor KOCH. Are?

Mr. GRINKER. Are.

Because that's the percentages of those who have come from that background.

Mayor KOCH. Which even makes my point more acceptable, because only 25 percent will not have the AIDS' virus.

Dr. BOUFFORD. No. Wait, wait.

Mr. GRINKER. No, will not be from a high-risk group.

Mayor KOCH. I'm sorry, just the other way around then.

Dr. BOUFFORD. They may not have it.

Mayor KOCH. They may not have it, okay.

Mr. WEISS. Can you tell us what the backlog is for people who want voluntary testing performed? I understood that sometime ago there was a three-month backlog. Is that still the case?

Mayor KOCH. Two to three weeks, I am told by the Doctor from the Board of Health, and if it is an emergency they will get expedited care.

Mr. WEISS. It seems to me that since public health experts agree that voluntary testing is best, we ought to make sure that the facilities are available for people who want to come forward and be tested on their own.

Mayor KOCH. Just so there is no mistake, 75 percent of the boarder babies are not in the high risk——

Mr. GRINKER. Are in the high risk group.

Mayor KOCH. Are in the high-risk group?

Why don't you state what it is.

Mr. GRINKER. Seventy-five percent of the children who are boarder babies would be in a high-risk group where the foster parents could request testing if they wanted to, and those are high risk because they are born from parents who have a history of drug abuse.

Dr. BOUFFORD. I think the "high risk" that is used by SSC is a social work definition that includes among it a parent who has a history of IV drug abuse, but also includes things like a teenage parent and others. There is a whole set of criteria for "high risk" that are not purely children of IV drug abusers. So it is very important to distinguish between a high risk, which is the broader definition, and the number of foster children who may be HIV infected, which in our experience, in looking at the Corporation hos-

pitals, we, at a point in which we had about 200 to 250 boarder babies—this was some months ago before the placement programs were accelerated—only about 10 to 12 or 15 children had AIDS. So it is a small subset of the boarder baby group that are actually AIDS infected, but the high-risk category goes beyond parents of IV drug abusers.

Mayor KOCH. Less than 10 percent is what you are saying, of the boarder babies that we had several months ago, would have in fact had the virus. Less than 10 percent.

Mr. WEISS. And, again, the hopeful sign apparently is that after some 6 to 9 months an infant may in fact build up its own immunity and is no longer considered to be positive for AIDS.

Mayor KOCH. And any child that goes to a foster parent, that child can be tested later on at the foster parent's request.

Dr. BOUFFORD. They should be followed up actually, on an intermittent basis, to make sure that they could convert back, if they do convert back.

Mr. WEISS. Finally, Mr. Mayor, you were good enough to suggest that we ought to waive the requirement for the 2-year waiting period for Medicare eligibility. As you may know, I have a piece of legislation which is cosponsored by a number of people in Congress and from New York, H.R. 276, which would do exactly that.

Mayor KOCH. I am supportive and I am aware of it. And I appreciate your having taken the lead a long time ago.

Mr. WEISS. Thank you so much.

Thank you, Mr. Chairman.

Mr. RANGEL. Let me thank you again, Mr. Mayor, for the leadership you provided for the nation through the Conference of Mayors. It seems to me that we may want to think about organizing again, whether it is the spiritual leaders or the Conference of Mayors, as we see this epidemic. And since it always appears, if it is a national problem we have more than our share——

Mayor KOCH. We will do it together?

Mr. RANGEL. We will do it together.

Mayor KOCH. Good. Like we did the last one, and we were very successful.

Mr. RANGEL. Thank you.

Mayor KOCH. May I leave with you this Inter Agency Task Force Report on AIDS, issued in April 1987, which provides most of the information in greater detail as expressed here.

Mr. RANGEL. We will be working with your staff this afternoon in Washington. And Senator D'Amato agreed to work on the Senate side as related to AIDS in the hospital.

[The prepared statement of Congressman Weiss appears on p. 121.]

Mr. RANGEL. We are indeed fortunate to have David Dinkins with us today. As a sensitive former legislator, a member of our New York State Constitutional Revision Delegation, certainly as someone who has served in our community for many years who realizes that the AIDS' epidemic, the drug epidemic are all a part of larger social needs, and we apologize for the many times that you have had to revise your schedule in order to meet the needs of this hearing committee, but you are the type of individual, for those of

us who are in politics, that make us proud to have chosen that profession.

I see that you brought with you two of your outstanding assistants, that on their own have made names for themselves in the New York City community, and I ask, for the record, if you would be kind enough to identify the names of the people who are sitting on your panel?

TESTIMONY OF DAVID N. DINKINS, PRESIDENT OF THE BOROUGH OF MANHATTAN, ACCOMPANIED BY BARBARA TURK AND SHARON KING

Mr. DINKINS. Congressman, thank you so much. Mr. Chairman, I am delighted to be here with two other good friends that you have with you, Congressman Ben Gilman, a longtime friend, and of course, Ted Weiss, Congressman, it is a pleasure to see you.

I am accompanied by Barbara Turk, to my immediate right, and Sharon King, and I am delighted that I have had the good fortune to attract these women to my staff.

Mr. RANGEL. Mr. President, pardon the interruption, but you have two staffers in the audience too, for the record.

Mr. DINKINS. Two people who work for me as well, Arnaldo Sagarra, a longtime friend; some think he's a movie star, but he is not. And Keith Wright who is in charge of our uptown operation. Bruce Wright is now referred to as the father of Keith Wright.

Mr. RANGEL. Well, the Chair appreciates that identification which once again shows your good judgment.

Mr. DINKINS. I am delighted to be here. I thank you, Congressman Rangel, my longtime friend and colleague, for this opportunity. And I am honored to be part of a hearing which includes such distinguished speakers as Dr. Koop. His outspoken and courageous leadership stands in welcome contrast to an otherwise anemic response by the Ronald Reagan administration. Likewise, I am grateful to Dr. Beny Primm and to President Jim Butler for their leadership. I am sure that this audience does not have to be told about them.

I appreciate the wisdom of my colleague in government, the Mayor Edward I. Koch, in appointing Dr. Stephen Joseph to head the city agency most involved in the AIDS crisis. I am especially pleased to note in our audience, as she may have gone now, Queen Mother Moore, who today, Congressman, Queen Mother Moore has reached her 89th birthday. I am sure you would wish to acknowledge that for the record. [Applause.]

Mr. RANGEL. The Chair begs the speaker to interrupt to ask Queen Mother Moore to please stand so that the Chair and this Committee could thank you for the years of service you have given to us. [Applause.]

And I would like to report to you that we will have hearings very soon on the Marcus Garvey bill that because of your inspiration and support, we hope that his name and memory will be exonerated by the U.S. Congress.

Mr. DINKINS. This gives me an opportunity to also, Congressman, acknowledge the fine work of the chief of Pediatrics here at Harlem Hospital, Dr. Margaret Heagarty. And it provides me with

an opportunity to thank Suki Ports of the Minority Task Force on AIDS. We have gotten an awful lot of fine help and cooperation from her. I know that everyone here is grateful for the compassionate example set by Mother Hale and her daughter, Dr. Lorraine Hale.

I will take this opportunity to briefly put the problem of pediatric aids and AIDS-related complex into perspective by describing some of my general concerns about the course of this epidemic and our attempts to address it. I will then attempt to outline and discuss these issues as they relate to children.

If New York City is the North American Epicenter of the AIDS crisis, Manhattan is the core of that epicenter. Manhattan residents account for 48 percent of all reported AIDS cases in New York City, and 41 percent of all deaths.

Six years into this epidemic there are few residents of the borough I represent who can say that they don't know or don't know of someone who has died of AIDS. We plead with the Congress and the Reagan administration to take heed and confront candidly the AIDS epidemic in this city and in this nation. The future face of this health crisis in most other cities in this country is here today, right now, in New York.

As with most crisis, AIDS does not exist apart from other chronic problems we face in our cities. The connections among AIDS and poverty, drug abuse, limited access to health care, the housing shortage, discrimination, illiteracy and other barriers to AIDS prevention and treatment must be acknowledged and explored. Without this perspective, effective measures cannot be undertaken.

AIDS is not only the product of certain risk activities, but also of social and economic conditions which place entire communities of New York City at greater risk than others.

AIDS is not simply a gay disease; AIDS also has a disproportionate impact on poor and minority people in this country. This is particularly true where children are concerned. The disproportion is reflected in both the surveillance data and in the lack of access to quality support services and health care. In the United States today, blacks constitute 12 percent of the total population and Latinos 6 percent; yet 25 percent of persons with AIDS are black and 14 percent are Latino. In New York City, the majority of people with AIDS—56 percent of reported cases—are black, Latino or Asian. Eighty-four percent of women with AIDS are a minority and 90 percent of children with AIDS are born to minority women.

The high incidence of drug abuse among minorities helps explain this disparity. We also know that the average life span of a white person with AIDS after diagnosis is two years, while the average minority person with AIDS lives only 19 weeks after diagnosis. We suspect that our two-tiered health system largely explains this disparity.

Because of limited financial resources and fear or ignorance of what assistance is available, poor and minority people tend to delay seeking medical attention until they are severely ill. The public health care system is further strained under the circumstances. Nearly 20 percent of the medical beds in our City's public hospital system are devoted to people with AIDS. Working to prevent AIDS is made difficult by prejudices which exist against racial

and ethnic minorities, poor people, drug abusers and gay people. Information developed by the Federal government and others has contributed to this prejudice by categorizing those with AIDS into so-called "risk groups."

Talking about risk groups rather than "risk behavior" has allowed people to deny their individual risk. This denial prevents people from taking actions necessary to protect themselves and their loved ones. At the community level, it keeps people from organizing to provide services and promoting unified action on behalf of people with AIDS.

This is a health crisis and responsibility for addressing it rests with all of us. In discussing the impact of AIDS on children, what we are really addressing is the impact of AIDS on heterosexual families. The number of children with AIDS is increasing because more women are infected, either because of their own drug use or by sexual contact with an infected partner. Therefore, preventing pediatric AIDS requires efforts to stop IV drug use and unprotected sex. The Federal government must seriously consider the enormous impact on existing programs that this circumstance has and will cause. The following situations are typical.

A woman whose partner used drugs and died as a result of AIDS is now beginning to show some symptoms herself. She has two young children. How does she support her family when she becomes too ill to continue working? What happens if she is evicted from her apartment, either because she loses her job and can no longer pay the rent, or because her landlord discovers she has AIDS and wants her out of the building? What happens when family members who might help support her and and her children reject her? What will happen to her children when she dies?

Consider also the infant born seropositive. Because the baby's mother is infected, the infant was born with a low birth weight and evidence of neurological damage. The baby's mother abuses drugs and traces are found in the baby's urine. Foster care takes the baby, but no placement can be found because the baby is infected with the virus.

Consider also the impact of AIDS on children who are not infected, but who live in a family where one or more members is symptomatic. That child faces the uncertain future brought on by the loss of one or both parents, and perhaps a baby brother or sister. The child may also face rejection experienced by anyone who lives with someone who has AIDS.

In New York City, there are hundreds of cases like these. One of the reasons that AIDS is so devastating is that we are not prepared for so many who are so young to die. The news that a parent or a child will die turns everything upside down. Some families are better equipped to deal with the consequences than others. But because so many of the families affected by AIDS are struggling to begin with, AIDS is easily the straw that breaks that family's back.

As I understand it, this Committee seeks to develop a response to some of these problems. Your interest stems from the fact that most children are afflicted with the AIDS virus because one or both of their parents uses drugs. I will suggest some areas which this Committee might consider in developing a response to this problem.

The most obvious and important thing this Committee can do for children is to continue its fight for additional Federal resources to prevent and treat drug abuse. At least one-third of those with AIDS in New York City contracted it by either using intravenous drugs or having sex with someone who uses intravenous drugs. It is with children that we most clearly see the awful impact of drug use and AIDS. Fully 81 percent of children with AIDS are infected because one or both of their parents uses or used drugs or had sex with someone who uses drugs.

Given what we know about AIDS transmission, the attempts of the Reagan administration to withdraw last year's pre-election commitment to drug prevention and treatment programs are particularly cruel. Between expanded narcotics enforcement efforts and increased awareness about AIDS, the number of addicted people seeking treatment is increasingly dramatic.

If the Federal administration is serious about preventing AIDS and fighting drug abuse, it will commit itself to the goal of providing treatment to every person who wants it. It has been suggested that a program that distributes clean needles and works to help active intravenous drug abusers might help prevent the spread of the virus. Though the end is commendable, the means is questionable. Drug use is unacceptable and we must not be satisfied with the notion that we can somehow make it safer. Instead, let the AIDS epidemic move us forward with the firmer resolve to prevent and treat drug abuse.

I also urge members of this Committee to exercise their leadership in addressing the other circumstances surrounding this problem.

AIDS has exposed gaping holes in the way we provide health care, housing and social services, as has no other single problem. Our health care system does not have the community orientation or flexibility necessary to handle large numbers of people whose health needs vary with the course of the syndrome.

Social service providers have limtited resources at their disposal and are severely overtaxed by the enormous task of counseling and helping families manage the many complicated arrangements which have to be made. The critical shortage of housing for low-income people is a severe obstacle to proper care and management of these families.

The Federal government's dwindling support for these services makes it almost impossible for service providers to help people with AIDS, their families and their loves ones cope with the life-changing circumstances created by terminal illness. There is no safety net for people with AIDS. This does not mean we should create a separate service system for people with AIDS. What we need is your support of a Federal budget which seeks to restore cuts in health care, housing and public assistance, which in turn translates into support for these families and children.

There are also some specific things which must be done. The Federal government must provide massive, candid public education about how the virus is transmitted. As the Surgeon General has noted in the past, this not only prevents the spread of the virus, but the kind of health care and other services we need are impossible to provide without it.

As long as landlords are afraid to rent to people with AIDS, as long as some health professionals quietly refuse to treat them and existing day care and foster care providers fail to accommodate them, as long as people are afraid to come forward for services, it will be impossible to help. Their fears are a barrier to proper care.

I urge this Committee to expand AIDS prevention efforts targeted to drug abusers. Last year our office successfully negotiated an increase in New York City's budget to provide for a mass media campaign aimed at IV drug abusers and heterosexuals. I would remind you that last year our budget was in deficit posture and there were not an awful lot of people interested in the distribution of resources for this kind of purpose. The first phase of that campaign was introduced in May. It is apparent, however, that we cannot do this alone; the Federal government must do more to support our efforts.

Support services for families and children affected by AIDS are another area of great concern. Our temptation with any new challenge is to set up a separate system to deal with it. While some special efforts are necessary to help children when they truly need separate care, we must not absolve our schools, our day and foster care programs and other institutions from their responsibility to provide services to all children.

In considering Federal funding for AIDS-specific programs, please consider that current Federal spending emphasizes research and surveillance.

These efforts are not unimportant, since we need to understand the progress of the syndrome and we all wait anxiously for a cure. However, as more people become infected, local and state governments desperately need assistance from Washington to provide adequate health care and related services for these families.

As the Federal government supports research which identifies women who are HIV positive, it must not walk away from them without providing funds to support the services which they and their children need.

Finally, there has been a lot of loose talk about mandatory testing. Mandatory testing is not a panacea. There is no convincing evidence that people who know their antibody status will change their behavior. Unless testing is undertaken voluntarily, with informed consent, and accompanied by counseling, it has the potential to be used as a weapon against the person who is tested.

There is no conceivable public health benefit to mandatory testing for specific groups of people. Our best and most effective weapon against the spread of the virus is education, not testing. I mention it today because it raises a host of issues with regard to the reproductive rights of women. Indeed, some have suggested that mandatory testing of women in their child-bearing years could lead to forced sterilization. Women should have access to voluntary, confidential testing. The decision to be tested must be made by the individual in consultation with her physician. It should never be a decision of the state.

I will close with what I call the Vermont example. Not long ago, the state of Vermont announced it was establishing a public education campaign about AIDS. Here in New York, many questioned why such a campaign was necessary, since Vermont at that time

had only seven reported cases. Of course, Vermont state officials reasoned that with so few cases, now was the time to start its prevention efforts. Many people could not understand this simple reasoning, since we're so accustomed to responding to a problem only when it becomes a crisis. Let the attitude of Vermont state officials be the attitude of the leadership of this nation: AIDS is already a crisis in many of our cities. It cannot be allowed to become a national crisis.

Sadly, it may already be too late. The epidemic is already well under way because the Federal administration has failed to act decisively and wisely. Even if the administration were to devote the necessary resources today for education and prevention, it cannot prevent the impact of the eventual sickness and death of millions of Americans who are already infected. The impact of this reality on children has been and will be tragic. Children with AIDS are the innocent victims of this shortsightedness and the failure to prevent drug abuse and to protect the health of the poor and minority people in this nation.

If some of our nation's leaders have found it impossible to find the compassion in their hearts to deal constructively with the health crisis which appears to them to deal death to drug users and gay men, let them consider carefully the problems of these children and think twice about dismissing this snowballing human catastrophe.

I'll be happy to try to respond to your question, Mr. Chairman.

Mr. RANGEL. Borough President Dinkins, you have really brought a lot of insight to these hearings. All of the witnesses have pointed out the large degree of incidents of AIDS in the black and minority community, but only you have reflected on some of the conditions that have caused the minority community to be more vulnerable. Recently, one of our City public officials had identified the color of street criminals as being black as though it was some type of secret. To me, this is just as dumb as identifying anybody who is involved in City corruption by their religion or background or Wall Street corruption by religion or background. But the fact is that if you must identify by color, whether it's street crime, whether it's drug abuse or whether it's AIDS, then an obligation has to be associated with it as you so clearly demonstrated in your testimony. Target attention to the problems that cause people to be drug abusers, to commit crime and to end up with AIDS.

It seems to me that you have, on your program, testified to this Committee that we have to do more with AIDS than just preventing our community women from going into prostitution or our young men from abusing their bodies or the fact that our prisons are just swollen with black men and women and young people that should really be given an opportunity to give to life instead of having liberty taken away from them. Unless we deal with education, employment opportunities, job training, decent housing, then the problems we are testifying to will always increase. Your testimony was the only comprehensive testimony that we have received to say that yes, do more to deal with this crisis, but at least go back to Washington with the understanding that it would only be a band-aid approach to a much more serious hemorrhage of social and economic problems. You've dealt with this as Borough Presi-

dent on all issues with the same broad understanding of the problem and I'm a better congressman because of your leadership. This Committee is better informed because of your testimony. I just wanted to publicly thank you.

Mr. DINKINS. I thank you very much, Mr. Chairman. With respect to that comment you made about that public official, I was pleased to note in today's press your quotes along similar lines. That is, along the lines of the root causes of crime, which has been the observation of our office as well. Until people can understand that we face a difficult circumstance in this neighborhood because, for instance, the infant mortality rate was 27.6 per thousand of live births in 1986, 23.3 the previous year and 16 per thousand in 1984—while in Yorkville, it is never greater than 10 and some years as low as eight. Until people understand that kind of thing, until they visit the prenatal clinic right here in Harlem Hospital and see some of the problems with which we are grappling and understand that it costs an awful lot less to provide treatment, they will not understand that many women who have children see the doctor for the first time when the child is delivered. We can do a lot better than that.

And so, until we, as you in your eloquent fashion point out, recognize that the problems of health care, housing, education and job opportunity are all interrelated, it is not only inaccurate but grossly unfair to suggest that the minority community is somehow peculiar with respect to some of these things. I'm pleased that you received our testimony as we intended it. I thank you.

Mr. RANGEL. Thank you. Mr. Gilman.

Mr. GILMAN. Thank you, Mr. Chairman. I certainly want to commend Borough President Dinkins for his presentation today and for emphasizing some of the important approaches. Borough President Dinkins, what amount of money has been allocated for the entire AIDS program in the City of New York? The Mayor indicated it was around $300 million.

Mr. DINKINS. I am told that that figure is the combined jurisdictions, state, local and federal, and of that which comes from the City, perhaps a third.

Mr. GILMAN. About a third of that. How is that money spent, that $300 million?

Mr. DINKINS. Some of it, a small amount is in education. Seven million is in education.

Congressman, I don't have the precise numbers at hand, but they are in that report. You know the report that the Mayor left as he was departing, it is in that, but it is certainly an appropriate question, how we spend that money. I don't know that we, one, spend enough or that we necessarily allocate it in the most useful fashion.

Mr. GILMAN. And you say that about one-third from the federal government, a third from the state and a third from local?

Mr. DINKINS. Well, no. I said a third comes from local government. I am not so sure of the breakdown of the other two-thirds.

About a third of that $300 million is ours.

Mr. GILMAN. I would be a bit concerned, when prevention is such an important aspect of all of this, that so little of that $300 million

is being spent on education. Is there some way that we could adjust that?

Mr. DINKINS. Well, we agree with you. As I said a moment ago, the money that was put in the budget in 1986 we, this office put in. And as you will recall, we were in a deficit posture so it was difficult to come up with money for almost anything. But we fought for that and I am sure Dr. Joseph will tell you, we think it is very important.

Incidentally, this gives me an opportunity to say that we are now—we met with Dr. Joseph in the last week, and we are now trying to see what we can do to help raise some private money. We anticipate we need about a million dollars to further publicize the pro bono ads that we were given. Mino Jones, which is a black advertising firm, has done some pro bono ads and we want to get that out and get them publicized.

We recognized also that the kind of outreach you need in the minority community, given the relationship to drug abuse, is not subway car ads. We need something far more intense.

Mr. GILMAN. Have you devised some special program to reach out to the minority communities?

Mr. DINKINS. Well, we believe that there are organizations that deal with the minority community, and people who have the credibility, like Dr. Beny Primm, from whom you will hear later, there are the Minority Task Force and Suki Ports. There are people like that with real credibility in the minority community who can be tremendously helpful, and these are the kinds of organizations that should be given the resources and to help them for their own use and to help them identify other such organizations that have the ability to reach out into the community.

Mr. GILMAN. Mr. Butler, who will be testifying a little later on behalf of public employees, indicates that there is no money in the budget for hiring the needed health-care workers in this area. Would you respond to that criticism?

Mr. DINKINS. What do we know about the numbers?

Mr. GILMAN. It points out how understaffed we are at the present time in health care for AIDS patients.

Mr. DINKINS. Well, I have met with Jim Butler from the union, who is, I might add, one of the most progressive, forward-looking labor leaders in the City, not just in our community, and I know of his concern for his workers and whether or not they get appropriately trained and educated and have the general resources. I can't speak intelligently to the numbers of workers. I am sure he would be able to.

I would add, anything that Jim Butler tells you, you can make book on it, as to accuracy.

Mr. RANGEL. Is that a gambling term that you used?

Mr. DINKINS. That is a gambling term that they use legally in Las Vegas.

Mr. GILMAN. Mr. Borough President, you heard the discussion earlier about the possible need for a special hospital dealing with AIDS patients; what are your thoughts about that for the City of New York?

Mr. DINKINS. I certainly would not dismiss it. That is a subject of some interest to Jim Butler, I might add. I have discussed this with

him, and whether that is what we need at this moment, as opposed to increased resources within certain hospitals, I don't know. I sort of leave such questions to the professionals. But it warrants consideration. I certainly would not dismiss it out of hand.

Mr. GILMAN. And just one last question: What would you feel is the most important thing that we in Congress can do to help in your fight against AIDS?

Mr. DINKINS. Well, I suppose, aside from further money for research and education, which I think is sort of obvious, I think it is hitting away at root causes. You and your Committee have done some fine work with respect to drug abuse, and in many respects that is where a large measure of this problem lies, certainly for the minority community, and I would urge continued work in that area.

I suppose the other thing with which some of us are very concerned is the enforcement, where we have such laws, enforcement of laws against prejudice and discrimination of people that they even suspect have AIDS. You can get some awful brutal, cruel treatment.

As you know, Congressman, I was the City Clerk for some ten years before the people in their wisdom, or lack of it, gave me this privilege.

Mr. RANGEL. How many times did you lose?

Mr. DINKINS. I lost a lot. [Laughter.]

Congressman, it is because of you that I finally succeeded.

But when I was City Clerk I had—among my jobs was running a marriage license bureau. One day it came to my attention that there was a woman who had come in seeking a marriage license and the groom, the intended groom was in the hospital. Now, it had been the custom for many years to require the man and woman to come into our offices. However, where there was illness, sometimes confined at home, sometimes confined in the hospital, in jails and certain other circumstances like that, we go to them. So this was not an unusual request, except that this woman made the mistake of bringing in a letter from the physician that said that the man had AIDS and, therefore, was terminally ill. Now the purpose of the letter was to say that this person was terminally ill, so hurry up and issue the license and please come to the hospital. If the doctor had said "terminally ill" and hadn't said with "AIDS,' the question would never have come up, but because he said with AIDS, one of my clerks said, "Oh, no, we can't handle that." Fortunately it came to my attention and I went, and I issued that license in the hospital room, and I issued two others, I believe, after that. And thereafter it was never a problem.

This is ignorance, really, the fear that they were going to contract AIDS by visiting that hospital. But I went into that hospital, into the room, and all I really had to determine was whether or not this patient understood what he was signing. He convinced me that he did; he signed with a witness there, and I left, and it was that simple, but it would not have been had it not come to my attention.

Mr. GILMAN. Thank you, Mr. Borough President.

Thank you, Mr. Chairman.

Mr. RANGEL. Congressman Weiss will inquire.

Mr. WEISS. Thank you very much, Mr. Chairman.

I simply want to associate myself with the comments that you and Mr. Gilman made about the importance and validity of the testimony given by the Borough President. It was important and very eloquently stated.

I couldn't agree with you more about the importance of education. To put this in context, last October the National Academy of Sciences suggested that by 1991 we ought to be spending a billion dollars a year each on research and on education. Well, we are coming very close. The federal government's budget presently being considered for fiscal year 1988, will be appropriating around $950 million for research and education.

But as far as FY 1987 education budget is concerned, the best number we can get out of the Public Health Service people that they have to spend spending, is somewhere around $80 million. And when we try to get specifics as to where it is going, it becomes very clear that hardly any of that has really been spent. So we have a long, long way to go before we start committing the kind of resources in the kind of ways that will reach people.

In that context, let me ask you: A long time ago, when I served as a young prosecutor here in New York, we used to have youth workers who went out to work with their youth gang; is anything of that kind being done in New York in relation to bringing the message about AIDS to the addicted population? I know that in Newark something like that is being done, but I haven't heard of it being done here in New York City.

Mr. DINKINS. No, but we had some money in this past budget, $350,000 for youth education. But there is not the kind of thing of which you spoke.

Now, Arnaldo Segurra, who is somewhere back there, that you, Congressman Rangel, referred to earlier, back in John Lindsey's days, did that kind of thing, not with respect to AIDS, but in terms of working with so-called youth gangs. I have served on the board for many years of a group called ICRY, Inner City Roundtable for Youth, which I describe as sort of a federation of youth gangs. We meet representatives from various gangs all over town, and I suspect that groups like that have the ability to go out into the community in a fashion that some cannot. And I think that it would frankly cost us an awful lot less to expand the resources in that kind of direction than some of the things that we do do.

I suppose the example I cite all the time is low birth rate babies, because while it is a different area, I think it is graphic. They tell me that we can spend upward of $1,000 a day and in some instances the child can remain in the hospital for as long as 20 weeks. Now, I don't know what the average time is, but I can see that it is a lot of money any way you slice it. Suppose we just provided the decent nutrition and education and health care, it would cost a whole lot less.

Beny Primm, I am sure, will tell you what it costs for drug treatment in a program. I don't know what the numbers are and he will tell you, but I imagine $10,000 or $15,000 per person per year, but it costs us in excess of $43,000 a year at Rikers. Now I just cannot understand how we in government don't do some things more intelligently.

Mr. WEISS. Finally, would you have any information concerning the backlog of people who go to the voluntary testing centers and how long they have to wait before they get tested?

Mr. DINKINS. Our information is two or three weeks. I heard that question put earlier, and I don't have any counter-information than the 2 or 3 weeks that they suggest, and I assume that they really can expedite it for an unusual circumstance.

We have our own little network and sometimes we get information which is different than the information that they are giving out in government, but in this instance we don't have any different information than that.

Mr. WEISS. Thank you.

Thank you, Mr. Chairman.

Mr. RANGEL. Let me thank the Borough President, as well as his able counsel that he brought to the table, which shows how he gets such strong support for his worthwhile ideas.

Thank you very much. We look forward to working with you.

Mr. DINKINS. Thank you. It's good to see you all.

Mr. RANGEL. I would like to call the next panel.

Truly when it comes to the community fights it is an honor for this Committee to have put together Dr. Margaret Heagarty, who is the Chief of Pediatrics of Harlem Hospital, who brings not only outstanding medical knowledge and expertise, but more important sensitivity and loving care for the many infants that have been delivered in Harlem Hospital under her direction. Dr. Lorraine Hall, the daughter of Mother Hale, who is the Executive Director of Hale House Center, and we certainly know that long before abandoned children or minority children were able to get public service for them, that Hale House was always open, which was Mother Hale's home, and always had the love and care of her mother, as well as her sister and Lorraine Hale. Dr. Beny Primm, who by any stretch of your imagination has to be one of the nation's foremost authority on drug abuse and has been called by every president for his advice in this very serious matter of treatment, and who heads up my brain trust on drug treatment, as well as AIDS, and was the first to point out the danger to the minority community. And Suki Ports, who has been involved with every struggle to improve the quality of life for all Americans, and especially of those who carry the additional burden in our society of being a minority American, and she heads the Minority Task Force on AIDS.

I can say without fear of contradiction that we have got on this panel the sensitivity, the expertise that the nation will be sharing through your testimony on this Committee. And I will take even the liberty now to ask all of you to consider duplicating this for the members of the National Black Caucus as we will have out here in September, because what all of you have been doing over the months and years, now your nation comes to you, one, to thank you; two, to ask you to continue the struggle; but most importantly to get your advice on how we can better the community that has been hit so hard.

So we thank you and we will ask Dr. Heagarty, please, to start off the testimony.

I say before you start that all of your testimony will be entered into the record as transcribed, and you may proceed, all of you, in a manner that makes you feel most comfortable.

[The prepared statement of Mr. Dinkins appears on p. 123.]

Dr. Heagarty.

TESTIMONY OF DR. MARGARET C. HEAGARTY, DIRECTOR OF PEDIATRICS, HARLEM HOSPITAL CENTER

Dr. HEAGARTY. Thank you, Mr. Congressman. And I want to thank you and your distinguished colleagues for this opportunity.

As the Director of Pediatrics for this hospital, I think I might be most useful to you if I simply tell you a little bit about the problem of AIDS and children as found here.

As you may know, as you no doubt do know, Harlem Hospital represents the major source of medical care for the children of this community. In the past two or three years we have been forced to confront this epidemic in children. At present I can report that we have about 60 or 70 children for whom we are responsible for their care, children with AIDS or its milder version, the AIDS-related complex. And about eight to 12 children are hospitalized in this hospital at any one time. All the evidence suggests that we are in the early stages of this epidemic, for in the past 18 months the numbers of children that we have become responsible for have tripled. These children are, for the most part, children of intravenous drug users or women who have had intercourse with intravenous drug users, and they present with serious symptoms, with severe growth failure, with chronic pulmonary or lung disease, and in the later stages, with severe neurologic deterioration, nervous system deterioration.

You have my formal testimony, so I will only make a few points and then will be glad to answer any questions that you might have.

First, while I realize that some might be inclined to be punative in their judgments about the parents of these children, we in the trenches have come to appreciate the tragedy of their lives. I don't wish to be dismissed as another soft-headed, knee-jerk liberal, because many of these parents are angry, hostile, not particularly cooperative people. But many, if not most, are courageous, appreciative, hard working within the limits of the tragedy of their lives, and they all, virtually all, love their children as you love yours.

Second, children with AIDS in this hospital are, by definition, poor. Harlem Hospital as the municipal hospital is the medical equivalent of Hill Street Blues. In the best of circumstances, this hospital is under-funded and lives from hand to mouth because it must rely upon the largesse of the City of New York to fulfill its mission. The AIDS epidemic has stretched the financial and human resources of this already-embattled institution to an almost intolerable limit. Without help from the Federal government, this hospital will not be able to continue to provide care, not only for the AIDS patients, but also for the others of this disadvantaged community who must rely upon this hospital for health care.

