S. HRG. 100-645

SOCIAL SECURITY BENEFITS FOR AIDS VICTIMS

HEARING

BEFORE THE

SUBCOMMITTEE ON SOCIAL SECURITY AND FAMILY POLICY

OF THE

COMMITTEE ON FINANCE

UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

FIRST SESSION

SEPTEMBER 10, 1987

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THURSDAY, SEPTEMBER 10, 1987

U.S. SENATE,
SUBCOMMITTEE ON SOCIAL SECURITY AND FAMILY POLICY,
COMMITTEE ON FINANCE,
Washington, DC.

The hearing was convened, pursuant to notice, at 10:02 a.m. in Room SD-215, Dirksen Senate Office Building, the Honorable Daniel Patrick Moynihan (chairman of the subcommittee) presiding.

Present: Senators Moynihan and Durenberger.

[The press release announcing the hearing and the opening statement of Senator Moynihan follows:]

COMMITTEE ON FINANCE
United States Senate
205 Dirksen Building
Washington, D.C. 20510

PRESS RELEASE #H-59

FOR IMMEDIATE RELEASE
September 8, 1987

FINANCE SUBCOMMITTEE ON SOCIAL SECURITY AND FAMILY POLICY TO HOLD HEARING ON BENEFITS FOR AIDS VICTIMS

Washington, D.C. -- Senator Daniel Patrick Moynihan (D., New York), Chairman of the Senate Finance Subcommittee on Social Security and Family Policy, announced today the subcommittee will hold a hearing on benefits for AIDS victims.

The hearing is scheduled for Thursday, September 10, 1987 at 10:00 a.m. in Room SD-215 of the Dirksen Senate Office Building.

The purpose of this hearing is threefold: 1) to examine the issues concerning social security benefits for disabled AIDS victims, 2) the fiscal impact on public institutions treating AIDS patients, and 3) the special needs of children with AIDS.

Senator Moynihan said the Social Security Administration has already taken steps to expedite disability benefits under Title XVI for individuals unable to work because of AIDS. This policy, however, is temporary and due to expire in February 1988. The committee, according to Senator Moynihan, is interested in learning what plans the Social Security Administration has for this policy.

"Many children with AIDS have been abandoned and are difficult to place in foster care homes. Hospitals, for the most part public, are increasingly bearing the costs of sheltering these babies," Senator Moynihan said. This hearing will provide an opportunity for the Finance Committee to hear from social service and health agencies about the problems of placing children with AIDS in foster care homes, he said.

AIDS: A Federal Response

Statement by

Senator Daniel Patrick Moynihan

We are here today to address the problem of AIDS -- Acquired Immune Deficiency Syndrome -- the first such hearing in Finance Committee.

This is important to note. It signifies the commitment in the United States Senate to dealing with the impact of AIDS in all areas. This is no small task, and we have a great deal left to learn in order to arrive at a comprehensive Federal response.

In March and April 1983, I introduced the first three bills which recognized AIDS as a public health emergency (S. 898, S. 971 and S. 972). The Senate failed to act on all three. By June of that year, 1071 individuals had died of AIDS and the Senate still had not acted.

By August 1987, the Centers for Disease Control reported 40,845 cases of AIDS and 23,559 deaths from AIDS to date.

As the numbers increase, so do the costs. Not just financial, but in terms of human life. AIDS patients are dying at the peak of their productive years, or worse, in the case of children, they are dying before they ever reach their productive years. While it is imperative that we continue our efforts to stop the spread of AIDS and find a cure, we must also find the means to care for AIDS patients during their illness.

This is an area which has been sorely neglected by Congress over the past six years. Out of 84 measures introduced dealing with AIDS in the past three Congresses, there have been

essentially only two major measures dealing with Medicare and Medicaid, the two primary forms of government reimbursement for health care services.

The first measure, S. 2527, was introduced by Senator Cranston in the 99th Congress. Specifically, it enabled States to provide Medicaid coverage for community and home-based services to AIDS patients. I was an original cosponsor of this measure and it was enacted into law as part of the Omnibus Budget Reconciliation Act of 1986 (PL 99-509). However, only two States, New Mexico and New Jersey, have taken advantage of this waiver to date.

The second measure, S. 24, is a bill I introduced on the first day of the 100th Congress, which would waive the 24 month waiting period for Medicare for those individuals with AIDS receiving Social Security Disability Insurance. Congressman Ted Weiss introduced a similar measure in the House. The estimated cost of S. 24 is $230 million in FY 1988.

DISABILITY FOR INDIVIDUALS WITH AIDS

The Social Security Administration has already taken steps in this direction. Those individuals no longer able to work are eligible for Disability benefits under Social Security and those with little income and few assets are eligible for Supplemental Security Income and Medicaid.

Over 17,000 individuals with AIDS have received disability since this regulation went into effect and currently, 5560 individuals with AIDS are receiving disability -- most of the other 11,000 disability recipients have died since 1985. This

policy is due to expire in February, 1988. One thing I hope to learn today is what plans the Social Security Administration has for this policy.

MEDICARE FOR AIDS PATIENTS

Disability payments are indeed important. But one must be impoverished enough to be eligible for Supplemental Security Income to also be eligible for Medicaid. What of those individuals who have worked long enough to be eligible for Social Security Disability Insurance? For these individuals, who do not receive Medicaid, there is a 24 month waiting period to receive Medicare benefits. This waiting period was originally established in order to ensure that only those who were truly disabled, enough so that they have received benefits for a full two years, would be eligible for additional health care coverage.

The AIDS patient does not live 24 months. The average life expectancy of an AIDS patients, from the date of diagnosis, is between 11.2 and 13 months. There is at present no prospect that AIDS patients will overcome their disability. Hence, there is no reason to delay granting them Medicare coverage. Without this coverage, in many cases private or employer-based health insurance runs out, and high medical bills force the individual with AIDS to deplete all his assets and become completely dependent on public support. These individuals have worked and contributed to society, by removing the current waiting period for Medicare coverage, we are simply giving AIDS patients the

health care coverage they have earned and are in need of at once.

I have not yet heard the Administration's opinion of this proposal, and I hope I might hear those views today.

COSTS TO HOSPITALS FOR AIDS TREATMENT

The costs to hospitals, in addition to the AIDS patients themselves, of treating AIDS are also growing rapidly. Depending on the area of the country, treatment can cost between $45,000 and $75,000 per patient. According to NYC Public Health Commissioner Stephen C. Joseph, New York City will have spent at least $250 million on AIDS treatment, education and counseling in FY 87, $75 million of which is city funds. He estimates that the costs of AIDS will rise to $385 million in FY 88, costing New York City at least $100 million.

To put this figure in context, I might add that in 1986, the Federal government spent an estimated $100 million in Medicaid costs as a result of AIDS. (Medicare costs are currently very small due to the limited number of individuals who are eligible for it.) We have here a situation where one city will spend as much by itself on this disease as the Federal government spends for the entire nation.

This is a tremendous financial burden to ask local governments to bear. What can be done at the Federal government, and in this Committee, to alleviate this great financial burden?

CHILDREN WITH AIDS

I have mentioned children with AIDS -- herein lies a most distressing aspect of the AIDS crisis -- an ever growing trauma with which we will have to learn to live. Most often, children with AIDS are born to Intravenous drug users, or women infected through sexual contact with drug users. According to the CDC, 440 out of 563 reported cases to date have resulted from a mother infected with the AIDS virus. These children are born and often are abandoned to be cared for in hospitals. But at some point, these children no longer require hospital care and must be placed in foster care homes.

One of the provisions of S. 24 asks the Secretary of Health and Human Services to conduct a study of children with AIDS. What are the numbers of children abandoned in hospitals? What are the costs of caring for these children? What are the alternative types of care that are currently available?

We will not find all the answers today. Perhaps not even one. But with this hearing, we command the attention of the Finance Committee to the current and future impact of AIDS and our responsibilities in dealing with it.

Senator MOYNIHAN. Let me say welcome and good morning to our witnesses and our guests and to our ever-valiant corps of coworkers seated by us here, after a month away.

This is a meeting of the Subcommittee on Social Security and Family Policy of the Committee on Finance, which is responsible for the trust fund and for the maintenance of the Social Security system in general.

This is the first meeting of the Committee on Finance to involve itself with the question of AIDS, Acquired Immune Deficiency Syndrome, as we have come to know it. The first diagnosed case of AIDS was in 1981; and since then, the Centers for Disease Control have recorded some 45,000 cases. These are active cases, and as it has shown, this is a disease which takes no prisoners. No one has been known as yet to have contracted the disease in its active form and to live. The normal time span between onset of the disease and death is somewhere between 11 and 13 months.

That is one of the things that will concern us this morning. The population that is actively infected, although the disease's trigger mechanism is not understood—and that is something we are looking at—is much larger in the City of New York alone, where it is estimated that some 450,000 persons carry the HIV virus. That does not mean that they have AIDS, in the sense that we recognize the disease, nor that they will get it, but some portion will. I believe that I was the first Senator to introduce legislation in this area, a normal event as I represent New York State and New York City; as the disease first appeared there and was recognized there, the other epicenter being San Francisco.

In a series of measures in March and April of 1983, we asked for research monies to begin finding out what was happening. It was something new, extraordinary, and terrifying that appeared. It is a disease that is most always fatal, which had already made its way into a large portion of the population, about which nothing was known—no cure, no treatment in any way available.

And it is usually the character of this disease that it exposes its victims to other diseases, and hospital personnel have no choice but to treat people for the succession of diseases that come as the aftermath of the effect of the disease on the immune system that suppress them or destroy them all together.

In addition to the lives affected, there is the specific financial burden on medical institutions which are beginning to find they are in strait financial circumstances and have the prospect of ongoing costs in the future.

Then, finally, we begin to encounter the phenomenon of children born with AIDS, and the care for them which is an extended period of time.

My good friend and colleague, Congressman Rangel, is chairing a hearing himself at this hour but hopes to join us sometime this morning on this matter.

With respect to the financing of this disease, I should mention that the three bills I introduced in 1983—S. 898, which was cosponsored by my colleagues, Senator D'Amato, Senator Cranston, and Senator Wilson. S. 971 and S. 972 got nowhere. None of these bills got anywhere.

Finally, last year, we did get a basic measure in the area of insurance, which enabled States to use Medicaid coverage in community and home-based services for AIDS patients. We had to put it under the reconciliation legislation, and it can't be said to have had any large impact—only New Jersey and New Mexico have chosen to take that waiver. Still, it is the law.

Now, we have before us a more important, a more substantial measure, S. 24, which I introduced on the first day of the 100th Congress. It has as its very specific purpose the provision of Medicare benefits or insurance to persons who have contracted AIDS and are receiving disability payments.

I would mention that the number "24" is meant to denote the fact that you now have a 24-month waiting period before a person, having been declared eligible for disability benefits, can receive Medicare benefits. And in that period, anyone who has contracted AIDS will have died. So, the purpose of S. 24 very simply is to waive that 24-month waiting period so total bankruptcy is not necessary for persons who are insured.

Under the Social Security program, persons under ordinary circumstances, with another kind of disability would receive this coverage after 24 months.

In the meantime, we are also concerned that the Social Security Administration will continue its provision of disability benefits and Medicaid to patients who have been disabled by AIDS.

A policy that was put in place in February of 1985 has been doing this, and it expires this February. I expect to hear from the Social Security Administration that it will be renewed, as I am sure it will be.

It would be interesting to mention some numbers—and then I will get on to our witnesses—that some 17,000 individuals with AIDS have received disability benefits since the regulation went into effect. And you get some sense of the toll of this disease when I tell you that, of the 17,000, there are 5,560 who are currently receiving disability insurance. The remaining 11,000 have died.

We don't know what we have at hand here. This is an event in our history that could change our civilization in a profound way. I don't think I am personally particularly qualified to explain what those ways are, but they are surely clear enough in a general range. It is a great challenge to the medical sciences. It is an even greater challenge to our personal behaviors.

And the medical sciences will probably come forward sooner than the behavioral changes, but we don't know. We are on the verge of an enormously threatening problem, to which we have very few answers.

In the meantime, at the level of providing care and making care financially possible, with institutions and individuals, that is something we can do and, if we can, we ought.

And with those few observations, I would like to begin our hearing this morning, noting that at 11:00 there will be a brief recess for a cloture vote.

We have, first, two witnesses from the Social Security Administration and the Health Care Financing Administration. We have Mr. David A. Rust, Associate Commissioner, Office of Disability, Social Security Administration, Department of Health and Human Serv-

ices in Baltimore, Maryland, and Dr. William Roper, who is the Administrator of the Health Care Financing Administration. I wonder if Mr. Rust and Dr. Roper might come up and appear jointly before us.

I will say that I have a number of questions that we will present to you in writing after this hearing. We welcome you indeed. As I say, this is the first hearing ever on AIDS, and perhaps you would be willing to submit your testimony for the record and let us know in your own words what it is you want to tell us this morning.

As you know we are interested in two things. We are interested in anything you have to say, but we are specifically interested to know that the benefits policy will be continued after February, and then I would like to hear your views on our legislation, S. 24.

The witness list has Mr. Rust first and then Dr. Roper. So, why don't we proceed in that manner? Mr. Rust, good morning to you.

STATEMENT OF DAVID A. RUST, ASSOCIATE COMMISSIONER FOR DISABILITY, SOCIAL SECURITY ADMINISTRATION, DEPARTMENT OF HEALTH AND HUMAN SERVICES, BALTIMORE, MD

Mr. RUST. Thank you, Mr. Chairman. Good morning. I am pleased to be here today with you to discuss how the SSA evaluates claimants with Acquired Immune Deficiency Syndrome (AIDS). We do it under two basic programs: the Social Security Disability Insurance (SSDI) Program and the SupplementaI Security Income (SSI) Program; about half of SSI participants are disabled.

We share your concern about the needs of AIDS patients, and we think that we have a good record in responding to those needs. We are committed to providing prompt, efficient, and compassionate service.

The definition of disability in the Social Security Act applies to both the SSDI Program and the SSI Disability Program; and it is a very tough and precise definition. It states that: "Disability is the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for at least 12 months."

Most claimants with AIDS meet this definition. Medicare benefits are available after Social Security disability beneficiaries have received payments for 24 months. Medicaid benefits are generally available upon eligibility for SSI.

I will briefly describe, Mr. Chairman, how we evaluate a claim for disability benefits and what our policy is in AIDS claims. We follow a five-step sequential evaluation process in determining if the person meets the definition of disability, which is stated in the Social Security law.

Senator MOYNIHAN. Could I interrupt?

Mr. RUST. Certainly, sir.

Senator MOYNIHAN. You won't mind if we go about this in a rather informal way?

Mr. RUST. Not at all, Mr. Chairman.

Senator MOYNIHAN. The physical or mental impairment must be expected to result in death? Of course, we all die, but——

Mr. RUST. Or be long-lasting.

Senator MOYNIHAN. Or be long-lasting.

Mr. RUST. Right. Twelve months or more.

Senator MOYNIHAN. Yes.

Mr. RUST. In the five-step sequential evaluation, we don't need to go through all five steps in all cases. If a decision can be made at one of the earlier steps, we do not have to go through the subsequent steps. These are the steps.

First, is the claimant working and earning at above the substantial gainful activity level? If the answer is no, we proceed to step two; if the answer is yes, we deny the claimant's application at that point. Step two: Does the person have a severe impairment? If the answer is no, we deny the claim; and at that point, if the answer is yes, we proceed to step three. Does the impairment meet or equal the listing of impairments in our regulations? If the answer is yes, we grant benefits at step three. If it is no, we proceed to step four.

Step four is: Does the claimant have the capacity to do his or her past work? Again, if the answer is yes, we deny; if the answer is no, we can grant benefits at that point or go to step five. And then step five is: Does the claimant have the capacity to do other work based upon his or her age, education, work experience? So, we work these cases through a five-step sequential evaluation, about three-quarters of which, by the way, stop at step three. They have impairments which are disabling on a medical basis alone, and we don't go beyond step three.

AIDS was initially identified by the Centers for Disease Control (CDC) in the summer of 1981, and CDC published criteria for identifying AIDS cases at that time. By the summer of 1983, AIDS was becoming a major national health problem, and SSA recognized that a person who met the CDC criteria had such a severe impairment that he or she met the statutory definition of disability. Thus, we issued instructions to our adjudicators that a person with CDC-defined AIDS has an impairment that meets or equals the level of severity in the listing of impairments. As long as the person is not working, he or she should be found disabled on a medical basis alone. Those instructions went out in 1983.

If a person who alleges AIDS does not meet the CDC definition and thus cannot be automatically assumed to meet the Social Security definition of disability, Social Security will evaluate the claim through the full sequential evaluation process. However, if a person has a severe impairment which prevents him or her from working, disability benefits are awarded. This is often the case in the AIDS-related complex claims—the ARC claims—in which, as you are aware, the severity of the impairment can vary widely.

As of August 27—as you mentioned in your remarks, Mr. Chairman—we had received 17,785 claims for disability, and we had allowed over 94 percent of them. That is for AIDS and ARC together.

Senator MOYNIHAN. Might I stop there? This is an important number. Ninety-four percent of the applications have been approved?

Mr. RUST. Yes, for both AIDS and ARC.

Senator MOYNIHAN. What would be the proportion, generally speaking, overall for disability claims? It was down to about four percent——

Mr. RUST. No, for everybody, if you would aggregate it all together, it is in the neighborhood of 35 or 36 percent.

Senator MOYNIHAN. So, really it is cut in half?

Mr. RUST. Yes.

Senator MOYNIHAN. Yes. Thank you.

Mr. RUST. A claimant for supplemental security income disability benefits may receive up to three months payment before SSA makes a formal determination of their disability. SSI is a means-tested program, and applicants must meet income and resource standards to be eligible.

Presumptive payments are not considered overpayments if SSA later determines that the person is not disabled; they don't have to pay it back. A finding of presumptive disability can be made at the local Social Security office or at the State Disability Determination Service if the evidence, although not complete, indicates a high degree of probability that the claimant is disabled.

In 1985, SSA issued regulations authorizing our local offices to make a finding of presumptive disability in AIDS cases after a confirming contact was made with the physician or other treating source to ensure that the AIDS met the CDC definition and that the person had been determined to be unable to work. This policy has been very helpful in easing the financial plight of most AIDS claimants since about 72 percent—and Mr. Chairman, I think that is an important percentage—72 percent of the AIDS claimants are eligible for either SSI or are concurrent SSI and SSDI claimants.

EXPLANATION OF DERIVATION OF 72 PERCENT FIGURE USED IN DAVID RUST'S SEPTEMBER 10, 1987 STATEMENT ON AIDS BEFORE THE SUBCOMMITTEE ON SOCIAL SECURITY AND FAMILY POLICY, SENATE FINANCE COMMITTEE.

The September 10 statement, in discussing SSA's policy on presumptive SSI disability payments in AIDS cases, said that about 72 percent of claimants with AIDS are eligible for SSI and thus for presumptive disability benefits. This was a very rough estimate based on preliminary data through December 1986 that of all claimants ever awarded DI or SSI benefits based on AIDS or ARC, 72 percent at one time have received SSI benefits. Based on later data (through June 1987), we now estimate that roughly two-thirds of claimants ever awarded DI or SSI benefits based on AIDS or ARC have at one time received SSI benefits.

For DI and SSI beneficiaries receiving benefits as of June 1987, it is estimated that only slightly less than 45 percent of such beneficiaries were then receiving SSI benefits. This is less than two-thirds because some claimants initially awarded SSI benefits later became entitled to DI benefits and left the SSI rolls.

We are in the process of obtaining better estimates of beneficiaries entitled to benefits based on AIDS or ARC and will furnish additional information when available.

Senator MOYNIHAN. Could I ask you to help us interpret that? When you say "eligible for SSI," does that mean simply a very low income, or does that mean that as people outside the Social Security system, such that Medicare would normally be available? Help me interpret that.

Mr. RUST. The way I would interpret it is: Right now most of the people coming to us and alleging AIDS are young and have rather erratic working patterns. They may not have worked; they may be too young to or because they are intravenous drug users or other things. They may not have worked a sufficient number of quarters to be insured; or if they have worked enough quarters, they may

have worked at such low levels of income that their benefits are low. So, even if they get SSDI, they may be eligible for SSI also.

Senator MOYNIHAN. Right. Your 74 percent figure——

Mr. RUST. Seventy-two.

Senator MOYNIHAN. Seventy-two percent. It tells us that we have a rather special population here. These are young.

Mr. RUST. Yes, sir.

Senator MOYNIHAN. They are unemployed, or they are erratically employed. They are a group of people you don't expect to have many of. I had a lot to do with the family assistance program, which is a guaranteed income which is meant to be for children, for aid for the blind and the aged and the permanently and totally disabled; and we took care of everyone but the children. But those categories, as I am sure you will recall, sir, were aid to the blind, aid to the aged, and aid to the permanently and totally disabled.

Mr. RUST. Yes, sir.

Senator MOYNIHAN. You are not describing those groups here. You are describing another group of people.

Mr. RUST. They are mostly males, mostly young—in their twenties and thirties—mostly urban. They are concentrated geographically in several parts of the country, and they tend to have very spotty work records for the most part; or if they have worked, they have worked at low level jobs rather erratically and are not entitled to much of an SSDI benefit based on their earnings.

Senator MOYNIHAN. Right. It is an almost new population.

Mr. RUST. Yes. It is a much different profile than the rest of the disability eligible.

Senator MOYNIHAN. It is a much different profile than we had anticipated when we provided for the blind and the disabled and the aged.

Mr. RUST. Yes, sir.

Senator MOYNIHAN. Thank you.

Mr. RUST. If you look at the other people on our rolls for SSDI, for instance, they tend to be about 51 when they come on the rolls——

Senator MOYNIHAN. About 51? Yes.

Mr. RUST. Their average age is late 50s. You know, it is a whole different deal. They have a long attachment to the work force. This is a very different subset of the disabled population than what we are accustomed to seeing.

Senator MOYNIHAN. Fine. I may show up one of these days at one of your offices with galloping arthritis, but it doesn't happen until you get to be old and gray. [Laughter.]

Mr. RUST. If you meet our listings and you are not working, Senator, we will grant you benefits. [Laughter.]

Senator MOYNIHAN. I have been working for these programs now for a quarter century, and I am heading for them myself.

Mr. RUST. I might add, just as an aside, when you were working on these programs in the early 1970s, I was a Hill staffer up here working with some of them from this end. So, I remember your interest in this very much.

Senator MOYNIHAN. Yes.

Mr. RUST. The 72 percent is important also because they may be Medicaid eligible. If claimants are either solely Title 16 or concur-

rently eligible under both titles, they generally become Medicaid eligible immediately upon a determination of disability. So, I would say three out of four are covered by Medicaid as soon as SSA makes a disability determination in their cases.

I know you are interested in our outreach activities from your letter, Mr. Chairman. So, let me just briefly tell you that we have been aggressive in the SSA field office structure in conducting outreach activities for people with AIDS. Not surprisingly, the New York region is one of our most active in this area. The regional office is represented on the Mayor's Task Force on AIDS.

We have a special Teleclaims procedure for AIDS claimants. We have designated AIDS liaisons in all of our field offices in New York City and in other areas of the State where it is appropriate. We have negotiated an agreement with New York City that accepts the SSI presumptive disability findings as establishing Medicaid eligibility. The claimant does not have to apply further for medical benefits.

We have set up special arrangements with advocacy groups and other health and social agencies to assist them in taking claims from individuals with AIDS and ARC or in referring them to SSA for the processing of their cases. And we have conducted seminars with hospitals and medical groups and so forth to explain our evidentiary requirements so that they can provide the evidence we need to make a determination that speeds the process quite a bit.

In closing, Mr. Chairman, let me note that there have been some recent developments in terms of the CDC definition that have attracted some media attention earlier this year and I am sure you want me to address them.

As you know, the CDC has changed its definition of AIDS effective September 1, and the revised definition reflects medical advances since the virus was discovered in 1981 and additional tests for the virus and early detection have become available. Two new conditions previously defined as ARC—that is Human Immunodeficiency Virus (HIV) dementia and HIV wasting syndrome—are now included in the CDC definition of AIDS; and they lay out specifications as to how they are to be diagnosed and measured.

After carefully studying the new CDC definition, we revised our operating instructions to the State Disability Determination Services (DDS) to make it clear that Social Security or SSI claimants who are not working and who meet the criteria of the new CDC definition—have an impairment so severe that they should be determined to be disabled for Social Security Program purposes. The revised CDC criteria are also used as the basis for our district offices making presumptive disability determinations in SSI cases.

I would like to thank you for this opportunity to outline the processes we use to evaluate claimants with AIDS. Let me assure you that we will continue to provide our regional and field offices and the State DDS's with the latest information on adjudicating these claims. And I will be glad, Mr. Chairman, to answer any questions you may have to the best of my ability.

Senator MOYNIHAN. Commissioner, thank you very much indeed. I think the record here—and we will be happy to hear from other witnesses here if they think otherwise—is that of a Social Security Administration, under your supervision, that has responded very

emphatically and positively in a situation where about one-third of claimants for disability benefits are successful.

You have a medical protocol; a doctor can say yes to the diagnosis, and 94 percent attests to your performance.

Mr. RUST. And for people with fully developed AIDS, under the old definition, it is almost 100 percent.

Senator MOYNIHAN. Almost 100 percent?

Mr. RUST. Yes, and with ARC it is almost 70 percent.

Senator MOYNIHAN. And you do hope that some people come in with this disease and find they do not?

Mr. RUST. That is right; some do not.

Senator MOYNIHAN. And it would be normal for some people to misdiagnose themselves; and understandably, it is good news when you say no, you are not. This most recent extension of the definition that you mentioned will expire in February? Is that correct?

Mr. RUST. The regulation we issued in February of 1985 expires in February of 1988, and it is the authority for the district offices to apply the presumptive disability determination process to AIDS cases. We are working on a regulation right now that will extend that authority until December of 1989.

Senator MOYNIHAN. Is it a routine of the Social Security Administration to put out regulations and say this is for a three-year period, and then we will renew it? Is that the process--to see how it is working?

Mr. RUST. This is somewhat atypical. We review a lot of our regulations all the time. We have the body divided up into 13 body systems, and those constantly need to be updated and changed because of changes in diagnostic techniques, rehabilitation techniques, treatment techniques, and so forth. So, we are constantly revising our regulations. A number of them do have sunset provisions that force us to cycle back and look at them.

It was never our intention to allow this authority to lapse.

Senator MOYNIHAN. Right.

Mr. RUST. The belief was that, as we learn more about AIDS, we are handling it a little atypically right now because it is so new; and we are still grappling with treatment and diagnostic elements. So, that is one of the reasons we are doing it in these small sets because we hope to evolve in the not too distant future to more permanent regulations and medical listings and so forth. But during this transitional period, we are relying more heavily upon CDC than we would in other areas; and we are extending it so that we are sort of forced to keep constantly reevaluating, to keep current with new developments.

Senator MOYNIHAN. It appears to me that you are being responsible and orderly in a constantly changing environment, which we hope continues to change as we learn more.

Mr. RUST. We hope so, and we hope that progress is made in treatment and prevention.

Senator MOYNIHAN. You will let this committee know if there appear to be any developments that might interfere with the continuation of your present presumptive regulations?

Mr. RUST. Right. The replacement regulation is moving very nicely through the process now and should be out well before February.

Senator MOYNIHAN. Fine. And you will let us know when it comes out?

Mr. RUST. Yes, sir.

Senator MOYNIHAN. I appreciate that, and thank you very much. Stay right where you are while we hear from your colleague, Dr. Roper, who is the Administrator of the Health Care Financing Administration. Dr. Roper, I don't have to tell you that this particular affliction has caused great financial strains in hospitals and other care systems, in some concentrated parts of some cities. Why don't we go ahead with your testimony? And I hope you will let us know what you think of our legislation, S. 24.

[The prepared statement of Mr. Rust follows:]

DAVID A. RUST

ASSOCIATE COMMISSIONER FOR DISABILITY

SOCIAL SECURITY ADMINISTRATION

THURSDAY, SEPTEMBER 10, 1987

MR. CHAIRMAN AND MEMBERS OF THE SUBCOMMITTEE:

I AM PLEASED TO BE HERE TODAY TO DISCUSS THE EVALUATION OF CLAIMANTS WITH ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS) UNDER THE SOCIAL SECURITY AND SUPPLEMENTAL SECURITY INCOME (SSI) DISABILITY PROGRAMS. WE SHARE YOUR CONCERN ABOUT THE NEEDS OF AIDS PATIENTS AND THINK WE HAVE A GOOD RECORD IN RESPONDING TO THESE NEEDS. WE ARE COMMITTED TO PROVIDING PROMPT, EFFICIENT, AND COMPASSIONATE SERVICE.

EVALUATION OF AIDS CASES

THE DEFINITION OF DISABILITY FOR THE SOCIAL SECURITY AND THE SSI DISABILITY PROGRAMS IS AN INABILITY TO ENGAGE IN ANY SUBSTANTIAL GAINFUL ACTIVITY (SGA) BY REASON OF ANY MEDICALLY DETERMINABLE PHYSICAL OR MENTAL IMPAIRMENT WHICH CAN BE EXPECTED TO RESULT IN DEATH OR WHICH HAS LASTED OR CAN BE EXPECTED TO LAST FOR AT LEAST 12 MONTHS. MOST CLAIMANTS WITH AIDS MEET THIS DEFINITION. MEDICARE BENEFITS ARE AVAILABLE AFTER A SOCIAL

SECURITY DISABILITY BENEFICIARY HAS RECEIVED PAYMENTS FOR 24 MONTHS; MEDICAID BENEFITS ARE GENERALLY AVAILABLE UPON ELIGIBILITY FOR SSI PAYMENTS.

I WILL BRIEFLY DESCRIBE HOW WE EVALUATE A CLAIM FOR DISABILITY BENEFITS IN GENERAL AND WHAT OUR POLICY IS IN AIDS CLAIMS. WE FOLLOW A FIVE-STEP SEQUENTIAL EVALUATION PROCESS IN DETERMINING IF A PERSON MEETS THE DEFINITION OF DISABILITY IN THE SOCIAL SECURITY LAW. HOWEVER, IF A DECISION THAT A PERSON IS OR IS NOT DISABLED CAN BE MADE AT ANY STEP, EVALUATION UNDER SUBSEQUENT STEPS IS NOT NECESSARY. THESE STEPS ARE: (1) IS THE CLAIMANT WORKING AND EARNING OVER THE SGA LIMIT; (2) DOES THE PERSON HAVE A SEVERE IMPAIRMENT; (3) DOES THE IMPAIRMENT MEET OR EQUAL THE REQUIREMENTS OF THE LISTING OF IMPAIRMENTS IN THE REGULATIONS; (4) DOES THE CLAIMANT HAVE THE CAPACITY TO DO PAST WORK; AND (5) DOES THE CLAIMANT HAVE THE CAPACITY TO DO OTHER WORK BASED ON HIS OR HER AGE, EDUCATION, AND WORK EXPERIENCE.

AIDS WAS IDENTIFIED BY THE CENTERS FOR DISEASE CONTROL (CDC) IN THE SUMMER OF 1981, AND THE CDC PUBLISHED CRITERIA FOR IDENTIFYING AIDS CASES. BY THE SUMMER OF 1983, AIDS WAS BECOMING A NATIONAL HEALTH PROBLEM AND SSA RECOGNIZED THAT A PERSON WHO MET THE CDC CRITERIA FOR AIDS HAD SUCH A SEVERE IMPAIRMENT THAT HE OR SHE MET THE STATUTORY DEFINITION OF DISABILITY. THUS, WE ISSUED INSTRUCTIONS TO OUR ADJUDICATORS THAT A PERSON WITH CDC-DEFINED

AIDS HAS AN IMPAIRMENT THAT MEETS OR EQUALS THE LEVEL OF SEVERITY IN THE LISTING OF IMPAIRMENTS AND, AS LONG AS THE PERSON IS NOT WORKING, SHOULD BE FOUND DISABLED ON A MEDICAL BASIS ALONE.

IF A PERSON WHO ALLEGES AIDS DOES NOT MEET THE CDC DEFINITION AND THUS CANNOT BE AUTOMATICALLY ASSUMED TO MEET THE SOCIAL SECURITY DEFINITION OF DISABILITY, SSA HAS TO EVALUATE THE CLAIM THROUGH THE FULL SEQUENTIAL EVALUATION PROCESS. HOWEVER, IF THE PERSON HAS A SEVERE IMPAIRMENT WHICH PREVENTS HIM OR HER FROM DOING PAST WORK OR OTHER WORK, DISABILITY BENEFITS ARE AWARDED. THIS IS OFTEN TRUE IN AIDS-RELATED COMPLEX (ARC) CASES WHERE THE SEVERITY OF THE IMPAIRMENT CAN VARY WIDELY.

AS OF AUGUST 27, 1987, WE HAVE RECEIVED 17,785 CLAIMS FOR DISABILITY BENEFITS UNDER THE TWO PROGRAMS BASED ON AIDS OR ARC AND HAVE AWARDED BENEFITS IN OVER 94 PERCENT OF THE CLAIMS.

SSI PRESUMPTIVE DISABILITY IN AIDS CASES

A CLAIMANT FOR SSI DISABILITY BENEFITS MAY RECEIVE UP TO 3 MONTHS' PAYMENT BEFORE SSA MAKES A FORMAL DISABILITY DETERMINATION IF HE OR SHE IS PRESUMPTIVELY DISABLED AND OTHERWISE ELIGIBLE. PRESUMPTIVE PAYMENTS ARE NOT CONSIDERED OVERPAYMENTS IF SSA LATER DETERMINES THAT THE PERSON IS NOT DISABLED. A FINDING OF PRESUMPTIVE DISABILITY CAN BE MADE AT THE LOCAL SOCIAL SECURITY

OFFICE OR AT THE STATE DISABILITY DETERMINATION SERVICE (DDS) IF THE EVIDENCE, ALTHOUGH NOT COMPLETE, INDICATES A HIGH DEGREE OF PROBABILITY THAT THE CLAIMANT IS DISABLED. IN 1985, SSA ISSUED REGULATIONS TO AUTHORIZE OUR LOCAL OFFICES TO MAKE A FINDING OF PRESUMPTIVE DISABILITY IN AIDS CASES AFTER A CONFIRMING CONTACT IS MADE WITH A PHYSICIAN OR OTHER TREATING SOURCE THAT AIDS, AS DEFINED BY THE CDC, HAS BEEN DIAGNOSED AND THAT IT HAS PROGRESSED TO THE POINT THAT THE INDIVIDUAL IS UNABLE TO WORK. (STATE AGENCIES WERE REMINDED AS EARLY AS 1983 TO USE THEIR EXISTING AUTHORITY TO CONSIDER AIDS CASES FOR PRESUMPTIVE DISABILITY.) THIS POLICY HAS BEEN VERY HELPFUL IN EASING THE FINANCIAL PLIGHT OF MOST AIDS CLAIMANTS SINCE ABOUT 72 PERCENT OF CLAIMANTS WITH AIDS ARE ELIGIBLE FOR SSI AND THUS FOR PRESUMPTIVE SSI DISABILITY BENEFITS. THE PERSON MAY THEN BE IMMEDIATELY ELIGIBLE FOR MEDICAID BENEFITS.

SSA OUTREACH ACTIVITIES

SSA REGIONAL AND FIELD OFFICES CONDUCT OUTREACH ACTIVITIES FOR PEOPLE WITH AIDS. NOT SURPRISINGLY, OUR NEW YORK REGION IS VERY ACTIVE. THE NEW YORK REGIONAL OFFICE:

- IS REPRESENTED ON THE NEW YORK CITY MAYOR'S TASK FORCE ON AIDS;
- HAS A TELECLAIMS PROCEDURE FOR AIDS CLAIMANTS;

- HAS DESIGNATED AIDS LIAISONS IN ALL FIELD OFFICES IN NEW YORK CITY AND OTHER FIELD OFFICES, AS NECESSARY;
- NEGOTIATED AN AGREEMENT UNDER WHICH NEW YORK CITY WILL ACCEPT AN SSI "PRESUMPTIVE DISABILITY" FINDING AS ESTABLISHING MEDICAID ELIGIBILITY WITHOUT ANY ADDITIONAL APPLICATION;
- SET UP SPECIAL ARRANGEMENTS WITH ADVOCACY GROUPS AND OTHER HEALTH AND SOCIAL AGENCIES TO ASSIST THEM IN TAKING CLAIMS FROM INDIVIDUALS WITH AIDS OR ARC, OR IN REFERRING THESE CLAIMANTS TO SSA: AND
- CONDUCTS SEMINARS WITH MEDICAL GROUPS AND HOSPITAL STAFFS TO EXPLAIN OUR EVIDENTIARY REQUIREMENTS IN ORDER TO SPEED DISABILITY DETERMINATIONS.

RECENT DEVELOPMENTS

THE CDC CHANGED ITS DEFINITION OF AIDS EFFECTIVE SEPTEMBER 1, 1987. THE REVISED DEFINITION REFLECTS MEDICAL ADVANCES MADE SINCE THE VIRUS CAUSING AIDS WAS IDENTIFIED, AND THE TEST FOR IT WAS MADE AVAILABLE. TWO NEW CONDITIONS PREVIOUSLY CONSIDERED TO BE ARC-- "HUMAN IMMUNODEFICIENCY VIRUS (HIV) DEMENTIA" (ENCEPHALOPATHY) AND "HIV WASTING SYNDROME"--ARE INCLUDED IN WHAT CDC NOW CONSIDERS AIDS, PROVIDED THAT THEY ARE DIAGNOSED UNDER METHODS SPECIFIED BY CDC.

AFTER CAREFULLY STUDYING THE NEW CDC DEFINITION, WE REVISED OUR OPERATING INSTRUCTIONS TO THE DDSS TO MAKE IT CLEAR THAT SOCIAL SECURITY OR SSI CLAIMANTS WHO ARE NOT WORKING AND MEET THE CRITERIA OF THE NEW CDC DEFINITION HAVE AN IMPAIRMENT SO SEVERE THAT THEY SHOULD BE DETERMINED TO BE DISABLED FOR SOCIAL SECURITY PROGRAM PURPOSES WITHOUT PROCEEDING THROUGH THE FULL SEQUENTIAL EVALUATION PROCESS. THE REVISED CDC CRITERIA ARE ALSO USED AS THE BASIS FOR OUR DISTRICT OFFICE PRESUMPTIVE DISABILITY DETERMINATIONS IN SSI CASES.

CONCLUSION

THANK YOU FOR THE OPPORTUNITY TO OUTLINE HOW WE EVALUATE CLAIMANTS WITH AIDS. LET ME ASSURE YOU WE WILL CONTINUE TO PROVIDE OUR REGIONAL AND FIELD OFFICES AND THE STATE DDSS WITH THE LATEST INFORMATION FOR ADJUDICATING CLAIMS OF PERSONS WITH AIDS.

MR. CHAIRMAN, I WOULD BE GLAD TO ANSWER ANY QUESTIONS YOU OR THE COMMITTEE MEMBERS MAY HAVE.

STATEMENT OF DR. WILLIAM L. ROPER, ADMINISTRATOR, HEALTH CARE FINANCING ADMINISTRATION, DEPARTMENT OF HEALTH AND HUMAN SERVICES, WASHINGTON, DC

Dr. ROPER. I will be glad to do that, Senator. I appreciate the opportunity to be here today to talk about Medicare and Medicaid as they relate to the AIDS problem. I had the chance yesterday to be one of the opening speakers before the President's Commission on the HIV Epidemic, and quite a lot was said by Secretary Bowen and me and the others about the monumental proportions of the AIDS epidemic. It is truly an enormous national problem, and part of that problem is how to pay for the care of persons with AIDS.

As you pointed out in your statement, New York has a particular concentration of people with AIDS. A couple of weeks ago, I went to New York City and met there at our regional office in Manhattan with officials from the State of New York, including Dr. Lloyd Novick, and then toured several facilities—Harlem Hospital, the Spellman Center at St. Clare's Hospital, and the Gay Men's Health Crisis Center.

Senator MOYNIHAN. That is my old neighborhood—St. Clare.

Dr. ROPER. I spent quite a while going through there, seeing what the public and private sectors are doing together in New York to meet the problem, and I think people there are really working diligently to deal with the issue.

We are a national program and are interested in those developments, as well as what is happening across the country.

As you pointed out, people who qualify for disability income or Social Security may also be eligible for Medicare after having received those benefits for 24 months. That waiting period is an important part of the program, and it is what is largely responsible for the fact that only a very small number of individuals with AIDS—about one percent of them—receive benefits under the Medicare Program.

AZT is the new drug that people are now being treated with, and it offers some real hope for prolonging life, though not curing AIDS. With AZT and other similar drugs coming on-line, we expect that more and more people will become eligible for Medicare and that expenditures under the program, which are under $50 million a year now for people with AIDS, will grow substantially in the future.

AIDS patients who qualify for disability under SSI—Supplemental Security Income—are automatically eligible for Medicaid, as Mr. Rust just pointed out. I won't go over with you, as he did, how to get on SSI; but immediately on entry into that program, one is eligible for Medicaid.

Senator MOYNIHAN. Could I, Doctor, just for the record make this distinction?

Dr. ROPER. Surely.

Senator MOYNIHAN. SSI is an amalgam of a series of programs that began in the 1930s for persons who are not insured and who are basically indigent. SSI corresponds with Medicaid, which is the same, inasmuch as Medicare would take care of people who were not.

Mr. Chairman, a very good morning.

Congressman RANGEL. I was hoping to get your attention.

Senator MOYNIHAN. Dr. Roper and Mr. Rust, would you have the kindness to step back for just a moment while we hear from our distinguished friend and colleague and neighbor?

Dr. ROPER. Surely.

Senator MOYNIHAN. It is a very great honor for our committee on the first hearing that the Committee on Finance has ever held and in the Subcommittee on Social Security and Family Policy on the subject of Acquired Immune Deficiency Syndrome, or AIDS, to have the very distinguished chairman of our counterpart in the House of Representatives, who has distinguished himself as someone who not only speaks to these needs but who understands this issue and has, in the most gripping personal encounters with that reality, dealt with it. Mr. Chairman, we welcome you, sir, and ask you to proceed exactly as you wish.

We particularly want to thank you for your appearance here. It does indeed establish the fact that this committee is at last engaged in this issue.

STATEMENT OF THE HON. CHARLES B. RANGEL, A U.S. CONGRESSMAN FROM THE STATE OF NEW YORK

Congressman RANGEL. Thank you, Mr. Chairman, and I would like your permission to have my entire statement made a part of the record.

Senator MOYNIHAN. Without objection.

Congressman RANGEL. Thank you very much, and let me thank the good doctors for the courtesies extended. As my staff has told you, we are holding hearings now.

Senator MOYNIHAN. You are holding your own hearings?

Congressman RANGEL. Right, on the effect of drugs in the sport industry; but I really welcome this opportunity to share my views with you and to thank you for your constant leadership in this area because your stature in the Congress and the nation and indeed in the world causes people to look and to hear what you have to say. And that brings this very serious problem to their attention.