Third, medical care is in many ways the simplest of the needs of the children of this community with AIDS. They and their families need resources outside the hospital in the form of housing, home

care, respite care. Unfortunately, our current system of social services is organized into categories that are no longer, if they ever were, functional and relevant. In our desire to ensure that only the eligible can apply for this or that program, we have placed bureaucratic paper barriers that only the most socially organized could hurdle. We must find ways to provide comprehensive programs that are responsive to the needs of these patients and their families rather than to spend the enormous amount of time and effort we must to fit the patients to the requirements of the program.

Most of the children—and I should be clear—most of the children for whom we provide care are at home where their parents or relatives are trying to cope not only with the tragedy of their illnesses, but also to find the money to provide what these children need. However, right now, on the 17th floor of this hospital are five little boys with AIDS, the same five little boys that were here a year ago when you toured last August. They have been in this hospital from 12 to 18 months. None of these children require hospital care at this time, but their families, for a variety of reasons, cannot care for them. They have become the children of my staff and to the eternal credit of my staff, they have responded with love to these children. They care for them as if they were their own.

If you were to come up, you would find children sitting on the laps of already overworked nurses as they write their notes in the medical record. You would find young doctors carrying them around on rounds as they make their rounds with their attending staff. You would find the young cleaning man who mops the floor carrying on a conversation with them as he mops the floor. But they are our children, and we know they deserve better than a hospital ward. They deserve the sun and the trees and the laughter of a family for the duration of their abbreviated lives.

For this small group of children, either foster care in an individual family or in a small, and I do mean small group home, as Dr. Hale will describe, is what is required. But we need the money and the resources by which to construct these programs.

Now, I don't pretend to know exactly how to write the legislation or the regulations necessary to begin to provide care the medical and social care these children need. But it strikes me that if we are going to provide catastrophic health care for the elderly as I note you passed last week, in justice we should consider some additional funding for these children. For how we as a community, as a society, deal with this new disease, how we respond to the needs of these children is a more important test of our values and norms than almost any other problem this country faces or has faced in the past.

Again, I want to thank you for your interest that is sufficient enough to come to Harlem Hospital to see for yourself, and I'll be delighted to answer any questions you might have.

Mr. RANGEL. Doctor, thank you for your very moving and sensitive testimony. The Committee has agreed to hear the whole panel before we question Dr. Lorraine Hale.

[The prepared statement of Dr. Heagarty appears on p. 141.]

TESTIMONY OF DR. LORRAINE HALE, EXECUTIVE DIRECTOR, HALE HOUSE

Dr. HALE. Good afternoon. Thank you, Congressman. As you know, it usually falls to my mother to make these talks, but she said that today she might forget and call you by your first name, since she's known you for so many years.

First of all, I'd like to thank Dr. Heagarty, Chief, Pediatrics here at Harlem Hospital. Certainly, no one I know is as close on a daily basis to the children we are talking about here today than you are.

When AIDS first came to Hale House two and a half years ago, my mother, staff and I were just scared. Dr. Heagarty sent a handsome young man named Dr. Nicholas of Hale House to meet with all of us. After he explained how the virus was transmitted, our fears diminished somewhat. Since then, seven other babies have been hospitalized.

Congressman Rangel, throughout the turbulence of events surrounding the outbreak of this disease, your leadership has always been present. We are so pleased that you kept your focus on the issue of drug abuse as a primary cause of the social, moral and economic disintegration of this community. Today, as a result of your wisdom, we are gathered here in Harlem Hospital to discuss AIDS, another dimension of drug abuse and to make recommendations for solutions. For this, we owe you a very large debt.

Our appreciation is also for Mayor Koch who recognized that though the numbers are small today, the potential for the spread of the disease is enormous. Both Mother and I know of his care and concern for the infants and the children in this City. Of course, there is Borough President Dinkins. We have been gratified by his long history in the effort to eradicate drugs from New York City. We agree with him, certainly halting or reducing the importation of drugs will significantly reduce the spread of AIDS.

Unfortunately, the rapid spread of this disease among non-drug using populations has caused further alarm. We know that within the African-American community, 12 percent of heterosexual cases of AIDS have not been closely related to, nor the result of needle-sharing and drug use.

This should come as no surprise when we acknowledge that there are only 47 Afro-American males to every 100 females between the ages of 18 and 25. Given this statistic, the exploratory nature of men and the sexual needs of women, unless extraordinary educational steps are taken to inform young adults regarding precautionary measures, the continued spread of this virus can be anticipated. As of today, the spread of the virus is not limited to one ethnic group or one age group or one social class; the virus has already demonstrated its ability to infect indiscriminately.

The one absolute victim of both the habit which becomes a disease and the disease which kills, is the newly born. This leads me to thank the inspiration for our forging ahead with the concept of the Hale House cradle to the Surgeon General Koop. This past April in Philadelphia at the Children's Hospital, I attended the conference on Pediatric AIDS. I recall the quote from the report:

There is much that we do not understand about this disease, but we do know enough and we have enough knowledge to treat these children so that the quality of

their lives is improved. It is our responsibility to ensure that they receive the medical and social care they need to live humane and civilized lives. It is our moral obligation to do so.

The day following the end of the Philadelphia workshop, our staff spent endless hours planning, discussing, arguing and revising our program for pediatric AIDS patients. I was adamant about only two things: that we move as expeditiously as possible to ensure our input, experience and commitment to these children, and that we operate a program in conjunction with Dr. Heagarty and the Pediatric Department of Harlem Hospital.

Incidentally, I should add that one of the other things that I wanted to do was to call it "Koop's Cradle," but that went thumbs down. He was not terribly interested.

We have moved to re-create a program similar to the current Hale House. Hence, Hale Cradle will be a small, residential facility, a group home, a residence for unrelated babies born addicted to drugs, but who, in addition, will have the positive antibodies for the virus, AIDS.

This is not only local, but national. Everywhere Mother and I travel—Chicago, Philadelphia, Boston, Detroit, California—we are asked, what can we do? How can we help here in our own state? Our answer is always the same: we can organize, we can educate and you have to persevere.

For many years, many people have spoken about Hale House as a model for infant care in a group setting where parents get a fair deal and where they are always respected. Yes, Hale House is a model. But more than that, it represents the ability of ordinary Americans to see a community need and to identify and organize the resources necessary to address that need. Today, we have the same faith and courage we had 19 years ago. People ask if we are afraid of our new commitment, are we afraid of the babies with AIDS. Our answer is "No," for to us faith and fear cannot co-exist.

Pediatric AIDS in simple talk just means a baby, a sick baby. Our mandate at Hale House is to care for babies, well or sick. During those times when the babies are not ill, they will live full, active, unsegregated lives: runny noses, bruised knees, torn socks, lost mittens. We'll probably run out of mittens on a regular basis. Activities during these times will include infant stimulation, toddler developmental activities, preschool games and learning. Physicians, teachers, nurses, child care workers, occupational therapists and psychologists will all be available to teach, to play and—best of all—to give love to each and every child. The goal, as always with Hale House tradition, is to reunite children and families.

Special staff will work with family members, support groups and other social agencies to prepare the way for an eventual homecoming. While the children are under our care, when symptoms develop and they will develop, we will deal with them medically: hospitalization when required, no hospitalization when not required.

For those who die, and many will die, Hale House Cradle will always be there for the children and for the survivors. Grief share is grief survived.

For AIDS children in foster care, here too Hale House Cradle will serve as a support mechanism, a place to share problems and gain strength. For research, what we learn, we've been told, will be

invaluable to the entire nation. In siblings, why does one have the virus and not the other? We shall provide, along with Harlem Hospital, training for health care workers, community education and be a source of public information.

The dozens and dozens of unknown questions that need to be answered will be answered. The end result: a precise and systematic methodology for all America. That and more. That's Hale House Cradle.

Money is required, but the cost of maintaining a child at Hale House Cradle is significantly less than in a hospital. Permit me to explain. Ten years ago, it was estimated that in New York State there were 28,000 female drug users, 26,000 of child-bearing age, capable of giving birth to 3.5 babies over a 15-year period. Given today's statistics, we find that there are 75,000 women just in methadone maintenance programs; 63 percent or 47,250 have positive antibodies for the virus. They too are capable of giving birth to 3.5 babies over a 15-year period, for a total of 165,375 babies, the vast majority of whom will also test positive for the antibodies.

The cost of maintaining one baby in Harlem Hospital for one day, as has been told to me by Dr. Heagarty, is $600, or $219,000 for a year. Simple calculation can reveal that the hospital care is greater than the cost of the care at Hale House, which is only $161 per day per child.

We expect Medicaid or foster care to pay for all of these children in homes or in hospitals. In other words, the American people—you—will pay the cost for the care of these infants.

On the other hand, and I say this with some great concern, we have managed to stay out of political phraseology because we wanted to. But I have seen some things happen in New York about which I have a lot of concern. For example, the monies allocated by New York State, public funds, if you will, are in the hands of those unwilling or unable to share, another small cadre of men setting themselves above the will of the people, delaying progress with petty jealousies, demarcation and territorial disputes, personal grudges and squabbles. Perhaps Suki Ports will be talking a little bit about that.

This epidemic is an enormous problem with survival implications for the entire American population. Why then did the State of New York deliver the fate of the poor, the black, and the disorganized to a group, a handful of self-servers without reins.

Let us hope that on the national level, funds will be distributed on a fair and equitable basis.

In conclusion, today we have an opportunity to learn from history. In the 1950's, drug abuse, though known and documented to be an American disease, was deliberately and systematically relegated to a condition affecting only the black community. And it was allowed to flourish, destroying two generations of African-American youth. But, as with all diseases, it has spread. Eventually it has affected the lives of almost every American.

I see the same pattern emerging today—AIDS. A black disease. It is being suggested rather surreptitiously, statistics are skewed, innuendoes, half-truths, lies, are running rampant. Researchers are rubbing their hands in glee at a new industry, a researchable breed of animals, black men, women and now, babies.

I ask you to remember the history. Stop the disease here in Harlem today so that all Americans everywhere can live tomorrow. The wisdom in this room, I feel certain, will make the right recommendations to the Congress. Further than that, I also feel certain that the right legislation, if legislation is required, will be passed. There are times in history when the right thing is done because the right thing must be done. I believe, and my mother believes, that this is one of those times.

Thank you so very much.

[The prepared statement of Dr. Hale appears on p. 152.]

Mr. RANGEL. Thank you for your very informed statement.

Dr. Beny Primm.

TESTIMONY OF DR. BENY PRIMM, EXECUTIVE DIRECTOR, ADDICTION RESEARCH AND TREATMENT CORPORATION

Dr. PRIMM. Mr. Chairman and Mr. Gilman, first I really would like to thank you for getting interested as early as 1985 in this problem and holding the first Congressional hearing here in New York concerning this problem.

I'm highly appreciative, and today I'm very thankful and exhilarated by your presence here in the Harlem community where I think the problem of substance abuse unquestionably is the most pressing and probably the greatest in all of the United States. Unquestionably, the problem of AIDS is also, and I just applaud you for your presence.

You have my prepared statement and I'd like to excerpt and extrapolate from that statement and highlight some things that I think are very important.

You have heard all the awesome statistics today from my fellow panelists, and both described and defined this devastating health catastrophe that is pediatric AIDS. I've chosen to recommend to this Committee, however, what I feel from my personal, professional experiences with the addict population, what I think that could possibly make a dent in this progressively worsening problem.

While the following recommended measures may seem a bit Draconian and drastic, I think that this population needs such recommendation. It's so scattered and uncontrollable and volatile that presently employed control mechanisms that we have in place only seem to further undermine the problems that we are encountering with this population.

For example, urine testing of all newborns in municipal hospitals does result in the identification of infants born to mothers who have used drugs and sort of paves the way for legal intervention regarding their future custody and care and alerts to the possibility of HIV infection. Though such a method may be effective for the protection of the future health and well-being of these infants, these methods are not adequate to control or curtail the primary and persistent occurrences of maternal AIDS virus transmission to newborns.

What I propose and recommend strongly for your consideration, Mr. Chairman, is that all men and women, and note that I say all men and women, in drug treatment programs be mandated to attend courses in sex and birth control education. These courses

should be conducted in the treatment programs that are now provided, and subsidized by either the City, the State or the Federal government. Included in these programs should be the availability of all acceptable contraceptives, condoms, diaphragms, the sponge, spermicides, tubal ligation and vasectomy, as alternatives to unprotected sexual intercourse among this population.

Number two, that there should be voluntarily HIV 1 and 2 intigen and antibody testing and it must be available in all drug treatment programs and alcohol treatment programs. Treatment program participants should be strongly encouraged and urged—and note I said urged—to take the test and be informed of their antigen or antibody test results with detailed counseling before, while awaiting and after reported test results on a consistent basis must follow this informing process. I think it's absolutely necessary.

Planned parenthood counselors must be made available in all drug treatment programs for those men and women who are of child-bearing age. Responsible sexual behavior must become an integral part of the treatment process. Social service agencies in conjunction with drug treatment programs must monitor levels of understanding of sex education by means of a testing instrument. This instrument may be used as an indicator of further education approaches that may be called upon.

Finally, those men and women who are using drugs and are not in a treatment program, but who are in receipt or City or State support, must be mandated to enroll in such a program and given the necessary guidance to this end. Should that not fulfill this requirement, their support should be jeopardized.

Mr. Chairman, we further need to talk about the drug abuse problem, not in relationship to AIDS, but because I think the focus here has primarily been on AIDS itself among that population and the transmission of the virus to the newborn. There are many other disease entities that addicts have long since suffered from that do go unabated and unrecognized. We end up here in Harlem Hospital and many other treatment centers treating these diseases.

I'm talking about subacute bacterial endocarditis, I'm talking about meningitis, tetanus and any number of severe infections. But most important among all of them is the incidence and prevalence and the rise in the incidence and prevalence of tuberculosis in this community. In 1985, there were 90 cases reported in Harlem for 100,000 people; in 1986, 110 cases per 100,000 people. Now, these sound like a 20-case rise per 100,000 people, but when you compare that to other portions of the City where there are hardly any cases of tuberculosis among 100,000 people, this is astronomical.

What's further important about this incidence and prevalence of tuberculosis in this community is that many of these cases are resistant to antibodies and resistant to normal tuberculosis treatment. Not only do we see it in adults, but we are also seeing it in our children.

You might recall that in Borough President Dinkins' presentation, he talked about the Vermont experience where they had about seven cases in Vermont and a great number of dollars allocated for education and prevention efforts in that state. I'd like to report to you that in yesterday's New York Times, there was an article that talked about Alaska having one case and there was

$300,000 already allocated and free condoms being handed out by a pharmacist in northern Alaska. We here in Harlem have about seven cases per 10-block area and in this community, we don't have $300,000 committed to education and prevention efforts in your own district. I think that that's criminal and I think it is the responsibility of the City and the State of New York and the Federal government to see that money is sent to this community for education and prevention efforts.

We presently have offered to the Gay Men's Health Crisis—and I'm going to call out the name, I think that Lorraine was a little bit too nice—we have a $25,000 commitment to that group to research how to reach the minority community. The Gay Men's Health Crisis presently has no blacks nor Hispanics on its staff and has to reach out to people like me and other blacks and Hispanics in this town to teach them how to research and reach our people in terms of prevention and education efforts with AIDS. I think that that is an insult, both to Harlem and to the black and Puerto Rican and minority community in this town in general. I think that the practices of awarding grants ought to be looked into very, very carefully by this Committee, those people who sit on review boards who look at grants and finally make the award procedure because unquestionably we are called on to do the work for those organizations when we could ourselves receive those grants and awards and do the work in our communities ourselves. We are capable, we are fiscally responsible, but we are overlooked by those State, Federal and City agencies. I want to make that clear.

There is only one testing site in this community and that is at 145th Street and supported by the State. When the Mayor sits here and talks about what is going on in this community, I don't see it and I'm out here every day in the streets doing what I have to do, so is Suki Ports and so is Lorraine Hale. What we need to do is to look at this situation very closely. I want to thank this Committee and you particularly for your indulgence and for coming here and for being allowed to testify before you. Thank you very much.

Mr. RANGEL. Thank you, Dr. Primm.

[The prepared statement of Dr. Primm appears on p. 160.]

TESTIMONY OF SUKI PORTS, MINORITY TASK FORCE ON AIDS

Ms. PORTS. Mr. Rangel and Mr. Gilman, I would like you to know how appreciative we are of having this opportunity as probably the newest kid on the block in the area of AIDS. But we feel that our daily working with patients here at Harlem Hospital or at other hospitals out in the community, gives us a different look at what's happening with AIDS. So, I'm going to divert from the written testimony that you have to present some of the cases as we see it.

Under the umbrella of the Council of Churches of the City of New York, the Minority Task Force on AIDS was created by a diverse group of community-concerned individuals who attended the first conference held in New York City—and it's our understanding, in the nation—to open the question to the public of AIDS in minority communities. The only person who could give us that information from the minority community was Dr. Beny Primm—

and yet, the AIDS 101 circuit of those traveling around the country is large—just one minority person.

Entitled "AIDS is Also a Minority Community Crisis," the panelists raised many issues of the ramifications of AIDS upon minority communities with particular references to the poor, and AIDS as it affects people of color, women, children, gays and the impact of IV drugs. The task force has evolved into a minority community group providing an education prevention program with very little funds. As it has been mentioned earlier, there are very clearly reasons for that lack of funds.

We need a program to train people to help minorities and families with AIDS and provide an array of other services, including dinner, babysitting, a women's support group, and special holiday observances including birthday surprises. For most of our patients, it is their last. We are also advocates for those who can least speak for themselves: the babies and drug addicts. We also seek policies which are at the same time compassionate in serving the needs of the people who have AIDS and their families, as well as comprehensive, cost-effective and relevant for the population, sensitive to local needs, languages, history and traditions. We realized very clearly how many of our persons with AIDS problems are not those of any other location. So, while I'm referring specifically to the crisis we feel here in New York City in our minority communities, I appreciate the attention those on committees from other locations with other problems have. However, as New York City is seeing such a growth of patient case load as well as the problems, the solutions we find together here may provide invaluable planning time for other areas.

With 55 of the adult cases of AIDS of minority origin translated into black, Hispanic, Asian and native American, 5,726 people compared to 4,676 white people and 169 babies of black and Hispanic mothers compared to 18 babies. So, when we're talking of percentages, we have to look at the people behind those percentages.

The impact of AIDS on the lowest income cannot be separated from the problems we have yet to solve and which the one elected official here in New York City—not including those in Washington—but those in New York City, David Dinkins has spoken out time and time again, bringing back as he did today the root causes of what some of these problems are. The impact of AIDS on the lowest income groups cannot be separated from the problems we have yet to solve within the existing racism and sexism and classism which we face here in this community. We cannot hide ourselves from tourists. The homeless are there. We cannot hide corporations moving because their employees cannot find affordable housing. We cannot hide our hungry. Three hundred line up in the snow and in the rain and in the heat at the little church next door to us. But a mother with AIDS is sometimes too weak to cook or to line up in that line.

Our shelters burst and TB blooms. Our drug users live and die with AIDS, but that's only one more intrusion. If we can together face the solution, those now suffering may be suffering less. The quality of their life is very different in our communities from the quality of life of a person with AIDS in other communities.

A spirit of cooperation is necessary now to begin to solve the problems we have looked at less intensely, and to begin to attack the two-tier health system and life systems we have in our major urban or rural areas. We need educations which provide and prepare our future youngsters to cope in ways which they can understand and not how we think they should understand. There are perhaps many ways that we could tell them how not to share drugs, how not to do sex, to say no. But the reality is that they are, and we have to talk in a way that they can understand, and that may include their educating themselves by their peers.

There are three major starting points that I would suggest towards a comprehensive way of looking at this problem in our communities. One, a comprehensive case management system which will upon entry at any level tie together all members of the family and all existing services. This would aid a mother with a sick baby who may herself be free of drugs, but has a mate who is not, deal with three or four possible caseworkers in addition to the housing people and the utility people. It would help her to deal with this new crisis in her life from coping with illness to managing limited funds.

Two, creation of a Federal AIDS care corps managed by local communities. Building upon the experience of the Peace Corps or the VISTA Corps, we can develop a new source of family care, support system for the medical and social services arms, both trying to tie bits and pieces together in overloaded casework. This would help people whose children have grown up, public assistance individuals who would like to receive new training, people who would rise to a challenge from a less people-oriented corporate job, new graduates. We will soon face service shortages throughout the City, but in this hospital and in some communities, that shortage already is there.

I see daily what is happening to individual's lives because so many are trying to live against the greatest obstacles and they are weak with illness.

The last and perhaps most critical is housing. The inappropriate housing is a major problem for any family or individual. To have AIDS in addition becomes a pain for everyone. Those who are the housing care givers of last resort, your hospital staff, are trained to save lives and care for the sick, not be innkeepers. Individuals want to be with their children and families, not have to wear a flapping gown and eat institutional food when eating is a major weight loss problem and then have to wake up not to a phone call, but a thermometer call.

Your interest and presence here at Harlem Hospital is encouraging. Upstairs, miracles are being performed by unsung heroes and heroines, but they will get tired. The communities will see other needs unmet and still, unless we plan now, to tie together all of our people's needs and treat them together, the drug treatment, the family care, the worker out on the street, the infant needs and the emotional needs of those already diagnosed and worrying, the families with those already ill, the needs will be repeated over and over again. Unless we change that, it will happen over and over again.

It goes without saying that "No" to drugs or "No" to uninformed sexual practices should be practiced. However, we must someday

remove the causes of why there is drug abuse in the first place. We must move to educate in ways not how we the educated think they should learn, but how they can do it themselves, whether it is in street theatre, whether it's in comic books, whether it's in picture books, whether it is for example your captive audience in the emergency room of a hospital sitting there—they would certainly respond to a group that is acting out a way of presenting an AIDS information message.

I'd like to close this with some quotes from a person with AIDS: "Most of every day my life looks so hopeless. I think about my dead son and blame myself. Now I think every day of the little white coffin. I didn't know when I was 16 that you shouldn't share needles. I think of the hurt my family feels, the way people treat people with AIDS and their family. It hurts real bad when people don't want to be near you, or touch you like you're dirt. People don't understand people with AIDS need love also. Most times, they really try here at Harlem Hospital, but they need help."

[The prepared statement of Ms. Ports appears on p. 164.]

Mr. RANGEL. This panel could not have concluded its testimony in a more eloquent fashion. We want the panel to know that this isn't just a Committee that is running through Harlem and just had a hearing. We have a history of not restricting ourselves to just Federal problems. If a kid has a problem, it's not up to the parents to decide whether it's a City, State or Federal problem. If it's a political problem that you are facing in this work, we stand very anxious to be with you in trying to straighten it out.

I haven't the slightest idea as to where you're having this problem with the grantsmanship that you were talking about. You can recite it publicly or this afternoon you can share with me where this poor judgment has been as it relates to the grants for our communities.

In addition to that, I don't know whether Dr. Smith is still with us, but Dr. Heagarty is and that's what counts, I hope that Dr. Heagarty, you might assist me in drafting my letter to Columbia University and to assist me in presenting a proposal to the Federal government.

As to the type of problems that you're facing, that relates directly to poverty. The thing, the people that you have to treat, the diseases that you have, are directly related to the problems that Suki Ports was talking about, that exist in our community. It just seems to me that, for example, if you're dealing in a developing country, you cannot bring a treatment that you would be giving to more industrialized countries. You have special kinds of problems which cause you not just to specialize in pediatrics but to have to specialize in tuberculosis and AIDS and in other drug rehabilitation problems.

Perhaps with the recommendations that have been made by Dr. Primm and with the tuberculosis crisis that's been shared with me by Dr. Felton, and certainly with the emotion which you shared with me today as to why your staff has to take care of our community's children, you could present to me, perhaps not in technical language but just in language which another part of my constituency, Columbia, could understand. They have indicated their willingness to carry some of the share of the responsibility for the com-

munity in which they are an institution. This is an educational institution that has no problem in drafting the proposals to get the research in other areas, and they would lend their staff to assist this hospital in drafting recommendations to the Federal government.

I also will be asking Columbia and other institutions that have the type of resources we need to help us make Hale House the type of model that we have to have. Clearly, to me, it is a spending reduction proposal. There is no question in my mind that Hale House, besides providing the sensitive care that our children need, is saving this broad society a heck of a lot of money by being to open up its doors and its hearts to children that have no place else to go.

Dr. Hale, you had mentioned some statistics as to the availability of black men. I hope you might share with me what resource material you used, because I am thoroughly convinced that this crisis, whether we're talking about how many black males are killed on the street as kids, how many are in the army and in the ground forces, how many are warehoused in our jails, how many necessarily will be dying as a high proportion of their age, I can see that black males are going to be an extinct species if we don't really focus attention on poverty and drug abuse. I hope you will work with me separate and apart from that.

Finally, I do hope that we can get this panel together in a nonhearing type of environment. We resume perhaps in September. We can meet in central Harlem and you might suggest to me other people that can make a contribution. I will be bringing some City and State and Federal officials to that meeting so that we can come together and really show that this is not a problem just for black and Puerto Rican infants, but a problem that our communities have which we have to wrestle with.

I can't tell you how proud we are. The record is going to remain open especially as it relates to Hale House. Ben Gilman shares with me that perhaps only the President and the Harlem community may know the good work that you're doing, but you will have a chance to enter into the record any additional testimony as it relates to the broad mission that Hale House has taken. That goes for the other witnesses that may want to add additional material.

As a member that is elected from the community in which this hospital and hearing is located, I can't tell you how proud you've made me feel today, not just as a member of Congress, but certainly as someone that was born and still lives in Harlem. It is with great pride that I can have brothers and sisters from the community that are taking care of the problems to provide the leadership for our government. This leadership is not going unnoted as we struggle together to get some answers for the rest of the country.

Mother Hale, you know when you've known me as long as you have, it is not that I'm afraid that you would not call me Congressman, it's just that you've known me when I was a kid. You just might call me some other things that I deserve. But you are totally an inspiration to all of us. You have proven what people can do without anything. We hope to give you the tools so that your leadership would be able to provide inspiration for the rest of our nation.

Mother HALE. I want to thank you, Mr. Congressman. In fact, I always knew he was charming as a boy growing up. But I always said you would be somebody. Now that you are a Congressman, you represent Harlem. Thank you again, Charlie.

Mr. RANGEL. Thank you, Mother Hale.

Mr. GILMAN. Thank you, Mr. Chairman. I'll just be brief. The panel has given us so much food for thought in each of and their respective ways and expertise. We were discussing earlier today, the Chairman and I, turning over our entire testimony today to the new Blue Ribbon commission that the President appointed on AIDS so that they can have the benefit of your expertise in this field. We will provide them with an executive summary so they don't have to read through all of this.

I think that each of you made a valid point. Dr. Heagarty pointed out that this is a national disaster, it needs that kind of approach, it needs a whole family approach of taking a look at the housing problems and taking a look at the need for providing counseling and home care and respite care. I think that's certainly something that's going to need a great deal of attention from not only those of us at the national level, but state and local level. It is not a singular problem of taking care of the pediatric patient; it means more, to reach out beyond that patient to take care of the family.

In Suki Ports' proposal for an AIDS-care corps, I think that's certainly a meritorious, innovative suggestion that should be looked at. Certainly the hospitals don't have the kind of volunteer corps that is so needed in this field. With the fear out there with regard to the disease, I think a corps of that nature could do a great deal of good.

Dr. Hale's Cradle House is, of course, a road, a remedy for taking care of the hospital boarder babies that are beginning to grow now as this disease becomes more and more prevalent.

Dr. Primm's mandated sex and birth control ideas certainly are meritorious and are something this Committee will try to promote.

I want to join my Chairman in thanking our panelists for taking the time to give us their thinking. We're certainly going to make good use of the ideas that you have suggested here today.

Thank you, Mr. Chairman.

Mr. RANGEL. Thank you. May the record indicate that this Chairman has no way to enforce the rule against applause for this panel.

Mr. GILMAN. Will the next panel please take seats at the witness table?

Mr. RANGEL. Let me apologize, but I guess both of you are veteran testifiers and understand how these things can happen. We're certainly glad that both of you were able to stay with us. The panels ran past the point that we had hoped, but the testimony, I think that you would agree, were support enough for us not to hold unto the strict provisions that we have in our rules.

Dennis Whalen, Executive Assistant to the Director of New York State Division of Substance Abuse Services, I really hope that you will be able to clear up some of the testimony from the previous panel as it relates to grants. I have no knowledge specifically as to what they were referring to. James Butler is the president of Local 420 of the Hospital Workers Union. I hope that if it's not in your

testimony, Jim, that you would give to us a list of the things that concern hospital workers generally in this issue. I intend that you too would be a part of this panel that I will be bringing together to see what resources are we able to take care of as it relates not only to the patients but certainly those who are dedicated and anxious to provide care for them. I want to thank you for the cooperation that you have given to this committee and certainly to the community.

Perhaps we will start off with Mr. Whalen.

TESTIMONY OF DENNIS WHALEN, EXECUTIVE ASSISTANT TO THE DIRECTOR, NEW YORK STATE DIVISION OF SUBSTANCE ABUSE SERVICES, ACCOMPANIED BY JAMES BUTLER, PRESIDENT, LOCAL 420, AFSCME, HOSPITAL WORKERS UNION

Mr. WHALEN. Thank you, Chairman Rangel. I want to thank you and the Committee and Mr. Gilman for the opportunity to present testimony today, and certainly to thank you on the occasion of this second hearing regarding AIDS and intravenous drug use. We are happy to provide testimony.

I note that you had indicated that the full written testimony will be entered into the record. Therefore, I will just briefly comment on a few points.

Mr. RANGEL. Without objection.

Mr. WHALEN. Certainly I think this hearing is evidence, as was the earlier one, of the importance and the need for attention to this issue. Other people testifying today have noted that it was not until the media began publicizing the spread of HIV to the general population that there was very much attention or concern was given to the problem of AIDS among the IV drug using population. This is reflective of the uphill battle that we face.

We desperately need attention to be given to this problem and we must be tsue that it is the proper kind of attention.

The efforts that the New York State Division of Substance Abuse Services are undertaking are generally in three specific areas: treatment, prevention and outreach. In the treatment area, we have begun nearly 5,000 new treatment slots over the past year and I certainly do not need to indicate to you or the Committee the problems that are encountered in opening new programs in any community. Despite the increase in treatment services, we are still seeing waiting lists for individuals who want to get into treatment but are unable to do so.

Part of this is directly related to the problem of our inability to get communities to welcome programs into their areas. This problem will certainly grow worse as drug programs become equated with the word "AIDS." The community reaction to programs is something that requires attention.

Prevention we view as equally important. In fact, we view the drug treatment of an individual as prevention in itself, because when that individual is in treatment, he or she is stabilized and we have the opportunity to talk with him or her about behavior change related to IV drug use and HIV risk reduction.

The third area, outreach, is equally as important because as this Committee knows, there will be individuals who may never come

into drug treatment because they have no desire to do so. We therefore began about a year ago a program employing street teams of ex-addicts. It's currently operating in Manhattan, Queens, Bronx and Brooklyn, where teams of ex-addicts go out onto the street to do face-to-face counseling with individuals, to talk about condom use, and to talk about cleaning of needles. We utilize a van—as which I think Congressman Town had suggested before—which brings the team into an area. They work around the van, and the van provides to the general community a general education while the team is out working on the streets with the active IV users.

In terms of suggestions for Congressional steps that might be taken, we certainly think increased funding for treatment is something that needs to be considered, perhaps particularly in relation to the block grant which, as you know, is under discussion at the current time for possible alterations in formula. We think there needs to be a prevention and education initiative, and perhaps one of the most important things, I think, would be a concerted, unified message from Washington that this is our position, this is the message that we're communicating. Now we're hearing a whole assorted range of messages from "just say no" to other things. I think we need to speak with one, unified voice.

The third thing is consideration of funding for expansion of these outreach and prevention programs, because individuals that you are not going to reach through treatment programs certainly need to be reached through the home or through working the streets. We feel that the face-to-face education strategy is vitally important. These teams of ex-addicts who are out on the street know the community, they know how to quickly establish a rapport with the drug users and they come with no vested interest. They lay it right out on the line and say, "Look, here's why I'm here. I'm not here to talk to you about law enforcement or anything else. If you want to get help and get into treatment, we can do that. If you want to get tested, we can refer you to a place that will do the testing. If you are not going to stop drug use, here are the things that you have to know."

They do it in the street style, and it's very effective. Consideration should be given at the Federal level to doing something similar.