Unlike our mayor, I don't believe that our U.S. Attorney in my area represents any serious threat to your tenure, but I would want the record to indicate that, when you have the person who does the job the best, if it ain't broke, I don't think we should bother trying to fix it. And I am certain that the mayor was misquoted, but I will share my views with him when I get back home.

This problem is addressed in your bill, and what struck me is the fact that you mention I.V. drug use in connection with AIDS. I have had an opportunity to talk with the recently appointed Commission—the Presidential Commission—and it is abundantly clear that they have not focused on this, but they did express a willingness to look into it.

Surprisingly, they raised budgetary problems, and I tried to share my view that their job is not to balance the budget; they are just to raise the problems, and it is up to the Executive and the Legislative Branches to see what we have to do about it.

But I am so frightened, not only about the AIDS epidemic, which I think has focused America's attention on how the germ is communicated, but the fact that when you deal with homosexuality, it seems as though we are being pretty effective in getting that message out to the people, and they have done whatever they do to change their habits and to protect themselves.

But when you are dealing with drug users, that has to be considered the most rejected type of people that I have ever met in my life—a lot of them are without homes, without jobs—and the most tragic thing and the thing that my community misses more as a poor community—without hope. That is, there is nothing you can tell people to do—like they used to tell us to do—and if you do that, then the possibilities are very good that you can get a job and make a contribution. It is the gap that is growing between the poor and those that have been rather successful. It leaves a pool of people that we are going to have to deal with in this generation and the generations that follow.

When you tell them that abusing their bodies with heroin is going to have an adverse effect on their lives and future, they don't listen because there is no life and there is no future. But where it really struck me, Senator, is that when I was making a routine political inspection of Harlem Hospital and one of the doctors in pediatrics said that they wanted me to take a look at the children that were there, well, it wasn't an election year and I had enough pictures with children, so I didn't think there was any need for me to see infants; but they belabored the point, and I went there.

And I saw kids that were almost a year old in the pediatrics care unit. I asked why are these children here? I mean, why haven't they been picked up? They said, Congressman, we have a tragic story in our community and in communities like it around the world; and that is that when it is determined by the Department of Social Services that the mother of the child is unfit or where the child has just been abandoned, we have a process in the great City of New York where the Social Services Society comes in and arranges for foster care.

And fortunately, we have had in the past enough people that would be willing to share some love for some minor reimbursement to bring the children into their care. It is not a good system, but it is the best system that we have locked in place.

Now, these foster care parents have heard somewhere that if the parent were addicted to drugs, that this communicates AIDS; and they have other foster care children and natural children, and they are just saying—in uncomplicated terms—that I don't know what drugs and I don't know how AIDS is communicated; all I know is that I am a poor woman and I don't want to take risks with the health of our children.

And as you know, and as many sophisticated people know, having the virus doesn't mean that you have the disease; but you try explaining that to a mother. And certainly, you can see trying to explain it to some parents when the kids enter school. I thank God for Mother Hale because she has a reputation, even recognized by the President of the United States, of having a loving heart for children. She has done it for 50 to 60 years. And she has opened up the doors of her center to some of these children.

And more important than the health and safety of the children is shattering the myth that every mother who has been addicted to marijuana or cocaine can affect the child as relates to AIDS. It is so sad because I saw doctors and nurses and staffers picking up these kids, cuddling them and attempting to give as much love as their time would permit.

I was embarrassed to find out that what I thought was just some psychiatric theory that a child, in order to mature emotionally and mentally, has to be picked up and cuddled; and to see these children being born, Black and poor and unwanted and unloved, some with the virus, some without the virus, that even foster care parents didn't want to be bothered with, I said: If you don't have enough compassion individually to be moved, don't we have some type of obligation as to what legacy we are leaving for the next generation?

So, when I started looking at the I.V. drug problem—and you know what our companion committees have to deal with in Finance and Ways and Means—I just didn't need any more problems to bring to my legislative desk. But I don't see, Senator, how we can run away from it.

As soon as we tackle this—I know no one wants to talk about what goes on in our prisons. I know, as a Catholic, that I have to support my Cardinal when he says that he doesn't want condoms distributed in our prison system because it is an inference that we are morally supporting the homosexuality and the rapes and the sodomy that takes place in our prisons. But my problem, Mr. Chairman, is that you just can't be offended by people talking about condoms, when we have paid chaplains in these prisons who are not talking about the conditions where we warehouse people—which I guess is all right politically if you never saw them again—but people, who are being kicked out of the prisons, either because they have served their time or it is overcrowded, to make room for other people, leave that prison with no training, no incentives, no skills, but many with the AIDS virus. And they go out into the general community, maybe without a job, but they don't have any problem getting around their sexual preferences.

So, what you have done is allowed your national stature to be associated with a problem that most people wish we didn't have and would just go away; but we know it is not going to go away. I came over here not to campaign for you, but to laud your efforts in this field, even when it had not been reduced to legislation, and to let you know that I will be supporting your companion bill in the House. I wish this problem would go away; but unfortunately, it is not a local and State problem, as some people in the Administration would have us believe. And we are going to need a lot of help from the Administration in getting people to realize that you cannot find a solution to the problem unless first you are willing to admit that we have a problem. Thank you so much, Senator.

Senator MOYNIHAN. Mr. Chairman and colleague, that was moving testimony, the most I have ever heard in this aseptic committee where we talk about money, but we never talk about the babies. I have been in those wards, and it is just wrenching. You are absolutely right. I mean, children need to hear that heartbeat; I think doctors have learned that children need to hear the heart-

beat of the mother. They have wonderful women who just go down the rows of cribs and pick up and hold the babies for five minutes and put them down and just pick up and hold the next baby for five minutes.

The young doctors will come in and do it. The nurses will do it; but some people are afraid of those children. And you can see it in the hospital staff, in all fairness, that as you go down the education ladder, the fear increases. I mean, doctors and nurses know you can handle these children, even the ones that actively have AIDS. The others may not be as well informed.

You know, I have seen the children with AIDS in those neonatal boxes, and they stack them up and they put plastic over them as if maybe that will make it go away; and it is wrenching. The point you are making is that here we have the locus of the spread of this disease that takes no prisoners—into the heterosexual community. And if it leaps that barrier, as it has done—is that not right, sir?—It has done that.

Congressman RANGEL. No question about it.

Senator MOYNIHAN. Where is the next generation? I mean, we are talking about a life-threatening situation in terms of a civilization, not just one part of it.

Mr. Rust was testifying before you came in about the AIDS claimants that come to the Social Security Administration; 72 percent are eligible for supplemental Social Security insurance, which is to say they are destitute. And I asked him if that was a striking number, and we agreed that, yes, indeed, it is; and it is a wholly different population. These are young males, unemployed, vaguely employed; and they have not acquired any claims on Social insurance as is known you get through disability benefits by working regularly.

There is a new population, thoroughly destructive to itself, devastatingly destructive of others; and we don't know how to talk about it yet, do we?

Congressman RANGEL. It is tragic. I could not share publicly with you what The Netherlands are doing in Amsterdam because they have a different culture, and their communication system is far more graphic than is acceptable by our standards.

Senator MOYNIHAN. Have you been over there?

Congressman RANGEL. Yes. For those who believe that you can legalize anything and it is going to work out, it is not working out at all. But the protections that have to be given to the prostitutes, to the drug addicts that are there, it is hard to communicate with those people because they have made a determination by going to Amsterdam that they are checking out of this fast, fast world. So, we can't write little red books, you know, in the Department of Education and distribute it to people who can't read and who don't want to read.

In a recent Yale report that was cited in the New York Times recently, it indicated that while some message on drug abuse is being reached in the middle-class community, when you get involved with the minority unemployed group by generations, not only do they not see any worse-off harm coming to them where drugs are concerned, but that AIDS is just something that is going

to come with death. And why not have sex if you have a limited life? This whole bizarre type of thinking is frightening.

Now comes the question: Who is going to go communicate with that person? I mean, it is not going to be the entertainers on television. It is certainly not going to be speeches that you and I will be giving. They are out of it, and yet they are the time bombs that are rolling around communities like this around the country and indeed around the world.

Except in Amsterdam, they have sent people into the streets that talk the language. When I looked at the pamphlets and what they were describing these various condoms were to be used for, I asked the Chief of Health about it. He said: Listen, if you are dealing with Spanish, you have to talk Spanish. You know, we are dealing with whores; so, you have to talk so they understand. We are not giving a thesis, you know, what you would like to hear or would like to take back to the United States. We have their people out there working with them, talking their language because we are afraid.

Senator MOYNIHAN. And if you don't get yourself understood, somebody dies.

Senator Durenberger has arrived. I wish you had not had to be away so you did not hear the horrendous stories of drug addiction and children born of drug users and left in hospitals because people will not understand that, even though you may have a virus, you may not have the symptoms of AIDS. We have 450,000 people in our city with the virus, but the distinction is lost and the children are abandoned before they scarcely open their eyes on earth. You share the responsibilities on this committee, and I am sure you have some comments.

Senator DURENBERGER. Mr. Chairman, briefly, I express my regrets. Had I known Charlie was on, I am sure I would have been here earlier. I was at a hearing on ducks in Canada and the environment, I guess, by comparison, these are nearly as important as what Congressman Rangel has to deal with. These are kinds of problems that politicians cannot solve very well and, that they struggle to articulate. I think maybe this morning I had my priorities in the wrong place. Mr. Chairman, I thank the two of you who are in the forefront of the education of the rest of us—Congressman Rangel in the House and you in the Senate—for continuing to challenge us to exert some kind of a sense of responsibility. These are difficult problems. None of us has an easy answer.

Just appropriating money to solve these problems doesn't do it. What I heard Charlie talking about here are similar experiences that I have had myself, and I have seen the difficult position that the Surgeon General has been put in by the so-called Right Wing in America, an almost impossible position.

And I have heard Dr. Koop say from the bottom of his heart and his professional soul that America has a whole lot of ministers and priests and chaplains and things like that, but it has only one Surgeon General at a time. Sometimes that person has to do some very difficult things in the face of a totally new, different, and in some cases, insurmountable challenge.

The subject you are addressing here today in exploring this problem helps us to open this matter, and I hope we keep doing it as

part of our regular responsibilities. I hope Charlie keeps coming back to this side to remind us just how important that is.

Senator MOYNIHAN. I think we should take this opportunity to speak about the Surgeon General. I wonder if you would like to make some general comments?

Congressman RANGEL. I laud the Surgeon General's courage not only because of the pressures that are put on him outside of The White House, but the fact that he has been an influencing and educational factor from within. I don't normally use words that you can't throw money at the problems and expect that they would go away; but I felt quite proud of the Omnibus Drug Bill that passed last year.

Senator MOYNIHAN. Right—that you passed last year.

Congressman RANGEL. And yet, I am really concerned that with the money and the lack of leadership and the lack of accountability, I am really not certain that we have the chemistry to make this darned thing work. When the Attorney General says that law enforcement is a local and State problem, when the Secretary of Education indicates that he sees drug prevention and education as a local and State problem, and then you have to say that a Surgeon General is courageous, I say, because he is telling people how to avoid dying. Then, I wonder why should it be that there are a half a dozen of us who have to go around saying I have seen it, not only in our country but abroad. It can happen here; it can happen in your family. Everyone now knows somebody who has died with AIDS; and yet, we haven't shattered that barrier, feeling comfortable in discussing the subject matter.

Senator MOYNIHAN. And the Surgeon General has been exemplary, and I think that this committee ought to so state.

Congressman RANGEL. He has gone to every community. He has not concerned himself with the size of the audience. He has gone directly to the core of the problem. He has indicated that we have to do more.

Senator MOYNIHAN. He is a pediatric surgeon.

Congressman RANGEL. He was at Harlem Hospital. Because of legislation, we had to cancel a hearing; and he said just let him know when the next hearing was and he was there. So, he really is an international leader in this field.

And as little as we are doing, with my conversations with specialists around the world, we are doing more than they. So, we just have to concentrate more.

Senator MOYNIHAN. I have one point, and I would ask you if you agree. It is something you have been telling us; it is something the American people are going to have to hear and get it very clear, that this is a heterosexual disease as much as it is a homosexual disease. It may turn out to be more a heterosexual disease. It is not something to be put away in a closet of your mind and say it happens to other people. Children are being born with this disease. What more do you need to know?

I don't think the doctors have any sense of where it is going to stop, do you?

Congressman RANGEL. No. And clearly, the Centers for Disease Control said that money is not going to expedite finding a solution

to it; but I guess the one thing that we can do is try to get the information out there to educate people to change their behavior.

Senator MOYNIHAN. Yes, because apart from children born with it, if you will moderate your behavior, you can protect yourself against this disease.

Congressman RANGEL. I am getting beyond my line of legislative responsibility, but what could be more in the spiritual leaders' camp than that? In other words, they can decide whether they are blessing the arms in Nicaragua, or they can get involved in collecting money on television. And I have always said let them do what they have to do, as long as they don't violate the law.

But it would seem to me that, when you talk about a defenseless kid being born and being destined to die before the year is out, that clearly rather than just talking about the extent of sex education in the schools or the distribution of condoms in the prisons, that someone has to say that not only is this wrong spiritually, but assist us in getting the word out that talking about it won't allow your soul to burn eternally in hell, that if you are going to want to live that you are going to have to act in a certain way. And the way they should be advocating is really consistent with most of their training. I just don't see the outrage, Mr. Chairman, from our spiritual leaders about this life-threatening disease which really violates all of the things that we like to believe that God wants us to have in this limited time we have on earth.

Senator MOYNIHAN. The Sisters taught you well, Charlie Rangel. Thank you very much, sir.

Congressman RANGEL. Thank you, Mr. Chairman.

Senator MOYNIHAN. I would like to put the committee in recess for just a moment, and I thank our distinguished witnesses.

[Whereupon, at 11:05 a.m., the hearing was recessed.]

AFTER RECESS

Senator MOYNIHAN. The committee will resume, and could I ask Dr. Roper and Mr. Rust to return to the witness table?

I would say to my colleague, Senator Durenberger, Dr. Roper was going through his own testimony on S. 24 and related matters. So, Dr. Roper, would you just resume, sir?

[The prepared statement of Congressman Rangel follows:]

CHARLES B. RANGEL

ON

ACQUIRED IMMUNE DEFICIENCY SYNDROME

GOOD MORNING MR. CHAIRMAN AND MEMBERS OF THE SUBCOMMITTEE ON SOCIAL SECURITY AND FAMILY POLICY. I AM PLEASED TO HAVE THIS OPPORTUNITY TO COME BEFORE YOU CONCERNING PERHAPS THE MOST SERIOUS NATIONAL HEALTH THREAT EVER CONFRONTED BY THIS COUNTRY -- ACQUIRED IMMUNE DEFICIENCY SYNDROME -- AIDS.

EACH WEEK THE CENTERS FOR DISEASE CONTROL (CDC) RELEASE AIDS STATISTICS THAT INDICATE THE GROWING PROBLEM. TO DATE, MORE THAN 40,000 CASES HAVE BEEN REPORTED TO THE CDC SINCE 1981. WITH THE RECENT CHANGE IN THE CDC CASE DEFINITIONS, IT APPEARS THAT THE NUMBER OF AIDS CASES IS CLOSER TO 50,000. TRAGICALLY, MOST OF THESE INDIVIDUALS FACE DEATH IMMINENTLY.

ALTHOUGH THE THREAT OF AIDS IS CLEAR TO MOST AMERICANS, MANY MAY NOT BE AWARE OF THE RELATIONSHIP BETWEEN AIDS AND INTRAVENOUS (IV) DRUG ABUSE. IV DRUG USE IS ASSOCIATED WITH 24 PERCENT OF AIDS CASES. OR, IV DRUG USE IS THE SECOND MOST FREQUENT MEANS OF TRANSMITTING THE HUMAN IMMUNODEFICIENCY VIRUS (HIV) WHICH CAUSES AIDS.

IT IS BECAUSE OF THE ASSOCIATION BETWEEN AIDS AND INTRAVENOUS DRUG USE THAT AIDS HAS BECOME A MAJOR CONCERN OF THE HOUSE SELECT COMMITTEE ON NARCOTICS ABUSE AND CONTROL, WHICH I CHAIR. IN THE COURSE OF EXAMINING THE PROBLEM OF AIDS AND IV DRUG USE, THE COMMITTEE HAS FOUND THE RAMIFICATIONS OF THIS RELATIONSHIP TO BE VERY FRIGHTENING.

AIDS IS TRANSMITTED AMONG INTRAVENOUS SUBSTANCE ABUSERS THROUGH THE USE AND SHARING OF NEEDLES, SYRINGES, SWABS, OR OTHER DRUG-RELATED IMPLEMENTS, CONTAMINATED WITH HIV INFECTED BLOOD. ONCE THE VIRUS HAS ENTERED THE COMMUNITY, IT SPREADS RAPIDLY. BUT, THESE INDIVIDUALS ARE ONLY THE FIRST OF THE VICTIMS OF THE LINK BETWEEN AIDS AND INTRAVENOUS DRUG USE.

INTRAVENOUS DRUG ABUSE IS ASSOCIATED WITH MOST CASES OF AIDS AMONG WOMEN AND CHILDREN. AMONG WOMEN WITH AIDS, MORE THAN 50 PERCENT ARE INTRAVENOUS DRUG USERS. THE SECOND LARGEST GROUP OF WOMEN AT RISK FOR CONTRACTING AIDS ARE WOMEN WHO ARE THE SEXUAL PARTNERS OF INTRAVENOUS SUBSTANCE ABUSERS.

ACCORDING TO CDC, THERE ARE CURRENTLY MORE THAN 500 PEDIATRIC AIDS CASES. MOST INFANTS WITH AIDS CONTRACT THE DISEASE THROUGH THEIR MOTHER DURING PREGNANCY OR BIRTH. THE OVERWHELMING MAJORITY OF PERINATALLY ACQUIRED AIDS CASES ARE CHILDREN OF INTRAVENOUS DRUG USERS. THESE TINY VICTIMS OF AIDS ARE, THEREFORE, ALSO VICTIMS OF THE DRUG EPIDEMIC.

ALMOST 90 PERCENT OF THESE BABIES ARE BLACK OR HISPANIC. THIS FACT UNDERSCORES ANOTHER DIMENSION OF THE AIDS PROBLEM -- THE OVERREPRESENTATION OF MINORITIES AMONG AIDS CASES.

THE 500 CHILDREN WITH AIDS REPORTED BY THE CDC ARE, HOWEVER, NOT THE ONLY CHILDREN AFFECTED BY THIS DISEASE. 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. ALL OF THESE CHILDREN WILL NEED MEDICAL AND SOCIAL SERVICES.

I HAVE SEEN THE TRAGEDY OF BABIES WITH AIDS FIRST HAND. HARLEM HOSPITAL, WHICH IS IN MY CONGRESSIONAL DISTRICT, HAS CARED FOR MORE THAN SIXTY OF THESE CHILDREN. AT ANY ONE TIME

THERE ARE 10 TO 12 OF THESE CHILDREN IN THEIR CARE. SEVERAL MONTHS AGO I HAD THE OPPORTUNITY TO VISIT THE PEDIATRICS UNIT AND SEE THE BABIES. I HAD VERY MIXED EMOTIONS -- SADNESS AND ANGER, BUT I WAS ALSO MOVED BY THE COURAGE OF THE STAFF AND THE CHILDREN.

BECAUSE OF THIS EXPERIENCE, I ARRANGED FOR THE SELECT COMMITTEE ON NARCOTICS ABUSE AND CONTROL TO HOLD A HEARING AT HARLEM HOSPITAL ON PEDIATRIC AIDS. SURGEON GENERAL C. EVERETT KOOP; MAYOR ED KOCH; AND DR. MARGARET HEAGARTY, CHIEF OF PEDIATRICS OF HARLEM HOSPITAL TESTIFIED. WE ALSO INVITED A PANEL OF LOCAL WITNESSES TO TELL THE COMMITTEE HOW THIS DREAD DISEASE WAS IMPACTING THE COMMUNITY. AT THIS TIME, I WOULD LIKE TO THANK THE CHAIRMAN FOR SUBMITTING TESTIMONY FOR THE RECORD OF THAT HEARING.

THE SELECT COMMITTEE'S PEDIATRIC AIDS HEARING REVEALED TWO PROBLEMS THAT ARE THE SUBJECT OF LEGISLATION (S 24) INTRODUCED BY YOU, CHAIRMAN MOYNIHAN. THE PROBLEMS I AM REFERRING TO ARE THE NEED FOR IMMEDIATE FINANCIAL ASSISTANCE FOR THE MEDICAL CARE OF AIDS PATIENTS AND THE FOSTER CARE NEEDS OF CHILDREN WITH AIDS WHO ARE ABANDONED BY THEIR PARENTS AND LIVING IN HOSPITALS.

WHILE AIDS PATIENTS MAY QUALIFY FOR DISABILITY, THEY ARE CONFRONTED BY A TWO YEAR WAITING PERIOD FOR MEDICARE. MANY OF THEM WILL SIMPLY NOT LIVE LONG ENOUGH TO QUALIFY; THEIR NEED IS IMMEDIATE. YOUR BILL WOULD ADDRESS THIS PROBLEM BY WAIVING, FOR FIVE YEARS, THE 24-MONTH WAITING PERIOD FOR MEDICARE ELIGIBILITY ON THE BASIS OF A DISABILITY IN THE CASE OF INDIVIDUALS WITH AIDS. MR. CHAIRMAN, MAY I COMMEND YOU FOR THIS LEGISLATION. I AM COSPONSOR A HOUSE BILL WITH A SIMILAR PROVISION, H.R. 276, WHICH HAS BEEN INTRODUCED BY OUR COLLEAGUE FROM NEW YORK, TED WEISS.