We have communicated these ideas to NIDA because Mr. Schuster had earlier expressed an interest in hearing our thoughts. The final thing might be a consideration in terms of funding for treatment that takes into account the problem that's specific to New York in terms of finding program sites. It comes down to a question, almost, of real estate and having the wherewithal to find the buildings to house these programs. The Mayor has recently offered to give Director Martinez ten buildings; but we're finding that these "buildings" are basically four walls, sometimes without a roof. The construction money that is needed to bring these programs into usefulness is sometimes prohibitive. As you know, NIDA has taken a previous position that these Federal monies that come down for treatment cannot be used for capital construction. We think a reconsideration of that position would be in order.

Thank you.

[The prepared statement of Mr. Whalen appears on p. 170.]

Mr. RANGEL. Mr. Butler, we want to thank you for the great assistance that your Union has given in dealing with many of the social and medical problems that we face at Harlem Hospital and indeed, throughout communities similarly situated. We thank you for taking time out to arrange your schedule to share your thoughts and witness.

TESTIMONY OF JAMES BUTLER, PRESIDENT, LOCAL 420 AFSCME, NYC DEPARTMENT OF HOSPITALS

Mr. BUTLER. I want to thank you very much, Mr. Chairman, Congressman Rangel, and your Committee for inviting labor to be here. It would have been a disaster if you didn't invite labor, although we're on the tail end of this hearing. We are here.

I want to go on record to let you know that in reference to the 14,000 health care workers, Local 420 represents the American Federation, State, County, Municipal Employee Union, AFL-CIO, District Council 37. It is the largest public employee union in this country. It represents over 350,000 health care workers in the Unites States, including Panama.

We are involved, deeply involved. My membership are the ones on the front line in caring for the babies and the children that have been stricken with the disease called AIDS, and no one knows when there will be a cure for AIDS. I'm very happy that the site of this hearing is not at the Sheraton Hotel, nor at the State Office Building. The timing is right and the place is right: Harlem Hospital.

This Union has a slogan: "Decent health care for all Americans." We have another slogan we carry—the slogan in reference to decent health care for AIDS patients throughout the United States. Check the paint on the sign. It's not wet. We've been carrying that since 1986. Yes, AIDS patients are human beings.

My members spend more time with the AIDS patients than the doctors who come to the unit and say "How are you feeling?" The nurses aides are the ones who give the bed baths to them, those who are unable to bathe themselves. The nurses aides are the ones who clean them when they cannot control their bowels or their urine. They clean them. The help them into the wheelchair and take them to x ray, to any department they want to go to. Many times you see the dedicated workers—yes, my members are dedicated—they will put their arms around them and talk to them because some are on their way out because there is no cure for them at all.

The dietary aides are the ones who bring the trays to them and help them to feed themselves because they are unable and have no more strength in their bodies. The housekeeping aides are the ones who clean their rooms and make it comfortable for them, cares for them. The laundry worker processes their soiled linen and brings it back clean to them. And yes, men who are housekeeping aides have been stuck by needles that have been used on AIDS patients. But they continue to care for those patients because they are human beings.

The babies, the little tots that the doctor, the chief of pediatrics just spoke of, they are our future. But in order to get decent health care, there must be funds coming to the public hospitals. The public hospital is carrying the load. You heard the census. Four hundred, four hundred AIDS patients are occupying the public hospitals and they're playing Russian roulette up in Albany.

Take Lincoln Hospital. They are ready to open up 27 beds. You know what Dr. Axelrod said? You know what the State said? We are cutting beds, we're not giving beds. Now, if you get cut back some beds, we would give you the 27 beds for AIDS patients. That's not right. Go to Lincoln Hospital and see how many patients are in the emergency room waiting for beds.

Just a few weeks ago, we had a demonstration here to save 72 medical and surgical beds in this community. Funds are needed in order to give decent health care. There is a shortage of nurses aides. They're crying out to me, President Butler, I'm burned out! It's a stress for a human being to care for an AIDS patient, to see them every day, to see their body deteriorate. It's time for rotation, somebody else has got to come in and care.

There's a shortage. That old Christian song, "Heavy Load," that's what they're saying in the public hospital. A cutback in staff? We need more nurses aides to give decent health care to the AIDS patient. We need more housekeeping aides to give decent health care, for the rooms to be clean. We need more laundry workers so the linen could be processed on time. Dietary aides, we need them so they won't be receiving cold coffee in the morning. I don't like cold coffee and I know that the AIDS patient doesn't like it. That is what is happening in the public hospitals in the City of New York.

In our paper here, this is June, 1986. We went on record saying, "Open up a public hospital for AIDS patients." One is needed badly. When we had the epidemic of TB, we had Triborough Hospital, we had Manhattan Hospital, we had Seaview Hospital, we had another hospital at Kings County, a special hospital. You know why? The AIDS patient will rest in comfort.

Take, for example, Kings County Hospital. An AIDS patient used the public phone. The other patients with a normal diagnosis, they ripped out the phone. It's not right. It's not right. It's not right for the family who visited a patient with a diagnosis as a diabetic to point out the AIDS patient. They're not guinea pigs. It's a diagnosis of AIDS. It's not fair for the AIDS patient to be put in a room with a patient next to him with pneumonia. The family who has the patient there with pneumonia, they disagree with that. So you have internal fights in the hospital. A special hospital is needed for AIDS patients.

Where do we go? Morrissania, a strong hospital, still there, 167th Street and Walton Avenue, Roosevelt Island—you've got the Central School of Nursing, a large building, very strong. We could get research because we carry the high census of AIDS patients. This hospital here has the highest census of AIDS patients of any public hospital.

If AIDS continues to hit in this United States, we'll only have 47 beds. In the next three months it'll be 65 beds, it'll be 70, 80 beds. What's going to happen to that family who rushed in here with an

individual who might be diagnosed with a heart problem or maybe diabetic? Who will be in the beds? All your beds are going to be used for AIDS patients. We're going to run into a serious problems.

So, I urge this Committee that we recommend to you that the City of New York needs a special hospital for AIDS patients. The City of New York needs more Federal funds. There's not enough Federal funds in this community. We need more educational programs in reference to AIDS. We do not have them. You can walk from 147th street all the way down to Central Park—you don't see any kind of signs, no kind of posters, but you can go into other communities and see them.

Now, let's go up to Pelham Parkway to Bronx Municipal Hospital. Bronx Municipal has a day care hospital center for AIDS patients. Now take that community and compare it with Harlem and find out what's going on. It's not fair. It's not fair at all. We need a day care center here also in this community for those individuals who have AIDS. We're not getting our fair share in the minority community.

We need more social workers. We need more educational programs. We need the sound trucks to come to this community to encourage those who want to come in on their own. But it should be a decent facility so they could go in. You have many people who want to volunteer to have the tests to determine whether or not they have the AIDS virus. So, I close out in saying this to you, Congressman. Again, I want to salute you and your concern for decent health care. I remember at the State Office building you had the whole Harlem Hospital staff there, the Columbia University staff. I remember the Sydenham Hospital situation and your leadership with Patricia Harris, meeting at the State Office building and again, I want to salute you and your Committee for your concern about this crisis that we're faced with and I hope that one day that there will be a virus that will be able to combat this disease, AIDS.

Again, thank you very much.

[The prepared statement of Mr. Butler appears on p. 178.]

Mr. RANGEL. Thank you, President Butler.

The hospital workers and the union are fortunate to have someone of your dedication and leadership.

Tell me, on this hospital for AIDS' patients, I got the impression that there is not too much resistance from the City, they are saying they are open on that. Where is there resistance to this?

Mr. BUTLER. There are some pros and cons, Mr. Chairman. Some individuals who feel that a patient would be segregated. This is a big issue here. As you know, Houston, Texas had a first hospital for AIDS' patients. It wasn't a public hospital, it was a private thing. I think they ran into financial problems or what have you. But there are some individuals who were shaking their heads and saying, "Yes, it is a good idea." It would take off some of the heavy loads, like, for example, Harlem Hospital has four to 750; they could be transferred into this special hospital. And that means that the entire staff that would be especially trained to give the best of care to those AIDS' patients.

It was the same way when tuberculous hit this country. You have Sloan, everyone knows that Sloan is cancer. Joint Disease is orthopedic. You know you have Baby Hospital, special hospitals. I

feel that everyone is going to come to a yes on that very soon because the census is going to continue to increase. If the census continues to increase here at Harlem, there will be no beds for their regular medical patients or orthopedic patients and everything is going to go crazy. So that is what is needed.

I presented it to the Borough President and his staff is working on that. Dave Dinkins has been working very closely with that.

Mr. RANGEL. I am glad you told me that because that will save me a lot of initial work.

I want to publicly thank your hospital workers for really the dedication that they have shown. They have always shown sensitivity, especially to the illnesses that afflict the poor because historically they have been a part of the poor for so long. And especially in this area where people are so afraid to run away, they have demonstrated an understanding of the problem that nobody on any other level of professionalism has.

I personally will be reaching out this afternoon or tomorrow to David Dinkins to explore with you the feasibility of what you are proposing, and I hope that you send to me under separate cover, to my Congressional office, how I can be more helpful in making certain that those workers that have demonstrated the dedication are getting all of the protections that the unions would want to receive from the Health and Hospital Corporation. I want to thank you for your testimony.

Mr. Whalen, you have heard the testimony of Dr. Primm, and he was talking about making it mandatory for a certain type of sexual behavior to be taught and Planned Parenthood and the dangers of the spread of AIDS. I had assumed that with all state funded programs that those type of things he was talking about were part of the program.

Mr. WHALEN. No, not normally, they are not. We have just finished—and I will get extra copies for the Committee—a program called CARE, which is "Comprehensive AIDS Risk-Reduction Effort." Part of the problem has been that counselors in drug treatment, right from the beginning of the AIDS problem, have had difficulties in dealing with such emotionally charged subjects: Sexual behavior, continuing drug use. We have found is that there has been a tremendous demand for training on how to facilitate group discussions of things of this nature, and we have had about seven different training courses that we have provided. One is on issues of sexuality; another is on issues of death and dying.

Mr. RANGEL. So you mean that eventually the things that Dr. Primm was suggesting will be incorporated in state funded programs?

Mr. WHALEN. Yes, this has already started. The CARE program outlines it and I will make sure that the Committee receives copies.

Mr. RANGEL. Do you know how much of the federal funds that we were responsible in getting in our recently past congressional bill the state is receiving?

Mr. WHALEN. The anti-drug abuse——

Mr. RANGEL. Yes.

Mr. WHALEN. I think it was a total of about $24 million. The Division of Substance Abuse Services, our agency, was able to—because of the AIDS problem—convince the state legislature that the

money for treatment should be immediately allocated so that it could go to start programs. The legislature, however, was concerned about the prevention portion and withheld the monies for prevention and treatment services for the multiply disabled, and made that subject to state law which was passed about 2 weeks ago. They have provided the money that was earmarked for prevention in schools directly to the State Education Department.

Mr. GILMAN. Would the gentleman yield?

Mr. RANGEL. Yes.

Mr. GILMAN. Mr. Whalen, how much more is now made available to the state as a result of the Omnibus bill, as a result of the state legislature's action this year for treatment and rehabilitation? How much more is available this year as compared to last year?

Mr. WHALEN. For strictly treatment?

Mr. GILMAN. For treatment and rehabilitation.

Mr. WHALEN. I think between 7 and 10 million.

Mr. GILMAN. Seven to 10 million is more available this year——

Mr. WHALEN. As opposed to last year, yes.

Mr. GILMAN [continuing]. As opposed to last year.

How much more has been made available to the City of New York this year as compared to last year?

Mr. WHALEN. I don't have that number, but I can certainly give it to you.

Mr. GILMAN. Well, the majority?

Mr. WHALEN. The majority of the funds.

Mr. GILMAN. Most of the funds go into the City of New York?

Mr. WHALEN. Correct.

Mr. GILMAN. How is that being utilized then if there is such a need for all of these things? We are hearing about the lack of funding, if there is 7 or 10 million dollars more available this year than last year, where is that money being spent?

Mr. WHALEN. As I indicated, we started about 4,600 treatment slots over the last 2 years alone, which is quite a large amount, and the problem is that the demand for treatment is still outpacing the system's ability to open it.

Mr. GILMAN. Have you made more treatment slots available this year as compared to last?

Mr. WHALEN. Yes.

Mr. RANGEL. Can I regain my time here?

Tell me, how do you work with a hospital like Harlem Hospital as relates to rehabilitation? Do you give direct grants to the hospital?

Mr. WHALEN. No. In New York City public hospitals we contract with Health and Hospital Corporation and they provide the funding to the hospitals.

Mr. RANGEL. Do you monitor that grant as you would with any other group that you were funding, the HHC grant?

Mr. WHALEN. Normally we would work with HHC, although we would come out to the programs to look at quality of services and things of that nature.

Let me stress that these would be drug treatment programs which are generally handled separately from the normal health care services in the hospital.

Mr. RANGEL. But you do have drug treatment programs here at Harlem Hospital, don't you?

Mr. WHALEN. Harlem Hospital operation methadone maintenance treatment program.

Mr. RANGEL. How closely does the state associate your mission in drug abuse education and the AIDS epidemic? Do you work with the Commissioner of Health?

Mr. WHALEN. Yes. We have worked with the Commissioner of Health. We work very closely with AIDS Institute, which is the unit within the New York State Department of Health which handles AIDS funding.

Mr. RANGEL. What is this AIDS Institute?

Mr. WHALEN. That is simply a unit within the New York State Department of Health.

Mr. RANGEL. Who is in charge of that?

Mr. WHALEN. Dr. Axelrod is the Commissioner of the Department of Health, and then I believe the Director of the AIDS Institute is Mr. Mel Rosen.

Mr. RANGEL. Well, it is clear that we are going to have to take a look at the testimony and see more specifically what the community leaders were talking about. But I hope that you share with Commissioner Axelrod that we will be making inquiries as to the questions that have been raised by this Committee.

Mr. WHALEN. I certainly will, Congressman.

Mr. RANGEL. And, again, President Butler, I hope that you put together the concerns that your workers have because when we have front-line fighters such as the members in your union, we want them to know that they have back-up in what they are doing, because whether they are servicing at Harlem Hospital or some central location, they are the ones that are laying the fears, not only of the loved ones and families of the patients, but of the general community at large, and we want to make certain that they know that not only as a Congressional Committee, but as a Committee that is concerned with enforcing local and state provisions, that we will be working with them.

Mr. Gilman.

Mr. GILMAN. Thank you, Mr. Chairman. I want to commend President Butler for his testimony and for focusing attention on the need for a specialized center. I am totally in agreement with you. I think the AIDS population out there warrants that kind of specialized treatment. We explored it with the Mayor, as you heard earlier, and I hope that we are going to see that come about.

I think you are right in your recent editorial that we are playing around with putting a bandaid on a hemorrhage and it is important that we start getting on the ball and doing the kinds of things that are needed. I commend you for your testimony.

Mr. Whalen, I hope that the state agency is going to make certain that the funding that we have made available in the Omnibus Drug Act of 1986 gets down to the levels of where it is truly needed. We have found that occasionally this bureaucratic red tape ties up these funds and delays it getting out to where it should be going. And I would hope that you would take a look, after hearing all the testimony today, of what we can do to allocate more of those funds towards the AIDS problem.

Mr. WHALEN. That is certainly a priority of ours. And let me just explain where that money is going, just so that you know.

The treatment money did get appropriated directly to our agency. The prevention monies, as Congress expressed a preference for I believe in drafting the legislation and your earlier testimony from the then State Education Commissioner, were appropriated directly to the State Education Department, which will be providing grants to schools.

Mr. RANGEL. Did the State provide money of its own in these areas, in addition to what the federal government provided?

Mr. WHALEN. Yes.

Mr. RANGEL. What was the spending level compared to last year's state spending level? Was there an increase?

Mr. WHALEN. Yes, there was an increase. I don't know what the specific level was, but we can find out for you.

Mr. RANGEL. I don't need this specifically.

Mr. WHALEN. Then with the remainder of the money they created a special task force for chemically dependent youth, and that task force is comprised of the commissioners of our agency, the Division of Alcoholism, the State Education Department, and the Office of Mental Health. And they will be administering by RFP and grant proposals the remainder part of that money.

Mr. GILMAN. What is your agency doing specifically with regard to AIDS treatment?

Mr. WHALEN. We have a program basically of treatment prevention, outreach and research. We believe that the most important and immediate step that can have an impact of the AIDS problem is to get people into treatment. So we have been pushing for expansion of treatment programs, primarily in New York City, to open up treatment to as many people that come seek it.

Mr. GILMAN. How are you doing that?

Mr. WHALEN. We are expanding present programs, making sure that the greatest capacity possible is set up in those programs.

Mr. GILMAN. Well, do you give money to hospitals to do that?

Mr. WHALEN. In some cases hospitals receive funds to do that, yes, if they operate a drug treatment program.

Mr. GILMAN. This division in the Health Department, what is their function, the AIDS Division?

Mr. WHALEN. The AIDS Institute—I can speak generally about it, but I don't know specifically. They administer the Health Department's AIDS program in terms of——

Mr. GILMAN. Do they get involved in treatment?

Mr. WHALEN. They provide funding to hospitals; set up guidelines for hospitals——

Mr. GILMAN. Do you work together? Is this in cooperation——

Mr. WHALEN. We work with them regarding the drug treatment end of things and outreach activities and so on.

Mr. GILMAN. What about on AIDS, do you work together with them on AIDS?

Mr. WHALEN. Yes; that is what I was referring to when I said in terms of drug treatment, preparation of materials and so on. They carry out their other functions with hospitals separate from involvement with our agency.

Mr. GILMAN. Who coordinates all of the AIDS activity in the state?

Mr. WHALEN. That is Commissioner David Axelrod, Health Department.

Mr. GILMAN. Thank you. I want to thank the panelists for your testimony.

Mr. RANGEL. Let me thank you again.

Let the record thank our staff for the remarkable job that they have done in putting together our national leaders that happened to be in the City that has most of the problems. They certainly did bring the people that know the most about it, and I hope to institutionalize these panels as we go on in trying to find better answers to this serious problem.

The Committee now will stand adjourned, subject to the call of the Chair.

[Whereupon, the hearing was adjourned at 2:30 p.m.]

PREPARED STATEMENTS

OPENING STATEMENT

BY

THE HONORABLE CHARLES B. RANGEL

CHAIRMAN

SELECT COMMITTEE ON NARCOTICS ABUSE AND CONTROL

ON

PEDIATRIC AIDS

JULY 27, 1987

HARLEM HOSPITAL AUDITORIUM

135TH & LENOX AVENUE

NEW YORK CITY

9:30 AM - 1:00 PM

GOOD MORNING. TODAY'S HEARING OF THE SELECT COMMITTEE ON NARCOTICS ABUSE AND CONTROL WILL FOCUS ON THE PROBLEM OF PEDIATRIC AIDS, AS IT RELATES TO INTRAVENOUS DRUG USE.

I WANT TO BEGIN THIS HEARING BY EXPRESSING MY THANKS TO THE ADMINISTRATION OF HARLEM HOSPITAL FOR ALLOWING THE COMMITTEE TO HOLD OUR HEARING HERE. SEVERAL MONTHS AGO I HAD THE OPPORTUNITY TO TOUR THE HOSPITAL'S PEDIATRICS UNIT AND OBSERVE FIRST HAND THE INFANTS WHO ARE THE VICTIMS OF THIS DREADFUL DISEASE. THIS HOSPITAL HAS REACHED OUT TO CARE FOR THESE BABIES. THEREFORE, I BELIEVE THAT IT IS MOST APPROPRIATE THAT WE HOLD OUR HEARING AT THE HOSPITAL. LATER IN THE MORNING WE WILL HEAR FROM DR. MARGARET HEAGARTY WHO IS CHIEF OF THE HOSPITAL'S PEDIATRICS UNIT.

ONE MIGHT ASK WHY THE SELECT COMMITTEE HAS CHOSEN TO ADDRESS THIS PROBLEM. WHAT IS THE ASSOCIATION BETWEEN PEDIATRIC AIDS AND DRUG USE?

IN FACT, PEDIATRIC AIDS IS ANOTHER MANIFESTATION OF THE DEVASTATING EFFECTS OF DRUG USE, SPECIFICALLY INTRAVENOUS DRUG USE. THE VAST MAJORITY OF INFANTS WITH AIDS CONTRACT THE DISEASE THROUGH THEIR MOTHER. THE DISEASE IS MOST OFTEN PASSED FROM MOTHER TO CHILD DURING PREGNANCY OR BIRTH. SINCE MOST AIDS CASES AMONG WOMEN ARE ASSOCIATED WITH IV-DRUG USE, EITHER THEIR OWN OR THEIR PARTNER'S, THESE BABIES ARE VICTIMS OF THE DRUG EPIDEMIC.

WHAT IS PRESENTLY BEING DONE TO HELP THESE BABIES? WHAT MUST BE DONE TO PREVENT MORE BABIES FROM BECOMING THE VICTIMS OF THIS FRIGHTENING DISEASE? WHAT ARE THE HEALTH AND SOCIAL SERVICE ISSUES THAT MUST BE ADDRESSED TO ENSURE QUALITY CARE FOR THESE CHILDREN? WHAT ROLE SHOULD FEDERAL, STATE AND LOCAL GOVERNMENTS PLAY IN COMBATTING THIS DISEASE AND PROVDING CARE FOR THE VICTIMS?

THESE ARE THE ISSUES THAT THE SELECT COMMITTEE ON NARCOTICS ABUSE AND CONTROL WILL CONSIDER THIS MORNING. WE WILL HEAR FROM THOSE WHO PROVIDE CARE TO THESE BABIES AND SEE THIS TRAGEDY ON A DAY TO DAY BASIS, AS WELL AS THOSE RESPONSIBLE TO DEVELOPING POLICIES AND PROGRAMS TO ADDRESS THIS PROBLEM. WE HAVE INVITED FEDERAL, STATE, AND CITY WITNESSES TO TESTIFY. I HOPE WE WILL LEAVE THIS HEARING NOT ONLY WITH A BETTER UNDERSTANDING OF THIS PROBLEM, BUT A DIRECTION AND A COMMITMENT TO RESPOND EFFECTIVELY.

THE WITNESSES WILL INCLUDE:

C. EVERETT KOOP	SURGEON GENERAL OF THE UNITED STATES
EDWARD I. KOCH	MAYOR OF NEW YORK CITY
DAVID DINKINS	MANHATTAN BOROUGH PRESIDENT
DR. MARGARET HEAGARTY	CHIEF OF PEDIATRICS HARLEM HOSPITAL
DR. LORRAINE HALE	EXECUTIVE DIRECTOR HALE HOUSE CENTER
DR. BENY PRIMM	EXECUTIVE DIRECTOR, ADDICTION RESEARCH AND TREATMENT CORPORATION
DENNIS WHALEN	EXECUTIVE ASSISTANT TO THE DIRECTOR NEW YORK STATE DIVISION OF SUBSTANCE ABUSE SERVICES

JAMES BUTLER — PRESIDENT LOCAL 420, AFSCME/HOSPITAL WORKERS UNION

SUKI PORTS — MINORITY TASK FORCE ON AIDS

AS OF JULY 1, 1987, THE CENTERS FOR DISEASE CONTROL (CDC) REPORTED OVER 500 PEDIATRIC AIDS CASES (PATIENTS UNDER 13 YEARS OF AGE AT THE TIME OF DIAGNOSIS). SINCE JANUARY OF 1987, CDC REPORTS MORE THAN 9,000 NEW AIDS CASES AND OVER 100 OF THESE CASES ARE PEDIATRIC AIDS CASES.

ALTHOUGH THE PROBLEM IS NATIONWIDE, MOST PEDIATRIC AIDS CASES ARE CONCENTRATED IN NEW YORK, NEW JERSEY, AND FLORIDA. AS OF JUNE 1987, THE NEW YORK CITY DEPARTMENT OF HEALTH REPORTED 199 PEDIATRIC AIDS CASES.

PEDIATRIC AIDS IS TRAGIC BECAUSE OF THE RAPID MORTALITY AND HIGH MORBIDITY. THE MAJORITY OF THESE CHILDREN DIE BEFORE THEY REACH THE AGE OF THREE. OF THE NEW YORK CHILDREN IDENTIFIED AS HAVING THE DISEASE, 145 OR 73 PERCENT HAVE DIED.

THE NUMBER OF PEDIATRIC AIDS CASES IS SMALL IN COMPARISON TO THE TOTAL NUMBER OF AIDS CASES -- OVER 38,000 AS OF JULY. YET, EVEN IF THE HUMAN COSTS WERE NOT AS GREAT AS THEY ARE, THESE NUMBERS WOULD STILL BE VERY SIGNIFICANT. PEDIATRIC AIDS IS A KEY INDICATOR OF THE AIDS PROBLEM, PARTICULARLY THE RELATIONSHIP BETWEEN AIDS AND IV-DRUG USE.

AT THE PRESENT TIME, APPROXIMATELY 80 PERCENT OF MATERNAL TRANSMISSION AIDS CASES ARE CHILDREN OF IV-DRUG USERS. AND, A GROWING NUMBER OF PEDIATRIC AIDS CASES [illegible] EXPECTED, AS MORE WOMEN BECOME INFECTED THROUGH INTRAVENOUS DRUG ABUSE AND SEXUAL INTERCOURSE WITH INFECTED MEN. BY 1991, THE PUBLIC HEALTH SERVICE ESTIMATES THAT 3,000 CHILDREN WILL HAVE SUFFERED FROM THIS DISEASE AND VIRTUALLY ALL WILL DIE.

IF WE LOOK AT THE GEOGRAPHIC DISTRIBUTION OF PEDIATRIC AIDS CASES IN NEW YORK CITY, THE ASSOCIATION BETWEEN AIDS AND IV-DRUG USE IS ALSO MANIFESTLY CLEAR. BY BOROUGH OF RESIDENCE, 35 PERCENT OF THE PEDIATRIC AIDS CASES ARE FROM THE BRONX, 25 PERCENT ARE FROM BROOKLYN, AND 25 PERCENT ARE FROM MANHATTAN. THIS PARALLELS THE AREAS WHERE AIDS IN WOMEN AND IV-DRUG USERS HAS BEEN MOST LIKELY TO OCCUR.

PEDIATRIC AIDS CASES ARE A REFLECTION OF IV-DRUG USE. EFFECTIVELY ADDRESSING THE AIDS PROBLEM, IN GENERAL, AND THE PEDIATRIC AIDS PROBLEM IN PARTICULAR, MEANS CONFRONTING THE IV-DRUG USE PROBLEM.

AMONG THE PEDIATRIC AIDS POPULATION, BLACK AND HISPANIC BABIES ARE OVERREPRESENTED. OVER HALF OF ALL BABIES BORN WITH AIDS ARE BLACK; ANOTHER 25 PERCENT ARE HISPANIC. IN NEW YORK, BLACK AND HISPANIC BABIES COMPRISE A DISPROPORTIONATE NUMBER OF THE PEDIATRIC AIDS CASES. EXCLUDING TRANSFUSION ASSOCIATED WITH PEDIATRIC AIDS CASES, 57 PERCENT OF THE BABIES ARE BLACK AND 33 PERCENT ARE HISPANIC.

EXPECTATIONS ARE THAT THE NUMBER OF NON-TRANSFUSION TRANSMITTED PEDIATRIC AIDS CASES WILL CONTINUE TO INCREASE. THIS IS BECAUSE OF THE HIGH CONCENTRATION OF FEMALE AIDS CASES AMONG WOMEN IN THEIR CHILD-BEARING YEARS. AIDS IS NOW THE LEADING CAUSE OF DEATH FOR WOMEN IN NEW YORK BETWEEN THE AGES OF 25 AND 34. SINCE OVER EIGHTY PERCENT OF THESE WOMEN ARE MINORITY WOMEN, THE STATISTICS INDICATE A SERIOUS CRISIS IN THE MINORITY COMMUNITY. AIDS AMONG WOMEN AND CHILDREN IS NOT SOLELY A MINORITY PROBLEM, BUT THE MINORITY COMMUNITIES HAVE CLEARLY BEEN DISPROPORTIONATELY AFFECTED BY THE AIDS PROBLEM.

WHAT IS MOST FRIGHTENING ABOUT THE PEDIATRIC AIDS PROBLEM IS THE FACT THAT THE AVAILABLE STATISTICS ONLY INDICATE THE OBVIOUS CASES. THE CENTERS FOR

DISEASE CONTROL USE A VERY RESTRICTIVE DEFINITION. THEREFORE THE NUMBER OF INFANTS AND CHILDREN SUFFERING THE EFFECTS OF THIS DISEASE ARE EVEN GREATER THAN THE STATISTICS INDICATE.

IT HAS BEEN ESTIMATED THAT FOR EACH CASE OF AIDS IN CHILDREN, THERE ARE THREE TO FIVE TIMES AS MANY CHILDREN WITH AIDS-RELATED ILLNESSES. SOME OF THESE CHILDREN WILL FALL VICTIM TO LIFE-THREATENING DISEASES. OTHERS MAY LIVE REASONABLY HEALTHY LIVES, FOR SOME YEARS, ALTHOUGH THERE IMMUNE SYSTEMS ARE IMPAIRED. WHAT WE DO NOT KNOW IS HOW LONG THESE CHILDREN WILL SURVIVE AND WHAT THEIR MEDICAL AND RELATED SERVICES NEEDS WILL BE. AND, WE WILL HAVE TO PROVIDE HEALTH AND SOCIAL SERVICES TO THESE CHILDREN, AS WELL AS THOSE MOST SERIOUSLY ILL.

WHAT IS CLEAR IS THAT THE PROBLEM OF PEDIATRIC AIDS MUST BE CONFRONTED AND WE MUST DO SO NOW. WHAT IS LESS EVIDENT IS WHAT CAN BE/MUST BE DONE. QUALITY HEALTH CARE THAT IS ADEQUATELY FINANCED, INTEGRATED IN-PATIENT AND OUT-PATIENT HEALTH CARE, COORDINATED HEALTH AND SOCIAL SERVICES, INCREASED DRUG ABUSE TREATMENT, AND PREVENTION AND EDUCATION ARE ALL CRITICAL ELEMENTS OF A COMPREHENSIVE APPROACH TO THIS PROBLEM. BUT, WHAT MUST BE DONE SPECIFICALLY IN EACH OF THESE AREAS?

HOW DO WE REACH THE WOMAN USING DRUGS INTRAVENOUSLY WITH INFORMATION ABOUT AIDS; HOW DO WE CONVINCE HER TO ENTER TREATMENT? HOW DO WE ENCOURAGE MEN TO BE MORE RESPONSIBLE, WITHOUT OFFENDING CULTURAL MORES? WHERE DO WE FIND THE RESOURCES TO ENSURE THAT ALL THE BABIES CURRENTLY AFFECTED BY THIS DISEASE, IN ANY WAY, RECEIVE THE BEST POSSIBLE CARE? THESE QUESTIONS MUST BE ANSWERED.

TO ADDRESS THE PROBLEM OF PEDIATRIC AIDS WE WILL NEED THE CONCERTED SUPPORT OF ALL LEVELS OF GOVERNMENT AND ALL SEGMENTS OF THE COMMUNITY. THAT INCLUDES

THE PRESIDENT AND THE EXECUTIVE BRANCH, CITY AND STATE GOVERNMENT, HEALTH AND SOCIAL SERVICES PROFESSIONALS, COMMUNITY LEADERS, AND CITIZENS, AS WELL AS THE CONGRESS.

IN THE CONGRESS, WITH MY COLLEAGUES BEN GILMAN AND FRANK GUARINI, I HAVE INTRODUCED H.R. 2626, A BILL TO INCREASE FEDERAL FUNDING FOR AIDS EDUCATION, PREVENTION, AND TREATMENT. WE NOW HAVE OVER 30 COSPONSORS, INCLUDING COMMITTEE MEMBER ED TOWNS, WHO IS HERE TODAY.

I WILL ALSO BE INTRODUCING A BILL WHICH WILL FOCUS SPECIFICALLY ON THE PROBLEM OF AIDS AND IV DRUG USE. THE PURPOSE OF THIS LEGISLATION WOULD BE TO PROVIDE FEDERAL ASSISTANCE FOR PROGRAMS TO REDUCE THE INCIDENCE OF PEDIATRIC AIDS, TO IMPROVE THE CARE OF AIDS BABIES, TO EXPAND TREATMENT FOR IV DRUG USERS TO PREVENT THE TRANSMISSION OF AIDS, AND TO EXPAND SCHOOL AND COMMUNITY-BASED EFFORTS DESIGNED TO PREVENT THE SPREAD OF AIDS THROUGH IV DRUG USE.