WITH RESPECT TO THE NEEDS OF CHILDREN WITH AIDS WHO ARE, IN EFFECT, OUR NEW HOMELESS, WE WILL NEED ADDITIONAL RESOURCES. IT IS DIFFICULT TO DETERMINE THE NATURE AND EXTENT OF THESE NEEDS. FOR THAT REASON, I COMMEND THE CHAIRMAN FOR PROPOSING IN S 24 THAT THE SECRETARY OF HEALTH AND HUMAN SERVICES CONDUCT, OR PROVIDE FOR THE CONDUCTING OF, A SURVEY TO DETERMINE THE NUMBER OF CHILDREN WITH AIDS WHO HAVE BEEN ABANDONED, THOSE CHILDREN WITH AIDS WHO HAVE BEEN PLACED IN FOSTER CARE, THE PROBLEMS ENCOUNTERED BY SOCIAL SERVICES IN PLACING THESE CHILDREN, AND RECOMMENDATIONS FOR CARING FOR THESE CHILDREN.

I ALSO RECOGNIZE THAT S 24 PROVIDES FOR $75 MILLION FOR GRANTS FOR EDUCATION AND INFORMATION PROJECTS CONCERNING AIDS. WE IN THE CONGRESS MUST PROVIDE FUNDS FOR THIS MUCH NEEDED EDUCATION IF WE ARE TO HAVE ANY HOPE OF PREVENTING THE SPREAD OF THE AIDS VIRUS.

FOR THAT REASON, EARLIER THIS YEAR I INTRODUCED H.R. 2626, THE "ACQUIRED IMMUNODEFICIENCY SYNDROME EDUCATION, INFORMATION, RISK REDUCTION, TRAINING, PREVENTION, TREATMENT, CARE AND RESEARCH ACT OF 1987." THE BILL, A COMPANION TO S. 1220 WHICH WAS INTRODUCED IN THE SENATE BY MR. KENNEDY, PROVIDES $550 MILLION FOR FISCAL YEAR 1988 FOR A COMPREHENSIVE PROGRAM OF EDUCATION, INFORMATION, RISK REDUCTION, TRAINING, PREVENTION, TREATMENT CARE, AND RESEARCH CONCERNING ACQUIRED IMMUNODEFICIENCY SYNDROME. $350 MILLION WOULD BE AUTHORIZED FOR AIDS EDUCATION.

OF THE TOTAL FUNDS PROVIDED IN H.R. 2626, $100 MILLION IS AUTHORIZED FOR RESEARCH GRANTS AND PROJECTS TO DEMONSTRATE EFFECTIVE METHODS TO REDUCE THE TRANSMISSION OF AIDS AMONG IV DRUG USERS AND TO PROVIDE TREATMENT TO IV DRUG USERS WITH AIDS. IF WE ARE TO CONFRONT THE AIDS PROBLEM EFFECTIVELY, AS PART OF OUR STRATEGY WE MUST ADDRESS THE NEEDS OF SPECIFIC POPULATIONS

MOST VULNERABLE TO AIDS. THIS INCLUDES THE POPULATION OF INTRAVENOUS DRUG ABUSERS AND THOSE IMPACTED BY THE RELATIONSHIP BETWEEN AIDS AND INTRAVENOUS DRUG ABUSE.

TO FURTHER MEET THE NEEDS OF THE VICTIMS OF THE PERNICIOUS RELATIONSHIP BETWEEN AIDS AND IV DRUG USE, I WILL BE INTRODUCING THE "INTRAVENOUS SUBSTANCE ABUSE AND AIDS PREVENTION ACT OF 1987," NEXT WEEK. THIS LEGISLATION WOULD PROVIDE $400 MILLION DOLLARS FOR GRANTS TO EXPAND DRUG ABUSE TREATMENT SERVICES FOR INTRAVENOUS DRUG ABUSERS, FOR DEMONSTRATION PROJECTS TO REDUCE AND PREVENT THE INCIDENCE OF AIDS IN INFANTS AND TO PROVIDE SUPPORT TO INFANTS WHO HAVE AIDS, AND FOR PREVENTION PROGRAMS TO ARREST THE SPREAD OF AIDS RELATED TO INTRAVENOUS DRUG ABUSE.

LET ME JUST CONCLUDE BY TELLING YOU THAT LAST WEEK I HAD THE PRIVILEGE OF PARICIPATING IN A SITE VISIT WITH THE PRESIDENTIAL COMMISSION ON THE HIV EPIDEMIC TO SEVERAL AIDS CARE FACILITIES IN NEW YORK CITY. WHILE I WAS WITH THE COMMISSIONERS, I REPEATEDLY EMPHASIZED THE NEED FOR THE COMMISSION TO CONSIDER AIDS AS A NATIONAL PROBLEM, REQUIRING NATIONAL SOLUTIONS. I URGED THEM TO BE BOLD IN THEIR RECOMMENDATIONS TO THE PRESIDENT SO THAT WE MAY EFFECTIVELY COME TO GRIPS, AS A NATION, WITH THE AIDS EPIDEMIC.

AIDS WILL NOT SIMPLY DISAPPEAR. IF WE WAIT FOR A CURE, MANY WILL DIE UNNECESSARILY. IT IS ONLY THROUGH A CONCERTED EFFORT ON THE PART OF ALL SEGMENTS OF THE COMMUNITY AND ALL LEVELS OF GOVERNMENT THAT WE CAN PURGE OUR NATION OF THIS DISEASE. WE IN THE CONGRESS MUST PLAY A LEADERSHIP ROLE IN THIS EFFORT.

I WANT TO THANK YOU MR. CHAIRMAN, AND MEMBERS OF THE COMMITTEE, FOR THIS OPPORTUNITY TO TESTIFY BEFORE YOU. SOMEWHAT SADLY, I HOPE THAT WE WILL CONTINUE TO WORK TOGETHER ON THE PROBLEM OF AIDS AS LONG AS THAT MAY BE NECESSARY. WE MUST DO SO UNTIL SUCH TIME AS AIDS, LIKE SMALL POX AND POLIO, BECOMES A DISEASE OF OUR PAST, NOT OUR PRESENT AND FUTURE.

Dr. ROPER. Yes, sir. I had talked about Medicare and AIDS and had just begun Medicaid and AIDS. I will be brief and summarize the remainder of my statement.

About 40 percent of people with AIDS—AIDS patients—are served by the Medicaid Program. The program this year, we estimate, will spend $400 million on the care of people with AIDS, a little more than half Federal money and the rest State money. As you know, the Medicaid Program is managed by the States and funded jointly by the States and the Federal Government. We believe that the Medicaid Program is paying for 25 percent of the costs of health care for people with AIDS. Therefore, Medicaid is the largest payor for health care services of AIDS patients, and that number is very large in New York. There, we estimate 60 percent of people with AIDS are on Medicaid; and in the hospital facilities, 80 percent of AIDS patients are on Medicaid.

Senator MOYNIHAN. Now, that again is describing a population.

Dr. ROPER. Yes, indeed, I think because of the particular population served by the Health and Hospital Corporation. The care of people with AIDS is expensive. Estimates of health treatment costs range a great deal, but we estimate that now it is about $50,000 to $75,000 over the lifespan of a person with AIDS. A number of innovative things are being done; and through the Medicaid Program, we are granting waivers to States for them to give out-of-hospital treatment at lower costs. New Jersey, New Mexico, and North Carolina have such waivers in place right now.

Senator MOYNIHAN. North Carolina?

Dr. ROPER. Yes, sir. And we have received applications and interest from other States. We are encouraging those kinds of efforts. Because we have a lack of cost data on AIDS patients, we funded a two-year study with the Rand Corporation to design a new data collection system to forecast future AIDS costs because that will be important in public policy deliberations now and in the future.

I share your concern and Senator Durenberger's and Congressman Rangel's and others' concerns about the urgency of the AIDS issue. You asked that I comment on S. 24, your bill; and let me just do that in closing.

AIDS is a devastating disease, but other illnesses are as well—cancer, Alzheimer's disease, and so on. In the nature of my bona fides, I have been to Harlem Hospital and visited the pediatrics ward there with my friend, Margaret Haggarty, who is the pediatrician in charge of the ward. I walked down the hall a couple of weeks ago, and Margaret said that these children are children who are infected with the AIDS virus, and she wanted to show them to me. And we were talking about them as we walked along, and I really didn't think about how I would react until she picked up one of them and held him out to me. And I embraced the child and stood there talking with her with the child in my arms. It is a very moving experience to see the children that Charlie Rangel described to you just a few minutes ago who have AIDS through no fault of their own and who are—some of them—desperately ill, but others of them would be able to go home if there were a place for them to go.

Those are heart-rending cases, and we as a society need to deal with those issues. But there are other kinds of illnesses. My wife is

an oncologist, a cancer specialist, and her patients with cancer are heart-rending as well. I am a pediatrician, and children with illnesses other than AIDS are heart-rending as well.

Therefore, I have to tell you that I am opposed to a disease-specific change in the Medicare and Medicaid programs. If we are going to talk about waiving or changing the 24-month waiting period, let's talk about it for all terminally ill patients or, for example, all patients who are on disability, but not just patients with AIDS. Surely, that is a troubling issue for us as a nation, but I think we ought not deal with AIDS on a disease-specific basis.

I am sure you will want to talk about that, but let me just conclude by saying that I think the public and private sectors have got to work together to solve this problem. One of my major concerns is that we keep the private sector insurance companies involved in paying for the care of people with AIDS; otherwise, we will certainly have a Federal entitlement program financing the care of AIDS patients. I don't think that is good public policy, and I think public and private sectors need to continue working together. Thank you, sir.

Senator MOYNIHAN. We thank you, Doctor. I just want to record one thing here. You say that you have been spending $400 million on AIDS this fiscal year, and you estimate total Federal and State Medicaid costs will rise to $2.4 billion in 1992?

Dr. ROPER. Yes, sir.

Senator MOYNIHAN. That is a six-fold increase in five years?

Dr. ROPER. Yes, sir. That is based on projections made by the Public Health Service regarding numbers of patients becoming ill over that period of time and likely health care costs that would result from that.

Senator MOYNIHAN. Senator, we are talking about $2.4 billion per year.

Senator DURENBERGER. Dr. Roper, I can't disagree with the suggestion that, as national public policy, we broaden the scope of the financing services in the public and the private sector. And I don't believe I can disagree with the thought that we tackle the financing of the health and related services for victims of AIDS in a fashion similar to the approaches we would take with Alzheimer's and other chronic terminal illnesses. I just wonder—and I haven't read your formal statement—if you have any thoughts, from the experience we have had with the President's Commission or the Secretary's Commission on Catastrophic Insurance, the data base that goes along with these various diseases and what we know about their treatment? Do you have any figures that would give us a national dimension of the costs of dealing with AIDS in the same contaxt that you would recommending dealing with Alzheimer's and other diseases?

Do you have any information regarding how we can control or manage the appropriateness of the setting for this treatment? And then, do you have some recommendations as to where the Administration is headed between now and January in coming to the Congress with some specific recommendation on catastrophic financial access to treatment for the chronically ill through the catastrophic health system or insurance system—whatever we may want to call it?

Dr. ROPER. You gave me a long list. If I forget something, please remind me. You asked about recommendations for financing the care of people with AIDS beyond Medicare and Medicaid. One of the key recommendations of Secretary Bowen's report to the President was that States be encouraged to set up innovative arrangements to finance and provide health insurance for people without insurance. Of late the most often discussed mechanism to that end is risk pooling; and I know, Senator, you have offered legislation that would help the States to do that. That is something we have under very active review in the department right now, and we encourage you and are interested in that idea. That is something that has a great deal of merit.

As I said in closing my statement, we believe that we have got to find a way to keep the private sector involved in this process; and I think the risk pools are a good means to that end. The President, as you know, has asked the Treasury Department to study some of the Secretary's recommendations about the tax incentives for financing of catastrophic illness, and that may well yield other suggestions for the future.

We, along with the Public Health Service, are seeking the best information about how most effectively—most cost-effectively—to treat patients with AIDS. The Health Resources and Services Administration has funded some studies for largely the outpatient care and have demonstrated what one would assume, and that is that it is more effective to treat someone out of hospital than in hospital. And that is why the figures that you are seeing about total costs of caring for a person with AIDS are going down. The most recent figures are now around $50,000 instead of $150,000, which was earlier projected, but still with rising numbers of people, it is a lot of money in any event.

Senator DURENBERGER. I have another follow-up question, but the other question was the dollar dimension, and maybe you could respond to that?

Dr. ROPER. Oh, yes. The Public Health Service has estimated—and they will be refining that estimate later this fall—that by 1991, we will be spending between $8 and $16 billion per year in the health care system to care for people with AIDS. Our figure for Medicaid for 1991 is $1.8 billion; that would represent 2.4 percent of Medicaid expenditures in that year. Medicare spending in that year, assuming things continue as they are, would be about $50 million, a very small portion of the Medicare Program.

Senator MOYNIHAN. That is because of the 24 months?

Dr. ROPER. The 24 months. Yes, sir.

Senator MOYNIHAN. When you are not alive.

Dr. ROPER. Yes, sir. The point I would draw about that is that, while these are truly staggering health care costs—again 2.4 percent of Medicaid expenditures—there is an awful lot that Medicaid pays for even beyond these very large payments on behalf of people with AIDS. AIDS is a relatively smaller part of the Medicaid Program, even projected out into the long term.

Senator DURENBERGER. What is the rest of the dimension of chronic illnesses? On this committee, we keep referring to our former colleague, the then senior Senator from the State of New York, Jake Javits, who came in here a number of times with his

attendants and his oxygen to plead with us to deal with the problem of the chronically ill, and we are not doing that this year. We are dealing with another part of the catastrophic system. We haven't dealt with that because we haven't had the confidence to know how best to deal with it.

What is the dimension for the rest of the chronically and terminally ill?

Dr. ROPER. Let me try to answer that by giving some figures that we have just developed this week about the 24-month waiting period that the Chairman has asked about. And let me be careful and not just burden you with too many figures, but I think it makes the point.

If we were to eliminate the 24-month waiting period for AIDS patients—AIDS patients alone—that would add additional costs to the Medicare program over a five-year period—and these are all going to be five-year costs—of $2.1 to $8.3 billion. The range is there because we have to project a range based on some uncertainties.

If, on the other hand, we eliminate the 24-month waiting period for all terminally ill patients—not just AIDS, but cancer and Alzheimer's and whatever else—the additional cost to Medicare would be $7.7 billion to $13.9 billion, again over the five-year period.

Senator DURENBERGER. Those are additional costs, or that is inclusive of AIDS?

Dr. ROPER. That includes the costs due to AIDS patients. And then, finally, if we were to eliminate the 24-month waiting period for all disabled patients—in other words, if once they got on Mr. Rust's program, they immediately were on Medicare—that would add Medicare costs of from $35.3 billion to $41.5 billion, again over the five-year period; and again, that does not include the costs of AZT.

So, in answer to your question, there is a lot more out there than AIDS.

Senator DURENBERGER. Thank you.

Senator MOYNIHAN. Could we have those later from you in writing for the record?

Dr. ROPER. Yes, sir.

[The prepared statement of Dr. Roper follows:]

WILLIAM L. ROPER, M. D.

ADMINISTRATOR

HEALTH CARE FINANCING ADMINISTRATION

I AM DR. WILLIAM L. ROPER, ADMINISTRATOR OF THE HEALTH CARE FINANCING ADMINISTRATION. I AM PLEASED TO BE HERE TODAY TO DISCUSS MEDICARE AND MEDICAID COVERAGE FOR AIDS PATIENTS. AIDS IS ONE OF THE HIGHEST PRIORITY ITEMS ON THE SECRETARY'S AGENDA. I WANT TO ASSURE YOU THAT DOCTOR BOWEN AND I HAVE DISCUSSED AT LENGTH THE SERIOUSNESS OF THIS TRAGIC DISEASE AND THE HOPE OF EVENTUALLY FINDING THE CURATIVE TREATMENTS AND A VACCINE THAT WILL PREVENT THE HIV VIRUS INFECTION THAT CAUSES AIDS. UNTIL SUCH A BREAKTHROUGH, WE ARE CONFIDENT THAT STATE AND LOCAL GOVERNMENTS AND PRIVATE PROVIDERS ARE USING MEDICARE AND MEDICAID TO HUMANELY AND COMPASSIONATELY EASE THE FINANCIAL BURDEN OF ELIGIBLE AIDS PATIENTS.

NEW YORK CITY IS ONE AREA THAT HAS BEEN SEVERELY AFFECTED BY THE AIDS EPIDEMIC. ON AUGUST 28, I VISITED NEW YORK TO EXAMINE THE ISSUES FACING THAT CITY, THE STATE, AND THE PROVIDERS OF CARE TO AIDS PATIENTS. I WAS EXTREMELY IMPRESSED WITH THE DEDICATED EFFORTS OF THE HEALTH CARE WORKERS IN NEW YORK AND WANT TO NOTE THE IMPORTANCE OF THEIR CONTRIBUTIONS. I REVIEWED THE STATE'S SPECIAL PLAN FOR PROVIDING CARE TO AIDS PATIENTS THROUGH DESIGNATED AIDS HOSPITAL CENTERS WHICH WILL PROVIDE OR COORDINATE ALL LEVELS OF CARE FROM THE ACUTE HOSPITAL TO THE HOME OR HOSPICE SETTING.

I VISITED THE GAY MEN'S HEALTH CRISIS CENTER, THE SPELLMAN CENTER FOR THE TREATMENT OF PERSONS WITH AIDS AT ST. CLARE'S HOSPITAL AND HEALTH CENTER, AND HARLEM HOSPITAL. THE SPELLMAN CENTER IS THE FIRST HOSPITAL TO BE DESIGNATED AN OFFICIAL AIDS CENTER BY THE STATE OF NEW YORK. AT HARLEM HOSPITAL, WE FOCUSED ON THE SPECIAL PROBLEMS OF CHILDREN WITH AIDS.

I MET WITH DOCTOR LLOYD NOVICK, THE DIRECTOR OF COMMUNITY HEALTH FOR NEW YORK STATE AND OTHER STATE OFFICIALS, AND WAS BRIEFED ON NEW YORK'S PLAN TO ESTIMATE THE NUMBER OF PERSONS WITH AIDS ANTIBODIES THROUGH A CONFIDENTIAL BLOOD TESTING PROGRAM.

ONE OF THE MAJOR ISSUES WE DISCUSSED WAS THE FINANCING OF CARE FOR PATIENTS WITH AIDS. AS DAVID RUST FROM THE SOCIAL SECURITY ADMINISTRATION EXPLAINED, PEOPLE WHO QUALIFY FOR DISABILITY BENEFITS MAY ALSO BE ELIGIBLE FOR MEDICARE. MEDICARE IS AVAILABLE TO DISABLED PERSONS WHO HAVE RECEIVED SOCIAL SECURITY DISABILITY BENEFITS FOR 24 MONTHS. BECAUSE OF THE RELATIVELY RAPID AND FATAL COURSE OF AIDS AND BECAUSE MOST AIDS PATIENTS ARE YOUNGER INDIVIDUALS, ONLY A VERY SMALL NUMBER OF INDIVIDUALS WITH AIDS - ABOUT 1 PERCENT - RECEIVE BENEFITS UNDER THE MEDICARE PROGRAM.

AS DRUGS AND OTHER TREATMENTS BECOME AVAILABLE, LIFE EXPECTANCIES WILL IMPROVE, BUT IT IS DIFFICULT AT THIS TIME TO ESTIMATE THE NUMBER OF PERSONS WITH AIDS WHO WOULD ULTIMATELY QUALIFY. SPENDING UNDER THE MEDICARE PROGRAM FOR PEOPLE WITH AIDS IS CURRENTLY ESTIMATED TO BE UNDER $50 MILLION ANNUALLY AND IS ESTIMATED TO REMAIN UNDER $100 MILLION THROUGH FISCAL YEAR 1992.

AIDS PATIENTS WHO QUALIFY FOR DISABILITY UNDER SUPPLEMENTAL SECURITY INCOME (SSI) MAY ALSO BE ELIGIBLE FOR MEDICAID. LIKE OTHER RECIPIENTS, THEY MUST MEET PRESCRIBED INCOME AND RESOURCE LIMITS TO QUALIFY FOR SSI. FOR THOSE WHO EXCEED THE SSI LIMITS MEDICAID ELIGIBILITY MAY BE ESTABLISHED IF THE STATE HAS A MEDICALLY NEEDY PROGRAM. THIRTY-SIX STATES PROVIDE SOME FORM OF MEDICALLY NEEDY COVERAGE.

UNDER MEDICAID, THERE IS NO WAITING PERIOD AS UNDER THE MEDICARE PROGRAM. THE SOCIAL SECURITY ADMINISTRATION HAS MADE IT POSSIBLE FOR AIDS PATIENTS WHO FILE FOR SSI TO QUALIFY ALMOST

IMMEDIATELY FOR UP TO 3 MONTHS OF CASH BENEFITS AND MEDICAID. THIS IS DONE UNDER PRESUMPTIVE DISABILITY RULES THAT GRANT BENEFITS PENDING A FORMAL DISABILITY DETERMINATION.

WE ESTIMATE THAT ABOUT 40 PERCENT OF CURRENT AIDS PATIENTS ARE SERVED BY THE MEDICAID PROGRAM. THE FEDERAL AND STATE GOVERNMENTS, THROUGH THE MEDICAID PROGRAM, WILL SPEND AN ESTIMATED $400 MILLION ON AIDS PATIENTS THIS FISCAL YEAR. WE ESTIMATE THE TOTAL FEDERAL AND STATE MEDICAID COSTS FOR AIDS WILL RISE TO APPROXIMATELY $2.4 BILLION BY FISCAL YEAR 1992. THESE ESTIMATES DO NOT INCLUDE THE COST OF AZT ITSELF WHICH COULD RANGE UP TO $50 MILLION FOR THIS CALENDAR YEAR AND COULD REACH $150 MILLION IN CALENDAR YEAR 1988. THERE ARE, OF COURSE, OTHER FEDERAL, STATE, AND LOCAL RESOURCES. A ONE-TIME SUPPLEMENTAL APPROPRIATION FOR FISCAL YEAR 1987 INCLUDES $30 MILLION FOR AZT AND OTHER DRUGS THAT MIGHT PROLONG THE LIVES OF PEOPLE WITH AIDS. THESE FUNDS ARE BEING ADMINISTERED BY THE HEALTH RESOURCES AND SERVICES ADMINISTRATION AND ARE TO BE USED EXCLUSIVELY FOR THE PURCHASE OF AIDS DRUGS FOR LOW INCOME INDIVIDUALS WHO ARE NOT COVERED UNDER THE MEDICAID PROGRAM OR BY THIRD PARTY PAYORS. I AM INFORMED THAT THESE FUNDS HAVE ALREADY BEEN DISTRIBUTED TO 49 OF THE 50 STATES.

CARING FOR AIDS PATIENTS IS EXPENSIVE, BUT NOT UNLIKE OTHER HIGH COST ILLNESSES. ESTIMATES OF LIFETIME DIRECT MEDICAL COSTS FOR AIDS PATIENTS HAVE RANGED UP TO $150,000, THOUGH COSTS IN THE $50,000 TO $75,000 RANGE SEEM MORE LIKELY, BASED ON RECENT EVIDENCE.

LIKE NEW YORK, SOME STATES HAVE ALREADY BEGUN TO ADDRESS THE NEED FOR PROVIDING COST-EFFECTIVE HEALTH CARE FOR MEDICAID-ELIGIBLE AIDS PATIENTS THROUGH THE USE OF INNOVATIVE DELIVERY SYSTEMS. UNDER WHAT IS KNOWN AS THE HOME AND COMMUNITY-BASED SERVICES WAIVER PROGRAM, STATE MEDICAID PROGRAMS HAVE THE OPPORTUNITY TO

PAY FOR A WIDE RANGE OF CARE DELIVERED AT HOME AND IN THE COMMUNITY FOR THOSE WHO MIGHT OTHERWISE BE INSTITUTIONALIZED. TWO WAIVERS TARGETED SPECIFICALLY TOWARD MEDICAID-ELIGIBLE INDIVIDUALS WITH AIDS OR AIDS-RELATED COMPLEX HAVE BEEN APPROVED BY THE HEALTH CARE FINANCING ADMINISTRATION. THE NEW JERSEY WAIVER WAS EFFECTIVE MARCH FIRST OF THIS YEAR AND THE NEW MEXICO WAIVER WAS EFFECTIVE ON JULY FIRST. THERE IS ALSO A NORTH CAROLINA MODEL WAIVER, WHICH COVERS BOTH AIDS AND VENTILATOR DEPENDENT PATIENTS, THAT BECAME EFFECTIVE JULY FIRST.

NEW JERSEY NOW PROVIDES SERVICES UNDER THIS WAIVER PROGRAM SUCH AS PERSONAL CARE, MEDICAL DAY CARE, NARCOTIC AND DRUG ABUSE TREATMENT, PRIVATE DUTY NURSING CARE, AND INTENSIVE FOSTER CARE FOR PEDIATRIC PATIENTS. NEW MEXICO PROVIDES CASE MANAGEMENT, PRIVATE DUTY NURSING, ADULT DAY CARE, HOMEMAKER AND PERSONAL CARE SERVICES. NORTH CAROLINA PROVIDES CASE MANAGEMENT, SCREENING, ASSESSMENT, NURSING, RESPITE CARE, AND MEDICAL SUPPLIES.

IN ADDITION, THE STATE OF WASHINGTON RECEIVED APPROVAL TO ADD TO ITS STATE PLAN CASE-MANAGEMENT SERVICES TARGETED TO MEDICAID-ELIGIBLE AIDS PATIENTS. WE HAVE RECEIVED INQUIRIES FROM SEVERAL OTHER STATES WHICH ARE CONSIDERING WAIVERS AND CASE-MANAGEMENT SERVICES FOR AIDS PATIENTS. WE ARE SUPPORTING AND STRONGLY ENCOURAGING STATES TO TAKE ADVANTAGE OF THESE WAIVERS AND CASE-MANAGEMENT OPTIONS UNDER MEDICAID.

I WANT TO EMPHASIZE THAT STATES HAVE OTHER OPTIONAL SERVICES WHICH THEY CAN PROVIDE UNDER MEDICAID, WHICH ARE OF SPECIAL BENEFIT TO AIDS PATIENTS. HOSPICE IS A GOOD EXAMPLE.

BECAUSE OF THE LACK OF COST DATA ON AIDS PATIENTS, THE HEALTH CARE FINANCING ADMINISTRATION FUNDED A TWO-YEAR STUDY WITH THE RAND POLICY CENTER TO DESIGN A COMPREHENSIVE DATA COLLECTION AND ANALYTIC METHODOLOGY TO FORECAST AIDS COSTS. THIS WILL PROVIDE

EXPENDITURE AND OTHER INFORMATION SO THAT WE CAN BETTER EVALUATE THE FISCAL IMPACT OF AIDS. WE ARE ALSO COLLECTING COST DATA INDIVIDUALLY FROM STATES AND ENCOURAGING STATES TO PARTICIPATE IN A MEDICAID STATISTICAL INFORMATION SYSTEM.

I SHARE YOUR CONCERN ABOUT THE URGENCY OF THE AIDS ISSUE. THE MEDICARE AND MEDICAID PROGRAMS HAVE HISTORICALLY PROVIDED SERVICES FOR THE ELDERLY, THE DISABLED AND THE NEEDY FOR A WHOLE RANGE OF MEDICAL PROBLEMS. WHILE AIDS IS A DEVASTATING DISEASE, SO ARE OTHER ILLNESSES SUCH AS ALZHEIMER'S DISEASE AND CANCER. I BELIEVE WE MUST CONTINUE TO VIEW MEDICARE AND MEDICAID IN THEIR BROADER PERSPECTIVE, AND NOT AS DISEASE SPECIFIC PROTECTIONS. TO DO OTHERWISE RAISES QUESTIONS OF EQUITY FOR THOSE SUFFERING FROM OTHER EQUALLY DEVASTATING ILLNESSES. I BELIEVE THE PUBLIC AND THE PRIVATE SECTORS MUST CONTINUE TO WORK TOGETHER ON THIS PROBLEM. OUR PLURALISTIC HEALTH CARE SYSTEM IN THE UNITED STATES WHICH RELIES NOT ONLY ON THE PRIVATE AND PUBLIC SECTORS, BUT ALSO ON PARTICIPATION AT ALL LEVELS - FROM THE FEDERAL GOVERNMENT, TO STATE GOVERNMENTS, TO THE LOCAL COMMUNITY - MUST BE FULLY UTILIZED TO EFFICIENTLY MEET THE COST BURDENS OF AIDS. TAKING THIS APPROACH WILL ALSO ALLOW STATES THE FLEXIBILITY THEY NEED, BECAUSE THE AIDS PROBLEM VARIES IN DIFFERENT PARTS OF THE COUNTRY.

AS THE AGENCY RESPONSIBLE FOR FINANCING THE MEDICARE AND MEDICAID PROGRAMS, THE HEALTH CARE FINANCING ADMINISTRATION HAS WORKED CLOSELY WITH THE PUBLIC HEALTH SERVICE, THE SOCIAL SECURITY ADMINISTRATION AND WITH STATES TO ENSURE MAXIMUM COORDINATION OF EFFORTS IN RESPONDING TO THE AIDS CRISIS. THE HEALTH CARE FINANCING ADMINISTRATION IS COMMITTED TO ENSURING THAT APPROPRIATE CARE AND SERVICES ARE DELIVERED TO AIDS AND OTHER PATIENTS WITH CATASTROPHIC MEDICAL EXPENSES.

PROPOSAL: Eliminate the 24 month waiting period for patients with AIDS/ARC

Cost of the proposal (in billions):

Low	CY	Medicare Cost	Medicaid Offset	Net Cost
	1988	0.2	1/	0.2
	1989	0.3	0.1	0.2
	1990	0.4	0.1	0.3
	1991	0.5	0.1	0.4
	1992	0.7	0.2	0.5

High	CY	Medicare Cost	Medicaid Offset	Net Cost
	1988	0.7	0.2	0.5
	1989	1.1	0.3	0.8
	1990	1.5	0.4	1.1
	1991	2.1	0.6	1.5
	1992	2.9	0.9	2.0

PROPOSAL: Change the waiting period to 12 months for patients with AIDS/ARC

Cost of the proposal (in billions):

Low	CY	Medicare Cost	Medicaid Offset	Net Cost
	1988	1/	1/	1/
	1989	0.1	1/	0.1
	1990	0.1	1/	0.1
	1991	0.1	1/	0.1
	1992	0.2	1/	0.2

High	CY	Medicare Cost	Medicaid Offset	Net Cost
	1988	0.2	1/	0.2
	1989	0.3	0.1	0.2
	1990	0.4	0.1	0.3
	1991	0.5	0.2	0.3
	1992	0.8	0.2	0.6

PROPOSAL: Eliminate the 24 month waiting period for Medicare benefits for the terminally ill.

Cost of the proposal (in billions):

CY	Medicare Cost	Medicaid Offset	Net Cost
1988	0.9	0.3	0.6
1989	1.0	0.3	0.7
1990	1.1	0.3	0.8
1991	1.2	0.4	0.8
1992	1.4	0.4	1.0

1/ negligible (less than $50 million)

PROPOSAL: Change the waiting period for Medicare benefits to 1 year for the terminally ill.

Cost of the proposal (in billions):

CY	Medicare Cost	Medicaid Offset	Net Cost
1988	0.1	1/	0.1
1989	0.1	1/	0.1
1990	0.1	1/	0.1
1991	0.1	1/	0.1
1992	0.2	1/	0.2

PROPOSAL: Eliminate the 24 month waiting period for Medicare benefits for all disabled.

Cost of the proposal (in billions):

CY	Medicare Cost	Medicaid Offset	Net Cost
1988	5.2	1.5	3.7
1989	5.8	1.7	4.1
1990	6.5	1.9	4.6
1991	7.3	2.1	5.2
1992	8.4	2.4	6.0

PROPOSAL: Change the waiting period for Medicare benefits to 1 year for all disabled.

Cost of the proposal (in billions):

CY	Medicare Cost	Medicaid Offset	Net Cost
1988	2.2	0.6	1.6
1989	2.5	0.7	1.8
1990	2.8	0.8	2.0
1991	3.1	0.9	2.2
1992	3.6	1.0	2.6

1/ negligible (less then $50 million)

Senator MOYNIHAN. And there is more to this legislation than the 24-month waiver. We particularly asked the Secretary of Health and Human Services to conduct a study of the total number of children who have AIDS, who have been left in hospitals, who have the virus. We were not only speaking of the foster care problem. Do you have any views on that?

Dr. ROPER. Just at a personal level, I think that is useful information, but foster care is beyond my responsibilities.

Senator MOYNIHAN. I don't expect anybody to get much out of OMB these days. If it sounds like something that needs doing, they don't want to find it out; that is not your fault, Doctor. I do think the point should be made, though, that there is an interchangeability between Medicare and Medicaid. I mean, these costs are picked up by the Federal Government in one form or another.

Dr. ROPER. Indeed. And the figures I will supply to you, Senator, will show the offsets to the Medicaid Program.

Senator MOYNIHAN. And will you tell us what you really mean about your concern about the private insurance? I mean, I know you have something in mind there.

Dr. ROPER. Surely.

Senator MOYNIHAN. If you say it out very slowly and clearly, I will probably be able to follow it, I am sure.

Dr. ROPER. Yes, and it is that I think we as a society need to make sure that people who are employed and who have work-related health insurance or in some other way are in the private insurance sector continue to have their AIDS health care needs paid for by that work-related or other private health insurance.

Senator MOYNIHAN. Put that down and spell it out for us, will you, and make it very clear?

Dr. ROPER. Surely.

Senator MOYNIHAN. There is opposition, and we have to understand what is on your mind.

Dr. ROPER. Senator Danforth and I had a chance to talk about this a couple of months ago. You know, he has a personal interest in the matter as well.

Senator MOYNIHAN. Fine. Could I just say to Senator Durenberger that the testimony from Mr. Rust was very impressive. We spend a certain amount of time being cranky with the Social Security Administration, but let's, for a change, just take note that in respect to persons with AIDS applying for disability insurance, 94 percent of the claims are approved; and that contrasts overall with a 35 percent or something like that.

The six percent who are not approved are obviously lucky people who turn out not to have what they think they might have had, and I would like to say that that is a very open attitude. I mean, it is hardly good luck when the disability insurance is provided you; and yet, that is what this insurance is for, and you are doing it, and I would like to tell you thank you very much for what you are doing.

Mr. RUST. Yes, sir.

Senator MOYNIHAN. And thank you, Dr. Roper.

Dr. ROPER. Yes, sir.

Senator MOYNIHAN. We now have a panel we are looking forward to of persons who are there on the ground with the subject.

Dr. Jo Ivey Boufford, Dr. John Schunhoff, and Dr. James Haughton are here, and we welcome you all.

I think Dr. Boufford is first in line, and she comes, of course, from the New York City Health and Hospital Corporation. Do you not know each other? Well, meet Dr. Haughton who is from Houston, and Dr. Schunhoff who is from Los Angeles.

We will begin with Dr. Boufford. Your testimony will be put in the record, of course; and you might want to summarize it. We will go through the three of your testimonies, and then we will ask questions.

STATEMENT OF DR. JO IVEY BOUFFORD, PRESIDENT, NEW YORK CITY HEALTH AND HOSPITAL CORPORATION, NEW YORK, NY

Dr. BOUFFORD. All right. Fine, thank you very much for the opportunity to talk to you. Let me just tell you briefly about the corporation, or HHC, as we call it. We are the largest municipal hospital system in the nation. We have 11 acute care hospitals, five long-term care facilities, and over 40 community-based health centers in the City of New York.

We provide about 20 percent of all the inpatient care in New York City and about 50 percent of all of the ambulatory care, and about 45 percent of all the emergency services. So, we are a major component of the overall health care delivery system in New York; but because our mission is to provide care to all regardless of ability to pay, we tend to serve a much larger proportion of minorities and poor individuals than in the voluntary hospitals. We serve about 80 percent minority population, largely Black and Hispanic, compared to about 25 percent in the voluntary hospitals in the city, and our population is about 60 percent Medicaid compared to about 25 to 30 percent in the voluntary hospitals. So, it is a different patient population.

Historically, we believe public hospitals like HHC have been health care providers most affected by the social and economic changes in our society. In the 1960s, we became the family doctor for the inner city residents who lacked health insurance, especially for ambulatory care. In the 1970s, we assumed the burden of carrying for the mentally ill who had been deinstitutionalized through State policy and Federal policy. In the early 1980s, we felt the effects of homelessness, treating increasing numbers of individuals who, once their medical or mental health were taken care of, had no place to live.

And finally, now the tragedy of AIDS and increased drug abuse, which I have to continue to link because it is a crucial linkage for us, as Congressman Rangel indicated, are now dramatically affecting public hospitals; and our patient population certainly reflects this impact.

We have about one-quarter of the medical/surgical beds in the City of New York and are taking care of about 33 percent of all of the AIDS patients. Our daily AIDS census in our 11 acute care hospitals is about 400 patients on a given day. This is compared to about 150 in March of 1985. So, you can see the very dramatic increase. A full 75 percent of our patients contracted AIDS through I.V. drug abuse, either direct I.V. usage, sexual contact with an

I.V. user, or as a child of a drug abuser. By contrast, I.V. drug abusers make up about 10 percent of the AIDS population in San Francisco and about one-third in New York City as a whole.

As the numbers of persons with AIDS continues to increase dramatically, especially among the I.V. drug population, we expect to see this burden falling even more heavily on public hospitals, both in our city as well as around the country.

And this relationship is really crucial because I think the epidemiology is shifting in this disease, and we see an increasing incidence of AIDS among I.V. drug abusers. The difficulties in treating these patients for their addiction is exacerbated by the concurrent diagnosis of AIDS. Patients who are able to be kept in drug detox programs very often really lose heart in that therapeutic process when they find out they have AIDS, and then their underlying medical problems complicate the medical management of their AIDS secondary infections, which increase the cost of care.

Let me try to describe briefly what we are doing with our AIDS population. We are focusing our inpatient services on an interdisciplinary team approach which aims to coordinate the care of individual AIDS patients using physicians, nurses, social workers, who work both as support system for the staff who have the direct care responsibility, as well as being responsible for case management for these patients through each level of care—ambulatory care, inpatient hospital care, and long-term care. We also have beds for AIDS patients in our long-term care facilities—now about 30 on any given day—and we plan to double that size and believe that will be an area that will require increasing numbers of beds for patients with AIDS.

Overall, about 15 percent of our AIDS patients are homeless and do not qualify for long-term care services—medical services; and this is another need that we have, for housing for these individuals, which is really not addressed in any major way. And I would stress, I think, to this committee the issue of long-term care as being a major area for AIDS care, both home health, housing and long-term care. We have some extensive ambulatory programs and are intending to provide special focus on women who are at risk who are partners of drug abusers, because of the problems of children with AIDS.

There have been about 199 cases of CDC defined AIDS in children in New York City, and about half of them have been treated in our facilities. We have developed some special programs, especially an AIDS day care center for pediatric patients in the Bronx, which provides an environment to support the development of these children when they are able to leave the hospital.

Moving to the financial impact, I think the problems of AIDS and AIDS patients is really exacerbated; it points out the fundamental weaknesses in our health care financing system in terms of the lack of health insurance coverage for a large segment of the population. New York City is spending about $385 million in fiscal year 1987 on AIDS; about $36 million of that was tax levy support for patients who are uninsured and getting care in our hospitals, which is about 12 percent of our patients. And I think the treatment costs certainly varied among parts of the country because pa-

tients' diagnoses are different. Our I.V. drug abuse population tends to be sicker and require more intensive hospital care.

I have several specific recommendations on page 8 of the testimony, which I think are relevant to this committee. Certainly, we would support very strongly, Senator, your proposed bill to waive the 24-month wait for Medicare eligibility. We also feel strongly that HCFA should be asked to develop DRGs for AIDS that adequately reflect the costs, intensity of illness, and length of stay because these DRGs are often used to model the Medicaid Program and reimbursement in other States.

Senator MOYNIHAN. They don't now have one?

Dr. BOUFFORD. No, they use a variety of diagnoses and secondary diagnoses, but they often are actually under the 1.0 severity mixture. So, there is no standardized DRG for AIDS, as I understand it.

Senator MOYNIHAN. Would you let our committee have a piece of paper on that?

Dr. BOUFFORD. Certainly.

Senator MOYNIHAN. Thank you. That is our responsibility.

Dr. BOUFFORD. Again, we want to stress the long-term institutional care and home health Medicare coverage for AIDS patients. We would also urge consideration of waiving the 20 percent inpatient limit and the hospice program under Medicare, which we feel is particularly problematic for patients who lack the family support systems that most patients in the hospice program perhaps do have.

And certainly, we would support a Federal initiative in education and prevention testing and health services delivery. We feel very strongly that this is a national program that requires a Federal initiative on both the AIDS issue as well as the drug abuse prevention issue and would indicate that we think those two topics have to be addressed together or there will be really no comprehensive approach to the problem and that this issue of reimbursement for AIDS must be added to catastrophic coverage in order to prevent the burden from falling disproportionately on cities like New York and most especially on public hospital systems that are already burdened with large numbers of patients who are unable to pay for their care. Thank you.

Senator MOYNIHAN. Thank you, Doctor. I see a point here where you say New York City represented 52 percent of all AIDS cases; today the figure is 30 percent. I mean, that is called epidemiology—right?

Dr. BOUFFORD. That is right, and I think here the issue is that the incidence is growing in other parts of the country.

Senator MOYNIHAN. Yes.

Dr. BOUFFORD. It is no longer a New York City problem or a large city problem.

Senator MOYNIHAN. Dr. Schunhoff, the bell for our cloture vote has rung. It takes me about five minutes to get back and forth, and then we can take plenty of time to finish. Would you mind if we

just put the committee in recess for just a few moments? I will be right back.

Dr. SCHUNHOFF. No.

[Whereupon, at 11:35 a.m., the committee hearing was recessed.]

AFTER RECESS

Senator MOYNIHAN. We were just getting to you, Dr. Schunhoff, and you, of course, are the Assistant Administrator of the AIDS Program in the Los Angeles County Department of Health Services. We welcome you from across the country, and we look forward to your testimony.

[The prepared statement of Dr. Boufford follows:]

TESTIMONY OF THE
NEW YORK CITY HEALTH AND HOSPITALS CORPORATION

THANK YOU FOR THIS OPPORTUNITY TO SPEAK ON THE EXPERIENCES OF THE NEW YORK CITY HEALTH AND HOSPITALS CORPORATION IN MEETING THE HEALTH CARE NEEDS OF PERSONS WITH AIDS.