WE CANNOT IGNORE THE VICTIMS OF PEDIATRIC AIDS. THESE ARE OUR CHILDREN. EVEN IF THEY ONLY LIVE FOR TWO OR THREE YEARS, WE MUST SEE THAT THOSE FEW YEARS ARE THE BEST THAT WE CAN PROVIDE. WE ARE ALL RESPONSIBLE.

AS A PARENT, AS A MEMBER OF THE CONGRESS, I HAD HOPED TO LEAVE A BETTER WORLD TO THE NEXT GENERATION. WHEN I SEE THE HAVOC THAT HAS BEEN WREAKED ON THIS NATION, ON THE WORLD, BY DRUG TRAFFICKING AND ABUSE, I DESPAIR. I CAN ONLY HOPE THAT WE ARE NOT TOO LATE.

OPENING STATEMENT

BY

THE HONORABLE BENJAMIN A. GILMAN

RANKING MINORITY MEMBER

SELECT COMMITTEE ON NARCOTICS ABUSE AND CONTROL

ON

PEDIATRIC AIDS

JULY 27, 1987

HARLEM HOSPITAL AUDITORIUM

135TH & LENOX AVENUE

NEW YORK CITY

9:30 AM - 1:00 PM

OVER THE PAST DECADE, THIS COMMITTEE HAS TAKEN TESTIMONY FROM A HOST OF INDIVIDUALS WITH FIRST HAND KNOWLEDGE OF THE TRAGEDY OF DRUG ABUSE. YET TODAY'S HEARING AT HARLEM HOSPITAL WILL FOCUS ON THOSE INNOCENT CHILDREN WHO HAVE BECOME KNOWN AS "AIDS BABIES," AND FOR WHOM AN EARLY DEATH IS A CERTAINTY.

MOST OF THESE TINY BABIES CONTRACTED THE AIDS VIRUS WHILE STILL IN THE WOMB. THEIR MOTHERS ABUSE ILLICIT DRUGS INTRAVENOUSLY, OR THEMSELVES WERE INFECTED WITH THE VIRUS BY A SEXUAL PARTNER. GIVING BIRTH SHOULD EVOKE JOY -- INSTEAD, FOR A GROWING NUMBER, THE JOY GIVES WAY TO ANGUISH. THE PROBLEM OF ABANDONED BABIES, THE NEED FOR SPECIALIZED SOCIAL SERVICES, TARGETED PREVENTION EFFORTS, AND A MYRIAD OF OTHER CONSIDERATIONS ARE WHAT WE HOPE OUR DISTINGUISHED WITNESSES WILL ADDRESS THIS MORNING.

I AM ESPECIALLY PLEASED THAT OUR SURGEON GENERAL, DR. C. EVERETT KOOP, HAS BEEN ABLE TO JOIN US THIS MORNING. HIS DEDICATION TO THE PUBLIC'S HEALTH, AND HIS MANY YEARS OF COMMITMENT TO OUR NATION'S CHILDREN CANNOT BE QUESTIONED. DR. KOOP HAS APPROACHED THE SERIOUS PROBLEM OF AIDS HEAD-ON, AND I AM SURE, WILL BE OF GREAT ASSISTANCE TO THIS COMMITTEE IN RESPONDING TO THIS MOST RECENT CRISIS.

OUR FORMER COLLEAGUE IN CONGRESS, MAYOR ED KOCH, IS ALSO WELCOMED THIS MORNING. HE HAS NEVER SWAYED FROM DISCUSSING SERIOUS ISSUES, AND HAS ALWAYS PROVIDED THIS COMMITTEE WITH THE BENEFIT OF HIS UNIQUE EXPERTISE AND PERSPECTIVE. AS NEW YORK CITY CONFRONTS SPECIAL PROBLEMS, IT ALSO MANAGES TO OFTEN DEVISE SPECIAL SOLUTIONS. THE PROBLEM OF PEDIATRIC AIDS REQUIRES A SPECIAL APPROACH, SINCE IT IS EXPECTED THAT THE NUMBER OF PEDIATRIC AIDS CASES WILL RISE.

CONGRESS HAS RESPONDED WITH ADDITIONAL FUNDING FOR RESEARCH, BUT MANY MORE WILL DIE BEFORE A CURE OR EFFECTIVE TREATMENT IS FOUND. WE MUST, THEREFORE, COMPREHENSIVELY ASSESS THE MANY IMPLICATIONS OF PEDIATRIC AIDS AND THE HIV VIRUS. ULTIMATELY, THE AIDS VIRUS AFFECTS ALL OF US SINCE IT INFECTS THE NON-ABUSING HETEROSEXUAL POPULATION THROUGH SEXUAL CONTACT WITH ABUSERS OF INTRAVENOUS DRUGS OR THEIR PARTNERS.

WHEN THIS COMMITTEE FIRST ADDRESSED THE ISSUE OF AIDS AND DRUG ABUSE, WE DID REALIZE THAT THIS NATION WAS BEING CONFRONTED WITH AN EPIDEMIC OF MONUMENTAL PROPORTIONS THAT KNOWS NO SOCIO-ECONOMIC STATUS, RACE, OR RELIGIOUS ORI YET, THE PROBLEM OF PEDIATRIC AIDS IS ONE PRIMARILY AFFECTING BLACK AND 'ANIC WOMEN.

A CHILLING STATISTIC, BUT ONE WHICH IS MOST TELLING, IS THAT THE HIV VIRUS IS NOW THE LEADING CAUSE OF DEATH FOR WOMEN IN NEW YORK BETWEEN THE AGES OF 25 AND 34. AND OF THE 199 PEDIATRIC AIDS CASES REPORTED IN NEW YORK CITY SINCE 1979, FULLY 73 PERCENT HAVE DIED.

WE MUST REACH OUT TO THESE WOMEN AND THEIR CHILDREN. OUR RESPONSE MUST BE COORDINATED AND COMPREHENSIVE. I HOPE OUR WITNESSES THIS MORNING WILL BE ABLE TO PROVIDE US WITH SOME OF THE ANSWERS TO THE MANY CRUCIAL QUESTIONS SURROUNDING THIS COMPLEX ISSUE, AND LOOK FORWARD TO A CANDID ASSESSMENT FROM EACH OF THEM.

STATEMENT BY SENATOR D'AMATO

HEARING ON PEDIATRIC AIDS

JULY 27, 1987

GOOD MORNING. I AM PLEASED TO JOIN THE MEMBERS OF THE HOUSE SELECT COMMITTEE ON NARCOTICS ABUSE AND CONTROL FOR THIS HEARING ON PEDIATRIC AIDS. I COMMEND CHAIRMAN RANGEL, CONGRESSMEN GILMAN AND TOWNS, FOR THEIR LEADERSHIP IN THE AREAS OF DRUG ABUSE AND AIDS.

INTRAVENOUS DRUG USE AND AIDS ARE COMBINING IN A "DOUBLE PLAGUE" GROWING MORE DEADLY BY THE DAY. IT IS NOW SPREADING TO THE MOST INNOCENT, THE DEFENSELESS AIDS BABIES WE WILL DISCUSS TODAY.

THE NEED FOR AN ALL OUT WAR ON DRUGS IS MORE URGENT THAN EVER. 80 PERCENT OF THESE BABIES HAVE AIDS BECAUSE THEIR MOTHERS ARE EITHER DRUG USERS OR PARTNERS OF MEN WHO ARE I.V. DRUG USERS. WHILE I.V. DRUG USERS ARE COMMITTING SLOW SUICIDE, THEY ARE SENTENCING THEIR INFANTS TO DEATH: 74 PERCENT OF ALL CHILDREN DIAGNOSED WITH AIDS HAVE DIED.

IN MAY 1987, 1500 CHILDREN WERE REPORTED TO HAVE SYMPTOMS OF AIDS INFECTION. THEIR NUMBER IS INCREASING DRAMATICALLY. THE SITUATION IS MUCH WORSE THAN THESE NUMBERS

INDICATE. THE NUMBER OF AIDS BABIES IS SERIOUSLY UNDER-REPORTED.

The "double plague" of drugs and AIDS is straining scarce resources to the breaking point. By the Summer of 1988, there may be hospitals in New York that will be so filled with AIDS patients that they will not have the spaces needed for other patients.

How long can we afford the lost productivity, unemployment, sickness, and crime due to drugs that costs our economy $100 billion per year? AIDS costs an additional $10 billion per year. By 1991 that cost will increase to $65 billion.

In New York City, AIDS is the leading cause of death among women ages 25 to 34. An estimated 1,500,000 people throughout the country are infected with the AIDS virus. Current projections are that the number of AIDS cases will increase 10-fold in the next 5 years.

The drug epidemic is not on the wane. It is out of control. There are 200,000 heroin addicts in the New York metropolitan area, and more than 60 percent of them are infected with the AIDS virus. That percentage is increasing at a rate of about 8 percent a year. Either we end this double plague or it will end us. We must:

1) RECOGNIZE AIDS AS A PUBLIC HEALTH EMERGENCY. THIS MEANS:

A. AIDS MUST BE A FEDERAL BUDGET PRIORITY. WE MUST EXPEDITE THE DRUG APPROVAL PROCESS; GIVE EVERY POSSIBLE SUPPORT TO RESEARCHERS, INVESTIGATORS AND CAREGIVERS; AND TRAIN MEDICAL PROFESSIONALS IN THE CARE OF AIDS PATIENTS.

B. WE MUST IDENTIFY THE AIDS BABIES AND OTHER AIDS PATIENTS THAT WE SHOULD BE CARING FOR AT HOME OR IN HOSPICES. THE ISSUE OF HOSPITAL CARE AND CROWDING MUST BE ADDRESSED IN A SERIOUS, COMPASSIONATE AND INTELLIGENT MANNER>

C. $200 MILLION ANNUALLY IS NEEDED FOR A MASSIVE EDUCATION PREVENTION CAMPAIGN DIRECTED TO BOTH THE GENERAL POPULATION AND SPECIFIC RISK GROUPS. DESPITE ALL THE PUBLICITY, TOO MANY YOUNG PEOPLE DO NOT KNOW THE RISKS THEY CONFRONT. WE MUST EDUCATE THEM THAT DRUG ABUSE --AND ESPECIALLY INTRAVENOUS DRUG USE-- CAN MEAN CERTAIN DEATH, FOR THEM AND THEIR CHILDREN.

2) ALL-OUT WAR ON DRUGS. We must stop kidding ourselves about our commitment in the so-called "war on drugs". We have not developed national drug prevention models. We have 30,000 methadone maintenance slots and 6,000 drug-free

treatment slots in a city with more than 400,000 heavy drug abusers.

Look around Harlem to see what our commitment is. There are the overcrowded drug-free centers (Addicts Rehabilitation Center and Reality House) and the methadone maintenance centers operated by Beth Israel and Harlem Hospitals, and Dr. Beny Primm. Is that enough? Is that full commitment? There is Mother Hale. Does she get enough support or help?

Then look at what we are doing overseas, where the heroin and cocaine originate. In our foreign policy, anti-drug efforts must be raised to a much higher priority. We must offer the countries that want to cooperate with us the help they need. But any country that refuses to try must be held accountable, with no exceptions. If cutting off aid to those countries is the only way we can persuade them to cooperate, then so be it.

For the sake of our children and their future we must build an anti-drug program that is second to none. It must involves every segment of society, school district, and level of government.

We had better start now. We are running out of time.

(16)

STATEMENT BY DANIEL PATRICK MOYNIHAN ON CHILDREN WITH AIDS
BEFORE THE HOUSE SELECT COMMITTEE ON NARCOTICS HEARING
IN NEW YORK CITY, JULY 27, 1987

Mr. Chairman

I thank you for the opportunity to offer some remarks about the condition we are facing today regarding children with AIDS.

On the first day of the 100th Congress, I introduced S. 24, a comprehensive bill on AIDS. One of the provisions of this bill asks the Secretary of Health and Human Services to conduct a study of children with AIDS. This study would address the numbers of children abandoned in hospitals, the cost of care for these chidren, and alternative types of care that are currently available to children with AIDS. The purpose of this study is to better inform the Congress on what would be the most appropriate Federal response to this crisis -- one which does not appear will be alleviated in the near future.

If there is one personal trauma that we are all going to have to learn to live with, it is infants who are born with AIDS. I have seen them in New York hospitals, namely Harlem Hospital. These are children of mothers who have acquired the disease, typically through hyperdermic needles and drug use.

They are born in those hospitals and abandoned. Yet hospitals are only their shelter: it is the doctors and nurses who care for them. Our hearts must go out to all involved - the agony of caring for a child knowing that child will inevitably die must be unbearable.

These individuals must not be alone in their fight. We must help them. We must address the causes of the spread of AIDS, in this case, drug abuse. Chairman Rangel and I are quite familiar with this area. In the 98th and 99th Congresses we introduced bills to provide funds for state and local governments for drug treatment and rehabilitation as well as funds for local drug law enforcement. We were most pleased to see that last year's Anti-Drug Abuse contained $170 million for drug abuse treatment and rehabilitation and $230 million for grants to state and local law enforcement agencies for drug law enforcement.

To conquer AIDS completely will be a long and difficult battle. And in this battle we must address all those affected by this disease -- most especially our children. They are the victims of circumstances they can do nothing to prevent. Consequently, it is up to us to prevent them.

I intend to work with the Chairman in this endeavor and do all I can in the Senate to assist in obtaining federal support for AIDS patients as well as those communities which strive to care for them best that they can.

I thank the Chairman for allowing me the opportunity to address this issue.

STATEMENT OF

C. EVERETT KOOP, M.D., Sc.D.

SURGEON GENERAL

U.S. PUBLIC HEALTH SERVICE

AND

DEPUTY ASSISTANT SECRETARY FOR HEALTH

DEPARTMENT OF HEALTH AND HUMAN SERVICES

BEFORE THE

SELECT COMMITTEE ON NARCOTICS ABUSE AND CONTROL

U.S. HOUSE OF REPRESENTATIVES

JULY 27, 1987

Mr. Chairman and Members of the Committee:

I am C. Everett Koop, Surgeon General of the Public Health Service and Deputy Assistant Secretary for Health. I am pleased to be able to appear today and discuss with you the serious and extremely difficult problem of AIDS in children. This is a problem that is all the more devastating because it affects the most defenseless of us and because its cause, its impact, and its solutions lie not only in our health system but also in our fundamental social and moral underpinnings.

I want to talk briefly about what we know about pediatric AIDS. As you know, AIDS is a recently discovered disease. The agent which causes AIDS has been known for a very short time, and we are still working to unravel the mysterious workings of this virus and the enormous public health implications of this disease.

AIDS in children was first described in 1982 by physicians in New York City, New Jersey, and Miami. Since that discovery, a number of meetings have brought together experts to discuss the disease and to set a course for dealing with its consequences. In 1984, the Health Resources and Services Administration (HRSA) Division of Maternal and Child Health held an ad hoc meeting to try to delineate the nature of the problem. The meeting was here in New York City, where infants were occupying acute-care hospital beds unnecessarily because no alternative living arrangements were available. It is a commentary on the nature of this problem that that situation still exists today at this and other hospitals.

A number of components of the Department of Health and Human Services cosponsored the first National meeting on Pediatric AIDS in Florida in November 1984. Attendees at this meeting, which was held before the discovery of the AIDS virus, agreed that AIDS did occur in children, that the number of children involved was vastly underestimated, and that infected infants and children and their families were subject to discrimination and were sometimes barred from basic services. Participants told of initial efforts to provide care and eliminate discrimination.

A second National Pediatric AIDS meeting was held in New York City in March 1986. A larger group of physicians, other health workers, child welfare workers, and educators exchanged information about the clinical spectrum of the disease. They described treatment efforts that were under way. Solutions to other problems appeared to be available in some areas, partly because of the knowledge that had been gained about the etiology and transmission of AIDS. It was especially heartening to hear how the State Health Department, the Hemophilia Treatment Center, and the local school had worked together in Swansea, Massachusetts, to retain a boy with AIDS in school in a manner that evoked the best instincts of his classmates and their families.

AS OF JUNE 15, 1987, JUST OVER 1.4% OF THESE WITH AIDS HAD CHANGED

~~Since the time of the first identification of AIDS in children,~~ ~~nearly~~ 500 cases in children under the age of 13 have been reported to the Centers for Disease Control (CDC). An estimated two to three times that number of children have been diagnosed with human immunodeficiency virus (HIV) infection who do not meet the CDC definition of AIDS. The majority of children acquired the virus in the perinatal period and were born to mothers who have been either intravenous (IV) drug users themselves or the sexual partners of men who are IV drug users. I am going to focus on these children with perinatally acquired AIDS, although the benefits of our work on this problem will also accrue to the small number of children who acquired AIDS through a blood transfusion or through treatment for hemophilia before we had a mechanism for preventing contamination of blood and blood products.

To date, just over 2000 cases of AIDS have been reported in women, 95% of whom are of child-bearing age. This number is expected to increase to over 20,000 cases by the end of 1991. As more women become infected, more children born to these women will be infected. HIV infection in children is likely to become a more common pediatric infection.

RESEARCH EFFORTS

Research on pediatric AIDS is taking many approaches and looking at many facets of the problem. CDC-supported activities have focused on defining the occurrence of pediatric AIDS and HIV infection, the epidemiologic characteristics of children and heterosexual men and women with the infection, the transmission patterns of HIV in these populations, and the natural history of the disease in children acquiring HIV from their mothers. To monitor the occurrence of AIDS and to determine the epidemiologic characteristics of the patient populations, CDC established surveillance for AIDS in 1981 shortly after reports of the first cases. More recently, studies have begun to monitor transmission and infection rates in various populations.

To define patterns of transmission from mothers to their infants, CDC has two ongoing studies in New York City of pregnant women and infants at increased risk for HIV infection. As you know, Harlem Hospital is participating in one of those studies. These studies, as well as a third study being conducted in Newark, New Jersey, will also help us understand better the natural history of HIV infection in children who acquire the virus from their mothers.

In addition, the National Institutes of Health (NIH) is supporting a number of studies designed to help us understand this disease, with the ultimate goal of trying to combat perinatal transmission. Among those projects are a National Institute of Child Health and Human Development (NICHD) seroprevalence study of newborns in the Northeast United States and a joint NICHD-National Cancer Institute study of the natural history of the disease. This study is looking at the rates of perinatal transmission, the full

spectrum of perinatally acquired disease, and the developmental outcome of perinatally infected children. NIH is also supporting, through the National Institute of Allergy and Infectious Diseases, AIDS Treatment Evaluation Units that will evaluate the drugs Retrovir (formerly called AZT) and Ribavirin in small numbers of children with AIDS.

Such research has taught us many things about pediatric AIDS.

First, we have some idea now, though we still have a great deal to learn, about how common this disease is and about the characteristics of children who get the disease. As I mentioned earlier, the number of cases of AIDS in children has increased steadily in the past 5 years. As of May 4, 1987, 494 children under 13 with AIDS had been reported to CDC, accounting for about 1% of all reported AIDS cases. 81% of the pediatric cases have been reported since 1985.

AIDS, as currently defined by CDC, represents the most severe manifestation of HIV infection; the numbers therefore do not include children with less severe symptoms or those with primarily neurologic manifestations. Physicians treating large numbers of these children report that about one-third to one-half of the children with HIV infection meet the CDC case definition. Thus, CDC estimates that around 1000 to 1500 children have had symptomatic HIV infection. The epidemiologic characteristics of children with less severe forms of HIV infection are the same as those of children with reported AIDS.

Through the National surveillance system, CDC collects information on the cases that are reported. Analysis of those data has allowed us to describe the epidemiologic characteristics of this population. In the majority (73%) of the perinatally acquired cases, the mothers are either IV drug users or the sex partners of men who use IV drugs. This is not surprising, since 67% of all AIDS patients who are heterosexual are IV drug users or their sex partners. 14% of these children were born to women who come from countries where heterosexual transmission of AIDS is thought to be the major mode of transmission (i.e., Haiti and Central Africa). A small proportion of the children were born to women who are the sexual partners of men at increased risk for other reasons or women who had received blood or blood product transfusions.

The majority (70%) of the children with perinatally acquired AIDS are from three states: New York, New Jersey, and Florida, reflecting the occurrence of AIDS cases in IV drug users (75% of whom are from New York or New Jersey) and in Haitian immigrants (79% of whom reside in Florida or New York). The proportion of children reported from other states, however, has increased over time from 24% in 1982-1984 to 34% in 1985-1986. This trend in reporting is expected to continue over the next 5 years as the AIDS epidemic spreads to other areas in the United States. The NICHD has initiated a study designed to look at populations in states that currently have varying incidence of pediatric AIDS, so

that those areas might be able to predict more accurately the problem they will face in future years.

Cities with large populations of IV drug abusers can expect to observe increases in the number of perinatally acquired AIDS cases as the rate of infection in this population increases.

Since the majority of perinatally acquired AIDS cases are linked to IV drug abusers, the demographic characteristics of these children are similar to those of IV drug users with AIDS. Most (88%) of these children are black or of Hispanic ethnicity. The prevalence of AIDS in black and Hispanic children is 15 and 9 times that in white, non-Hispanic children.

Over 85% of these children were diagnosed in the first 3 years of life (half have been diagnosed by 9 months of age). However, a small number (2%) were not diagnosed until 6 to 8 years of age, indicating that the incubation period can be quite long.

The prognosis for children with perinatally acquired AIDS is grim. They are subject to many kinds of infections, all of which are life-threatening. For example, health providers are seeing an alarming number of bacterial infections such as pneumococcus and hemophilia influenza. The full impact and extent of these infections are unknown at this time. Over 60% of the children who have been reported to CDC have died. Half of the children with perinatally acquired AIDS died within 11 months following their diagnosis. Children who are diagnosed under 1 year of age have a more rapid course of disease, with half dying within 6 months after the diagnosis.

Because symptomatic HIV infection follows an incubation period of months to years, children reported to CDC at present represent those who acquired infection in the past. To monitor infection rates or rates of transmission, it is necessary to test individuals who may be at risk, but who have not, as yet, developed signs or symptoms of illness. Infection rates among populations of children are unknown, as no studies of this type have been published. Studies of IV drug abusers show varying infection rates in different cities. In one study, as many as 60% of IV drug users in New York City were found to be infected. Another study of IV drug users in San Francisco found 1 of 10 to be infected. Studies of infection rates among recent Haitian immigrants to the United States show that around 5% of them are infected.

The frequency with which infected persons transmit or pass the virus to their sex partners also varies. Studies show that about 10-15% of the partners of persons who were infected through blood transfusions and partners of men with hemophilia acquired the virus through sexual contact. As many as 50% of the partners of IV drug users and infected Haiti-born men may be infected.

The infection rate among the general female population is unknown. Infection rates among female blood donors average around 5 per 100,000; rates among female military recruit applicants average around 60 per 100,000. These populations may not be representative of the U.S. female population at large, but they do give us an estimate of overall rates among women who perceive themselves to be at low risk for HIV infection, since both the military and blood donation centers discourage persons with high-risk behaviors from applying. Perhaps more compelling data are obtained from two hospital-based studies here in New York City. All women who gave birth in these hospitals over a several-month period were examined for evidence of HIV infection. In one hospital, 2 percent of the women were infected; in the other, 3.5 percent were infected. If these results are extrapolated even to the New York City metropolitan area, this forecasts a staggering number of pediatric AIDS cases in the future.

We have also learned something about how HIV is transmitted from mothers to babies. It has been hypothesized that transmission could occur during pregnancy, through passage of the virus through the placenta; during labor and delivery, through exposure to infective maternal blood and vaginal secretions; or after birth, through breast feeding. There is evidence that transmission can occur through all of these modes. The occurrence of AIDS in children who had no further contact with their mothers following birth and the identification of virus in fetal tissue are evidence of transmission occurring during pregnancy or at the time of birth. Three reports of HIV infection in infants born to women who became infected via blood transfusions given shortly after birth and who breast fed their infants suggest that transmission can occur through this route. HIV has also been isolated from breast milk. This latter route of perinatal transmission is probably rare in the United States, since the vast majority of transmitting mothers, most of whom are IV drug abusers, have not breast fed their infants.

We cannot answer with certainty how infected mothers transmit the virus to their babies. In one study of mothers who had already delivered one infected baby, 50% transmitted the virus to their subsequent children. Transmission rates in other studies have been lower. Based on current knowledge, CDC estimates that about one-third to one-half of infected mothers will give birth to infected infants.

So far, our studies have not enabled us to predict which mothers are likely to pass the virus to their infants. Such factors as the amount of virus in the mother's blood, the severity of HIV disease, continued exposure to the virus during pregnancy, environmental factors, and other factors are being studied. STUDIES SHOW 30-50% DO.

We know that many infectious diseases are more severe in pregnant women. The combined effects of pregnancy and HIV infection in women are still being studied. In one ongoing prospective study,

none of the women progressed in their stage of HIV disease during pregnancy. The long-term effect of pregnancy on the course of HIV disease is, however, not known.

We are continuing to learn how better to care for these infants and how to use available resources in the most effective way to assist these children. The Health Resources and Services Administration (HRSA) currently supports AIDS Service Demonstration Projects in the cities of Miami, Los Angeles, San Francisco, and New York. We are very hopeful that what is being learned in these projects will eventually provide some models for approaching the problem in other places. For example, the Trust of Dade County, the AIDS Service Demonstration Program grantee in Miami, is emphasizing the provision of specialized inpatient and outpatient pediatric care at the Jackson Memorial Hospital, as well as the development of arrangements for child care, housing, and foster homes. Here in New York, the Montefiore, Beth Israel, Bronx Lebanon, and St. Luke's/Roosevelt hospitals, all affiliated with the HRSA-funded AIDS Service Delivery Consortium, the parent organization of the New York City AIDS Service Demonstration project, provide a broad range of counseling, treatment, and referral services. Male and female IV drug users are counseled about the risks of infection during pregnancy, and for infants and children requiring housing, assistance is sought through the New York City Human Resources Administration pediatric unit or the New York State baby foster care program. Although this kind of coordinated approach, which brings together Federal, State, and local resources, is exactly what is needed, as you know, the system is not a perfect one yet, and there is a substantial backlog for foster placement of AIDS infants and children.

PREVENTION

Clearly, the ultimate goal of all of this research is the prevention of perinatal HIV infection. A good understanding of the epidemiological characteristics, occurrence of the disease, transmission patterns, and natural history of the disease are necessary for developing and implementing effective prevention programs. Based on information from studies in all of the areas I have described, CDC issued general guidelines for prevention of perinatally acquired HIV infection in December 1985. The guidelines state that prevention of perinatally acquired HIV infection requires prevention of infection among women and prevention of pregnancy among HIV-infected women.

It is imperative that we reach out aggressively to the following groups of women: IV drug users in treatment, IV drug users not in treatment, partners of IV drug users, and prostitutes.

Women who work as prostitutes are at an increased risk of exposure to the AIDS virus based on a number of factors, including multiple sex partners, anonymous sex with partners who may be seropositive or who may fall into a high-risk group, high-risk sexual activity,

IV drug use, and decreased vigilance about proper safe sex practices because of the use of alcohol or drugs.

It is difficult to isolate prostitution from the issue of IV drug use, as it is estimated that one-third of all prostitutes are also IV drug users. International and National studies of this problem indicate that IV drug use should be considered the primary risk factor for female prostitutes. Among female prostitutes, special attention must be paid to the teen-aged prostitute. One study found that 52% of a sample of teen-aged prostitutes thought they were at little or no risk for developing AIDS.

Several major challenges face us in mounting outreach efforts to these high-risk groups of women. The first is that many of these women, due to lack of disclosure by their partners, do not know that they are at risk and are thus a "hidden" and difficult-to-reach population. A second challenge is that the majority of women with AIDS come from ethnic minority groups. Education and prevention programs must be sensitive, both linguistically and culturally, to the norms prevailing in these minority groups.

Perhaps the greatest challenge, however, is the fact that knowledge about AIDS transmission and risk may have little impact on behavior. Changing health and sexual behaviors is extremely difficult, and must involve a multifected program in which education is only one component. Preventing the spread of AIDS among sexual partners of IV drug abusers may be more difficult than preventing the transmission (by sharing "works") among IV drug abusers. The behavior changes required to prevent heterosexual and <u>in utero</u> transmission require disruption of sexual relationships and, in some cases, decisions not to have children.

Despite the successes of prevention and education efforts aimed at the homosexual and bisexual male communities, similar prevention efforts may not be as successful when aimed at women at risk for AIDS. Researchers in the area of health behavior change have learned that one's ability to utilize health education information and to make changes in one's behavior largely depends on socioeconomic status, educational level, sense of power and control, and vocation. The women we need to reach have low socioeconomic status, a low educational level, a sense of powerlessness and helplessness, and are either unemployed or work as prostitutes.

For these groups of women, more personal and intensive communications will be needed to bring about sustained behavior change. We must modify these women's beliefs about the likelihood of behavioral changes leading to favorable outcomes and give them the coping skills necessary to implement changes. Enhancing these women's belief in their own abilities to effect change, changing their attitudes about the potential efficacy of their actions, and combatting their sense of hopelessness and powerlessness, while

increasing their understanding of their risk of AIDS if preventative measures are not taken, will all be critical to the intervention efforts focused on this population.

While we recognize that we face formidable challenges in designing education and prevention programs aimed at these high-risk women and their children, I'm proud to say that the Department is moving forward with a number of important initiatives in this area. The National Institute on Drug Abuse (NIDA), for example, is undertaking a comprehensive community outreach demonstration project designed to reach and effectively communicate AIDS information to three high-risk populations -- IV drug abusers, their sexual partners, and prostitutes. The goals are to encourage high-risk individuals to enter treatment and/or to change drug-using and sexual behaviors that put them at risk. Grants will be awarded to at least five cities that have a high incidence of reported AIDS IV drug abuse cases, and each city will employ a series of outreach/early intervention methods that have proven to be effective in prior drug research.

NIDA is also funding a 3-year project which will specifically target the female sexual partners of IV drug abusers and prostitutes in three cities. That project will make use of a variety of community institutions and resources and of strategies carefully designed to find these high-risk women, to reach them with AIDS information and counseling, and to empower them to make necessary changes in their lives. We recognize that in order for education and outreach to prevent the transmission of AIDS to women and their children, a multilevel approach is required, involving a variety of organizations which provide services to women. We plan to reach out to women through all of these.

We also know that methods that involve these women in the development and delivery of their own programs are most likely to be successful. In every population, there are individuals who are highly respected and recognized by other members of the group and make up an informal network of community helpers. These individuals will be an integral part of our educational efforts and will be used to bridge the gap between formal organizations and the various targeted populations of high-risk women.

Opportunities for HIV testing and counseling will be a part of all of these projects. However, while we recognize the value of routine testing, I want to be clear that prevention and education is our ultimate goal. High-risk women have been told that they should be tested for the AIDS virus prior to pregnancy and should avoid becoming pregnant if they test positive, but telling them is not enough. The fact that some women have had one child with AIDS and have gone on to have others should be stark proof of the power of denial and of the difficulty in changing behavior even in the face of tragic consequences. Counseling women about the risks is important, but that information will be translated into positive action only if these women believe that their own lives are worth saving.

In our efforts to educate and change the behavior of high-risk women, we should not lose sight of the fact that the behavior and attitudes of their male partners also need to be changed. Any prevention efforts aimed at high-risk women must be part of a larger and more comprehensive effort aimed at our entire population.

PLANS FOR THE FUTURE

What do we have planned for the future?

As you know, our interest in the problem of AIDS, and certainly in the problem of pediatric AIDS, has not waned. Each year we have committed greater effort and more resources to understanding and trying to prevent this tragic epidemic. I do not foresee that either the Congress or this Administration will turn back. We are dedicated to stemming this epidemic and to doing the best job we can for the people who have already been affected.

Let me give you just a few examples of what we have definitely planned for the future relative particularly to pediatric AIDS.

CDC plans to continue and expand studies of women and children, such as the one being conducted here, to define better perinatal transmission patterns, natural history, and treatment. Studies of women and children to determine infection and transmission rates are being developed to allow for better direction of efforts to prevent HIV infection. Studies to assess social service and health care needs of these children are being developed. Funding and assistance to conduct studies of ways to affect changes in high-risk behaviors among teenagers will be announced soon.

The NIH, through its National Institute of Allergy and Infectious Diseases (NIAID), will initiate a cohort study of pregnant women at high risk of HIV infection and their offspring, designed to determine the risk of transmission from an infected mother to her offspring, factors influencing the probability of transmission, and the time during pregnancy transmission is most likely to occur. Of approximately 15-20 new Clinical Study Groups that will be funded by NIAID, several will focus on pediatric populations. The National Institute of Child Health and Human Development will begin a study of the epidemic among pregnant women in Puerto Rico, expand their surveillance of populations in low-prevalence areas, and begin a study of whether intravenous gamma globulin given to infected children will prevent the complications of HIV infection and prolong the survival of these children.

The HHS Office of Human Development Services is looking at many of the extra-health aspects of this problem, including how to solve the situation of "hospital-abandoned" babies.

Convening the recent (April 1987) Surgeon General's Workshop on Children with HIV Infection and Their Families provided an

opportunity to summarize the current knowledge about AIDS in children and to make recommendations about future directions in research, prevention, and amelioration of the effects of pediatric AIDS. Surgeon General's Workshops, of which this is the ~~fourth~~ FIFTH, have been useful vehicles for bringing experts together to combine efforts to improve the health of mothers and children. Representatives of major professional and voluntary organizations as well as from the various components of the Public Health Service and the Department participate actively in the planning. This ensures not only a broad comprehensive coverage of the subject during the Workshop but also a network to disseminate and implement the recommendations for action.

At this Workshop, it was inspiring to hear, from experts representing areas having the largest numbers of infants with AIDS, presentations on their pioneering and heroic efforts in developing information about the condition and about methods to care for those afflicted. Especially valuable were the contributions of individuals from the New York metropolitan area relative to proposed models for out-of-hospital care.

I asked the participants in that Workshop to focus particularly on three major issues: the development of an expanded knowledge base, the identification of necessary health resources and services, and a sense of the social strategies appropriate to assure the best application of our knowledge and resources to achieve better health for our children. We owe our children and their caregivers and their families nothing less than a thorough evaluation of these issues, and we are committed to that.

Like the others, this Workshop will have both published Proceedings and Recommendations. They will help us focus on this problem and what we can do, in cooperation with States, localities, and the private sector, to solve it. In order to retain the momentum of the Workshop, I have arranged for a large printing of the Recommendations; we will give it very broad distribution. These Recommendations represent a comprehensive, careful, and independent assessment and appraisal. I may not agree with all of them; however, they constitute valued expert judgment, and I am considering and weighing the merits of each very thoroughly. More importantly, I look forward to the consideration and use of these recommendations by State and local health departments, medical and other professional societies, educational organizations, and other community groups which must respond to problems of children with AIDS.

CONCLUSION

This epidemic is bound up within the broader social problems of poverty and ignorance. These problems are manifested in IV drug abuse, promiscuity, and poor self-image. The consequences of drug-abusing parents, paternal bisexuality, and low socioeconomic

status are visited upon the children. Many will not survive until school age.

How do we help the children? How do we turn concern into action?

The Surgeon General's Workshop in April was a reflection of these concerns. I am going to share with you some of the ideas generated by over 200 of the Nation's top thinkers on issues related to children and AIDS. Among those were Dr. Stephen Joseph, your Commissioner of Health, Dr. Margaret C. Hagarty, Director of Pediatrics here at the Harlem Hospital, Dr. Margaret Hilgartner of New York Hospital, ~~and~~ Dr. Pauline Thomas of your Health Department, AND LORRAINE HALE WHO IS ON THE SCIENTIFIC PANEL THIS MORNING

In addition to this National Workshop, I would also like to bring to your attention "The Invisible Emergency, Children and AIDS in New York," a report by the Citizen's Committee for Children of New York, Inc. This report is similar to the Surgeon General's Workshop Report, but very specific to New York City's special needs.

o With AIDS, the first response must always be prevention:

We should routinely offer counseling and testing to all pregnant women as early in pregnancy as possible.

Risk assessment, access to counseling and testing, should routinely be done at family planning clinics, STD clinics, drug treatment clinics, and health centers for women and their sex partners.

HIV infection status should be on the medical record to facilitate appropriate obstetrical and pediatric care. Confidentiality must be assured.

Donors of breast milk should be screened for HIV positivity.

Knowledge that unprotected sex and sharing of IV drug syringes and needles spreads AIDS should be widely known.

Knowledge of risk-reduction modalities such as condoms and use of sterile syringes and needles should be widespread.

o In caring for children with AIDS, I suggest a family-centered approach which counsels families, with the aim of providing moral support, discussing pregnancy risk, and reducing high-risk behavior.

o We must educate communities about AIDS to the point that foster care is available to children with AIDS, children who are HIV

infected, and children who test negative but have HIV-positive parents.

- We must get the parents off drugs.

- We must eliminate high-risk sexual behavior.

- We must target intravenous drug users, adolescents, those with language barriers, homosexuals, and others, who are not being reached with educational messages that are conveyed through traditional media.

- Specifically, the public and private sectors should work in concert to:

  Translate materials into appropriate languages, especially Spanish.

  Improve communication with the leadership, media, and health professionals in the Black and Hispanic communities and enlist them to take the lead in educating their communities.

  Disseminate information about HIV risk to intravenous drug users through urban community and outreach programs.

Since this past January, I have tried to draw attention to the need for discussion among Federal, State, and municipal health officials and political figures and the private sector to do three things: (1) assess the cost of AIDS on an annual basis in the future and consider how the money will be raised, what it will be used for, and who will make those decisions; (2) consider the role of insurance in the cost factors related to AIDS; and (3) plan for alternative types of care for terminally ill AIDS patients. Because of this important pediatric AIDS workshop, I will stop calling for such actions and will try to effect them as soon as possible.

In the Surgeon General's Report of October 1986, I called upon communities to set up task forces to anticipate every phase of community life and of the social fabric affected by the AIDS epidemic. Many sections of the Nation have not yet encountered the problem of pediatric AIDS. In these States, governmental and professional leaders in medicine, public health, education, and human services must begin immediately to plan for what they are going to do when their cities do have a number of HIV-infected children. I will facilitate this process by providing consultation through our well-established network of State, Territorial, and municipal health offices as soon as possible.

In this brief time, I have tried to give you a sense of the problems and some beginning steps.

I don't have the answers. We are talking about major behavioral changes for individuals and society.

The enemies are the old enemies -- fear and ignorance, poverty, racism, death, and suffering.

AIDS has raised the stakes. The battle must be enjoined at a higher level of commitment and concern.

I will be pleased to answer any questions you may have.

REVISED

REMARKS BY MAYOR EDWARD I. KOCH
ON PEDIATRIC AIDS
BEFORE THE HOUSE SELECT COMMITTEE ON NARCOTICS ABUSE & CONTROL
9:30 A.M. -- MONDAY, JULY 27, 1987
HARLEM HOSPITAL -- NEW YORK CITY

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GOOD MORNING, MR. CHAIRMAN AND MEMBERS OF THE COMMITTEE. I APPRECIATE THE OPPORTUNITY TO SPEAK WITH YOU THIS MORNING ABOUT THE EFFECT OF AIDS ON CHILDREN IN NEW YORK CITY.

AIDS IS A TERRIBLE AND TRAGIC DISEASE FOR ANYONE WHO SUFFERS FROM IT. BUT IT'S PARTICULARLY TERRIBLE, PARTICULARLY TRAGIC WHEN IT AFFLICTS CHILDREN: PARENTS ARE ROBBED OF THEIR MOST PRECIOUS POSSESSION. INFANT CHILDREN ARE ROBBED OF A FUTURE.

SINCE THE DISEASE WAS FIRST RECOGNIZED BY THE FEDERAL CENTERS FOR DISEASE CONTROL, 199 CHILDREN IN THIS CITY HAVE BEEN IDENTIFIED AS HAVING AIDS. THREE-QUARTERS HAVE DIED, MOST OF THEM BY AGE THREE.

AND FOR EACH CHILD WITH FULL-BLOWN AIDS, ANOTHER TWO OR THREE ARE ESTIMATED TO HAVE AIDS-RELATED ILLNESS. AS MANY AS 1,000 CHILDREN INFECTED WITH THE AIDS VIRUS ARE EXPECTED TO BE BORN IN NEW YORK CITY IN THE COMING YEAR.

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AIDS CHILDREN ARE TRUE INNOCENTS. THEIR SUFFERING IS NOT OF THEIR OWN MAKING. AIDS AMONG CHILDREN IS INEXTRICABLY LINKED WITH INTRAVENOUS DRUG ABUSE. THE MAJORITY OF SUCH CHILDREN WERE INFECTED BY THEIR MOTHERS, 80 PERCENT OF WHOM WERE EITHER NEEDLE-USING DRUG ADDICTS OR THE SEX PARTNERS OF DRUG ADDICTS. MOST OF THEM LIVE IN AREAS WITH A HIGH CONCENTRATION OF POVERTY AND DRUG USE. THE OVERWHELMING MAJORITY ARE BLACK OR HISPANIC.

THESE ARE THE TRAGIC FACTS, THE SOBERING REALITIES AND THE CHALLENGE NEW YORK CITY FACES. AND WE ARE MEETING THAT CHALLENGE. WE HAVE DONE MORE THAN ANY OTHER CITY IN THE COUNTRY TO ADDRESS THE FULL RANGE OF NEEDS OF AIDS VICTIMS, WHETHER INFANT OR ADULT. AIDS SPENDING FOR TREATMENT, TESTING, COUNSELING, EDUCATION, AND OTHER PROGRAMS IN FISCAL 1988 WILL BE $387 MILLION, OF WHICH $100 MILLION IS CITY FUNDS.

HOW ARE WE SPENDING THOSE HUNDREDS OF MILLIONS OF DOLLARS? FOR YOUR CONSIDERATION, I AM SUBMITTING TO THE COMMITTEE THE MOST RECENT REPORT OF MY INTERAGENCY AIDS TASK FORCE ON THE PROGRAMS INITIATED TO SERVE AND CARE FOR THOSE WITH AIDS. IT IS AN IMPRESSIVE ARRAY OF SERVICES. LET ME DISCUSS SOME OF THEM.

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THERE IS CURRENTLY NO CURE FOR AIDS. BUT WHETHER IN INFANTS OR ADULTS, AIDS CAN BE PREVENTED. FOR CHILDREN, PREVENTION IS BEST ACHIEVED BY EDUCATING WOMEN OF CHILD-BEARING AGE AND THEIR SEXUAL PARTNERS. IN FISCAL 1988, PROJECTED SPENDING FOR DEPARTMENT OF HEALTH AIDS PREVENTION ACTIVITIES WILL BE $8.2 MILLION DOLLARS, INCLUDING $1.1 MILLION FOR ANONYMOUS COUNSELING AND TESTING SITES AND $7.1 MILLION FOR PREVENTION CAMPAIGNS DIRECTED TO THE GENERAL PUBLIC AND TO TARGETED GROUPS SUCH AS PEOPLE ENGAGED IN HIGH-RISK SEX AND DRUG ABUSE.

IN ADDITION, TEAMS OF PUBLIC HEALTH EDUCATORS ARE TAKING THE MESSAGE OF AIDS PREVENTION INTO NEIGHBORHOODS WHERE IV DRUG USE IS CONCENTRATED. THIS YEAR WE'RE EXPANDING THIS PROGRAM FROM 9 TO 15 COMMUNITIES, INCLUDING CENTRAL HARLEM, EAST HARLEM, THE LOWER EAST SIDE, BEDFORD-STUYVESANT, THE SOUTH BRONX, TREMONT, JAMAICA, FORT GREENE, AND BUSHWICK/WILLIAMSBURG.

A CAMPAIGN TO PROMOTE LATEX CONDOM USE AS A WAY TO PROTECT AGAINST AIDS INCLUDES DISTRIBUTION OF ONE MILLION CONDOMS. A SERIES OF MULTI-MEDIA CAMPAIGNS PROMOTING THE USE OF CONDOMS,

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STRESSING ABSTINENCE AS A MEANS OF AVOIDING AIDS TRANSMISSION, AND DISCOURAGING THE SHARING OF NEEDLES BY I.V. DRUG USERS ARE EITHER ALREADY FINISHED OR UNDER DEVELOPMENT BY THE DEPARTMENT.

OUR INTENSIVE VOLUNTARY, CONFIDENTIAL COUNSELING AND HIV ANTIBODY TESTING PROGRAM ALSO INCREASES PEOPLE'S AWARENESS OF THEIR RISK, AND ENCOURAGES THEM TO CHANGE THEIR BEHAVIOR TO REDUCE THE CHANCE OF BECOMING INFECTED OR INFECTING OTHERS. PHYSICIANS ARE ENCOURAGED TO TALK ABOUT AIDS INFECTION AND RISK-AVOIDANCE BEHAVIOR WITH PATIENTS, PARTICULARLY WOMEN OF CHILD-BEARING AGE AND THEIR PARTNERS, AND TO OFFER COUNSELING AND TESTING TO PATIENTS WHO MAY BE AT RISK. TESTING IS AVAILABLE IN NEW YORK CITY THROUGH FREE, ANONYMOUS COUNSELING AND TESTING SITES, THROUGH ANY LICENSED PHYSICIAN, AND AT HEALTH DEPARTMENT SEXUALLY TRANSMITTED DISEASE CLINICS.

ON AN AVERAGE DAY, SOME 400 PERSONS WITH AIDS, INCLUDING 30 CHILDREN, ARE INPATIENTS IN HEALTH AND HOSPITAL CORPORATION HOSPITALS. WHILE HHC FACILITIES HAVE LESS THAN ONE-QUARTER OF THE MEDICAL BEDS IN THE CITY, THEY NOW PROVIDE CARE FOR 37

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PERCENT OF THE CITY'S HOSPITALIZED AIDS PATIENTS ON ANY GIVEN DAY. THREE-QUARTERS OF OUR AIDS PATIENTS CONTRACTED THE VIRUS FROM IV DRUG USE, SEXUAL CONTACT WITH AN IV DRUG USER, OR BEING BORN TO AN IV DRUG ABUSER OR SEX PARTNER.

EIGHT PERCENT OF HHC AIDS CASES ARE CHILDREN. FIFTY PERCENT OF THE CITY'S HOSPITALIZED PEDIATRIC AIDS CASES ARE IN HHC FACILITIES. HARLEM HOSPITAL CURRENTLY HAS 6 PEDIATRIC INPATIENT AIDS PATIENTS.

THE BRONX MUNICIPAL HOSPITAL CENTER AND ITS AFFILIATE, THE ALBERT EINSTEIN COLLEGE OF MEDICINE, HAS DEVELOPED THE NATION'S FIRST PEDIATRIC DAY CARE PROGRAM FOR CHILDREN WITH AIDS. IT PRESENTLY CARES FOR 17 CHILDREN UP TO THE AGE OF 7 AND HAS A CAPACITY FOR UP TO 25 CHILDREN.

THE PROGRAM GIVES THESE CHILDREN A PLACE WHERE THEY CAN TAKE PART IN THE ACTIVITIES NECESSARY TO THEIR NORMAL DEVELOPMENT, WITH SKILLED MEDICAL BACKUP AVAILABLE IF NEEDED. IT ALSO GIVES A NEEDED RESPITE TO THE NATURAL FAMILIES OR FOSTER PARENTS OF MANY OF THE CHILDREN.

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IN COOPERATION WITH HHC, OUR HUMAN RESOURCES ADMINISTRATION ADDRESSES THE CRITICAL NEED TO INTEGRATE THE SOCIAL SERVICES AND MEDICAL CARE PROVIDED TO THOSE WITH AIDS. FOR CHILDREN WITH AIDS, PROTECTIVE AND FOSTER CARE SERVICES ARE PARTICULARLY IMPORTANT.

THERE ARE NOW ABOUT 30 BABIES WITH AIDS OR ARC WHO HAVE BEEN ORPHANED OR ABANDONED BY PARENTS UNWILLING OR UNABLE TO CARE FOR THEM. WE ARE IN THE MIDST OF AN INTENSIVE EFFORT TO RECRUIT AND RETAIN FOSTER PARENTS FOR THESE UNFORTUNATE CHILDREN. TO ALLAY THE FEARS SOME PROSPECTIVE FOSTER PARENTS HAVE EXPRESSED, WE WILL SHORTLY ADVISE PROPSECTIVE PARENTS OF HIGH RISK CHILDREN THAT THEY CAN REQUEST THAT THE CHILD BE TESTED FOR THE VIRUS. THE DEPARTMENT OF HEALTH WILL CONDUCT THE TEST AT THE REQUEST OF SSC.

ONE VOLUNTARY FOSTER CARE AGENCY, LEAKE AND WATTS CHILDREN'S HOME, IS PRIMARILY RESPONSIBLE FOR LOCATING FOSTER HOMES FOR CHILDREN WITH AIDS AND AIDS-RELATED ILLNESS AND SERVES ABOUT 22 CHILDREN. ANOTHER 35 TO 40 CHILDREN ARE IN FOSTER HOMES RUN BY OTHER AGENCIES.

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HRA HAS ENTERED INTO A CONTRACT WITH THE NEW YORK FOUNDLING HOSPITAL TO RUN A PROGRAM MODELED AFTER THE LEAKE AND WATTS INITIATIVE. THE FOUNDLING HOSPITAL IS IN THE PROCESS OF RECRUITING FOSTER PARENTS, AND WILL SERVE 10 CHILDREN. HRA IS ALSO WORKING WITH HHC TO PUT IN PLACE BY THIS SUMMER A VISITING NURSE SERVICE FOR CONTINUING HOME CARE FOR CHILDREN WHO RETURN HOME AFTER DISCHARGE FROM THE HOSPITAL.

HRA HAS ALSO IDENTIFIED NEW SERVICE AREAS TO HELP SUPPORT FAMILIES IN WHICH A PARENT, CHILD, OR IN THE WORST CASE, SEVERAL FAMILY MEMBERS HAVE AIDS. A PILOT AIDS FAMILY CASE MANAGEMENT UNIT WILL TAILOR SERVICES TO THE NEEDS OF FAMILIES WHERE ONE OR MORE PERSONS HAVE AIDS. THE UNIT WILL PROVIDE REFERRAL FOR HOME CARE AND HOMEMAKING SERVICES, FAMILY COUNSELING, HELP WITH CHILD CUSTODY ISSUES AND PLANNING FOR SURVIVORS, SUBSTANCE ABUSE COUNSELING, BEREAVEMENT COUNSELING, AND CONTRACEPTION TRAINING.

THIS CITY WILL NOT SHIRK ITS RESPONSIBILITY TO CARE FOR PEOPLE OF ALL AGES WITH AIDS. BUT WE CANNOT SHOULDER THE BURDEN ALONE. NEW YORK CITY ONCE ACCOUNTED FOR ALMOST HALF OF THE

NATION'S AIDS CASES. TODAY IT HAS LESS THAN 30 PERCENT AND, AS THE DISEASE SPREADS THROUGHOUT THE NATION, WILL HAVE ONLY 15 PERCENT IN 1991.

AIDS, IN OTHER WORDS, IS NOT JUST A LOCAL PROBLEM. IT'S A FEDERAL PROBLEM, TOO. REGRETTABLY, THE FEDERAL GOVERNMENT -- ESPECIALLY THE WHITE HOUSE -- HAS BEEN VERY SLOW TO RECOGNIZE THAT. THE WHITE HOUSE HAS NAMED A COMMISSION, BUT ITS BEEN RELUCTANT TO COMMIT RESOURCES TO HELP STATES AND LOCALITIES DEAL WITH A PROBLEM THAT WILL GROW AND GROW UNTIL WE FIND A CURE.

OBVIOUSLY, THEN, THE WHITE HOUSE MUST NOW BEGIN TO PUT ITS RESOURCES WHERE, TO DATE, ONLY RHETORIC HAS BEEN. IT MUST JOIN WITH THE CONGRESS IN MAKING SURE THERE ARE ADEQUATE FUNDS FOR AIDS RESEARCH, TREATMENT, TESTING AND EDUCATION. AND IT MUST DO SO WITHOUT ROBBING FROM OTHER MEDICAL RESEARCH OR TREATMENT PROGRAMS.

AS A FIRST STEP, I WOULD URGE THE WHITE HOUSE TO SUPPORT A BILL THAT HAS BEEN INTRODUCED BY THIS COMMITTEE'S CHAIRMAN AND CONGRESSMAN GILMAN IN THE HOUSE AND TED KENNEDY IN THE SENATE --

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THE AIDS INFORMATION, RISK REDUCTION, TRAINING, PREVENTION, TREATMENT, CARE AND RESEARCH ACT OF 1987.

WHERE ELSE DO WE NEED THE INCREASED SUPPORT OF THE FEDERAL GOVERNMENT? THERE WILL BE NO SLOWING THE SPREAD OF AIDS TO CHILDREN UNTIL WE INCREASE ACCESS FOR IV DRUG USERS TO DRUG TREATMENT PROGRAMS AND PUBLIC HEALTH EDUCATION PROGRAMS TO REACH THIS DIFFICULT POPULATION. THE FEDERAL GOVERNMENT MUST PROVIDE MORE MONEY FOR EFFORTS RANGING FROM DRUG INTERDICTION AT THE INTERNATIONAL LEVEL TO MORE FEDERAL DOLLARS TO STATES AND COMMUNITIES FOR EDUCATIONAL TREATMENT PROGRAMS. OF PARTICULAR IMPORTANCE FOR CHILDREN AND FAMILIES WITH AIDS ARE RESIDENTIAL DRUG TREATMENT PROGRAMS GEARED TO THE NEEDS OF WOMEN WITH CHILDREN, NOT ONLY SINGLE MALE ADDICTS, AS HAS BEEN THE CASE.

AS THE SCOPE OF THE EPIDEMIC WIDENS, OUR MASSIVE PUBLIC HEALTH EDUCATION RISK REDUCTION EFFORTS REQUIRE INCREASED FEDERAL SUPPORT. THIS INCLUDES MORE MONEY TO INCREASE CONFIDENTIAL VOLUNTARY RISK REDUCTION COUNSELING AND HIV ANTIBODY TESTING FOR PEOPLE OF CHILD-BEARING AGE. SERVICES THAT HELP KEEP FAMILIES

TOGETHER, AND HELP THEM REMAIN INDEPENDENT WITHOUT TURNING TO DRUGS, REQUIRE INCREASED FEDERAL SUPPORT.

OUR EFFORTS TO RECRUIT AND RETAIN MORE FOSTER PARENTS ALSO REQUIRE INCREASED FEDERAL SUPPORT. I WOULD URGE THE WHITE HOSUE TO SUPPORT AND THE CONGRESS TO ADOPT S.945, INTRODUCED BY SENATOR METZENBAUM, WHICH PROVIDES FUNDS FOR THE TRAINING OF CHILD CARE WORKERS AND FOSTER CARE PERSONNEL IN THE SPECIAL NEEDS OF CHILDREN WITH AIDS.

ONE FINAL POINT. AIDS IS A MULTIDIMENSIONAL PROBLEM. AND IN RESPONDING TO IT, NOT ONLY MUST THE FEDERAL GOVERNMENT ADDRESS THE PROBLEMS OF CHILDREN WITH AIDS, BUT THE PROBLEMS OF ANYONE WITH AIDS. PARTICULARY IMPORTANT IN THIS REGARD IS LEGISLATION THAT HAS BEEN INTRODUCED BY SENATOR MOYNIHAN AND CONGRESSMAN WEISS TO WAIVE FOR FIVE YEARS THE CURRENT 24 MONTH WAITING PERIOD FOR MEDICARE ELIGIBILITY OF PERSONS WITH AIDS WHO RECEIVE SOCIAL SECURITY DISABILITY. CURRENTLY, THOSE WHO HAVE THE MISFORTUNE TO SUFFER FROM END STAGE RENAL DISEASE DO NOT HAVE TO WAIT TWO YEARS FOR MEDICARE COVERAGE. THOSE WHO HAVE THE MISFORTUNE TO SUFFER

FROM AIDS SHOULD BE ACCORDED THE SAME OPPORTUNITIES TO BE ASSURED THAT THEIR MEDICAL NEEDS WILL BE MET.

AIDS POSES CRITICAL CONCERNS FOR NEW YORK CITY, AS WELL AS FOR THE REST OF THE COUNTRY. AS EVERY CITY AND EVERY STATE STRUGGLES WITH THE AIDS EPIDEMIC, I AM PLEASED THAT WE HAVE SUCH STRONG ALLIES ON THIS COMMITTEE AND IN THE CONGRESS. YOU HAVE STOOD BY US AND WALKED WITH US IN DEVISING SOLUTIONS TO THE PROBLEMS WE FACE.

BUT MUCH MORE REMAINS TO BE DONE. TOGETHER, WE HAVE WON MANY EARLIER BATTLES. TOGETHER, WE CAN WIN THE BATTLE AGAINST AIDS. WHAT IT REQUIRES IS THAT ALL OF US -- LOCAL GOVERNMENT, STATE GOVERNMENT, THE CONGRESS, AND THE WHITE HOUSE -- SHOW THE RESOLVE AND COMMIT THE RESOURCES TO DO SO. IF WE DO THAT, THERE WILL BE HUNDREDS OF THOUSANDS OF AMERICANS IN THIS GENERATION AND MANY GENERATIONS TO COME WHO WILL BE FOREVER GRATEFUL.

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OPENING STATEMENT BY THE HONORABLE TED WEISS (D-N.Y.)
AT A HEARING ON PEDIATRIC AIDS
BY THE SELECT COMMITTEE ON NARCOTICS ABUSE AND CONTROL
HARLEM HOSPITAL, NEW YORK
JULY 27, 1987

Many terrible effects flow from the drug abuse crisis in the United States. In recent years, with the spread of the human immunodeficiency virus (HIV), HIV infection and AIDS are two of them. The AIDS epidemic continues to grow to an alarming size and to horrible proportions. As of July 13, over 38,000 American men, women, and children have been diagnosed with this severe disease; 10,000 have been New Yorkers. Many of these Americans became infected, directly or indirectly, through the use of intravenous drugs.

There are many personal and social tragedies which spring from these dual crises of drug abuse and AIDS. One tragedy, which demands our immediate attention and action, befalls infants and young children who have been abandoned in hospitals by drug-addicted or AIDS-afflicted parents who unable or unwilling to care for them.

Some of these abandoned infants and children are initially hospitalized for drug addiction which was developed in utero. An ever-increasing number of these babies are infected with the AIDS virus or suffering from AIDS or ARC (AIDS related complex). Without appropriate caretakers outside the hospital, they live in a limbo created by non-existent families and out-of-reach foster care. For a home, they have only a hospital ward. For a family, they have a team of health care professionals. These "boarder babies" and their extended hospital stays are a great cost to our society from both financial and humanitarian standpoints. Many of these babies are well enough to be released from the hospital into foster or respite care. However, placement in foster care is very difficult. Approriate respite care is generally unavailable.

I am so pleased to be here today to take part in this hearing. It is urgent that we all come to understand the dimensions and ramifications of these problems, and quickly begin our attack.

Last Wednesday, I joined Mr. Owens of New York, along with Mr. Rangel and Mr. Waxman, in introducing the Abandoned Infants Assistance Act, which would help these "boarder babies." The bill contains a number of provisions, funded as demonstration projects through grants to local governments, which would ameliorate many aspects of this tragic situation.

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One component of the legislation concerns foster care. Incentives would be provided for the placement of these young children in foster care. In addition, foster care personnel would be trained to provide for the special needs of these infants and children and their parents. This provision of adequate support services would ensure that children with capable parents and intact homes could be returned as soon as possible.

Second, for those children who cannot be placed in foster care, the legislation would provide Federal funds for the purpose of establishing respite homes.

These projects could be carried out for $20 million in each of Fiscal Years 1988, 1989, and 1990. In return for this modest investment, we would be providing nurturant care, decent homes, and the prospect of happiness, to children who have begun their lives with such grim prospects.

Such legislation provides a first step in Federal assistance for this problem. Today we will learn as much as possible in order to extend such efforts.

DAVID N. DINKINS
TESTIMONY BEFORE THE SELECT COMMITTEE ON NARCOTICS
UNITED STATES HOUSE OF REPRESENTATIVES

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JULY 27, 1987

GOOD MORNING. MY NAME IS DAVID DINKINS AND I AM PRESIDENT OF THE BOROUGH OF MANHATTAN. I THANK MY FRIEND AND COLLEAGUE, THE HONORABLE CHARLES RANGEL, AND THE MEMBERS OF THIS COMMITTEE FOR ALLOWING ME THIS OPPORTUNITY TO APPEAR BEFORE YOU TODAY. I AM HONORED TO BE PART OF A HEARING WHICH INCLUDES SUCH DISTINGUISHED SPEAKERS AS DOCTOR KOOP. HIS OUTSPOKEN AND COURAGEOUS LEADERSHIP STANDS IN WELCOME CONTRAST TO AN OTHERWISE ANEMIC RESPONSE BY THE REAGAN ADMINISTRATION. LIKEWISE I AM GRATEFUL TO DR. BENY PRIMM AND TO PRESIDENT JIM BUTLER FOR THEIR LEADERSHIP. I APPRECIATE THE WISDOM OF MY COLLEAGUE IN GOVERNMENT, MAYOR EDWARD I. KOCH, IN APPOINTING DR. STEPHEN JOSEPH TO HEAD THE CITY AGENCY MOST INVOLVED IN THE AIDS CRISIS. AND FINALLY, I KNOW WE ALL STAND GRATEFUL FOR THE COMPASSIONATE EXAMPLE OF MOTHER HALE AND HER DAUGHTER, DR. LORRAINE HALE.

I WILL TAKE THIS OPPORTUNITY TO BRIEFLY PUT THE PROBLEM OF PEDIATRIC AIDS AND AIDS-RELATED COMPLEX INTO PERSPECTIVE BY DESCRIBING SOME OF MY GENERAL CONCERNS ABOUT THE COURSE OF THIS EPIDEMIC AND OUR ATTEMPTS TO ADDRESS IT. I WILL THEN OUTLINE AND DISCUSS THESE ISSUES AS THEY RELATE TO CHILDREN.

IF NEW YORK CITY IS THE NORTH AMERICAN EPICENTER OF THE AIDS CRISIS, MANHATTAN IS THE CORE OF THAT EPICENTER. MANHATTAN RESIDENTS ACCOUNT FOR 48 PERCENT OF ALL REPORTED AIDS CASES IN NEW YORK CITY AND 41 PERCENT OF OF ALL DEATHS.

SIX YEARS INTO THIS EPIDEMIC, THERE ARE FEW RESIDENTS OF THE BOROUGH I REPRESENT WHO CAN SAY THAT THEY DON'T KNOW OR DON'T KNOW OF SOMEONE WHO HAS DIED. WE PLEAD WITH THE CONGRESS AND THE REAGAN ADMINISTRATION TO TAKE HEED AND CONFRONT CANDIDLY THE AIDS EPIDEMIC IN THIS CITY AND IN THIS NATION. THE FUTURE FACE OF THIS HEALTH CRISIS IN MOST OTHER CITIES IN THIS COUNTRY IS HERE TODAY IN NEW YORK.

AS WITH MOST CRISES, AIDS DOES NOT EXIST APART FROM OTHER CHRONIC PROBLEMS WE FACE IN OUR CITIES. THE CONNECTIONS AMONG AIDS AND POVERTY, DRUG ABUSE, LIMITED ACCESS TO HEALTH CARE, THE HOUSING SHORTAGE, DISCRIMINATION, ILLITERACY AND OTHER BARRIERS TO AIDS PREVENTION AND TREATMENT MUST BE ACKNOWLEDGED AND EXPLORED. WITHOUT THIS PERSPECTIVE, EFFECTIVE MEASURES CANNOT BE UNDERTAKEN

AIDS IS NOT ONLY THE PRODUCT OF CERTAIN RISK ACTIVITIES, BUT ALSO OF SOCIAL AND ECONOMIC CONDITIONS WHICH PLACE ENTIRE COMMUNITIES OF NEW YORK CITY AT GREATER RISK THAN OTHERS. AIDS IS NOT SIMPLY A QUOTE, "GAY DISEASE."

AIDS ALSO HAS A DISPROPORTIONATE IMPACT ON POOR AND MINORITY PEOPLE IN THIS COUNTRY. THIS IS PARTICULARLY TRUE WHERE CHILDREN ARE CONCERNED. THE DISPROPORTION IS REFLECTED IN BOTH THE SURVEILLANCE DATA AND IN THE LACK OF ACCESS TO QUALITY SUPPORT SERVICES AND HEALTH CARE.