THE CORPORATION -- OR HHC, AS IT IS USUALLY CALLED -- IS THE LARGEST MUNICIPAL HEALTH CARE SYSTEM IN THE NATION. WE HAVE 11 ACUTE CARE HOSPITALS WITH 8,300 BEDS, FIVE LONG TERM CARE HOSPITALS WITH NEARLY 2,500 BEDS, AND OVER 40 COMMUNITY-BASED AMBULATORY CARE CENTERS. WE ALSO OPERATE THE CITYWIDE EMERGENCY MEDICAL SERVICES SYSTEM, WHICH RESPONDS TO APPROXIMATELY 775,000 CALLS ANNUALLY.

OUR MISSION IS TO PROVIDE HIGH-QUALITY MEDICAL CARE TO ALL WHO COME TO OUR DOORS, REGARDLESS OF THEIR ABILITY TO PAY. OUR PATIENT POPULATION IS PREDOMINATELY FROM LOW-INCOME AND MINORITY COMMUNITIES.

WE ARE A MAJOR PROVIDER IN NEW YORK CITY, PROVIDING HALF OF ALL AMBULATORY AND EMERGENCY ROOM VISITS, A THIRD OF ALL ACUTE PSYCHIATRIC SERVICES, A THIRD OF ALL INPATIENT DRUG DETOXIFICATION SERVICES, AS WELL AS ABOUT 10-15 PERCENT OF OUTPATIENT DRUG TREATMENT SLOTS.

HISTORICALLY, PUBLIC HOSPITALS LIKE HHC HAVE BEEN THE HEALTH CARE PROVIDERS MOST AFFECTED BY THE SOCIAL AND ECONOMIC CHANGES IN OUR SOCIETY. IN THE '60s, WE BECAME THE FAMILY DOCTOR FOR INNER-CITY RESIDENTS WHO WERE LEFT WITHOUT PRIMARY CARE SERVICES BECAUSE THEY HAD NO HEALTH INSURANCE OR ADEQUATE COVERAGE FOR AMBULATORY CARE. IN THE '70s, WE ASSUMED THE BURDEN OF CARING FOR THE MENTALLY ILL WHO WERE VICTIMS OF A POLICY OF DEINSTITUTIONALIZATION, AND IN THE EARLY '80s, WE FELT THE EFFECTS OF HOMELESSNESS, TREATING INCREASING NUMBERS OF INDIVIDUALS WHO, WHEN THEIR MEDICAL OR MENTAL HEALTH PROBLEMS ARE CURED OR UNDER TREATMENT, HAVE NOWHERE TO GO BUT TO A SHELTER.

MORE RECENTLY, THE TRAGEDY OF AIDS AND INCREASED DRUG ABUSE ARE DRAMATICALLY AFFECTING PUBLIC HOSPITALS, AND OUR PATIENT POPULATION REFLECTS THIS. WHILE WE HAVE LESS THAN ONE-QUARTER OF THE MEDICAL-SURGICAL BEDS IN THE CITY, WE ARE NOW PROVIDING THIRTY-THREE PERCENT OF THE CITY'S INPATIENT CARE FOR PERSONS WITH AIDS. OUR DAILY AIDS CENSUS IS CURRENTLY OVER 400 PATIENTS-DOUBLE OUR CENSUS OF TWO YEARS AGO.

A FULL 75 PERCENT OF OUR AIDS PATIENTS CONTRACTED THE VIRUS AS A RESULT OF INTRAVENOUS DRUG USE -- EITHER THROUGH DIRECT IV USE, SEXUAL CONTACT WITH AN IV USER, OR BEING BORN TO AN IV DRUG ABUSER. BY CONTRAST, IV DRUG ABUSERS MAKE UP LESS THAN 10 PERCENT OF THE AIDS POPULATION IN SAN FRANCISCO AND ONLY ABOUT ONE-THIRD IN THE CITY OF NEW YORK. AS THE NUMBERS OF PERSONS WITH AIDS CONTINUES TO INCREASE DRAMATICALLY, ESPECIALLY AMONG IV DRUG USERS, HHC'S AIDS PATIENT POPULATION WILL INCREASE CORRESPONDINGLY.

I BELIEVE THE RELATIONSHIP BETWEEN AIDS AND DRUG ABUSE WILL BE INCREASINGLY APPARENT THROUGHOUT THE COUNTRY. IT IS RARE TO HAVE AN EPIDEMIC OF THIS MAGNITUDE AND SEVERITY IN WHICH SUCH A LARGE PERCENTAGE OF OUR PATIENTS ARE AFFLICTED WITH AN ASSOCIATED ADDICTION AND EXHIBIT RISK BEHAVIOR THAT MAKES IT DIFFICULT TO ATTRACT THEM INTO CARE OR RETAIN THEM IN THERAPY. TREATING ANY MEDICAL PROBLEM IS MADE MORE DIFFICULT WHEN THE PATIENT IS A SUBSTANCE ABUSER, BOTH BECAUSE OF THE FREQUENT LACK OF COOPERATION BY THE PATIENT IN HIS OR HER TREATMENT COURSE AND BECAUSE OF THE CONCURRENT MEDICAL PROBLEMS THAT OFTEN ACCOMPANY DRUG ABUSE. THESE PROBLEMS ARE EXACERBATED WHEN THE PATIENT'S PRIMARY MEDICAL PROBLEM IS AIDS-RELATED.

WE HAVE FOUND THAT MOST ADDICTED PERSONS WITH AIDS DO NOT FOLLOW THROUGH ON DRUG TREATMENT. ON THE OTHER HAND, PATIENTS WHO HAVE COME TO US FOR DRUG TREATMENT AND THEN TEST POSITIVE FOR AIDS ARE OFTEN SET BACK IN THEIR DRUG TREATMENT COURSE BECAUSE OF THE GREAT STRESS INVOLVED IN BEING A PERSON WITH AIDS IN OUR SOCIETY. DESIGNING AN EFFECTIVE TREATMENT STRATEGY FOR THIS PATIENT POPULATION CHALLENGES THE RESOURCEFULNESS OF THE HEALTH CARE DELIVERY SYSTEM.

LET ME DESCRIBE WHAT WE ARE DOING FOR OUR AIDS POPULATION. THE CORE OF HHC'S HOSPITAL-BASED SERVICES FOR PERSONS WITH AIDS IS THE INTERDISCIPLINARY PATIENT CARE TEAM, CONSISTING OF A PHYSICIAN, A PSYCHIATRIST, A NURSE CLINICIAN, AND A SOCIAL WORKER. SINCE MOST OF OUR AIDS PATIENTS ARE MAINSTREAMED IN OUR MEDICAL SERVICES, THESE TEAMS PROVIDE CONSULTATION AND SUPPORT TO EXISTING HOSPITAL STAFF, COORDINATE THE MOVEMENT OF AIDS PATIENTS BETWEEN LEVELS OF CARE, AND ESTABLISH LINKAGES WITH THE APPROPRIATE CASE WORKERS. THE INPATIENT TEAMS ALSO PROVIDE COORDINATION AND CONSULTATION TO OUTPATIENT SERVICES. THE GOAL IS TO PROVIDE CONTINUITY OF CARE FOR THE PATIENT.

HHC'S LONG-TERM CARE AIDS PROGRAM IS A MODEL PROGRAM ADMINISTERED BY INTERDISCIPLINARY TEAMS SIMILAR TO THOSE IN THE ACUTE CARE FACILITIES I JUST DESCRIBED. ONCE IN THE PROGRAM, THE TEAMS MONITOR THE PATIENTS CAREFULLY TO DETECT AND TREAT EVOLVING OR RECURRING ILLNESS EARLY, MINIMIZING THE NEED FOR REHOSPITALIZATION IN AN ACUTE CARE SETTING. ONE ISSUE PARTICULAR TO OUR AIDS POPULATION IN LONG-TERM CARE IS THE NEED TO MANAGE ONGOING METHADONE MAINTENANCE OR OTHER SUBSTANCE ABUSE TREATMENT WHILE IN THE LONG-TERM CARE FACILITY.

OVERALL, ABOUT 15 PERCENT OF OUR AIDS PATIENTS ARE HOMELESS AND DO NOT QUALIFY FOR LONG-TERM CARE SERVICES. WHILE SOME HOUSING IS BEING PROVIDED THROUGH CITY AGENCIES, MORE NEEDS TO BE DEVELOPED. IN GENERAL, THE LACK OF ADEQUATE LONG-TERM CARE, HOME HEALTH SERVICES, AND HOUSING HAS BEEN OVERLOOKED BY GOVERNMENTAL AND REGULATORY BODIES. HOSPITALS MUST NOT BE PENALIZED FOR LACK OF APPROPRIATE PLACEMENTS -- NOT ONLY FOR AIDS PATIENTS BUT FOR OTHERS AS WELL.

AT OUR COMMUNITY-BASED AIDS CLINIC WE PROVIDE MEMBERS OF RISK GROUPS WHO HAVE AIDS-RELATED ILLNESS WITH A THOROUGH PHYSICAL AND PSYCHOSOCIAL ASSESSMENT, AND REFER THE "WORRIED WELL" FOR APPROPRIATE SERVICES. WE WILL OPEN TWO MORE AIDS CLINICS IN OTHER AREAS OF THE CITY SHORTLY. WITH A SPECIAL FOCUS ON OUR DRUG TREATMENT AND WOMEN'S HEALTH SERVICES, WE PLAN TO INTEGRATE EXTENSIVE OUTREACH AIDS EDUCATION IN THESE PROGRAMS AS WELL AS ENCOURAGE VOLUNTARY SCREENING AND COUNSELING FOR HIGH-RISK WOMEN.

THERE HAVE BEEN 199 REPORTED CASES OF CDC-DEFINED AIDS IN CHILDREN IN NEW YORK CITY, HALF OF THEM HAVE BEEN TREATED IN HHC FACILITIES. CARE FOR THESE CHILDREN IS COMPLICATED BY THE FACT THAT ONE OR BOTH PARENTS IS LIKELY TO BE AN INTRAVENOUS SUBSTANCE ABUSER. AS A RESULT, THE FAMILY STRUCTURE MAY BE WEAK OR NON-EXISTENT. A SIGNIFICANT NUMBER OF THE CHILDREN ARE EITHER ORPHANS, ABANDONED, OR THEIR FAMILY CIRCUMSTANCES ARE SUCH THAT THEY REMAIN IN THE HOSPITAL BEYOND MEDICAL NECESSITY. THESE CHILDREN ARE DIFFICULT TO PLACE IN FOSTER CARE BECAUSE OF THE SOCIAL STIGMA OF AIDS. MANY OF THEM LIVE IN THE BRONX WHERE WE HAVE ESTABLISHED A SPECIALIZED PEDIATRIC DAY CARE PROGRAM FOR CHILDREN WITH AIDS. THE CENTER PROVIDES AN ENVIRONMENT WHERE THESE CHILDREN CAN PARTICIPATE IN ACTIVITIES TO ENCOURAGE NORMAL DEVELOPMENT AND RECEIVE ROUTINE MEDICAL MONITORING AND REFERRAL AS NEEDED.

LET ME TURN NOW FROM THE CLINICAL AND PROGRAMMATIC ISSUES TO THE FINANCIAL IMPACT OF THE AIDS EPIDEMIC ON THE PUBLIC SECTOR.

THE NATIONAL ACADEMY OF SCIENCES' 1986 REPORT, CONFRONTING AIDS, POINTS OUT THAT AN ESTIMATED 80 MILLION AMERICANS HAVE INADEQUATE HEALTH INSURANCE COVERAGE. THESE SHORTCOMINGS IN THE HEALTH CARE FINANCING SYSTEM ARE MAGNIFIED WITH AIDS CASES BECAUSE OF THE GREATER EXPENSES USUALLY INVOLVED. UNLESS SIGNIFICANT CHANGES ARE MADE, THE OVERWHELMING BURDEN OF CARING FOR THESE INDIVIDUALS IS LIKELY TO CONTINUE TO FALL DISPROPORTIONATELY ON LOCALITIES AND ESPECIALLY ON PUBLIC HOSPITALS. WE ESTIMATE THAT IN CITY FISCAL YEAR 1987, $278 MILLION WAS SPENT ON AIDS SERVICES IN NEW YORK CITY. OF THAT AMOUNT, $74 MILLION WAS PAID DIRECTLY FROM CITY FUNDS. FOR CITY FISCAL YEAR 1988, WE ESTIMATE A DRAMATIC INCREASE IN THESE COSTS: A TOTAL OF $389 MILLION FOR SERVICES TO PERSONS WITH AIDS.

AS STATED EARLIER, HHC PROVIDES THIRTY-THREE PERCENT OF ALL INPATIENT CARE FOR NEW YORK CITY RESIDENTS WITH AIDS. SEVENTY PERCENT OF THESE PATIENTS ARE COVERED BY MEDICAID, SIX PERCENT HAVE BLUE CROSS, ONE PERCENT ARE COVERED BY MEDICARE, AND LESS THAN ONE PERCENT HAVE COMMERCIAL INSURANCE. TWELVE PERCENT ARE, HOWEVER, SELF-PAY AND THESE TRANSLATE TO UNREIMBURSED COSTS OF APPROXIMATELY $36 MILLION A YEAR. IN THE FACE OF INADEQUATE FEDERAL AND

STATE REIMBURSEMENT, FUNDING FOR UNREIMBURSED CARE FOR AIDS PATIENTS IS PROVIDED BY THE CITY THROUGH GENERAL SUPPORT.

TREATMENT COSTS MAY VARY SIGNIFICANTLY FROM ONE LOCALITY TO ANOTHER AND IT IS IMPORTANT THAT YOU UNDERSTAND SOME OF THE REASONS FOR THIS. AIDS PATIENT POPULATIONS DIFFER IN VARIOUS PARTS OF THE COUNTRY, AND, AS A RESULT, MUNICIPALITIES HAVE RESPONDED TO THE CRISIS WITH DIFFERENT APPROACHES. WE HAVE A PARTICULARLY COSTLY CASE MIX OF AIDS PATIENTS, AS WE TREAT A DISPROPORTIONATE SHARE OF INDIVIDUALS WHO ARE SUBSTANCE ABUSERS. WE WOULD THEREFORE EXPECT OUR DATA TO REFLECT THE MORE COSTLY ADMISSIONS. IN LOOKING AT THE DIAGNOSIS, IN SAN FRANCISCO ABOUT 31 PERCENT OF THE ADMISSIONS HAVE PNEUMOCYSTIS. ON THE OTHER HAND, IN NEW YORK CITY OVER 60 PERCENT OF THE CASES REPORTED BY THE HEALTH DEPARTMENT HAVE PNEUMOCYSTIS, AND ABOUT 60 PERCENT OF PNEUMOCYSTIS PATIENTS ARE DRUG ABUSERS. I THINK THIS MAY EXPLAIN THE PREDOMINANCE OF MORE INTENSIVE AND COSTLY HOSPITALIZATION IN OUR SYSTEM.

WE HAVE ALSO TAKEN A FOCUSED LOOK AT SPECIFIC FACTORS IN THE COSTS OF HOSPITALIZATION, OTHER THAN THE FUNDAMENTALLY POORER HEALTH STATUS OF MANY OF OUR PATIENTS WHO ARE DRUG ABUSERS. A STUDY THAT WE DID ON NURSING CARE HOURS, USING A PATIENT CLASSIFICATION SYSTEM, SHOWS THAT AIDS PATIENTS ON THE MEDICAL-SURGICAL UNITS REQUIRE ABOUT 40 PERCENT MORE DIRECT NURSING CARE THAN OUR AVERAGE MEDICAL-SURGICAL PATIENT AND THAT PEDIATRIC AIDS PATIENTS REQUIRE MORE THAN TWICE THE NURSING CARE HOURS REQUIRED BY OUR AVERAGE PEDIATRIC PATIENT.

STUDIES IN TWO OF OUR LARGER HOSPITALS SHOW THAT THE COST OF DRUG TREATMENT IS TWICE AS HIGH FOR AIDS PATIENTS, THAT THEY CARRY ABOUT TWICE AS MANY SECONDARY DIAGNOSES AS THE AVERAGE MEDICAL-SURGICAL PATIENT, AND THAT THE LENGTH OF STAY IS CONSIDERABLY LONGER -- ABOUT 14 DAYS LONGER. THE AVERAGE LENGTH OF STAY FOR AIDS PATIENTS IN OUR HOSPITALS IS NOW 21 DAYS, COMPARED WITH ABOUT 11 DAYS IN SAN FRANCISCO.

NEW YORK STATE HAS PROPOSED TO ENHANCE PER DIEM REIMBURSEMENT UNDER MEDICAID FOR HOSPITALS DESIGNATED AS AIDS CENTERS WITH A COMPREHENSIVE APPROACH TO

CARE LINKING INPATIENT SERVICES, AMBULATORY CARE, HOME HEALTH CARE, PSYCHIATRIC AND PSYCHOSOCIAL SERVICES, HOUSING, AND LEGAL AND FINANCIAL ARRANGEMENTS. WE ARE CONCERNED THAT THE REIMBURSEMENT RATE PROPOSED FOR SUCH CENTERS MAY NOT COVER THE INCREMENTAL COSTS OF WHAT WE AGREE ARE AN IMPORTANT ARRAY OF SERVICES.

WE AT HHC FEEL VERY STRONGLY THAT AIDS, LIKE DRUG ABUSE AND HOMELESSNESS, IS A NATIONAL ISSUE THAT DEMANDS ENLIGHTENED AND AGGRESSIVE FEDERAL LEADERSHIP IN THE AREAS OF RESEARCH, PREVENTION, EDUCATION, AND DIRECT PATIENT CARE SERVICES DIRECT HEALTH SERVICES SHOULD BE A FEDERAL ONE. THE FEDERAL GOVERNMENT MUST TAKE RESPONSIBILITY FOR ENSURING THAT STATE AND LOCAL GOVERNMENTS HAVE THE RESOURCES NEEDED TO CARE FOR PERSONS WITH AIDS. SPECIFICALLY, THE CONGRESS SHOULD :

- WAIVE THE TWO-YEAR WAITING PERIOD FOR MEDICARE ELIGIBILITY FOR PERSONS WITH AIDS AFTER THEY ARE CERTIFIED AS DISABLED. WE STRONGLY SUPPORT SENATOR MOYNIHAN'S PROPOSAL FOR SUCH AN EXEMPTION SINCE 50 TO 70 PERCENT OF AIDS PATIENTS DIE WITHIN TWO YEARS OF DIAGNOSIS, NEVER BECOMING ELIGIBLE FOR MEDICARE.

- REQUIRE THE HEALTH CARE FINANCING ADMINISTRATION TO DEVELOP DRG'S FOR AIDS THAT ADEQUATELY REFLECT THE COSTS, LENGTHS OF STAY, AND INTENSITY OF ILLNESS. THIS IS ESPECIALLY IMPORTANT SINCE MANY STATES PATTERN THEIR MEDICAID REIMBURSEMENT ON THE FEDERAL DRG SYSTEM.

- BROADEN INSTITUTIONAL LONG-TERM CARE AND HOME HEALTH MEDICARE COVERAGE FOR PERSONS WITH AIDS.

- WAIVE THE MEDICARE HOSPICE REQUIREMENT THAT ONLY 20 PERCENT OF TOTAL PATIENT DAYS ARE REIMBURSABLE AT THE INPATIENT RATE.

- EXPAND FEDERAL EFFORTS IN PUBLIC EDUCATION AND MEDICAL RESEARCH. WE SUPPORT THE LEGISLATION INTRODUCED BY CONGRESSMAN RANGEL AND SENATOR

KENNEDY WHICH DESIGNATES AIDS AS A NATIONAL PUBLIC HEALTH EMERGENCY AND INCREASES INFORMATION, EDUCATION, TREATMENT AND RESEARCH.

CURRENTLY, THE BEST HOPE OF MANY AIDS PATIENTS FOR IMPROVED QUALITY OF LIFE AND SURVIVAL RESTS WITH AZT AND OTHER EXPERIMENTAL DRUG THERAPIES. IN DECEMBER 1986, HHC BEGAN TO PROVIDE AZT TREATMENT UNDER AN EXPERIMENTAL DRUG PROTOCOL TO PATIENTS IN AMBULATORY CARE CLINICS AT NINE HHC FACILITIES. IN MARCH 1987, AZT WAS LICENSED FOR MORE GENERAL RELEASE BY THE FOOD AND DRUG ADMINISTRATION. THE CITY AUTHORIZED FUNDING FOR AZT TREATMENT FOR AIDS PATIENTS IN FEBRUARY, 1987. OVER 200 PATIENTS ARE ENROLLED AND ARE RECEIVING AZT. WE EXPECT THIS TREATMENT WILL BE EXPANDED TO 800 PATIENTS IN FY 1988.

WE ARE PLEASED BY RECENT FEDERAL LEGISLATIVE INITIATIVES IN THE FISCAL 1987 SUPPLEMENTAL APPROPRIATIONS BILL WHICH AUTHORIZES GOVERNMENT PURCHASE OF AZT FOR THOSE WHO CANNOT AFFORD TO PAY.

IN CLOSING, I WOULD LIKE TO STRESS AGAIN THAT AIDS IS A NATIONAL ISSUE. WHILE FOUR YEARS AGO, NEW YORK CITY REPRESENTED 52 PERCENT OF ALL AIDS CASES NATIONWIDE, TODAY THAT FIGURE IS ONLY 30 PERCENT, LARGELY DUE TO INCREASING INCIDENCE ELSEWHERE IN THE COUNTRY. THE IDENTITY OF THE PRIME RISK GROUP HAS ALSO SHIFTED, A FACT THAT HAS GREAT SIGNIFICANCE FOR FUTURE PLANNING. FIVE YEARS AGO, IT WAS 14 PERCENT IV DRUG USERS NATIONWIDE; TODAY, NEARLY 45 PERCENT OF THE NEW CASES ARE IN THIS CATEGORY.

WE IN NEW YORK CITY'S PUBLIC HOSPITALS ARE SEEING THE IMPACT OF THIS SHIFTING EPIDEMIOLOGY -- THE COMPLEXITY OF THE TREATMENT PROGRAMS NEEDED, THE DIFFICULTY OF STAFF IN SUSTAINING THEIR WORK WITH A DIFFICULT AND OFTEN UNCOOPERATIVE GROUP OF PATIENTS, THE EXPENSE OF CARING FOR THE SEVERELY ILL WITH AIDS AND OF MOUNTING AN ADDITIONAL ATTACK ON THEIR DRUG ABUSE, THE INADEQUACIES OF CURRENT NATIONAL HEALTH POLICY ON PREVENTION STRATEGIES AND SUPPORT FOR TREATMENT PROGRAMS.

THE FEDERAL GOVERNMENT MUST PROVIDE DYNAMIC LEADERSHIP TO COMBAT AIDS AND THE ASSOCIATED PUBLIC HEALTH CRISIS OF DRUG ABUSE. PREVENTION STRATEGIES MUST BE LINKED WITH DRUG TREATMENT PROGRAMS AND CREATIVE APPROACHES TO REACH OUT TO

THE DRUG ABUSING AIDS POPULATION MUST BE ENCOURAGED. FINALLY, THE FEDERAL GOVERNMENT MUST ADD THE ISSUE OF REIMBURSEMENT FOR THIS CATASTROPHIC ILLNESS TO ITS AGENDA OF AIDS-RELATED CONCERNS. OTHERWISE, WE WILL ADD ANOTHER GROUP OF CITIZENS TO THE GROWING LIST OF THOSE DENIED ACCESS TO HEALTH CARE IN THIS NATION BECAUSE THEY LACK THE APPROPRIATE INSURANCE AND HAVE NO RESOURCES OF THEIR OWN. THANK YOU.

STATEMENT OF DR. JOHN SCHUNHOFF, ASSISTANT ADMINISTRATOR, AIDS PROGRAM, LOS ANGELES COUNTY DEPARTMENT OF HEALTH SERVICES, LOS ANGELES, CA

Dr. SCHUNHOFF. Thank you, Mr. Chairman. Thank you for the opportunity to testify this morning. Los Angeles County has an extensive health care system which operates six hospitals, 47 health centers, and two rehabilitation centers.

We have a special responsibility in Los Angeles for the care of the medically indigent and the poor. Four-fifths of our patients are either medically indigent or otherwise without access to health care, and two-thirds of those are not on MediCal. They are borne by the county. You will see when I talk about the AIDS statistics in a few minutes, those will be a little bit different.

To give you a brief overview of our AIDS statistics, we have 3,500 CDC-defined AIDS cases at the moment in Los Angeles. We are projecting up to 30,000 cases within the next five years.

Senator MOYNIHAN. Now, just hold it right there.

Dr. SCHUNHOFF. Yes.

Senator MOYNIHAN. That is a cumulative figure?

Dr. SCHUNHOFF. That is a cumulative figure.

Senator MOYNIHAN. But that is still a compounding rate, isn't it?

Dr. SCHUNHOFF. That is right. The other statistic is that we have about 1,300 persons living with AIDS at the moment in Los Angeles; and given a constant mortality rate with those 30,000 cases, we would have 11,400 persons alive with AIDS in another five years. It shows you that that is about a nine-fold increase in persons needing medical services.

Senator MOYNIHAN. Yes.

Dr. SCHUNHOFF. That does not include the ARC patients or persons with HIV positivity who have just minor symptoms but still need medical attention. In Los Angeles, we have a profile which is much different from the one presented by the woman from New York. We have 92 percent of our cases still in the homosexual and bisexual male category and only two percent are represented exclusively by I.V. drug use.

Senator MOYNIHAN. I noted you used the word "still" as if there is a pattern of development.

Dr. SCHUNHOFF. It is a concern of ours that the number of cases in the I.V. drug area will escalate. So far, it appears to us that the seroprevalence among I.V. drug users in Los Angeles is still very low, compared with New York and New Jersey, but that is our area of greatest concern at the moment.

In our system, we are seeing about one-third of the total patients in Los Angeles County; the other two-thirds are being seen by private providers. We have an average inpatient census in our county hospitals of about 40 patients, and we are following over 800 outpatients through our clinics. The patients we see are most likely to not have private insurance and are most likely to be dependent upon MediCal or upon county payment; and very few are eligible for Medicare simply because of the 24-month waiting period.

We spent approximately $9.3 million on AIDS in the department in 1985–1986, and we spent about $15 million in 1986–1987. Eighty-five percent of that in both those years was for medical care. Of the

medical care in this last year, which amounted to about $12.6 million, 65 percent of that was reimbursed by MediCal, about five percent of it was reimbursed by patients and insurance, 0.1 percent was reimbursed by Medicare, and the remaining 29 percent by the county. Case projections would project that we would have up to about $110 million worth of annual medical care costs within the five-year period, if those projections hold true.

Because of those costs, we are looking extensively at alternatives to inpatient care. At the moment in Los Angeles, we have almost nothing available for patients between the acute hospital bed and home; and even services at home are somewhat limited because the State has not yet applied for the waiver under MediCal (California's Medicaid) for home-based services. That is expected to come in in the next month and should be available for us to use about a year from now.

We are proceeding ahead in the county with a pilot program in various areas of alternatives to inpatient care, including developing subacute care, skilled nursing care, and supplementing the home-based care, particularly in the area of attendant care, which is currently not reimbursed under MediCal. We are also working on developing housing for AIDS patients. That is becoming a critical need within the county.

A couple of points as a conclusion: The increases that we have put in our budget this year from the county for AIDS have come from other health services, which is to say that there is a tradeoff. And to the extent that our AIDS expenditures increase, we may be faced with increasingly difficult choices in terms of cutting other health care services. This is particularly because of the constraints on the county for financing.

Finally, I would like to note that the county has as a part of its legislative policy for this year support of any legislation which removes the 24-month waiting period.

Senator MOYNIHAN. You will comment on that?

Dr. SCHUNHOFF. That is right. So, the county will support your bill, S. 24, to that effect.

Senator MOYNIHAN. We will take help anywhere we can find it. [Laughter]

We don't find much in Washington, but sometimes we get it in the country at large. Thank you, Doctor. Now, Dr. Haughton. Just for the record, Dr. Haughton is the Director of Health and Human Services for the City of Houston. May I say that Senator Bentsen sends his particular regards to you; he is abiding in other parts of the building, just as we all are. The first few days we are back, every committee holds hearings on everything; so we are a bit stretched. Dr. Haughton?

[The prepared statement of Dr. Schunhoff follows:]

JOHN F. SCHUNHOFF, Ph.D.
ACTING ASSISTANT ADMINISTRATOR, AIDS PROGRAM OFFICE
DEPARTMENT OF HEALTH SERVICES, LOS ANGELES COUNTY

BEFORE THE

SUBCOMMITTEE ON SOCIAL SECURITY AND FAMILY POLICY
U.S. SENATE COMMITTEE ON FINANCE
SEPTEMBER 10, 1987

A. INTRODUCTION

1. I am John F. Schunhoff, Acting Assistant Administrator, AIDS Program Office, Los Angeles County, California. Thank you for the opportunity to testify today.

2. I would like to give background information first, then describe our current patient load and financial picture, describe our projections for the future and finally discuss alternatives we are exploring.

B. BACKGROUND

1. Los Angeles County operates six hospitals, forty-seven ambulatory care and health centers, and two rehabilitation centers. The County also contracts with private hospitals, doctors, and other service providers for health care.

2. The County's mission is to prevent disease, promote health and provide high-quality personal health service within the County.

3. Los Angeles County maintains a special responsibility for the care of the medically indigent and those otherwise without access to health services. Approximately four-fifths of the people the County cares for are poor. Of these, about two-thirds are County indigents, those not qualified for Medi-Cal or other payment programs.

C. CURRENT AND PROJECTED CASE LOAD

1. As of July 31, 1987, there were 3,459 cumulative cases of Acquired Immune Deficiency Syndrome

(AIDS) in Los Angeles County. Of those, 1,294 are alive and in need of medical services. We have estimated that Los Angeles County will have as many as 30,000 cumulative AIDS cases by the end of 1991. Assuming a constant mortality rate, as many as 11,400 persons could be living with AIDS in the County in 1991. This is nearly a ninefold increase in persons needing medical services.

2. The AIDS case statistics do not show the entire picture. Many more persons are HIV-infected and the number of persons with AIDS-Related Complex (ARC) is estimated to be up to ten times the number of AIDS cases.

3. Ninety-two percent of the diagnosed AIDS cases in Los Angeles County to date are among homosexual/bisexual men. Only two percent are heterosexual IV drug users. Thus, Los Angeles has yet to see the large number and percentage of IV drug-related cases, as seen in New York and New Jersey.

4. We estimate that a third of the AIDS/ARC patients in Los Angeles County are being treated in County facilities. We have a caseload of over 800 patients in our outpatient clinics and an average inpatient hospital census in excess of 40. This inpatient census constitutes about 1.3% of our budgeted inpatient census capacity of 3,000.

5. A recent study of the AIDS outpatient clinic at LAC/USC General Hospital, confirmed that the County patient population contains greater percentages of Blacks and Latinos than found in the overall AIDS case statistics.

6. The patients seen at our hospitals and clinics are also less likely to have private insurance and are more dependent on Medi-Cal or are County patients.

7. Due to the 24-month waiting period, very few of our patients are eligible for Medicare.

8. Assuming that the County will continue to provide medical care for a third of all of the AIDS/ARC patients in Los Angeles County, if our case projections are correct, the outpatient clinics could be following over 6,000 persons by the end of 1991 and our average inpatient census could reach 350, or twelve percent of our current budgeted hospital capacity.

D. FINANCIAL IMPACT

1. Total spending for AIDS in the Department of Health Services rose from $9,348,000 in 1985-86 to an estimated $15,079,000 in 1986-87. Eighty-five percent of the expenditures in the past two years have been for inpatient and outpatient medical care in our hospitals.

2. Of the estimated $12,628,000 spent for medical care in 1986-87, 65% was reimbursed by Medi-Cal, 5% was reimbursed by patients, insurance and other payors, 0.1% was received from Medicare and the remaining 29% was paid from County funds.

3. Utilizing the case projections cited previously, and using an average inpatient cost per day of $725, Los Angeles County's annual inpatient hospital costs alone could exceed $92 million by the end of 1991. Total medical care costs could exceed $110 million. With current reimbursement percentages, the County's share of that would be $32 million.

E. DEVELOPMENT OF ALTERNATIVES

1. Because of the high costs of acute inpatient care and the projections of caseloads in the near future, a top priority of the Los Angeles Department of Health Services is the development of alternatives to acute inpatient care to enable us to care for patients in the most cost-effective manner.

2. In Los Angeles County there are essentially no available options between acute inpatient care

and home health care. Even home health care is restricted due to the limited reimbursement under Medi-Cal for such services. This problem should be alleviated somewhat by the approval of the waiver application which the California Department of Health Services will soon submit for Medi-Cal reimbursement of a broader spectrum of home-based services, without which patients must stay in acute beds longer than necessary.

3. In addition to increased home health services, we are working with community-based and private sector providers to develop other alternatives to acute inpatient care, including subacute care, skilled nursing care, and adult day care.

4. Another vital need is housing for AIDS patients who are unable to maintain themselves at home. The County is currently working with several community-based AIDS service organizations on the development of residential and residential/hospice facilities. A key problem here is also financing.

5. Because of the increased needs and expected overall cost savings, the Los Angeles County Department of Health Services has budgeted $1.5 million of its $38.5 million 1987-88 AIDS budget for a pilot program of alternatives to inpatient care. Included in this pilot will be an enhanced case management system, supplemental funding for home health care, a pilot day care project and supplements for residential and skilled nursing care.

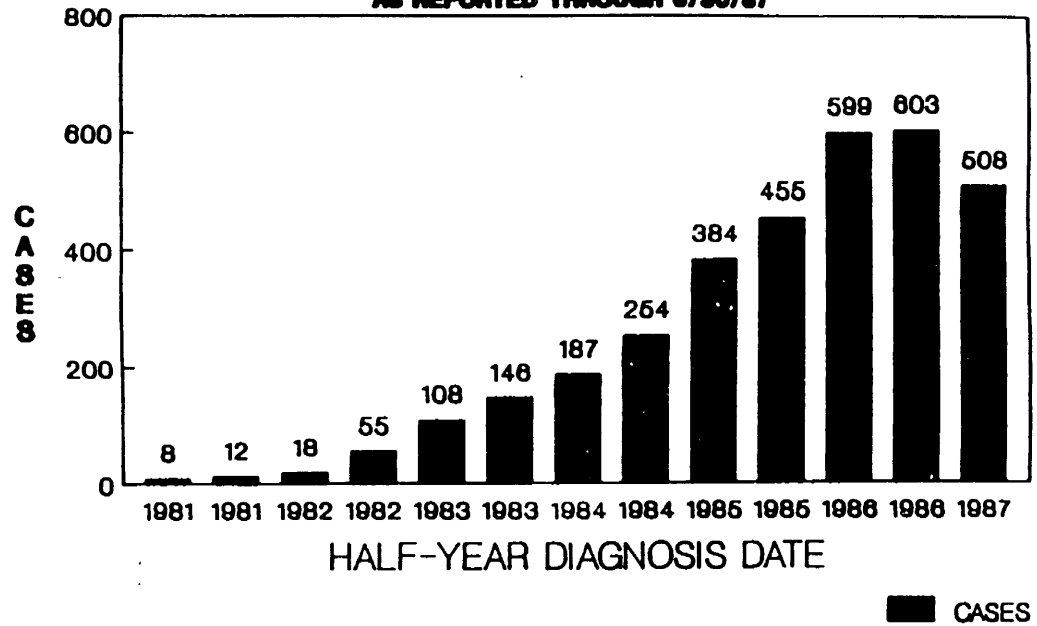
F. CONCLUSIONS

1. As briefly demonstrated here, AIDS is having a major impact on the health care system of Los Angeles County. We are only beginning to feel its effects. Without additional state and federal resources, we will be faced regularly with the difficult task of cutting other vital health care services in order to pay for the increasing costs of AIDS patients.

2. Now is the time to develop innovative alternatives and cost-effective programs in order to withstand the projected growth in cases in the next five to ten years.

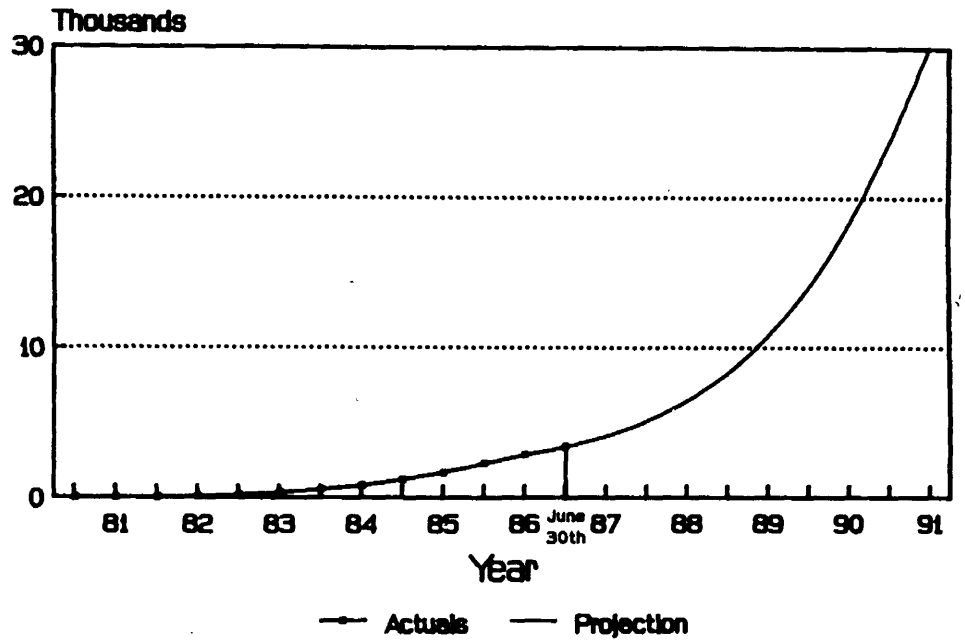
CASES OF AIDS BY HALF YEAR OF DIAGNOSIS
LOS ANGELES COUNTY

CASES DIAGNOSED 1/1/81-6/30/87
AS REPORTED THROUGH 6/30/87



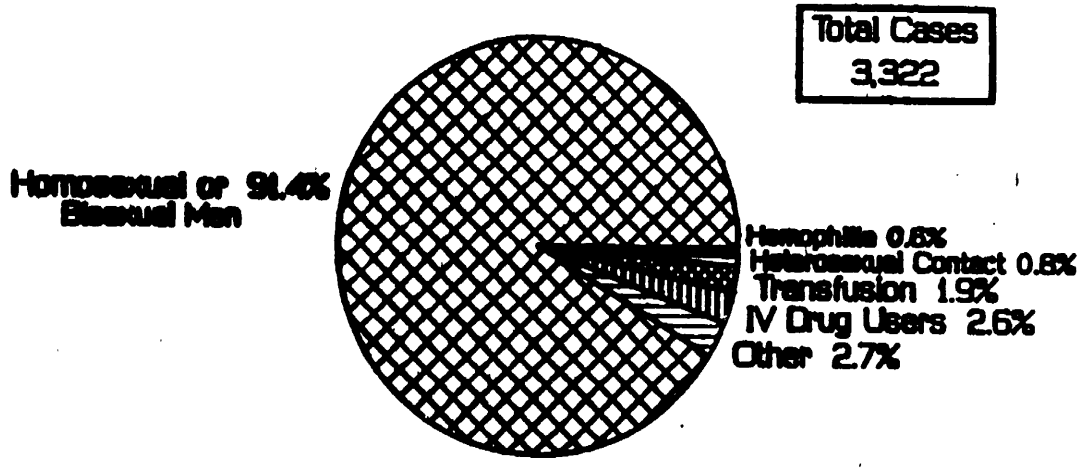
*EXCLUDES 3 CASES DIAGNOSED PRIOR TO 1981. DATA FOR RECENT MONTHS ARE INCOMPLETE.

CUMULATIVE CASES OF AIDS
LOS ANGELES COUNTY
1981-91

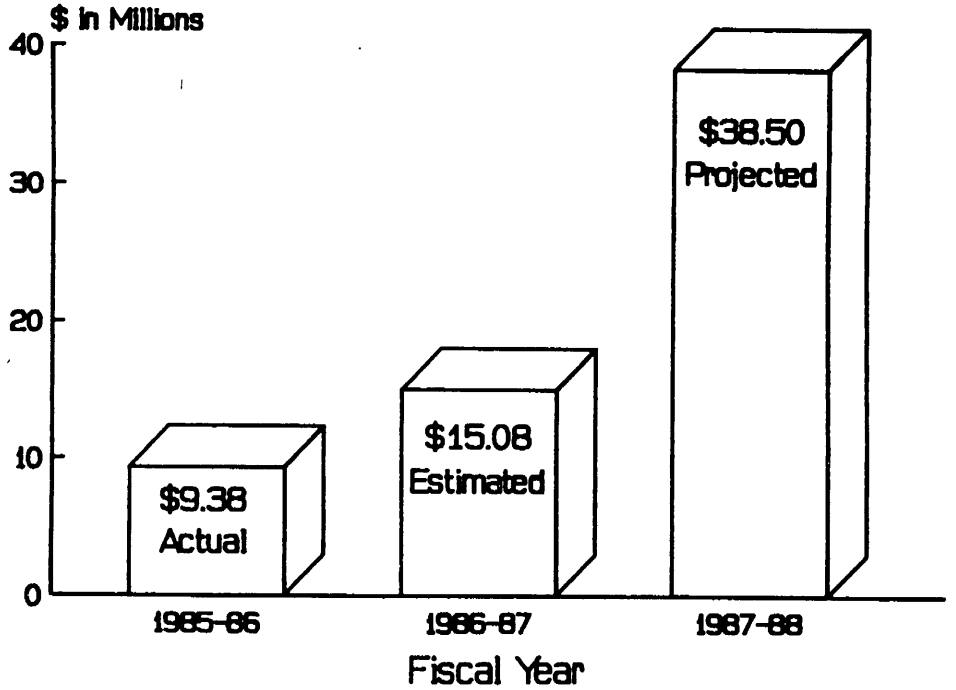


ADULT AIDS CASES
LOS ANGELES COUNTY
BY PATIENT CHARACTERISTICS

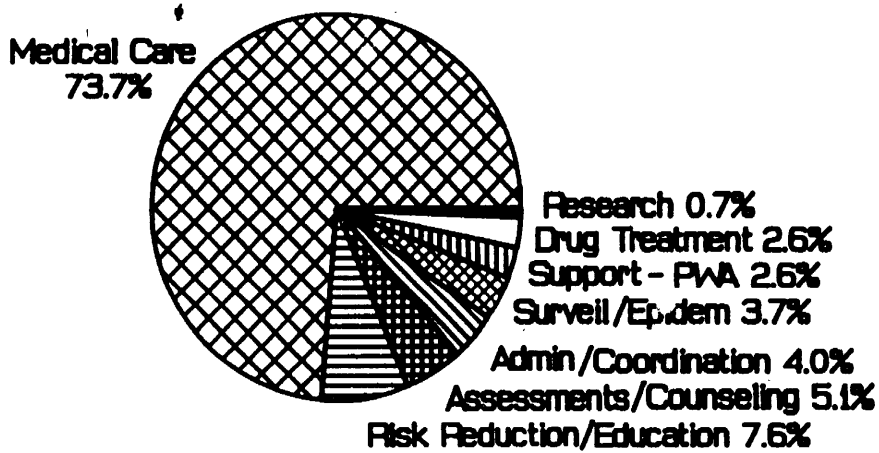
JUNE 1987



AIDS - RELATED EXPENDITURES
DEPARTMENT OF HEALTH SERVICES



AIDS - RELATED EXPENDITURES
DEPARTMENT OF HEALTH SERVICES
1987-88



USES

STATEMENT OF DR. JAMES G. HAUGHTON, DIRECTOR, HEALTH AND HUMAN SERVICES, CITY OF HOUSTON, HOUSTON, TX

Dr. HAUGHTON. Thank you, Senator. I appreciate the invitation to address your subcommittee. I am currently Director of Public Health and Human Services in the City of Houston, but I will soon be Medical Director of the King/Drew Center in the Los Angeles County Department of Health Services. I will be joining Dr. Schunhoff within the next month or so.