IN THE UNITED STATES TODAY, BLACKS CONSTITUTE 12 PERCENT OF THE TOTAL POPULATION AND LATINOS 6 PERCENT. YET 25 PERCENT OF PERSONS WITH AIDS ARE BLACK AND 14 PERCENT ARE LATINO. IN NEW YORK CITY, THE MAJORITY OF PEOPLE WITH AIDS - 56 PERCENT OF REPORTED CASES - IS BLACK, LATINO OR ASIAN.

EIGHTY-FOUR PERCENT OF WOMEN WITH AIDS ARE MINORITY AND 90 PERCENT OF CHILDREN WITH AIDS ARE BORN TO MINORITY WOMEN. THE HIGH INCIDENCE OF DRUG ABUSE AMONG MINORITIES HELPS EXPLAIN THIS DISPARITY.

WE ALSO KNOW THAT THE AVERAGE LIFE SPAN OF A WHITE PERSON WITH AIDS AFTER DIAGNOSIS IS TWO YEARS, WHILE THE AVERAGE MINORITY PERSON WITH AIDS LIVES ONLY 19 WEEKS AFTER DIAGNOSIS. WE SUSPECT THAT OUR TWO-TIERED HEALTH CARE SYSTEM LARGELY EXPLAINS THIS DISPARITY.

BECAUSE OF LIMITED FINANCIAL RESOURCES AND FEAR OR IGNORANCE OF WHAT ASSISTANCE IS AVAILABLE, POOR AND MINORITY PEOPLE TEND TO DELAY SEEKING MEDICAL ATTENTION UNTIL THEY ARE SEVERELY ILL. THE PUBLIC HEALTH CARE SYSTEM IS FURTHER STRAINED UNDER THE CIRCUMSTANCES. NEARLY TWENTY PERCENT OF THE MEDICAL BEDS IN OUR CITY'S PUBLIC HOSPITAL SYSTEM ARE DEVOTED TO PEOPLE WITH AIDS.

WORKING TO PREVENT AIDS IS MADE DIFFICULT BY PREJUDICES WHICH EXIST AGAINST RACIAL AND ETHNIC MINORITIES, POOR PEOPLE, DRUG ABUSERS AND GAY PEOPLE.

INFORMATION DEVELOPED BY THE FEDERAL GOVERNMENT AND OTHERS HAS CONTRIBUTED TO THIS PREJUDICE BY CATEGORIZING THOSE WITH AIDS INTO SO-CALLED "RISK GROUPS."

TALKING ABOUT RISK GROUPS RATHER THAN RISK BEHAVIOR HAS ALLOWED PEOPLE TO DENY THEIR INDIVIDUAL RISK. THIS DENIAL PREVENTS PEOPLE FROM TAKING ACTIONS NECESSARY TO PROTECT THEMSELVES AND THEIR LOVED ONES. AT THE COMMUNITY LEVEL, IT KEEPS PEOPLE FROM ORGANIZING TO PROVIDE SERVICES AND FROM PROMOTING UNIFIED ACTION ON BEHALF OF PEOPLE WITH AIDS. THIS IS A HEALTH CRISIS, AND RESPONSIBILITY FOR ADDRESSING IT RESTS WITH ALL OF US.

IN DISCUSSING THE IMPACT OF AIDS ON CHILDREN, WHAT WE ARE REALLY ADDRESSING IS THE IMPACT OF AIDS ON HETEROSEXUAL FAMILIES. THE NUMBER OF CHILDREN WITH AIDS IS INCREASING BECAUSE MORE WOMEN ARE INFECTED, EITHER BECAUSE OF THEIR OWN DRUG USE OR BY SEXUAL CONTACT WITH AN INFECTED PARTNER. THEREFORE, PREVENTING PEDIATRIC AIDS REQUIRES EFFORTS TO STOP IV DRUG USE AND UNPROTECTED SEX.

THE FEDERAL GOVERNMENT MUST SERIOUSLY CONSIDER THE ENORMOUS IMPACT ON EXISTING PROGRAMS THAT THIS CIRCUMSTANCE HAS AND WILL CAUSE. THE FOLLOWING SITUATIONS ARE TYPICAL.

A WOMAN WHOSE PARTNER USED DRUGS AND DIED AS A RESULT OF AIDS IS NOW BEGINNING TO SHOW SOME SYMPTOMS HERSELF. SHE HAS TWO YOUNG CHILDREN.

HOW DOES SHE SUPPORT HER FAMILY WHEN SHE BECOMES TOO ILL TO CONTINUE WORKING? WHAT HAPPENS IF SHE IS EVICTED FROM HER APARTMENT, EITHER BECAUSE SHE LOSES HER JOB AND CAN NO LONGER PAY THE RENT OR BECAUSE HER LANDLORD DISCOVERS SHE HAS AIDS AND WANTS HER OUT OF THE BUILDING? WHAT HAPPENS WHEN FAMILY MEMBERS WHO MIGHT HELP SUPPORT HER AND HER CHILDREN REJECT HER? WHAT WILL HAPPEN TO HER CHILDREN WHEN SHE DIES?

CONSIDER ALSO THE INFANT BORN SEROPOSITIVE. BECAUSE THE BABY'S MOTHER IS INFECTED, THE INFANT WAS BORN WITH A LOW BIRTHWEIGHT AND EVIDENCE OF NEUROLOGICAL DAMAGE. THE BABY'S MOTHER ABUSES DRUGS AND TRACES ARE FOUND IN THE BABY'S URINE. FOSTER CARE TAKES THE BABY, BUT NO PLACEMENT CAN BE FOUND BECAUSE THE BABY IS INFECTED WITH THE VIRUS.

CONSIDER ALSO THE IMPACT OF AIDS ON CHILDREN WHO ARE NOT INFECTED, BUT WHO LIVE IN A FAMILY WHERE ONE OR MORE MEMBERS IS SYMPTOMATIC. THAT CHILD FACES THE UNCERTAIN FUTURE BROUGHT ON BY THE LOSS OF ONE OR BOTH PARENTS AND PERHAPS A BABY BROTHER OR SISTER. THE CHILD MAY ALSO FACE THE REJECTION EXPERIENCED BY ANYONE WHO LIVES WITH SOMEONE WHO HAS AIDS.

IN NEW YORK CITY, THERE ARE HUNDREDS OF CASES LIKE THESE. ONE OF THE REASONS THAT AIDS IS SO DEVASTATING IS THAT WE ARE NOT PREPARED FOR SO MANY WHO ARE SO YOUNG TO DIE. THE NEWS THAT A PARENT OR A CHILD WILL DIE TURNS EVERYTHING UPSIDE DOWN. SOME FAMILIES ARE BETTER EQUIPPED TO DEAL WITH THE CONSEQUENCES THAN OTHERS. BUT BECAUSE SO MANY OF THE FAMILIES AFFECTED BY AIDS ARE STRUGGLING TO BEGIN WITH, AIDS IS EASILY THE STRAW THAT BREAKS THE FAMILY'S BACK.

AS I UNDERSTAND IT, THIS COMMITTEE SEEKS TO DEVELOP A RESPONSE TO SOME OF THESE PROBLEMS. YOUR INTEREST STEMS FROM THE FACT THAT MOST CHILDREN ARE AFFLICTED WITH THE VIRUS BECAUSE ONE OR BOTH OF THEIR PARENTS USES DRUGS.

I WILL SUGGEST SOME AREAS WHICH THIS COMMITTEE MIGHT CONSIDER IN DEVELOPING A RESPONSE TO THIS PROBLEM.

THE MOST OBVIOUS AND IMPORTANT THING THIS COMMITTEE CAN DO FOR CHILDREN IS TO CONTINUE ITS FIGHT FOR ADDITIONAL FEDERAL RESOURCES TO PREVENT AND TREAT DRUG ABUSE. AT LEAST ONE-THIRD OF THOSE WITH AIDS IN NEW YORK CITY CONTRACTED IT BY EITHER USING INTRAVENOUS DRUGS OR HAVING SEX WITH SOMEONE WHO USES INTRAVENOUS DRUGS. BUT IT IS WITH CHILDREN THAT WE MOST CLEARLY SEE THE AWFUL IMPACT OF DRUG USE AND AIDS. FULLY 81 PERCENT OF CHILDREN WITH AIDS ARE INFECTED BECAUSE ONE OR BOTH OF THEIR PARENTS USE OR USED DRUGS, OR HAD SEX WITH SOMEONE WHO USES DRUGS.

GIVEN WHAT WE KNOW ABOUT AIDS TRANSMISSION, THE ATTEMPTS OF THE REAGAN ADMINISTRATION TO WITHDRAW LAST YEAR'S PRE-ELECTION COMMITMENT TO DRUG PREVENTION AND TREATMENT PROGRAMS ARE PARTICULARLY CRUEL. BETWEEN EXPANDED NARCOTICS ENFORCEMENT EFFORTS AND INCREASED AWARENESS ABOUT AIDS, THE NUMBER OF ADDICTED PEOPLE SEEKING TREATMENT IS INCREASING DRAMATICALLY.

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IF THE FEDERAL ADMINISTRATION IS SERIOUS ABOUT PREVENTING AIDS AND FIGHTING DRUG ABUSE, IT WILL COMMIT ITSELF TO THE GOAL OF PROVIDING TREATMENT TO EVERY PERSON WHO WANTS IT.

IT HAS BEEN SUGGESTED THAT A PROGRAM THAT DISTRIBUTES CLEAN NEEDLES AND WORKS TO ACTIVE INTRAVENOUS DRUG ABUSERS MIGHT HELP PREVENT THE SPREAD OF THE VIRUS. THOUGH THE END IS COMMENDABLE, THE MEANS ARE QUESTIONABLE. DRUG USE IS UNACCEPTABLE AND WE MUST NOT BE SATISFIED WITH THE NOTION THAT WE CAN SOMEHOW MAKE IT SAFER. INSTEAD, LET THE AIDS EPIDEMIC MOVE US FORWARD WITH FIRMER RESOLVE TO PREVENT AND TREAT DRUG ABUSE.

I ALSO URGE MEMBERS OF THIS COMMITTEE TO EXERCISE THEIR LEADERSHIP IN ADDRESSING THE OTHER CIRCUMSTANCES SURROUNDING THIS PROBLEM.

AIDS HAS EXPOSED GAPING HOLES IN THE WAY WE PROVIDE HEALTH CARE, HOUSING AND SOCIAL SERVICES AS HAS NO OTHER SINGLE PROBLEM.

OUR HEALTH CARE SYSTEM DOES NOT HAVE THE COMMUNITY ORIENTATION OR FLEXIBILITY NECESSARY TO HANDLE LARGE NUMBERS OF PEOPLE WHOSE HEALTH NEEDS VARY WITH THE COURSE OF THE SYNDROME.

SOCIAL SERVICE PROVIDERS HAVE LIMITED RESOURCES AT THEIR DISPOSAL AND ARE SEVERELY OVERTAXED BY THE ENORMOUS TASK OF COUNSELING AND HELPING FAMILIES MANAGE THE MANY COMPLICATED ARRANGEMENTS WHICH HAVE TO BE MADE. THE CRITICAL SHORTAGE OF HOUSING FOR LOW-INCOME PEOPLE IS A SEVERE OBSTACLE TO PROPER CARE AND MANAGEMENT OF THESE FAMILIES.

THE FEDERAL GOVERNMENT'S DWINDLING SUPPORT FOR THESE SERVICES MAKES IT ALMOST IMPOSSIBLE FOR SERVICE PROVIDERS TO HELP PEOPLE WITH AIDS, THEIR FAMILIES, AND THEIR LOVED ONES COPE WITH THE LIFE CHANGING CIRCUMSTANCES CREATED BY TERMINAL ILLNESS. THERE IS NO SAFETY NET FOR PEOPLE WITH AIDS. THIS DOES NOT MEAN WE SHOULD CREATE A SEPARATE SERVICE SYSTEM FOR PEOPLE WITH AIDS.

WHAT WE NEED IS YOUR SUPPORT OF A FEDERAL BUDGET WHICH SEEKS TO RESTORE CUTS IN HEALTH CARE, HOUSING AND PUBLIC ASSISTANCE WHICH IN TURN TRANSLATES INTO SUPPORT FOR THESE FAMILIES AND CHILDREN.

THERE ARE ALSO SOME SPECIFIC THINGS WHICH MUST BE DONE. THE FEDERAL GOVERNMENT MUST PROVIDE MASSIVE, CANDID PUBLIC EDUCATION ABOUT HOW THE VIRUS IS TRANSMITTED. AS THE SURGEON GENERAL HAS NOTED IN THE PAST, THIS NOT ONLY PREVENTS THE SPREAD OF THE VIRUS, BUT THE KIND OF HEALTH CARE AND OTHER SERVICES WE NEED ARE IMPOSSIBLE TO PROVIDE WITHOUT IT.

AS LONG AS LANDLORDS ARE AFRAID TO RENT TO PEOPLE WITH AIDS, AS LONG AS SOME HEALTH PROFESSIONALS QUIETLY REFUSE TO TREAT THEM AND EXISTING DAY CARE AND FOSTER CARE PROVIDERS FAIL TO ACCOMODATE THEM, AS LONG AS PEOPLE ARE AFRAID TO COME FORWARD FOR SERVICES, IT WILL BE IMPOSSIBLE TO PROVIDE HELP. THEIR FEARS ARE A BARRIER TO PROPER CARE.

I URGE THIS COMMITTEE TO EXPAND AIDS PREVENTION EFFORTS TARGETTED TO DRUG USERS. LAST YEAR, I SUCCESSFULLY NEGOTIATED AN INCREASE IN NEW YORK CITY'S BUDGET TO PROVIDE FOR A MASS MEDIA CAMPAIGN AIMED AT IV DRUG USERS AND HETEROSEXUALS. THE FIRST PHASE OF THAT CAMPAIGN WAS INTRODUCED IN MAY. IT IS APPARENT, HOWEVER, THAT WE CAN NOT DO THIS ALONE. FEDERAL GOVERNMENT MUST DO MORE TO SUPPORT OUR EFFORTS.

SUPPORT SERVICES FOR FAMILIES AND CHILDREN AFFECTED BY AIDS ARE ANOTHER AREA OF GREAT CONCERN. OUR TEMPTATION WITH ANY NEW CHALLENGE IS TO SET UP A SEPARATE SYSTEM TO DEAL WITH IT. WHILE SOME SPECIAL EFFORTS ARE NECESSARY TO HELP CHILDREN WHEN THEY TRULY NEED SEPARATE CARE, WE MUST NOT ABSOLVE OUR SCHOOLS, OUR DAY AND FOSTER CARE PROGRAMS AND OTHER INSTITUTIONS FROM THEIR RESPONSIBILITY TO PROVIDE SERVICES TO ALL CHILDREN.

IN CONSIDERING FEDERAL FUNDING FOR AIDS-SPECIFIC PROGRAMS, PLEASE CONSIDER THAT CURRENT FEDERAL SPENDING EMPHASIZES RESEARCH AND SURVEILLANCE.

THESE EFFORTS ARE NOT UNIMPORTANT, SINCE WE NEED TO UNDERSTAND THE PROGRESS OF THE SYNDROME AND WE ALL WAIT ANXIOUSLY FOR A CURE.

HOWEVER, AS MORE PEOPLE BECOME INFECTED, LOCAL AND STATE GOVERNMENTS DESPARATELY NEED ASSISTANCE FROM WASHINGTON TO PROVIDE ADEQUATE HEALTH CARE AND RELATED SERVICES FOR THESE FAMILIES. AS THE FEDERAL GOVERNMENT SUPPORTS RESEARCH WHICH IDENTIFIES WOMEN WHO ARE HIV POSITIVE, IT MUST NOT WALK AWAY FROM THEM WITHOUT PROVIDING FUNDS TO SUPPORT THE SERVICES WHICH THEY AND THEIR CHILDREN NEED.

FINALLY, THERE HAS BEEN A LOT OF LOOSE TALK ABOUT MANDATORY TESTING. MANDATORY TESTING IS A PANACEA. THERE IS NO CONVINCING EVIDENCE THAT PEOPLE WHO KNOW THEIR ANTIBODY STATUS WILL CHANGE THEIR BEHAVIOR. UNLESS TESTING IS UNDERTAKEN VOLUNTARILY, WITH INFORMED CONSENT, AND ACCOMPANIED BY COUNSELING, IT HAS THE POTENTIAL TO BE USED AS A WEAPON AGAINST THE PERSON WHO IS TESTED.

THERE IS NO CONCEIVABLE PUBLIC HEALTH BENEFIT TO MANDATORY TESTING FOR SPECIFIC GROUPS OF PEOPLE. OUR BEST AND MOST EFFECTIVE WEAPON AGAINST THE SPREAD OF THE VIRUS IS EDUCATION, NOT TESTING. I MENTION IT TODAY BECAUSE IT RAISES A HOST OF ISSUES WITH REGARD TO THE REPRODUCTIVE RIGHTS OF WOMEN. INDEED, SOME HAVE SUGGESTED THAT MANDATORY TESTING OF WOMEN IN THEIR CHILDBEARING YEARS COULD LEAD TO FORCED STERILIZATION. WOMEN SHOULD HAVE ACCESS TO VOLUNTARY, CONFIDENTIAL TESTING. THE DECISION TO BE TESTED MUST BE MADE BY THE INDIVIDUAL IN CONSULTATION WITH HER PHYSICIAN. IT SHOULD NEVER BE THE DECISION OF THE STATE.

I WILL CLOSE WITH WHAT I CALL THE VERMONT EXAMPLE. NOT LONG AGO, THE STATE OF VERMONT ANNOUNCED IT WAS ESTABLISHING A PUBLIC EDUCATION CAMPAIGN ABOUT AIDS. HERE IN NEW YORK, MANY QUESTIONED WHY SUCH A CAMPAIGN WAS NECESSARY, SINCE VERMONT AT THAT TIME HAD ONLY SEVEN REPORTED CASES. OF COURSE, VERMONT STATE OFFICIALS REASONED THAT WITH SO FEW CASES, NOW WAS THE TIME TO START ITS PREVENTION EFFORTS. MANY PEOPLE COULD NOT UNDERSTAND THIS SIMPLE REASONING, SINCE WE ARE SO ACCUSTOMED TO RESPONDING TO A PROBLEM ONLY WHEN IT BECOMES A CRISIS.

LET THE ATTITUDE OF VERMONT STATE OFFICIALS BE THE ATTITUDE OF THE LEADERSHIP OF THIS NATION. AIDS IS ALREADY A CRISIS IN MANY OF OUR CITIES; IT CAN NOT BE ALLOWED TO BECOME A NATIONAL CRISIS. SADLY, IT MAY BE TOO LATE. THE EPIDEMIC IS ALREADY WELL UNDERWAY BECAUSE THE FEDERAL ADMINISTRATION HAS FAILED TO ACT DECISIVELY AND WISELY.

EVEN IF THE ADMINISTRATION WERE TO DEVOTE THE NECESSARY RESOURCES TODAY FOR EDUCATION AND PREVENTION, IT CAN NOT PREVENT THE IMPACT OF THE EVENTUAL SICKNESS AND DEATH OF MILLIONS OF AMERICANS WHO ARE ALREADY INFECTED.

THE IMPACT OF THIS REALITY ON CHILDREN HAS BEEN AND WILL BE TRAGIC. CHILDREN WITH AIDS ARE THE INNOCENT VICTIMS OF THIS SHORTSIGHTEDNESS AND THE FAILURE TO PREVENT DRUG ABUSE AND TO PROTECT THE HEALTH OF POOR AND MINORITY PEOPLE IN THIS NATION.

IF SOME OF OUR NATION'S LEADERS HAVE FOUND IT IMPOSSIBLE TO FIND THE COMPASSION IN THEIR HEARTS TO DEAL CONSTRUCTIVELY WITH A HEALTH CRISIS WHICH APPEARS TO THEM TO ONLY DEAL DEATH TO DRUG USERS AND GAY MEN, LET THEM CONSIDER CAREFULLY THE PROBLEMS OF THESE CHILDREN AND THINK TWICE ABOUT DISMISSING THIS SNOWBALLING HUMAN CATASTROPHE.

THANK YOU.

TESTIMONY OF
MARGARET C. HEAGARTY, M.D.
DIRECTOR OF PEDIATRICS
HARLEM HOSPITAL CENTER
TO
THE UNITED STATES HOUSE OF REPRESENTATIVES
SELECT COMMITTEE ON NARCOTIC ABUSE AND CONTROL
JULY 27, 1987

I am privileged to have the opportunity to testify before this distinguished Congressional committee about the problems of children with AIDS. In preparing this testimony, it occurred to me that I might be most useful to you if I simply describe the situation as it appears from this front line of medical care. I will leave to others the more global, perhaps more scientific or statistical approach.

As the the director of pediatrics of the Harlem Hospital Center, I and my colleagues in the department serve as a major source of medical care for the children of Harlem. Every year we care for about 2000 hospitalized children, 2500 to 3000 newborn infants and provide roughly 60,000 to 70,000 outpatient visits. About 30 fully trained pediatricians and 27 young physicians in training provide this pediatric care. Today I want to tell you the story of AIDS in children in Harlem.

I date the beginning of this sorry tale to a telephone conversation with the director of medicine here at Harlem in late winter, 1981. He said, "Did you see the article last week in the New England Journal of Medicine about this strange new disease found in homosexuals?" Since I never seem to have seen the latest article in the New England Journal, I assumed that I was down one, again, but aside from my medical curiosity, whatever this new disease was, it wasn't pediatric and so I wouldn't have to deal with it. So much for

my ability to see the future. It was only a few months later that a pediatrician in the department told me about one of his patients with swollen lymph glands, severe growth failure, and bizarre, rare infections. That child was the first of what has become an avalanche of children infected with what we have come to label the Human Immunodeficiency Virus or HIV virus.

Indeed we gradually have come to realize that we are in the midst of an epidemic of a new and terrifying disease of infants and children. Let me give you some idea of what has happened here over the past two or three years. We puzzled over that first patient for some months before we, as well as the rest of pediatrics, began to realize that this disease was not exclusive to homosexuals, but was also found in women and children.

The children usually come to us as infants with severe, sometimes rapidly fatal, infections, severe growth failure to the point of emaciation, chronic lung infections, and in late stages of the disease signs of severe neurological deterioration. By 1985, we had identified about 10 such infants and children, of which two or three were hospitalized at any one time. By spring of last year, we had identified 25 or more, and on average had 4 to 6 in the hospital at any one time. By this time we have cared for about 50 or 60 of these children, 8 to 12 are in hospital at any one time. In fact, the total number of children with this infection for whom we are responsible has tripled over the past year to 18 months.

Who are these children? In Harlem, as in the nation, most children contract the HIV virus from their mothers during pregnancy or during the process of delivery. When the virus is transmitted, during pregnancy or during delivery is uncertain at this time. And most of

these infected mothers are either past or present intravenous drug users or have had sexual relations with someone who is infected with the virus, usually an intravenous drug user, or perhaps a bisexual man. The mothers themselves may have no symptoms of the disease and thus be unaware of their infection. In more than one instance, we have made the diagnosis of AIDS in a child of a mother with no symptoms of AIDS, no history of intravenous drug use and no reason to suspect that she had contracted the infection during intercourse with a man who carried the HIV virus.

It is easy, I suppose, to judge, perhaps even condemn these parents, particularly those who are active drug users. But we here in the trenches have become less punitive in our judgments, for we have come to know them and their children, have come to appreciate the tragedy of their lives, to stand in awe before their grief as they watch their children slowly die of AIDS. Before you dismiss me as a middle aged, sentimental, liberal, do gooder, let me assure you that I do know that some of these parents have a form of social leukemia which, for whatever reason, has lost them to the larger society. And indeed they can be aggravating, hostile, abusive, frustrating people, but they also can be courageous, appreciative, and many, if not most, in their own fashion love their children as you love yours. And so first, and perhaps most important, I plead that you see these parents and their children as victims, rather than villains of AIDS. In the face of such a frightening disease as AIDS, it is tempting to look for someone or some group to blame, to make the scapegoat, but the fact is that AIDS is a viral infection, which is usually lethal, it is not a sin, it is not a crime committed by people or groups of people against

others.

The second obvious point to be made is that most children with AIDS in this country come from poor families. And because they are poor, they and their families must look to public general hospitals, like Harlem, for medical care. Public general hospitals, almost by definition, are embattled institutions that survive from hand to mouth, in large measure economically dependent upon the largess of the larger community through local tax funds for survival. But since local governments in many areas of the country, including New York City, have a fixed tax base but a variety of services they must provide, health care for the poor, with or without AIDS, must compete with other sectors of municipal government for scarce resources.

The AIDS epidemic has placed enormous financial stress upon these public general hospitals that in the best of circumstances barely manage to survive economically. Moreover it has not only affected the care of AIDS patients but imperils the entire municipal health care delivery system of this and other cities in which substantial numbers of poor AIDS patients are to be found. Or to give you a trivial example of what I mean. One winter day a year or two ago, I was told that the hospital had run out of Robitussin, as you know, a common cough syrup. So I went storming into the chief pharmacist with "What do you mean, we've run out of Robitussin?" and she said, " Yes, we don't have any right now, because last week I had to order $175,000 worth of antibiotics for the AIDS patients and we have a cash flow problem." Now this trivial example, after all cough syrup is not a critical drug, and we did get some more in a short time, illustrates the problem this epidemic has caused for the delivery of health care for all of the poor of this city.

Now to my naive mind, it seems reasonable to consider the AIDS epidemic analogous to a natural disaster. When a flood or hurricane or tornado occurs in this country, the central government, acting for the entire body politic, declares the region a disaster area and provides funds to help the area recover. I can't help wondering why the federal government doesn't consider AIDS, a disaster, and declare the areas of this country in which the disease has reached epidemic proportions, a medical disaster area to which national funds should be allocated on an emergency basis. But I did say naive, so I will leave to you who are expert in these matters the answer to that question, I'm sure it's more complicated than I could ever imagine.

Our experience with the children with AIDS at this hospital has forced us to face new problems. Despite the hospital's limited resources the provision of direct medical care for these children is in many ways the simplest of the problems we must solve. While there is much we do not understand scientifically about AIDS and while at the moment it has no cure, we do know now to give the antibiotics and other drugs that can prolong and improve the quality of these children's lives.

But the application of modern medical therapy is in some ways the least of the solutions these families need. Our existing public human service programs were designed in categories that are no longer valid or useful for this as well as other diseases and conditions. The statutory and regulatory requirements of these programs are so complex, dysfunctional, fragmented and disorganized that my professional staff often spends as much or more time dealing with a variety of local, state and federal governmental bureaucracies as they

do providing direct care and support for these children and their families. In our zeal to make absolutely certain that no rascals, no scoundrels get something to which we judge they are not entitled, we have constructed paper edifices and barriers that only the most socially organized and educated can master. And we wonder why the most socially disorganized and disadvantaged of our communities have trouble "getting on Medicaid" or registering for this or that social program. Indeed we sometimes blame them, call them unmotivated, non compliant, or worse. Let me suggest that you or I would have similar problems if we suddenly had to enroll in Medicaid, welfare or SSI. Indeed I, myself, have an acute anxiety attack when I have to face the Bureau of Motor Vehicles for a driver's license, I suspect I would decompensate entirely if I had AIDS and I had to manage to qualify for Medicaid or SSI. I wish that the legislative and executive branches of every level of government would remember for whom their laws, regulations and procedures are written.

Another malignant virus has recently attacked Harlem, a virus which complicates the already difficult problems for children with AIDS and one with which this committee surely has more expertise than I. In the past year to 18 months we, as all areas of the country, have encountered an enormous increase in cocaine or crack use among young men and women. But consideration of the children of these cocaine addicts has not received nearly as much publicity as other aspects of the so called crack epidemic. The number of newborns and other children with parents who are addicted to crack and who cannot take care of their children has escalated so sharply that the city's foster care system has been all but overwhelmed. We now have in this city legions of homeless children, most of whom are children of

parents who are addicted to cocaine or the older drug, heroin. Since many drug addicts use more than one type of drug, there is an inevitable overlap between crack and heroin users. Hence many of these homeless infants may have been infected with the HIV virus.

In the past fifty or more years we have come to understand that to grow and develop all children must have parents or parental surrogates. Children require more than a safe place to live, sufficient food and clothing. They must have the warmth and constancy of the personal interaction and relationship found in a family of caring adults. The absolute requirement for this type of parental relationship has led us to abandon the orphanage of the nineteenth century. We understand that to place children in large and inevitably impersonal institutions is to place their long term intellectual and emotional development in considerable jeopardy.

Now we, as a community, are faced with two groups of children, some with AIDS, some without AIDS, neither group have parents able to care for them. We must resist the temptation to reinvent the orphanage, the institutional placement of children, for we know absolutely that that solution will damage their potential. We must find a way to give these children either a family or something that closely approximates a family. In the case of children without AIDS it is possible, I think, if we have the will, and thus are willing to advance the financial resources and to use our ingenuity to find foster parents for these children.

However in the case of children with AIDS the issue is complicated by the general level of emotion and fear which the infection has engendered. Most of the children with AIDS for whom we

are medically responsible are cared for by their parents or other relatives. But upstairs on the seventeenth floor of this building right now, there are 5 wonderful little boys who are homeless and who have AIDS. Some of them have been in this hospital for as long as 18 months. My staff has taught them to walk and to talk. They have not seen sunlight or rain or birds or grass or flowers. From time to time each has been so ill that I thought he would die, but right now none are acutely ill, they just have no parents, no homes. Quite simply they have become the children of my staff, and to their eternal credit the nurses, doctors and other staff of this department have come to love these little boys. If you come upstairs you will find two six bed wards filled with toys and strollers and play pens, all donated by the staff or by the occasional community group or individual who have heard and responded to our pleas for help. And when you come up, you will find these little boys sitting on the laps of nurses as the nurses write their progress notes in the medical chart, toddling up and down the halls with nurses as they dispense medication, carried in the arms of young physicians as they make their daily rounds with their attending faculty, carrying on conversations with the floor's young cleaning man. So we have done the best we can for what have become, de facto, OUR children.

But remember this is a public general hospital, I told you earlier, we have no money and not nearly enough staff. And we know that these, OUR children, deserve better, for while we do the best we can for them, we often cannot devote nearly the amount of time real parents can. Moreover the cost of caring for children who are not acutely ill makes this situation even more ridiculous. In a recent close analysis of the cost of hospitalization for the first 37

children with AIDS for whom we have provided care, we found that 30% of the hospital days and 20% of the total cost was accounted for by unnecessary hospitalization. So it's not just that it's not humane to keep these little boys in hospital when they don't need it, it's not even economically sound.

In the best of all possible worlds, what do these children need. First, they need access to the best medical care we can provide. If we of the public sector are to continue to provide this care, you must make certain that we have the resources we need to do that job. While I am not expert in health care financing, it seems to me that the diagnosis of AIDS in a poor child should permit automatic access to some form of third party insurance, probably Medicaid. Second, they and their families must have the social and medical supports that will permit them to remain out of hospital as much as possible. And we must find ways to tailor our programs to fit their needs rather than spend so much time trying to fit their needs to existing social and health programs. We must be ready to experiment with the development of coherent, comprehensive programs that include improved housing, home care and respite care for this group of chronically ill children. And we must make such programs simple enough, without the usual bureaucratic barriers that make them inaccessible to all but the most determined. Third, we must be ready to experiment with models of foster care for those children for whom a natural family is not available. In addition to increased funding for families who provide foster care for children with AIDS, we must understand that these families will also need additional supports, social and practical, to be able to foster these children. Such items as home care, day care,

respite care will be as necessary for foster parents as for natural parents. I'm not sure how to do this, and maybe it can already be done but we just haven't mastered the details of the methodology, but couldn't we marry SSI or disability payments with Medicaid so that we could capture additional money to provide for the non medical requirements of these children. And again, is it not possible to make the diagnosis of AIDS in a child sufficient to shorten and simplify the process of application for these funds. I'm told by my department's social workers that it can take months for a child to qualify for SSI, and then only after a complicated application process. And you should remember, these children on average die within two years, while our bureaucratic wheels are grinding so exceedingly slowly, the children can die.

Finally for my children, my little boys upstairs we must consider the possibility of establishing small, and I do mean small, group homes that will give them something close to a family environment. I know that Dr. Hale will describe for you her dream of "Hale Cradle" a small group home specifically designed for these children.

AIDS is a new disease; it will demand that all of us, health and social service professionals, bureaucrats and politicians, together, invent new solutions and methods to cope with what is an inevitably increasing number of AIDS patients, both adults and children. And I mean the verb "demand" literally, for I consider this primarily a moral issue. We have no choice but to find ways to help these children and their families live their abbreviated lives with some degree of civility and dignity. How we as a community, as a society, deal with this new disease, how we respond to the needs of these children is a more important test of our values and norms than almost

any other problem this country faces or has faced in the recent past. Again I thank you for the opportunity to speak to you this morning.

HALE HOUSE CENTER, INC

Administrative Office
68 Edgecombe Avenue
New York, New York 10030
212.690-5623

Clara "Mother" Hale
Founder

Dr. Lorraine E. Hale
President and C.E.O.

"Your willingness to open your heart and home to these babies and to offer an island of hope to their mothers has moved me deeply. What a wonderful person you are and what an inspiration you are to others! God bless you for your concern. You are truly one of His angels here on earth..."

- Ronald Reagan

"People like you provide hope for our less fortunate children. You have seen a problem and with love and determination reached out to help. The Old Testament says "Train up a child in the way he should go: and when he is old, he will not depart from it." You have done this over and over with the children you have welcomed into your home and heart..."

-Daniel P. Moynihan

"Mother Hale is the hope for the many innocent drug addicted infants crying out for a new beginning in life."

- Alfonse M. D'Amato

"Your establishment of Hale House – a refuge for babies born to drug-addicted mothers is indicative of a level of loving commitment that few people possess. You have given hundreds of children a chance to make something out of what could have been an otherwise dismal life. It is my pleasure to extend warmest wishes to you on the occasion of your 30th birthday. And though it is true that we should not only praise someone on special occasions, I am grateful for this opportunity to reflect on your very rich life and sing your praises..."

- Edward I. Koch

Remarks of Dr. Lorraine E. Hale
Executive Director of Hale House before
Congressional Panel: "AIDS, Drugs and Children"
Harlem Hospital Auditorium, July 27, 1987

"AIDS, Drugs and Children"

First of all, I'd like to thank you, Dr. Hagearty, Chief, Pediatrics, Harlem Hospital. Certainly no one I know is as close, on a daily basis, to the children we're talking about here today, than you.

When AIDS first came to Hale House two and a half years ago, my mother, staff and I were frightened. Dr. Hagearty sent Dr. Nicholas to Hale House to meet with all of us. After he explained how the virus is transmitted our fears diminished. Since then, other babies have had to hospitalized.

Congressman Rangel, throughout the turbulance of events surrounding the outbreak of this disease, your leadership has always been present. We are pleased that you kept your focus on the issue of drug abuse, as a primary cause of the social, moral and economic disintegration of this community. Today, as a result of your wisdom, we are gathered here in Harlem Hospital to discuss AIDS, another dimension of drug abuse and, to make

recommendations for solutions. For this we owe you a large debt.

Our appreciation also for Mayor Koch, for you recognized that, though the numbers are small today, the potential for the spread of this disease is enormous. Both mother and I have long known of your care and concern for the infants and children of this city.

Borough President Dinkins, we have been gratified by your long history of involvement in the effort to eradicate drugs from New York City. We agree with you, Mr. Borough President, certainly halting or reducing the importation of drugs will significantly reduce the spread of AIDS.

Unfortunately, the rapid spread of this disease among the non drug using population has caused further alarm. We know that within the African/American community 12% of heterosexual cases of AIDS have <u>not</u> been closely related to, nor the result of, needle sharing and drug use.

This should come as no surprise when we acknowledge that there are only 47 African/American males to every 100 females between the ages of 18 and 25. Given this statistic, the exploratory nature of men and the sexual needs of women, unless extraordinary educational steps are taken to inform young adults regarding precautionary measures, the continued spread of the virus can be anticipated. As of today, the spread of the virus is not limited to one ethnic group or one age group or one social class. The virus has already demonstrated

its ability to infect indiscriminately. The one absolutely innocent victim of both the habit, which becomes a disease; and, the disease which kills, is the newly born.

This leads me to thank the inspiration for our forging ahead with the concept of the Hale House Cradle, Surgeon General Koop.

This past April, in Philadelphia, at the Children's Hospital, I attended your "Surgeon General's Conference on Pediatric AIDS". I recall the quote from that report, "There is much we do not understand about this disease, but we do have enough knowledge to treat these children so that the quality of their lives is improved. It is our responsibility to ensure that they receive the medical and social care they need to live humane and civilized lives. It is our moral obligation to to so."

The man who embodies this, our nation's Surgeon General, Dr. Everett Koop is here with us today and Mother and I would like to extend a deep and heartfelt thank you.

On the day following the end of the Philadelphia Workshop, our staff spent endless hours planning, discussing, arguing and revising our program for pediatric AIDS. I was adament about only two things: that we move as expeditiously as possible to ensure our imput, experience and commitment to these children; and,

that we operate our program in conjunction with the pediatric department of Harlem Hospital.

We have moved to recreate a program similar to the current Hale House, hence, Hale House Cradle will be a small residential facility, a group home, a residence for unrelated babies born addicted to drugs; but, in addition, these babies will also have positive antibodies for the virus, AIDS.

This need is not only local, but national - everywhere mother and I travel, Chicago, Philadelphia, Boston, Detroit, California we are asked - what can we do, how can we help here in our own State? Our answer is always the same. We say organize, educate and perservere.

For years, many people have spoken out about Hale House as a model for infant care in a group setting, where parents get a fair deal, and where they are always respected. Yes! Hale House is a model, but more than that, it represents the ability of ordinary Americans to see a community need, and to identify and organize the resources necessary to address that need. Today, we have the same faith and courage we had 19 years ago. People ask if we are afraid of our new commitment to these new AIDS infants? Our answer is no, for faith and fear cannot co-exist.

Pediatric AIDS in simple talk just means a baby, a sick baby. Our mandate at Hale House is to care for babies who are well or sick.

Dr. Lorraine Hale
July 27, 1987
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During those times when the babies are not ill, they will live full and active and unsegregated lives. Runny noses, bruised knees, torn socks and lost mittens. We'll probably run out of mittens on a regular basis. Activities during these times will include infant stimulation, toddler developmental activities, preschool games and learning. . . Physicians, teachers, nurses, child care workers, occupational therapists and psychologists will all be available to teach, to play, and --- best of all --- to give love to each and every child. The goal --- as always in the Hale House tradition --- is to reunite the family.

Special staff will work with family members, support groups, and other social agencies to prepare the way for an eventual homecoming.

While the children are under our care, when symptoms develop, and they will devlop, we will deal with them medically. Hospitalization when required, no hospitalization when not required.

For those who die, and many will die, Hale House Cradle will always be there --- for the children, and for the survivors. Grief shared is grief survived.

For AIDS children in foster care, here too, Hale House Cradle will serve as a support mechanism, a place to share problems, and gain strength.

For research, what we learn --- we've been told -- will be invaluable to the entire nation. In siblings, why does one have the virus and not the other?

We shall provide clinical training for health care workers, community education and be a source of public information. The dozens and dozens of unknown questions that need to be answered, will be answered: the end result, a precise and systematic methodology for all of America. That, and more, that's Hale House Cradle. Money is required, but the cost of maintaining a child in Hale House Cradle is significantly less than in a hospital.

Permit me to explain:
Ten years ago, it was estimated that in New York State, there were 28,000 female drug users, 26,000 of child bearing age, capable of giving birth to 3.5 babies over a fifteen year period. Given todays statistics, we find there are 75,000 women in methadone maintenance programs. 63% or 47,250 have positive antibodies for the virus. They too are each capable of giving birth to 3.5 babies over a fifteen year period, for a total of 165,375 babies, the vast majority of whom will also test positive for the antibodies.

The cost for maintaining one baby in Harlem Hospital for one day is $600.00 or $219,000 per year. Simple calculations reveal that the hospital care at Hale House Cradle will be $161.00 per day, per child or $58,765 per year.

We expect Medicaid or foster care to pay for all of these children, in homes or in hospitals. In other words the American people will pay the cost for the care of these infants.

On the other hand, the monies allocated by New York State, public funds, if you will, are in the hands of those unable or unwilling to share, another small cadre of men, setting themselves above the will of the people - delaying progress with petty jealousies, demarcation and territorial disputes, personal grudges and squabbles.

This edpidemic is an enormous problem with survival implications for the entire American population. Why then did the State of New York, deliver the fate of the poor, the Black and the disorganized to this group, a hand full of self servers without reigns?

Let us hope that on the national level, funds will be distributed on a fair and equitable basis.

In conclusion, today we have an opportunity to learn from history:
In the 1950's drug abuse, though known and documented to be an American disease, was deliberately and systematically religated to a condition affecting only the Black community. And it was allowed to flourish, destroying two generations of African/American youth, but as with all diseases, it spread. Eventually it has affected the lives of almost every American.

I see the same patterns emerging - AIDS, a Black disease, is being suggested surrepetitiously, statistics are skewed, innuendo, half truths, lies are running rampant, researchers rubbing their hands in glee at a new industry, a new researchable breed of animals - Black men, Black women and now babies, with AIDS.

I ask that you remember the history. Stop the disease here in Harlem today, so that all Americans, everywhere, can live tomorrow.

The wisdom in this room today, I feel certain, will make the right recommendations to Congress, and further than that, I also feel certain that the right legislation, if legislation is required, will be passed. There are times in history when the right thing is done because the right thing must be done. I believe, and my mother believes, this is one of those times.

Thank you.

TESTIMONY OF

BENY J. PRIMM, M.D.

EXECUTIVE DIRECTOR

ADDICTION RESEARCH AND TREATMENT CORPORATION

PRESENTED BEFORE THE

HOUSE SELECT COMMITTEE ON NARCOTICS ABUSE AND CONTROL

CONGRESSMAN CHARLES B. RANGEL, CHAIRMAN

SUBSTANCE ABUSE AND PEDIATRIC AIDS

Monday, July 27, 1987
Harlem Hospital Center
New York City, New York

Mr. Chairman, you have heard the awesome statistics from my fellow panelists that both describe and define that devastating health catastrophe that is pediatric AIDS. I have chosen to recommend to this committee what I feel from my personal professional experiences with the addict population that could possibly make a dent in this progressively worsening problem. While the following recommended measures may seem draconian and drastic, this population is so scattered uncontrollable, and volatile that presently employed control mechanisms only seem to further underline the problems so encountered.

(For example) Urine testing of all newborns in municipal hospitals does result in the identification of infants born to mothers who have used drugs and paves the way for legal intervention regarding their future custody and care and alerts to the possibility of HIV infection though such a method may be effective for the protection of the future health and well-being of these infants they are not adequate to control or curtail the primary, and persistent occurrences of maternal AIDS virus transmission to newborns.

I propose:

1. That all men and women in drug treatment programs be mandated to attend courses in sex and birth control education. These courses should be conducted in the treatment programs and subsidized by either the City, State or Federal Government. Included should be the availability of all acceptable contraceptives, (condoms, diaphragms, the sponge, spermicides, tubal ligation and vasectomey) as alternatives to unprotected sexual intercourse.

2. Voluntary HIV 1, and 2 antigen and antibody testing must be available in all drug treatment programs, and alcoholic treatment programs. Treatment program participants should be strongly encouraged and urged to take the test, and be informed of their antigen or antibody test results. Detailed counseling before, while awaiting and after reported results on a consistent basis must follow this informing process.

3. Planned Parenthood counselors must be made available in all treatment programs for those men and women who are of child bearing age.

4. Responsible sexual behavior must become an integral part of the treatment process. Social Service agencies, in conjunction with drug treatment programs must monitor levels of understanding of sex education by means of a testing instrument. This instrument may be used as an indicator of further education approaches that may be called upon.

5. and finally those men and women who are abusing drugs and not in a treatment program, but who are in receipt of City or State support must be mandated to enroll in such a program and given the necessary guidance to this end. should that not fulfill this requirement their support should be jeopardized.

It is clear, here, that treatment slots must be made available for this population that must be treated and it is here that a truly committed, and caring synergistic trilogy approach on the federal government must be generated into being. This must be done for if not then all other efforts to eliminate the transmission of AIDS are pure folly.

FURTHERMORE MR. CHAIRMAN I WOULD LIKE TO REPORT TO THIS COMMITTEE WHAT I PERCEIVE AS AN INJUSTICE TO THE PEOPLE IN YOUR DISTRICT, AND MINORITY PEOPLE IN THE NEW YORK CITY COMMUNITY. THE GAY MEN'S HEALTH CRISIS THAT HAS CURRENTLY NO BLACK AND REPORTEDLY NO HISPANIC EMPLOYEES, HAS BEEN AWARDED A CONTRACT BY THE FEDERAL GOVERNMENT TO CONDUCT RESEARCH ON HOW TO REACH THE MINORITY COMMUNITY FOR AIDS PREVENTION AND EDUCATION.

MR. CHAIRMAN THERE ARE AGENCIES IN YOUR DISTRICT AND OTHERS IN NEW YORK CITY THAT ARE MINORITY RUN THAT CAN QUALIFY FOR SUCH GRANTS AND CONTRACTS BUT ARE CONSTANTLY OVERLOOKED BY CITY, STATE AND FEDERAL AGENCIES WHEN SUCH AWARDS ARE CONSIDERED. I IMPLORE YOU AND THIS COMMITTEE TO LOOK PROFOUNDLY INTO THE MECHANISM FOR THE AWARDING OF CONTRACTS, AND GRANTS FOR EDUCATION AND TRAINING OF MINORITIES IN PREVENTION AND RISK BEHAVIOR REDUCTION THAT TRANSMIT THE HUMAN IMMUNODEFICIENT VIRUS 1 AND 2. CULTURALLY RELEVANT TRAINING AND EDUCATION HAS PROVEN TO BE MOST EFFECTIVE AND CREDIBLE WHEN CONDUCTED WHENEVER POSSIBLE BY CULTURAL AND ETHNICALLY SIMILAR PERSONS TO THOSE YOU ARE TRYING TO REACH. IT SEEMS ONLY LOGICAL THEN THAT MINORITY RUN FIRMS BE CONSIDERED AS THE RECIPIENTS OF SOME OF THESE AWARDS.

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TESTIMONY

It is an honor to present this testimony this morning. I would like to thank you for this opportunity to share some insights into the ramifications of AIDS as it impacts upon minority communities in New York City, particularly the poor and those least able to advocate in their own behalf: babies and drug users. Your interest and your presence here at Harlem Hospital today is encouraging. You have come to an institution which is serving an inner city community with limited funds and with staff members who are providing heroic service in spite of the daily crisis that occur. You are also visiting a hospital which reflects every problem we face in society today. We can only intelligently look at the problems of AIDS in the context of the people who provide service daily without the encouragement of knowing that planning is going on to bring relief. More enthusiastic and idealistic doctors; more compassionate well trained nurses who are sensitive to the cultures and needs of their patients; more social workers to help solve some of the family and individual needs of daily survival; more mental health professionals who are sensitive to the problems of survival and coping skills of the poor and who need help to deal with death and grieving children or mothers and fathers or grandparents; technicians who understand the urgency for prompt and accurate results, more nutritionists able to cope with the new needs of those with AIDS; the physicians and nurses assistants who need the clerical support to better perform their tasks; the recognition of the many support staffs who keep a large plant like this functioning smoothly or not- the maintenance, the secretarial, the security and the volunteers are all here. They have not all understood the impact of this new disease. They have not all received training which enables them to unstintingly provide care with compassion. Yet there are many who have, and they will soon burn out or go to another place where the caseload is lighter, where the physical plant may not be feeling the strains of overuse or go to a place where they might feel their long hours and doing that extra bit will be appreciated. But they have not left yet, and your being here can make a difference. I hope that this day will mark a beginning that will be a benchmark in the course AIDS takes in this city. I hope it will be a day when we can all begin the process of working together, keeping in mind the Black mother who said to me in clinic one day,"If I had only known. When my baby was born I counted her toes and her fingers. She was beautiful. I was so proud. Now my baby is upstairs dying of AIDS. I wanted to kill myself for doing that to my baby. If I had only known, but nobody told me." We must make history. We must do the undoable. We must work together to make sure that our goals are to provide prevention information for every potential mother and father. To provide coordinated, compassionate and yet cost effective treatment for many people who may not read well, who may not understand well, who may have serious drug addiction problems limiting their ability to cope with the only life prescription at present AZT, or people who have so many problems which must be dealt with and AIDS is only exacerbating this. We must start. the process of sorting

out which steps must come first to save lives by providing prevention education, provide services to enhance the quality of life and to enable those providing the daily care to have support and meaningful tools to get the job done. That means educational information, equipment, research based upon experience here at Harlem among other places and where the daily chores remove the possibility for taking time to compare data and see where trends are present or new facts which might be hidden in a chart, or reality limits what Help is offered.

This undoable means leaving aside the politics and religious morals, leaving aside - societal racism in which this disease finds itself, leaving aside the sexism and classism and saying if we are to protect all that we all hold important -the wonder of life, in our city, we must work together in a spirit of challenge and not defensiveness. This city is capable of the most heroic acts. This city has a heart which amazes visitors. This city can put on a show when we celebrate the wonder of all of the immigrants who sailed past the Statue of Liberty to call America home. But this city also lives on dollars of tourists and corporations and the UN and this city needs help. We cannot hide the T.B. plaguing the homeless and the many people with AIDS. We cannot hide the thousands of drug users awaiting treatment and who probably are seropositive. We will soon be unable to hide the grieving children and families who have lost a family member and have no help in the coping skills of being a survivor. Today, we can start towards developing answers for helping those whom many look away from. Many whom society wishes would just go away. We who serve in communities beset and overwhelmed by poverty before AIDS must welcome your presence here today to say we cannot afford the luxury of blame placing. We must not dwell on what we have not done for our poor here in the wealthy city of New York or the poor throughout this wealthy nation of contrasts. We cannot dwell upon the priorities we set prior to the onset of AIDS. Because here in New York City, we have 55% of the adult cases of AIDS of minorities-Black, Hispanic/Latina, Asian and Native American. 90% of the babies with AIDS have been born to a Black or Hispanic mother. The majority of these cases are in some way related to drugs. Women sex partners of drug users, the IV drug user themselves, the children of drug users, the inmates who were incarcerated for some drug related offense, and the gay men who in some cases also use drugs.

We seek a partnership with you - to find ways to prevent the spread of AIDS, to provide the quality of life we are capable of if we had the will and most importantly, to recognize the work of your critical committee. We must enhance and assist the street worker trying to help addicts. We must help their families to find housing. We must provide the best our society is capable of. If we start backwards with AIDS and can solve some of the problems we all face with this crisis, we will have tackled some of society's plagues - racism and sexism and ensuing poor education, homelessness, unemployment, a two-tier overburdened health system based upon emergencies and not long term preventive care and the escape into the world of self medication:drugs. Into this we bring the babies.

Where do we begin?

No magic can we suggest, but I would start with these. The AIDS CARE CORPS and Housing along with renewed efforts towards providing comprehensive treatment and life coping assistance for drug users.

THE AIDS CARE CORPS

Fashioned after the energies and enthusiasm surrounding the birth of the Peace Corps, the AIDS CARE CORPS would be a federally financed, though locally run program, designed to provide supports to the physicians, nurses and other medical technicians and to enhance the work of the social workers, mental health and drug counselors who are trying to hold the pieces together.

Mother with AIDS (Or other single adult household)

Every mother who becomes ill with AIDS faces the emotional crisis of her own diagnosis, but also faces the stress of what to do about the care of her children. Each time the mother becomes hospitalized, she must arrange for child care. Is there a family member who can step in? Usually this becomes a grandmother, an aunt or sister, and in some cases, the oldest teenager in the household. If not, the children become temporary foster care children. The children least in need of school disruption lose not only the continuity of school work, but the stability and support of their friends.

At present, homecare attendants come in to a home only with an adult. If the single parent is hospitalized, this source of assistance is gone.

A possible solution: The AIDS Care corpsperson. Possibly a mother whose children have grown up, a person on public assistance without children, a graduate student searching for some career, someone seeking to leave an unchallenging job.

The job would entail keeping the family together during the mother's hospitalization. Assessing the needs of the family and providing on the spot planning and evaluation would be invaluable to the over burdened social service systems dealing with foster care. The mother's return would be assisted by this person until she got back on her feet and could do all of the chores required of a household head.

In addition to the stability of the children in their own home, it would insure their not being homeless. In too many cases we have seen the person who is hospitalized lose their home with loss of benefits.

Child with AIDS

Some parents with several children in the home have difficulty coping with the need to visit a child in the hospital and having care for healthy children at home. Public assistance allowances do not take into consideration the hours needed away from home and baby or child care to say nothing of carfare extras.

A possible solution: The AIDS Care corpsperson who is a "floater" and is assigned to provide respite for the mother-this could include caring for children while the mother visits the hospital and particularly when the day comes when the baby is in the ICU and the parent feels a need to stay overnight and yet cannot leave children at home.

Additional roles

Community educators, buddies for people with AIDS (companions to provide some assistance with light chores but most importantly, a source of human companionship for someone who is without a family) secretarial back up teams for hospitals and clinics overburdened with paper and unsupported by skilled labor, nutritionists to help outpatients cope with neighborhood availability of foods etc. Development of technical assistance to assist communities must be examined much as the Peace Corps: auxillary transportation for patients with dementia or drug or both inability to meet rigors

of subway stairs or too fragile to be able to wait for bus/local cab service. In addition to transportation needs, food delivery to the homebound with AIDS, food preparation in large quentities for family use (as surplus etc.) and other services we have identified such as storage of belongings during hospitalization or when PWAs are homeless and disposal of belongings upon death. Management of finances is a crucial one, particularly among I.V. drug users.

This could not only be a source of newly trained labor, but it would provide a new supply of caregivers, particularly the mothers with experience that could be supportive for the children. The titles would be new, the job descriptions would be unlike anything previously done, but we are dealing with a disease, a phenomena of death unlike anything we have been called upon to provide before and for many people for whom additional emotional stress might be a critical problem, without adequate counseling and support.

Housing

Closely related to the survival needs of substitute parenting and counseling, is the need for housing. The streets may be full of the homeless, but we need to recognize the added problems for the undiagnosed or those with the diagnosis if they are not critically ill and in need of hospitalization. The cost of keeping someone with AIDS upstairs in the hospital is more than your hotel rooms with clean linen daily, the food you eat of choice, the clean and decorated space and the routine you chose to set to have your meals, shoes polished or clothes pressed. The difference is the quality of life as a patient or as an independent person. The difference is whether to demoralize staff trained to provide health and related services for someone ill, or to provide those same services for someone who does not need those services but has no where else to live. This goes for the mother of the child who might be in the floors upstairs, ill in the pediatric ward, or the child whose mother may already have died and no one will take care of the child left behind.

Again our most creative minds must be challenged to come up with housing solutions vividly necessary in N.Y.C. but particularly for stages of AIDS other than acute medical needs.

Many of the same needs of people with AIDS are those needed by seniors. We know we have a major need for affordable or public senior citizen housing. To build for that need, to rehabilitate for that eventual population would be both cost effective and economical in effort. But for the immediate crisis, these homes could be appropriated for individuals and families with AIDS. At present, there is only a minimal number of options for people with AIDS who are minority and former drug addicts, and poor.

We must provide the accompanying counseling and coping skills to live inspite of AIDS. This may be a whole new life situation and we cannot expect people to cope without some assistance. This will not come without expenditures of new funds.

In summary, we must avert the impending crisis of the numbers of cases of AIDS. For those suffering now, there already is a crisis.

We cannot isolate how we look at the babies or drug addicts from the problems of the communities they emmanate from. We must approach the problems of teenagers and their experimentation with sex and drugs as the critical populations to reach or they will not only be future AIDS statistics, but they will be unable to insure the availability of the next generations. The school drop outs of which we have many and the many adults who were yesterday's drop outs may in fact be today's addicts. We must engage them to learn about AIDS via picture books or street theatre or whatever visual means we have, we have the talents here in New York City to be sure.

The problems of drug users, their sexual partners and babies are intertwined with all of the problems of poor communities, racism, sexism and our looking the other way at inadequate education, unemployment, homelessness and two tiered health systems. The under educated or the addicted are, along with the babies not about to mount the self help health campaigns so effectively created by gay communities throughout the nation.

We must therefore put our most creative minds together. We can develop campaigns to create sophisticated weapons to kill. We can be just as creative to create weapons to help people live without suffering from AIDS.

The creation of the equivalence of the Peace Corps - an AIDS Care Corps can engage women and men whose children have grown up, women on public assistance without children at home, young people who went off to other countries yesterday, might be the young people who would be challenged by this national crisis.

We need to train caregivers to support, nurture and deal with the needs of children whose families have been torn apart by death. We may not want to, but we must face the spectre of hundreds of children throughout the nation grieving for their lost parents, and unable to cope with the fact that we did not train in time people who were able to understand their cultures, customs and grief.

There is going to be a major crisis in New York City. There are at present inadequate services for the people with AIDS and with ARC. We have a warning of what is to come, let us start today to plan and get into motion realistic ways to avert what could be a national catastrophe if we do not create the caregivers, the facilities in which to care for the ill and the homes for those who are the survivors. Together, it can be done.

Thank you for your concern and I look forward to The Minority Task Force on AIDS working with you in any way to assure culturally and language sensitive AIDS prevention and services to PWAs.

Presented by: Suki Ports, Director
The Minority Task Force on AIDS
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July 27, 1987

BACKGROUND HISTORY OF THE MINORITY TASK FORCE ON AIDS

The Minority Task Force on AIDS was created by concerned citizens who attended the "AIDS Is Also A Minorities Community Crisis" conference sponsored by The Council of Churches of the City of New York, in November of 1985. At follow-up meetings held in December and January, the Task Force was born, in response to the belief that the critical public health crisis in minority, particularly low-income, communities out of which 55% of the adult and 90% of the podiatric cases of AIDS originate was not being adequately addressed in a coordinated, comprehensive or compassionate manner.

It is the belief of the Task Force that there must be comprehensive and compassionate provision of support services to people with AIDS and ARC, their families and caregivers. Preventive education must also be provided to stem the spread of AIDS, particularly for communities still undergoing denial and still believing it to be a disease of the gay, white male. Housing is a particularly critical need and must be met. This is but one of the specific areas in need of advocacy, particularly for groups and individuals unable to speak in their own behalf including some substance users.

To develop policy recommendations which are at the same time cost-effective and compassionate, to be sensitive and mindful of the civil rights of the diverse ethnic, racial and cultural communities, each with their own historic traditions and roles for males and females and children, the Task Force has joined with other AIDS organizations to work towards the attainment of those goals in a formal coalition called the New York AIDS Service Delivery Consortium as well as informally with other groups not all in the consortium. including the Haitian AIDS Coalition and the Hispanic AIDS Forum. The Task Force has found permanent quarters in Harlem, on a street recently cited as being in the center of drug cultures. We have been welcomed to the building by the tenants, some of whom have lived here for many years and others who have been relocated by the city in their homeless priority program. The West Harlem Community Organization manages the building. Our space enables us to hold all meetings, dinners for the PWAS and their children and have privacy for confidential meetings with clients. We have also made the space available for consortium type meetings and have established a working relationship with the AIDS program of Goddard Riverside.

Testimony of Dennis P. Whalen
Executive Assistant to the Director
New York State Division of Substance Abuse Services
presented to the U.S. House of Representatives
Select Committee on Narcotics Abuse and Control

Mister Chairman,

Director Julio Martinez wanted to be here himself today to present this testimony, however, a previous and longstanding commitment has prevented him from doing so. He has asked me on his behalf to thank the Select Committee for this opportunity to testify on the important problem of AIDS in children. As I am sure you are already well aware, AIDS in children is one of the cruelest aspects of the epidemic. In addition to the suffering of the child, AIDS in a child creates severe anguish for the family and the dedicated health and social care providers who work with these patients.

Characteristics and Size of the Problem

I will describe the efforts of the State Division of Substance Abuse Services to cope with the problem of AIDS in children, but first it will be helpful to outline the relationship between intravenous drug use and AIDS in children and the likely size of the problem in the near future. To date, there have been slightly less than 200 cases of AIDS in children reported to the New York City Department of Health. In about 95 percent of these cases, the infection occurred through maternal transmission from the mother to the child, the other 5 percent occured through blood transfusions or the use of blood products. Because of the screening tests for blood donations, we can expect the transfusion/blood product cases to decline over time.

The number of children who develop AIDS because of maternal transmission, however, will continue to increase for the immediate future. This is because intravenous drug use is the primary source of AIDS virus infection in women of childbearing age. As you know, IV drug use in one or both of the parents is the source of AIDS infection in almost 80 percent of the cases of AIDS in children in New York City.

With the assistance of the City Department of Health, and funding support from the National Institute on Drug Abuse, the Division of Substance Abuse Services has been conducting research on the problem of AIDS in the children of intravenous drug users. I will use the results of that research to provide an estimate of the potential size of this problem. If you wish, Division staff will be pleased to provide the details of the findings at your convenience.

We estimate that there are approximately 250,000 intravenous drug users in the State of New York, of whom 200,000 are in New York City. Between 50 and 60 percent of the IV drug users in the City have already been exposed to the AIDS virus, and are thus capable of transmitting it to their future children. Approximately 25 percent of the IV drug users are females and could, therefore, transmit the AIDS virus in utero, at birth, or possibly through breastfeeding.

The 75 percent of the IV drug users who are male may transmit the virus to female sexual partners who do not inject drugs themselves. Thus a woman need not inject drugs herself to become infected and tramsit the virus to her future children. We estimate that there are at least 100,000 women in New York City who do not inject drugs but are at risk for AIDS infection because they have regular sexual relationships with males who do inject drugs. No one is certain how many of these sexual partners are already infected, but they clearly form a large potential group who may transmit the virus to their future children.

An illustration of the possible long-term importance of IV drug use-heterosexual-maternal transmission is the 4 percent of cases of AIDS in which neither parent injected drugs, but IV drug use was the ultimate source of the AIDS infection. In these cases, the mother became infected through a sexual relationship with a drug user, and then had a child with a man who did not inject drugs, but the virus was still transmitted to the child.

Working with conservative estimates, if half of the 50,000 IV drug-using women in New York City are already exposed to HIV, and if 5 percent of the 100,000 female sexual partners are exposed, then there are already 30,000 females who have been exposed to the virus due to drug injection. There are an additional 25,000 females who inject drugs and 95,000 who are regular sexual partners of male IV drug users who are at immediate risk for becoming infected.

Almost all IV drug users (and their sexual partners who do not inject) are within the ages when they are capable of having children, and we must expect them to have many more children. Our studies of drug users in treatment indicate that the birth rate for IV drug users is between 3 and 5 percent per year. Twenty-five percent of the drug users we studied indicated that they "intended" to have additional children, and another 25 percent were "not sure" if they would have additional children. The efficiency of transmission from an HIV-infected mother to a child has not yet been determined, but estimates range from 30 to 50 percent.

There are many uncertainties with respect to the number of maternal transmissions of HIV infection that will occur in New York, from the number of infected women of childbearing age to the rate of spontaneous miscarriages to the efficiency of in utero transmission. Working with these uncertainties, we would estimate that there will be between 300 and 800 children born in 1987 in the City who will be infected with the AIDS virus.

Response by DSAS

The Division of Substance Abuse Services is very concerned about the problem of AIDS in children and has undertaken a number of initiatives to reduce the problem. These initiaties have been undertaken in coordination with other agencies of the State government, particularly the Department of Health, and with the New York City Department of Health. This new work has begun during a time when there have been severe strains on the drug abuse prevention and treatment system, including providing drug abuse treatment to persons with AIDS and dealing with the Crack epidemic.

Our perspective has been to address the problem of maternal transmission of the AIDS virus within an overall attempt to limit infection among IV drug users. Clearly it is most effective to prevent the initial infection of drug users that occurs through the sharing of drug injection equipment. Because of heterosexual transmission from IV drug users to persons who do not inject drugs, it is also necessary to work with both male and female IV drug users at risk for infection in order to limit maternal transmission.

A major priority to limit the spread of HIV among IV drug users has been to increase the capacity of our treatment system for IV drug users and drug users at risk for starting to inject drugs. Over the last several years we have increased our treatment capacity by over 3,000 new treatment slots. Unfortunately, we still are in a waiting list situation, with more demand for treatment than supply. IV drug users who apply for treatment often are required to wait several months until a treatment slot becomes open for them. Because of the AIDS situation, any pregnant woman who is applying for treatment is automatically taken in, but this is clearly not adequate to reach all of the women at risk for HIV infection and for bearing children who may become infected with the virus.

We are establishing the position of AIDS Coordinator in our funded drug abuse treatment programs. The AIDS Coordinator is responsible for providing AIDS education to all clients in treatment, including information about "safer sex" in order to reduce the chances of heterosexual transmission of the AIDS virus and possible transmission to future children.

While providing treatment to persons who are abusing intravenous drugs may be the most effective way of reducing the risk of AIDS among drug users, we certainly will not be able to provide treatment to all IV drug users in time to prevent them from becoming exposed to the virus. We are, therefore, conducting AIDS education campaigns to warn IV drug users of the risk of sharing drug injection equipment, the need for practicing "safer sex," and the dangers of transmitting the virus to future children. These education campaigns include posters, pamphlets and, most importantly, face-to-face education efforts conducted by ex-addicts. We have a group of trained ex-addicts who go into high drug abuse areas of New York City to conduct face-to-face AIDS education. The education includes the dangers of heterosexual and in utero transmission, and the ex-addicts can provide referral for treatment and/or HIV antibody testing if the current drug user wishes.

We have also started a pilot project to keep youth from starting to inject drugs. This project is supported by funds from the Centers for Disease Control, and involves working with youth who are using large amounts of heroin but are not yet injecting it.

DSAS has worked with the State Health Department to establish antibody test sites so that persons who are considering having children may receive confidential counseling and antibody testing if they so wish. These "alternative test sites" provide the services with complete confidentiality and at no cost. Many women who are contemplating having children want to have

antibody testing, and then will postpone having children until more is known about in utero transmission, and how it might be prevented. There are, however, a significant number of men and women who want to have a child sufficiently to risk possible transmission of HIV to the child.

Summary

The problem of AIDS and HIV infection in children is large and growing rapidly. In areas like New York City, IV drug use by the mother or by a sexual partner of the mother is the predominant cause of the infection in the newborn child. The problem here in New York will clearly become worse in the near future as women who are already infected with HIV have additional children and as more women of childbearing age become infected either through their own drug injection or from heterosexual transmission from a man who injects drugs. As HIV infection spreads among drug users in other parts of the country, the very difficult situation we face here in New York will be repeated elsewhere.

In New York, we have mounted a number of efforts to reduce the potential transmission of HIV to children, and are evaluating those efforts to learn how they might be improved. The size of our present efforts, however, is not on the same scale as the size of the potential problem. We should be doing ten times what we are currently doing to prevent future cases of AIDS among children. Unfortunately, we are lacking financial resources, lacking

trained personnel, and lacking community acceptance for some of our efforts. In a time when it is critical to open new dru buse treatment capacity, we still find many community members strongly objecting to the opening of drug abuse treatment programs.

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DISTRICT COUNCIL 37
NYC DEPARTMENT OF HOSPITALS

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PRESIDENT JAMES BUTLER'S TESTIMONY
BEFORE THE SELECT COMMITTEE
ON NARCOTICS ABUSE AND CONTROL
JULY 27, 1987

Good afternoon, Mr. Chairman, The Honorable Congressman Rangel, my name is James Butler, President of Local 420, District Council 37, American Federation of State, County, Municipal Employees, AFL-CIO. I want to take this opportunity to thank you and your Committee for inviting me to testify today on one of our priorities in the health field, AIDS. Local 420 membership consists of over 14,000 health care workers that care for the sick and injured in the City of New York, Health and Hospitals Corporation. New York City Health and Hospitals Corporation is the largest public hospital system in the world.

Let me name the hospitals that we represent in the City of New York. Harlem Hospital, Bellevue Hospital, Metropolitan Hospital, Gouverneur, Bronx Municipal, Lincoln, North Central Bronx, Goldwater, Bird S. Coler, Kings County, Woodhull, Coney Island, Queens General, Elmhurst, Neponsit, Seaview, Sydenham Neighborhood Family Health Center, Morrisania Neighborhood Family Health Center, Cumberland Family Health Care Center, Brooklyn Central Laundry and several other satellite clinics in the various boroughs.

Mr. Chairman, my members care for the AIDS patients that are being hospitalized in the hospitals that I just named to you, and the outpatients with AIDS. Mr. Chairman, I must state to you and the Committee that we are faced with difficult days in the public hospitals in the City of New York, that now have a very high census in reference to inpatients with the diagnosis of AIDS, and for your information, the census will not decrease, the census will continue to increase.

Take for example, in this community, Harlem, and this hospital, Harlem Hospital, the census is one of the highest in the city (47).

Mr. Chairman, Local 420's slogan is "Decent Health Care For All Americans". Now there is another slogan we are carrying along with that slogan, "Decent Health Care For All AIDS Patients". Mr. Chairman, I just quoted our slogans to you and the Committee. My members want to give decent health care to all AIDS patients. You cannot give it if government is playing Russian Roulette with health care. What I am saying to you is that old famous reply from government, whether it be the federal government, the state or the city -- <u>There is no money in the budget for hiring additional health care workers</u>! But, Mr. Chairman, we are understaffed at this very moment and have been for the past number of years. In the meantime, the AIDS patient who is unable to bathe or feed himself, needs a Local 420 health care worker nurses' aide to perform these duties for him. When the patient's room needs to be cleaned, there must be a Local 420 housekeeping aide to clean that room. When the patient's linen is soiled and needs to be changed, the Local 420 laundry worker is responsible for providing

clean linens so that the patient can rest in comfort. Dietary Aides who prepare the trays of many varied diets for each patient, have the responsibility of making sure that each individual patient gets his proper tray in accordance with the diet prescribed for him.

Mr. Chairman, I hope that the Governor of the State of New York and the Mayor of the City of New York take a walking tour through the public hospitals and visit the AIDS patients, and see for themselves the shortage of staff assigned to care for AIDS patients, and witness the misery of these very ill human beings, in order that they may better understand what we are faced with in the City of New York in the AIDS crisis. Mr. Reagan must understand that of the half a billion dollars budget that has been appropriated for AIDS, the minority community should receive its fair share.

We would like to recommend to this Committee: (1) more federal funds must come in to the black community to help the fight against AIDS; (2) public education programs; (3) special health facilities staffed fully; (4) New York City must establish a special public hospital for AIDS patients; and (5) but not least, funds to be appropriated to fight against drugs in the black community.

Thank you very much, Mr. Chairman and Committee Members.

SUBMISSIONS FOR THE RECORD

Testimony of
Meredith Harris - Copp, Ed.D., P. T.
Director of Physical Therapy, Bronx Municipal Hospital Center (BMHC)
Director, Bronx Campus, Ithaca College, Division of Physical Therapy
To
The United States House of Representatives
Select Committee on Narcotic Abuse and Control
July 27, 1987

I am privileged to have the opportunity to submit testimony to this distinguished Committee about problems of children with HIV infection. I first saw children who were HIV infected when in October, 1986, I was asked to consult with physical therapists at Jacobi Hospital, Bronx Municipal Hospital Center (BMHC) , who were to provide physical therapy treatment for two infants both 3 months old. Both of these little girls had severe neurological and medical problems. Both had severe spasticity making it impossible for them to move the way a normal baby moves. Both had severe problems in feeding. In one this necessitated a feeding tube being inserted into the child's stomach. Both had severe respiratory complications. When I first saw them, I thought they were like other children with cerebral palsy that I had seen in my practice as a pediatric physical therapist . I also knew that regardless of the diagnosis, the problems that these children presented were amenable to physical therapy treatment. We had a role to play in getting these children to move more normally and thus prevent the stiffness and deformities that might occur in spasticity. We could improve their breathing patterns and therefore decrease the devastating effects on the lungs from the pneumonias that they contracted and yet survived .We could improve their ability to take in food through their mouths to improve their nutritional status and general health.

When I learned that AIDS was the diagnosis of these children , I was surprised since I had thought that AIDS was a disease of homosexual men. My naivete` was such that I had not made the connection between intravenous drug abuse and severely disabled babies.

I have now over the past year treated or consulted with physicians and therapists on over 30 infants and children. Of these four have died. Three infants are currently boarder babies at BMHC. Two of these are fortunate to be enrolled in the Day Care Center at Van Etten Hospital (BMHC). The children for whom we are able to provide regular physical therapy show positive results. Other boarder babies have been placed in foster care. These are lost to treatment until they are readmitted for acute care. We are currently seeing in physical therapy three newborns who are quite ill and are in the neonatal intensive care unit, but they are surviving and are progressing and will probably be discharged. Many who are discharged from the hospital are lost to follow up. They reappear only when they have contracted an infection which warrents hospitalization. When we see them again readmitted to the hospital, we find that they are more disabled than when they left. This may be due to the natural course of the disease but just as likely may be due to the fact that they receive no physical therapy once they are released to the community without monitoring, evaluation or treatment.

There is much clinical reasearch that is needed to determine the prognosis and progress of these infants and children. Since my discovery of this disease in infants and children and its devastaing effects, I met with the neonatologists and pediatricians at BMHC to find out more about these

infants. I wanted to be sure that they refer to physical therapy all infants and children diagnosed with HIV infection, those who have had stormy birth histories because the mothers were IV drug users, and any infants with suspected neurological or developmental disability. BMHC is one of the few public hospitals in the city which has a full staff of physical therapists (15) and therefore we have the capacity to evaluate and treat these children. Harlem Hospital like most public hospitals throughout the city, and I suspect throughout the country, does not have enough physical therapists to provide these children with the physical therapy that they so desparately need.

Physical therapy will not save the lives of these children , but I do see from clinical experience that those who do survive and who receive physical therapy are able to move with less stiffness and develop motor abilities in much the same way that retarded or cerbral palsy children do when they receive the appropriate physical therapy treatment. We are able to prevent them from developing more severe handicaps such as the contractures and deformities that can occur in children with neurological problems. We have seen that we can influence their ability to move more like normal babies and therefore have a chance to develop and perhaps have a greater chance at survival for a longer period of time. I am convinced that intervention in their feeding problems can help change their nutrition and their general health. Severe problems in feeding often lead to aspiration pneumonia which can cause death or severely damage the lungs. Statistics are not encouraging about the life expectancy of these children. Most die within one year of diagnosis, most from respiratory infection. However not all children die who

have HIV infection. Not all children with HIV antibodies go on to develop the disease.

There is still very little that is known about this devastating and pervasive disease. Many survive, but without the necessary medical and physical therapy services they become a new population of severely developmentally disabled childeren. But I am convinced that the quality of life for these children can be improved with the appropriate medical and therapy services. Their parents, foster parents, pediatricians, visiting nurses need to be taught that there are ways of caring for these children so that they learn to move, feed, and breath better so their survival continues.
Our health care system sorely lacks the resources necessary to provide comprehensive health services for these children, their parents and foster parents to prevent or slow the devastating effects of the disease. What is frustrating for me at BMHC is that I have some of the resources for acute physical therapy services, but the need is greater than that. There are some children who float in and out of the hospital for acute care, but there is no system to provide follow up to prevent this revolving door pattern. With each subsequent visit, I see a child becoming progressively debilitated, sicker, and closer to dying. I do not believe that this has to happen as frequently as it does.

I am strongly recommending that funding resources be made available to provide comprehensive medical, therapy, and education services. I am suggesting that resources be made available to : (1) educate women of child bearing age about the risk of sexual contact with intravenous drug users and about the devastating effects of drugs on the unborn infant and , (2)

provide prenatal care that begins early on in their pregnancy for mothers in poverty who have problems with drugs or who are partners of IV drug users, (3) provide resources for comprehensive evaluation, treatment, and regular follow up for these infants, children and their parents, (4) educate parents and foster parents on how to handle these children at home, (5) develop home care services particularly for infants, (6) educate and train visiting nurses , family physicians, and physical therapists to provide medical and therapy services in the home for families with infants or children who are too fragile, devastated, or ill or otherwise unable to seek help in other settings (7) provide preschool and day care facilities that will provide medical, therapy, and education services for these children.

I am also strongly recommending that post secondary education funds be provided to train more physical therapists. How do we address the issue of the problem of shortage of physical therapists? Earmark funds for college education for physical therapists, particularly minority students, who will commit to working in a public hospital in pediatrics after graduation. There is a model already in existance established by Rehabilitation Services Administration (RSA) to bring therapists into rehabilitation facilities. This model could be adapted to bring more minority students into physical therapy into the public sector, but it has to be specified that the population served is the pediatric population. Ithaca college a private institution in upstate New York which graduates 80 physical therapists a year. The college costs are over $13,000 a year. The minority enrollment in physical therapy is less than one per cent over the last five years. There is a nation wide shortage of physical therapists so that students graduating from this and other physical therapy programs do not routinely choose to work in the

public sector. Resources are needed to bring more minority students into the professional field at this college and other colleges and universities with excellent physical therapy programs, but are too expensive to be considered for the capable student with limited resources. Why am I suggesting earmarking funds for the minority student? Because the problems associated with poverty such as drug abuse, poor health care, and poor maternal and infant health affect the Black and Hispanic population to a disproportionate degree. We should be training those from the minority community who are sensitive to the problems of the community and who will become leaders to help to educate the general public and provide the needed health care services to minorities.

In Summary, the numbers of infants and children with HIV infection and those who are potentially at risk because of drug abuse are growing by geometric proportions at an alarming rate. It is particularly increasing at a disproportionate rate in the Black and Hispanic populations. I recognize that the major issue is to stop drug abuse and to eliminate those problems associated with poverty, discrimination, and socioeconomic deprivation that are historic and pervasive in minority communities. But because of my professional experience in physical therapy with developmentally disabled children, I also recognize that we have a population of children who are affected with devastating disabilities who do not die, but who are becoming increasingly disabled for whom services are not being provided and for whom appropriate timely intervention can make a difference in the quality of their lives. We all hope that a "cure" for AIDS will someday be forthcoming. But until it does we should be addressing the issue of preventing the severe handicaps that are preventable in this new population of

potentially developmentally disabled infants and children. Those who are infected or 'at risk' for HIV infection demonstrate neurological and developmental disability which is amenable to treatment. These will be lost unless swift and appropriate action is taken. I offer my testimony to bring your attention to the fact that there is some hope for some children and that their future is worth the commitment of resourses. I am engaged in a project to identify, track, and provide physical therapy treatment for as many of these infants and children as possible, but I cannot do it alone. Funding is needed so we may learn more about these children and provide them with the services that they and their families need before it is too late. The problem is much the same as many other health issues in developing countries and in poor communities. The underlying need to save lives is so pervasive that rehabilitation is often seen as a luxury. I am asking this Committee that in considering major issues as presented in other testimony at this hearing that you do not overlook the infants and children who are unnecessarily becoming progressively disabled. I am asking that resources be made available for clinical research in physical therapy, for resources to bring minority physical therapists into the communities that are grossly underserved, and that resources be directed to comprehensive health care and follow up for these children and their families.

Testimony of the American Psychological Association

before the

United States House of Representatives

Select Committee on Narcotics Abuse and Control

on the subject of

BEHAVIORAL ISSUES IN PEDIATRIC AIDS/HIV INFECTION

July 27, 1987

The Honorable Charles Rangel, Chairman
H2-234 House Annex 2

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Mr. Chairman and members of the Subcommittee, the American Psychological Association (APA) is pleased to submit testimony on the topic of pediatric AIDS and the important behavioral issues associated with children who have AIDS or are infected with the AIDS virus. The APA represents 87,000 psychologists, many of whom have substantive professional and scientific expertise in these issues.

The public policy issues surrounding pediatric AIDS are of growing concern to us. Since the earliest years of the AIDS epidemic, it has been recognized that children represent a special population of patients of this disease. Not only are the manifestations of the physical disease somewhat distinct from the symptoms of AIDS found among adults, but the social, psychological, legal and ethical issues of pediatric AIDS are unique.

The role of psychologists in dealing with the behavioral and psychological aspects of pediatric AIDS has been relatively limited up until now, because there are few cases, limited to a small number of regions around the country. However, we would expect to see a substantial increase in the involvement of psychologists in the future, as the numbers of pediatric cases rise and the disease spreads geographically. There are many areas that could benefit from the input of psychologists, including 1)psychosocial interventions with infected children and their families, 2)community education and prevention efforts which target changes in knowledge, attitudes and behavior, and 3)behavioral research.

Recognizing this unique character of pediatric AIDS, the Division of Child, Youth and Family Services of the APA convened a Task Force on Pediatric AIDS last year. The task force was charged with identifying issues and making recommendations for policy in areas relevant to the APA's concerns. The task force includes five psychologists, a pediatrician, and a social worker involved in AIDS related projects around the country. These individuals are involved with various aspects of pediatric AIDS/HIV infection, including: direct service to children with AIDS/HIV infection and their families, development of a model for psychosocial service delivery, counseling and education with hemophiliacs and their families, school system reactions, legal and ethical issues, and basic research on immunological aspects of the disease. This statement represents an interim report from that task force.

The Epidemiology of Pediatric AIDS/HIV Infection

The first cases of pediatric AIDS in this country occurred as early as 1979, although an official case definition including criteria for diagnosing children was not developed by the Centers for Disease Control (CDC) until several years later. As of June 29, 1987, the CDC has reported a total of 520 cases of pediatric AIDS (diagnosed between birth and 12 years) and 151 cases of adolescent AIDS (13 to 19 years). These constitute less than 2% of the total number of cases. Forty-one percent of the pediatric cases have been reported, however, in only the last 12 months. In other words,

although the numbers may seem small, they are rising rapidly. The National Academy of Science's 1986 report, Confronting AIDS, projected an almost ten-fold increase in the number of pediatric cases to more than 3,000 cumulative cases by the end of 1991.

The disease is affecting minorities disproportionately, with Blacks and Hispanics representing 53% and 25% of the pediatric cases, respectively. Over two thirds of the cases have been reported from New York (36.0%), New Jersey (13.7%), Florida (11.3%) and California (6.7%). Nearly two thirds of the states, as well as the District of Columbia and Puerto Rico, report at least one case.

Cases of AIDS represent only the most severe manifestations of Human Immunodeficiency Virus (HIV) infection. Many children are infected and ill but are not reported to the CDC because they do not meet the stringent case criteria for AIDS (a life threatening opportunistic infection or Kaposi's sarcoma, and a positive HIV antibody test). It is estimated that there are four children with other forms of HIV infection for every case of CDC-defined pediatric AIDS.

About 12% of the cases of pediatric AIDS have resulted from blood transfusions and another 6% are associated with treatments for hemophilia/coagulation disorders. Nearly 80 percent of the CDC-reported pediatric cases involve perinatal transmission from an infected mother to her unborn child. In the majority of these cases, the mother's infection can be linked either to the mother's intravenous (IV) drug use or that of a sexual partner. Most children infected perinatally develop symptoms within the first twelve months, including failure to thrive, neurological impairments, delayed development, recurrent bacterial infections and swollen lymph glands. In the future, perinatal transmission will be the primary mode of transmission to children, given that blood and blood products have been made virtually safe through screening and heat treatment procedures.

Treatment of the disease itself, with anti-viral drugs, is still in its infancy. Management of the secondary infections resulting from the immune deficiency has been more successful, and early recognition and treatment of the symptoms may prolong life. However, with no cure and no vaccine, the disease will be a major public health problem for many years to come.

Behavioral/Psychological Interventions

Although the medical aspects of HIV infection are devastating, the psychological and behavioral implications can be equally overwhelming. Often the family is from a lower socioeconomic background and the disease delivers another crippling blow to any efforts to achieve self-sufficiency. The overwhelming majority of families have no medical insurance for their infected child. The need for financial support and social services is often great. Comprehensive case management is essential to assure that the basic needs of the families are met and to facilitate prompt responses from the health and social service bureaucracies.

If transmission of the virus to the child has occurred perinatally, one or more family members also are infected with HIV and consequently at risk of a fatal disease. Regardless of who is infected, the response of the family system to the diagnosis is almost always one of severe stress. There is often a great deal of uncertainty surrounding the prognosis. Fears about loss of confidentiality, stigmatization, rejection, isolation, and abandonment by family, friends, neighbors, and co-workers, loss of housing and termination of employment are not unfounded. The need for counseling and therapeutic interventions from psychologists, social workers and other mental health professionals is great. The psychologist or other mental health professional can play a central role in any interdisciplinary team effort to address the family's psychosocial and medical concerns (e.g., the team model that is evolving at hemophilia centers around the country).

Obtaining baby sitting, respite care, day care and nursery school placements, and public school enrollment can be complicated procedures full of obstacles and risks of breaches of confidentiality. The media's reports of the reactions of school district administrators and parents of other children to knowledge of an infected child in the schools attest to the kinds of discrimination families may anticipate if the diagnosis is disclosed. With the death of one or both parents, or abandonment in some cases, foster care and residential placements must be found. Moreover, the already great need for such social services in some regions of the country is expeced to expand rapidly.

Increasingly, there is evidence that HIV infects the child's central nervous system, producing neurological impairments and developmental delays and disabilities, which often become worse as the disease progresses. Psychologists can play an important role in research and evaluation efforts to determine the degree and extent of the problem in HIV-infected children. Many important decisions on the kinds of educational and therapeutic interventions that may ameliorate the effects of central nervous system infection in the child will depend on culturally and linguistically appropriate psychological and neurological assessments. Funding sources may raise questions about what level of services should be provided as a function of the severity of the child's illness, potential for rehabilitation and life expectancy. Advocates of services should be prepared to respond.

Infected parents are also at risk of neurological impairments, including forgetfulness, confusion, poor concentration and dementia. Any interventions with them need to take this possibility into consideration. Psychological and psychiatriac evaluations of the parents will be helpful in making such determinations.

There is a need for educating families so that they can understand the diagnosis, what birth control and other preventive measures should be taken (estimates from limited data are that a mother of an infected child has a two in three chance of delivering another infected child), and the role of good hygiene, medical care and nutrition in health maintenance.

Recommendations

Based on all of these considerations, APA recommends that:

1. All necessary resources be directed to assure the development of psychosocial and educational programs for families of all children with HIV infection to enhance existing medical services. This represents in some cases an expansion of services to all HIV-infected children and not simply those with a diagnosis of AIDS to enhance existing medical services. The program should include:

o support for meeting basic needs, such as food, housing, transportation, medications, etc.

o emotional support and counseling to assist families in adjusting to the initial diagnosis as well as to disease progression in their child. Counseling must also be available for the infected parent. Such counseling must take neurological complications into account. Mental health professionals must be prepared to address problems of family functioning and community living related to discrimination, isolation, rejection, death and dying.

o a coordinated system of community-based services, with staff trained to address HIV-infected and ill children, to provide baby sitting, day care, home care, visiting nurse, respite care, and hospice supports for families. Innovative day care and nursery school programs, such as those developed in New York City and Newark, need to be considered as options for providing group care that allow peer interactions at younger ages. In situations where the family can no longer care for a child, foster care and innovative residential options need to be developed and supported.

o appropriate placements in public school programs to address the child's regular or special educational needs, including physical, occupational and speech therapy if necessary, in the least restrictive and isolative environment possible. Special considerations must be made for those children at the pre-school level who manifest developmental delays and neurological impairments. Either existing early intervention programs will need to be expanded and modified, or special programs will need to be developed. Both center-based and home-based options must be explored to deal with the developmental as well as health-related needs of these children.

In general, we support the guidelines of the CDC and the American Academy of Pediatrics for placement of school-aged and younger children who are infected with HIV. We do have concerns, however, that the recommendations regarding confidentiality may not adequately protect the family's right to privacy and that the guidelines require that more individuals than we believe necessary, considering the nearly non-existent risk of transmission, be informed of the child's infection status. Guidelines for children under age five may need revision or at least an

updated review based on more recent studies of household transmission. In particular, we are concerned about recommended precautions about saliva when there is no evidence that saliva can transmit the virus. Such mixed messages, we believe, create unnecessary concern and confusion.

o educational interventions for the families to provide information and to facilitate skill development and behavioral change. These interventions should be closely coordinated with counseling efforts and focused on prevention of further transmission of the virus, birth control, sexually transmitted diseases, well child care, hygiene, and nutrition. When appropriate, these activities should be coordinated with drug rehabilitation programs, although such educational services should be available regardless of whether active users are enrolled in drug rehabilitation programs.

o guidelines to assure that all services and educational materials are culturally and linguistically appropriate for the families being served.

o an organizational structure for program development and service delivery that assures that the full spectrum of services delivered are comprehensive, coordinated and integrated in a way that is both sensitive to the family's needs and cost effective.

o up-to-date and sensitive training programs on the psychosocial as well as medical aspects of AIDS/HIV provided to professionals who may be responsible for providing psychosocial and educational services to infected children and their families. Critical topic areas for training include confidentiality, death and dying, and differentiation of psychological and neurological effects of the disease. Target audiences include physicians, psychiatrists, psychologists, nurses, social workers, case managers, family counselors and therapists, teachers, teacher assistants, physical and occupational therapists, speech therapists, drug counselors, day care operators and staff, etc.

2. A range of funding alternatives, including federal, state, local and private, be explored and that each community establish priorities for funding that assure that limited resources are used maximally to address critical needs.

Community Education and Prevention Issues

It has been said that there are two AIDS epidemics, an epidemic of HIV infection and an equally invidious epidemic of fear. No clearer illustration of the epidemic of fear has there been than the vehement reactions of many parents around the country upon learning that a child with AIDS or infected with the virus was being enrolled in their child's school or school district. To address the panic and fear of these parents and modify their attitudes and behavior requires informational and behavioral interventions based on knowledge of how to change attitudes, social norms,

and behavior. Psychologists are in a unique position to provide valuable guidance in this area.

While it is apparent that information on the lack of transmission through casual contact must be communicated more effectively (e.g., emphasis on all the data from the household transmission studies which find no evidence for transmission except through sexual contact or sharing needles), it is also apparent that opportunities must be provided or encouraged for people to express their feelings and concerns and to deal with the issues at an emotional level if meaningful changes are to occur.

With no effective medical intervention (vaccine or cure) in sight to stop the epidemic, our only means to prevent the further spread of the virus to children is through education and counseling to produce behavioral change. Especially critical targets of these efforts should be those at highest risk for having infected children, such as women of child-bearing age who use IV drugs or who have or in the past had partners who use IV drugs. Similarly, wives of hemophiliacs and sexually active women living in regions of high incidence of HIV infection are especially at risk. Mental health professionals can play a critical role in these prevention efforts through their involvement in clinics, drug prevention and rehabilitation programs, and health and educational programs that deal with large numbers of young women.

While voluntary HIV antibody testing may be an adjunct of these educational and counseling efforts, mandatory or routine testing may frighten people away from necessary services out of fear that their antibody status will become a part of their medical record. Fears of loss of insurance or employment are still real. In addition, the psychological stress of knowing that one's antibody status is positive can be debilitating, especially as estimates of the number of infected who will progress to AIDS rise. Therefore, the role of testing in any prevention program deserves careful consideration. Even strict procedures to assure confidentiality do not guarantee that there will be no unwanted disclosure sometime in the future.

In accordance with the Surgeon General's statements on AIDS, children themselves, especially adolescents who may become sexually active or begin to experiment with drugs in the near future, are important targets for educational efforts. The school system's leadership in each community will be critical in determining whether panic and hysteria are fueled or dampened. There are already a number of relevant curricula in the schools upon which an AIDS education program can be developed, including health education and sex education.

Recommendations

Based on these considerations, APA makes the following recommendations regarding education and prevention:

1. The federal government should sponsor a comprehensive nationwide information campaign on the facts about AIDS. Such a campaign must be culturally and linguistically appropriate for the various communities to which it is directed. This kind of program would include mailings, public service announcements on radio, TV, and at the movies, billboards, advertisements in newspapers and popular magazines, etc. Transmission and prevention as well as psychosocial issues such as discrimination and isolation could all be addressed in such a campaign.

2. Guidelines, consistent with the Surgeons General's recommendations for the incorporation of AIDS education into health curricula and sex education curricula in the schools, should be developed. These guidelines should direct efforts nationally to assure that effective AIDS education programs with high quality content are developed for use at the elementary, junior high and senior high school levels. Guidelines should address such issues as: content (e.g., information on modes of transmission and prevention); developmental appropriateness of the structure and content of the material to the child's age; cultural and linguistic appropriateness; the use of clear and specific language; attitudes and social and interpersonal skill development as well as factual information on AIDS, consideration of the parents' perspective; and adequate training of personnel who present the curriculum and/or have an important role in reaching young people in the school system, including health educators, science teachers, guidance counselors, school psychologists, etc.

3. Drug prevention and rehabilitation programs should be expanded to assure that services are available to drug users who are seeking to change their behavior. Such programs should not be allowed to exclude HIV infected individuals. Moreover, such programs should be actively involved in delivering information on HIV transmission and prevention. For women, in particular, there should be a focus on the risks of transmission to unborn children through pregnancy if one is infected, the need to know one's own HIV status before considering unprotected sexual intercourse that could lead to pregnancy, and the types of birth control methods that both prevent pregnancy and protect the woman from infection or further infection.

4. AIDS-related educational activities and materials should be developed for all programs, especially in high incidence areas, with which potentially pregnant women may have contact, including programs at ob/gyn, family planning, and STD clinics. All AIDS-related activities and information should be consistent with CDC guidelines on the prevention of perinatal transmission.

5. Mandatory or routine testing for HIV antibodies is never appropriate. Antibody testing should be an adjunct to education and counseling efforts focused on prevention, rather than the primary focus; and such testing must be voluntary, with strict procedures for assuring confidentiality and preferably anonymity. Education and counseling should be available to anyone in a high risk group considering a pregnancy. Education and counseling should inform the individual of his or her risks,

modes of HIV transmission and methods of prevention, especially birth control in relationship to unborn children, the meaning of antibody test results, and the risks, especially with respect to loss of insurance, etc., involved with the test. If an individual elects to take the test, post-test counseling must be provided to explain the meaning of the results, whether positive or negative, and to help the individual deal with the results, if the test is positive. The possibility for follow-up counseling should also be made available.

Behavioral Research Issues Associated with Pediatric AIDS/HIV Infection

The previously identified clinical intervention and education issues are pressing concerns now. Yet, it would be short-sighted to create direct service programs without also considering the need for support for behavioral research efforts to expand the knowledge base on which more informed decisions can be made about service delivery.

In conducting research on children with AIDS/HIV infection and their families, there are many legal and ethical issues of which the investigator needs to be aware. Because of the stigma associated with AIDS, through its frequent link to homosexual practices and drug use, as well its nearly always fatal outcome, concerns about confidentiality are especially critical. Disclosure of information about the diagnosis to third parties could seriously jeopardize a family's well being. Informed consent that alerts a family to the problems in assuring confidentiality should always be obtained. Input from communities and groups from which research participants may be drawn should be solicited to assure that their perspective is represented in developing informed consent procedures and in designing studies that are appropriate and sensitive to the special concerns of the subjects to be investigated.

There are a number of issues related to children and AIDS that should be addressed through psychological and behavioral research. The following list is not intended to be comprehensive but rather illustrative. Because AIDS is more than a medical problem, it will take the combined efforts of medical researchers and social scientists to combat the problems that it poses to our society at so many different levels. Some of the highest priority research topics requiring investigation include:

o Evaluations of the effectiveness of various counseling, educational, and testing efforts in the prevention of the spread of the virus to as yet unborn children. In particular, the psychological and behavioral effects (e.g., stress, anxiety, prevention behaviors) of knowledge of one's HIV antibody status, especially in women who are considering pregnancy, need to be assessed.

o Model comparisions of effective mental health/social service delivery systems.

o Application of models of attitudinal change, perception of social norms and behavioral change to AIDS prevention.

o The role of behavior (e.g., personality factors, lifestyle changes, including diet, exercise, risk behaviors) and stress in disease progression and their relationship to immune system functioning (psychoneuroimmunology).

o Neurological and developmental implications of HIV infection.

o Investigations of the basic mechanisms of understanding in order to develop appropriate educational AIDS interventions for children, based on sound developmental theory and research.

o Effects of the diagnosis on family dynamics, including parent-child interaction, and the social and emotional consequences of the disease on children, their families and communities.

o Legal and ethical issues raised by AIDS/HIV infection, including testing, confidentiality, right to know, duty to warn, and protocols for treatments and vaccines.

Recommendation

Because of the range of complex psychological and behavioral issues that the AIDS epidemic has triggered, and the special concerns that are raised when children are the focus of attention in the epidemic, the APA recommends that adequate funding be appropriated to support research efforts directed at the above noted and related topics. Specifically, we urge Congress to provide $550 million in FY 1988 for AIDS research with $35 million of this amount allocated to the National Institute of Mental Health (NIMH).