Let me begin by presenting the proposition that AIDS is a national problem only to the extent that the virus seems to behave in the same way everywhere and that the modes of transmission are the same. Beyond that, the strong behavioral etiology of the disease makes it a different problem of control in different communities.

The first case of AIDS was diagnosed in Houston in 1980. Since then, we have had 1,393 cases reported, 94 percent of which have been in gay and bisexual men. A subset of those 94 percent are intravenous drug users as well, about 10 percent. We have had only 28 women with AIDS in Houston over these seven years; we have had only 11 children with AIDS. We believe that is because less than two percent of our cases have intravenous drug abuse as their solitary risk factor.

We have had only 22 cases of intravenous drug use related to AIDS in Houston over the last seven years. You have no doubt been told that Blacks and Hispanics are at greater risk of AIDS than are whites, and you have been quoted data which show that nationally, where 24 percent of AIDS cases have been Black, only 12 percent of the population is Black; and where 14 percent of the cases have been Hispanic, only six percent of our national population is Hispanic.

In my view, it is neither scientifically accurate nor ethically defensible, to infer from data so heavily skewed by drug use in New York, Newark, and Miami that Blacks and Hispanics have a special susceptibility to this disease. What we are really seeing is that, because Blacks and Hispanics and other minorities are overrepresented among the poor, they are also overrepresented among drug abusers; and that is the reason why we see that percentage of AIDS in those cities where drug abuse is a special problem.

When you look at other cities with large populations of AIDS—as two of us here represent—San Francisco, Los Angeles, and Houston—if you look at page II of my prepared testimony, you will see that in San Francisco, where 45 percent of the population is minority—that is, Black, Hispanic and Asian—only 14.5 percent of the cases are those minorities.

In Los Angeles, where 46 percent of the population is Black, Hispanic and Asian, 30 percent of the cases are in those three population groups. So, in parts of the country where intravenous drug use is not a major problem, then you don't find minorities overrepresented among the AIDS cases.

On the contrary, they are a smaller part of the AIDS cases.

Senator MOYNIHAN. So, the distribution of AIDS in this regard is a dependent variable in the behavioral etiology, as you described it?

Dr. HAUGHTON. Exactly. Now, in the City of Houston, we have a problem. One of my frustrations there is the limitations of my responsibility with regard to health services. I previously worked in New York City and Chicago and Los Angeles, where the scope of responsibility was much broader. In Texas, we have never had a strong Medicaid Program and, so, the State provides for the medically needy by authorizing counties to create hospital districts which are single-purpose units of government with their independent real estate tax base; but it also provides that if a county elects to create a hospital district, then no other local unit of government within that county can spend local funds for medical care. So, the public health department is limited to providing only preventive services.

The only diseases we treat are sexually transmitted diseases and tuberculosis. So, our responsibility as a health department in Houston is limited to surveillance, reporting, and education.

The three major sources of hospital care in Houston for people with AIDS are shown on page 3 of my testimony. M. D. Anderson Hospital and Cancer Institute is a State-supported cancer institution. They became involved in AIDS early on because, when Kaposi sarcoma appeared as a concomitant of AIDS, because of their interest in cancer research, they were curious about AIDS. So, they practically solicited all the AIDS patients in Houston over the next few years.

About two years ago, they decided that they could no longer support that much care for AIDS patients with their cancer funds; and so, at that time, the hospital district created an AIDS inpatient unit at Jefferson Davis Hospital. That is one of the hospitals of the local county hospital district there.

One other interesting phenomenon in Houston is that another large group of patients is being cared for at an investor-owned hospital called Park Plaza owned by American Medical International, the same organization that created what has been touted nationally as the only AIDS hospital in the country. You will see the difference in the cost of care at those three institutions. Incidentally, you may put in the number $1,652.00 a day in the Park Plaza column on page 3.

When I sent this down yesterday, I didn't have that number from them yet. At Park Plaza, their charges per day for an AIDS patient average about $1,652.00 a day.

Senator MOYNIHAN. And that is the private institution?

Dr. HAUGHTON. That is a private, investor-owned hospital. It is part of the AMI chain. At the county hospital, by comparison, their average cost per day is between $540.00 and $560.00 a day; and at M. D. Anderson, the State hospital—when they were still in the business of taking care of AIDS patients—their costs were about $1,000.00 a day, but they no longer take care of AIDS patients.

Clearly, this is a costly endeavor, and especially when one considers that the outcome has been uniformly fatal. Sixty-one percent of all the cases of AIDS in Houston have already died. Of the 1,393 cases that we have had reported, only 544 are still alive.

Now, because of the drain on their resources, M. D. Anderson decided almost two years ago that they would discontinue providing AIDS care, and they went into a joint venture with AMI to create

what has become known nationally as an AIDS hospital. It is really not a hospital; it is an institute for immunological disorders research.

Their plan was that AMI was supposed to provide $500,000 a year of uncompensated care, and $250,000 a year for research over a four-year period. The hope was that this institution would attract a lot of Federal research funds and perhaps medical care funds. That, of course, has not happened.

So, six months after the Institute for Immunological Disorders opened, they announced that they had already provided $1.5 million of uncompensated care and that they could not continue that. Then, two months ago—or last month, as a matter of fact—they announced that they would be closing the institute because they have now spent $2 million on uncompensated care. So, the Institute for Immunological Disorders Research is being phased out at this moment.

Part of the problem is what happens with patients in Texas. Under Texas Medicaid, there is a spell of illness policy which limits care to 30 days of hospital care, and the patient must be out of the hospital for 60 days before another spell of illness begins.

Here is a scenario. A patient who has had ARC and who has exhausted his health insurance may now be confirmed as a case of AIDS; he may now be unemployed. So, he has either exhausted his health insurance, or he has lost it because he is unemployed. He applies for SSI. He is approved for SSI, presumptively eligible, and he begins to get a small SSI check. That triggers his Medicaid benefits, but in Texas that means he can get ambulatory care and he can get hospital care for 30 days; and after that, he has to wait 60 days before the next 30 days can start.

So, he goes into the hospital with PCP, and he is there for 20 days; and he is discharged. Then a few weeks later, he is again hospitalized. On the tenth day, the clock stops ticking; and the hospital is now providing uncompensated care.

Another scenario. He does get his SSI, and then he needs hospitalization; but while he is in the hospital, he gets the good news that he has been found to be eligible for disability benefits. Now, he gets a bigger check from Social Security, but his Medicaid is cancelled. He now must wait 24 months before he is eligible for any Medicare benefits.

Senator MOYNIHAN. 24 months. Right.

Dr. HAUGHTON. I heard Dr. Koop speaking on television recently about doctors denying care to people with AIDS. It is true that there are some physicians and other health workers who misguidedly are afraid to deal with AIDS patients; but the fact is that—at least in my State—some of the reluctance is that you are playing Russian roulette financially. You don't know whether you are going to be paid for the care. So, doctors and hospitals as well are reluctant to get involved.

Senator MOYNIHAN. But Doctor, would you say that if we waived this 24-month period, that would solve that problem? Of course, Medicare is much more a national financial responsibility than is Medicaid.

Dr. HAUGHTON. Right.

Senator MOYNIHAN. It would relieve that?

Dr. HAUGHTON. It would be a major step forward because it would relieve the uncertainty of the providers as to whether or not the care they were providing was uncompensated care. In fact, with that provision, the Institute for Immunological Disorders might have survived.

Senator MOYNIHAN. That is an important point.

Dr. HAUGHTON. And with that research institute now no longer available, it means that there will be no AIDS treatment evaluation unit between San Diego and New Orleans.

Senator MOYNIHAN. Could I ask you if you could just send us a note as to what you just said?

Dr. HAUGHTON. Yes.

Senator MOYNIHAN. That had we had S. 24, the Institute would not be closing, and we would not find ourselves without—what did you say?—a single research facility between San Diego and New Orleans?

Dr. HAUGHTON. Right. There are AIDS treatment evaluation units that are testing the various drugs that are becoming available. When that institute closes, there will be no treatment evaluating unit of that kind between San Diego and New Orleans.

Senator MOYNIHAN. And it closes when?

Dr. HAUGHTON. They have announced that it is expected to be closed by January. They are now phasing it out.

Senator MOYNIHAN. All right. Now, that is all very solid and very real testimony.

[The prepared statement of Dr. Haughton follows:]

James G. Haughton, M.D., M.P.H.

Director, Houston Department of Health & Human Services

I am Dr. James G. Haughton. I am Director of the Department of Health and Human Services in the City of Houston and will soon be Medical Director of the King/Drew Medical Center of the Los Angeles County Department of Health Services in the City of Los Angeles.

I appreciate the invitation to address the subcommittee and welcome the opportunity to present you a sketch of the problem of AIDS in Houston.

Let me begin by presenting the proposition that AIDS is a national problem only to the extent that the virus seems to behave in the same way everywhere and that the modes of transmission are the same. Beyond that, because of the strong behavioral etiology of the disease, its control becomes a different problem in different environments.

The first case of AIDS was diagnosed in Houston in 1980. Since then 1393 cases have been reported. Of those, 94% have been in gay and bisexual men 10% of whom were also I-V drug abusers. 1.9% (28 cases) have been women and 0.8% (11 cases) have been children. Also worthy of note is that only 1.6% (22 cases) had I-V drug abuse as a solitary risk factor, and of the 11 children 7 resulted from maternal transmission from mothers at risk of AIDS. Heterosexual transmission has thus far been limited to 0.9% (12 cases).

That, so far, is the picture of AIDS in Houston after 7 years.

You have no doubt been told that Blacks and Hispanics are at greater risk of AIDS than are Whites, and you have been quoted data which show that nationally, 24% of AIDS cases have been Blacks and 14% have been Hispanics while these two groups represent only 12% and 6% of our national population respectively.

In my view, that presentation of the data is sophistic because it ignores the fact that if New York City, Newark, N.J. and Miami, Florida are excluded from the data, the picture changes dramatically. Furthermore, that presentation ignores the reality that in New York City 40% of the AIDS cases are I-V drug abusers, and in Newark and Miami the incidence is 60% and 16% I-V drug abuse cases respectively.

In those 3 cities minorities are, indeed, at great risk of AIDS simply because they form a large percentage of the drug abusing population.

In Houston, where only 1.6% of our AIDS cases cite I-V drug abuse as their only risk factor, 27% of our general population is black but only 10% of our cases are black; 21% of our population is hispanic but only 8% of our cases are hispanic. By contrast, 50% of our population is white, but 79% of our AIDS cases are white.

Therefore, in Houston, it is the white population which is at special risk of AIDS.

Similar analyses of the problem in San Francisco and Los Angeles in California reveal pictures similar to Houston.

In San Francisco, of the 3661 cases reported through July, 1987, 97% were in gay and bisexual men and 1.2% were I-V drug abusers.

The ethnic distribution of cases compared to the distribution of the general population is

CASES		POPULATION	
85%	white	53%	white
6%	black	12%	black
7%	hispanic	12%	hispanic
1.6%	Asian	21%	Asian

In Los Angeles, of the 3459 cases reported through the same date, 91.6% were gay and bisexual men and 3% were I-V drug abusers. The ethnic distribution of cases compared to the distribution of the general population is

CASES		POPULATION	
70%	white	53%	white
14%	black	12.6%	black
15%	hispanic	27.6%	hispanic
1%	asian	5.8%	asian

It is, therefore, clear from these data that it is not <u>who</u> one is, but what one <u>does</u> that puts him/her at risk of AIDS.

Fortunately, from the financial perspective, thus far the great majority of persons with AIDS have been young, employed people between 20 and 40 years of age many of whom have had employer-provided health insurance benefits. These have covered the early costs of their medical care; but in too many cases such benefits are exhausted during the course of the illness and before Medicare coverage begins.

Thus the AIDS dilemma presents many problems, and these problems differ with locale.

Clearly, the problem cannot be resolved on the east coast of our country without major attention to the problem of I-V drug abuse. This presents a major task for several reasons:

1. Education is currently our only reliable weapon against this syndrome, but I-V drug abusers do not readily present themselves as subjects for education, nor are they usually receptive to education when found.

2. Many drug abusers are black or hispanic and present special communication problems even when they are identified and receptive.

3. Their addiction must be overcome before AIDS education can be effective to remove them from the pool of carriers.

In the remainder of the country education must be aimed at a broader spectrum of citizens. Young people just beginning to be sexually active or beginning to experiment with drugs should be a special target of our educational efforts because hopefully we can convince them to avoid those behaviors.

In Houston, in the 1986-87 school year, the Department of Health and Human Services assisted the Houston Independent School District (HISD) in preparing a teaching film to inform school principals, teachers and nurses about AIDS, and last semester the District began pilot projects on family life education including information on AIDS in three middle schools.

Since then, the Harris County Medical Society and Houston Academy of Medicine (HCMS) has prepared a teacher-training film which HISD is now using. In addition, the HCMS has prepared a booklet on AIDS aimed at teenagers and has made it available to HISD.

The District intends to make these booklets available to teenagers 16 years and older at the discretion of the school principal and with parental consent. HCMS has also prepared a film for teenagers which HISD intends to show to the District's Parent-Teacher Association before using it in the schools. And this year the family life education program will be expanded to all the middle schools in the District.

We have been taking education to employee, civic and church groups, and we have reached large numbers of people through television and radio programs. In the meantime, organizations in the gay community have conducted major educational efforts within that portion of our community with outstanding success. Our sexually transmitted disease data bear witness to the fact that behavioral changes have taken place in the gay community.

We believe that it is as important to educate our population with regards to how AIDS is <u>not</u> spread as it is to teach the modes of transmission. Many citizens who are not

at risk of AIDS are very afraid of AIDS and must be constantly reassured, because they tend to be the opinion makers who influence public policy. We have managed to dampen hysteria in Houston by constantly informing this segment of our population about the latest knowledge on the subject.

AIDS is a serious national and international problem and merits important attention and serious financial support from the Congress, but this support should not continue to be provided by the diversion of resources from other important health programs. Our scientists have made great strides in addressing the problem in a very short time, and with your financial support and understanding will continue to decipher the riddle while we in public health continue our educational efforts to contain the growth of the problem by effecting behavioral change.

SOURCES

1. Houston Department of Health and Human Services
2. San Francisco Department of Health and Human Services
3. Los Angeles Department of Health Services
4. Park Plaza Hospital, Houston, Texas
5. M.D. Anderson Cancer Institute, Houston, Texas
6. Harris County Hospital District, Houston, Texas

AIDS SURVEILLANCE REPORT
HOUSTON DEPARTMENT OF HEALTH AND HUMAN SERVICES
BUREAU OF EPIDEMIOLOGY
September 8, 1987

LOCATION[1]	# CONFIRMED CASES CUMULATIVE[2]	# SUSPECT CASES CUMULATIVE[3]	TOTAL
Houston	1186	407	1593
Harris Co. (Non-Houston)	146	55	201
TOTAL	1332	462	1794
Montgomery County	11	2	13
Fort Bend County	24	9	33
Brazoria County	18	7	25
Liberty County	6	1	7
Waller County	2	0	2
SMSA CASE LOAD	1393	481	1874
Patients treated in the Houston SMSA who are from other parts of Texas, other states and countries.			318
Under investigation			35
TOTAL CASE LOAD			2227

SOURCE OF REPORT	CASES	PERCENT OF TOTAL
Hospital	1069	77%
Physician	205	15%
State Health Dept	42	3%
Vital Statistics	36	3%
National (CDC)	20	1%
Other agencies	21	1%
Total	1393	100%

[1]Location determined by residency at onset of illness suggestive of AIDS.
[2]Confirmed cases meet the Centers for Disease Control (CDC) definition for an AIDS case.
[3]Suspect cases are patients with conditions suggestive of AIDS but do not meet the CDC definition, or people with the preliminary signs and symptoms of AIDS.

Acquired Immunodeficiency Syndrome (AIDS)
HOUSTON SMSA Cases Meeting the CDC Surveillance Definition
Surveillance Report - 09/08/87

1. Disease Category

	Adult/Adolescent		Pediatric		Total	
	Cases (%)	Deaths (%)	Cases (%)	Deaths (%)	Cases (%)	Deaths (%)
KS without PCP	231 (17)	140 (61)	0 (0)	0 (.)	231 (17)	140 (61)
Both KS and PCP	145 (10)	112 (77)	0 (0)	0 (.)	145 (10)	112 (77)
PCP without KS	727 (53)	408 (56)	2 (18)	2 (100)	729 (52)	410 (56)
OI without KS or PCP	279 (20)	184 (66)	9 (82)	3 (33)	288 (21)	187 (65)
Total	1382 (100)	844 (61)	11 (100)	5 (45)	1393 (100)	849 (61)

2. Age

	Cases (%)
Under 13	11 (1)
13-19	4 (0)
20-29	369 (26)
30-39	699 (50)
40-49	227 (16)
Over 49	83 (6)
Unknown	0 (0)
Total	1393 (100)

3. Race/Ethnicity

	Adult/Adolescent Cases (%)	Pediatric Cases (%)	Total Cases (%)
White, Not Hispanic	1087 (79)	4 (36)	1091 (78)
Black, Not Hispanic	155 (11)	5 (45)	160 (11)
Hispanic	137 (10)	2 (18)	139 (10)
Other	3 (0)	0 (0)	3 (0)
Unknown	0 (0)	0 (0)	0 (0)
Total	1382 (100)	11 (100)	1393 (100)

4. Patient Groups

	Adult/Adolescent Males (%)	Females (%)	Total (%)
Homosexual or bisexual Men	1163 (86)	0 (0)	1163 (84)
Intravenous (IV) drug User	17 (1)	5 (18)	22 (2)
Homo/Bi IV drug User	132 (10)	0 (0)	132 (10)
Hemophiliac	2 (0)	0 (0)	2 (0)
Heterosexual contact	2 (0)	10 (36)	12 (1)
Born in NIR Country	1 (0)	1 (4)	2 (0)
Transfusion with blood/products	7 (1)	6 (21)	13 (1)
None of the above/Other	30 (2)	6 (21)	36 (3)
Total	1354 (100)	28 (100)	1382 (100)

	Pediatric Males (%)	Females (%)	Total (%)
Hemophiliac	1 (20)	0 (0)	1 (9)
Parent at risk/has AIDS	4 (80)	3 (50)	7 (64)
Transfusion with blood/products	0 (0)	3 (50)	3 (27)
None of the above/Other	0 (0)	0 (0)	0 (0)
Total	5 (100)	6 (100)	11 (100)

Acquired Immunodeficiency Syndrome (AIDS)
HOUSTON SMSA Cases Meeting the CDC Surveillance Definition
Surveillance Report - 09/08/87

5. Reported Cases of AIDS and Case-Fatality Rates by Half-Year of Diagnosis.

Half-Year of Diagnosis	Number of Cases	Number of Deaths	Case-Fatality Rate
Before 1980	0	0	----
1980 Jan -June	0	0	----
July-Dec	1	1	100%
1981 Jan -June	2	1	50%
July-Dec	6	5	83%
1982 Jan -June	5	5	100%
July-Dec	13	12	92%
1983 Jan -June	30	29	97%
July-Dec	47	46	98%
1984 Jan -June	81	74	91%
July-Dec	95	80	84%
1985 Jan -June	137	120	88%
July-Dec	188	143	76%
1986 Jan -June	257	167	65%
July-Dec	251	111	44%
1987 Jan -June	253	53	21%
July-Sep 8	27	2	7%
Totals	1393	849	61%

AIDS CASES AMONG ADULT MALES

HOUSTON - AUGUST 3, 1987

	WHITE	BLACK	HISPANIC	ASIAN	AMERICAN INDIAN	TOTAL
HOMO-BI MALE	907	111	102	1	1	1122
IV USER	3	10	3	0	0	16
HOMO-IV USER	107	8	14	0	0	129
HEMOPHIL	0	1	0	0	0	1
SEX CON	2	0	0	0	0	2
BORN NIR CNTY HAITIAN	0	1	0	0	0	1
B-TRANS	5	2	0	0	0	7
OTHER-UNK	13	9	6	1	0	29
TOTAL	1037	142	125	2	1	1307

TABLE I

COMPARISON OF TRANSMISSION CATEGORIES
HOUSTON SMSA VS OTHER U.S. CASES
JANUARY 1980 THROUGH AUGUST 3, 1987

Risk Factor	Houston Cases	Other U.S. Cases
Homosexual/Bisexual Male	84%	66%
I.V. Drug User	1.6%	16%
Homosexual/Bisexual Male and I.V. Drug User	10%	8%
Hemophiliac	0.08%	1.0%
Heterosexual Cases	0.9%	4%
Transfusion recipient	1.2%	2%
Parent at Risk for AIDS	0.5%	1.1%
Other/Unknown at this time	2.5%	3%
Women	1.9%	7%

TABLE 2

AIDS BY SELECTED RISK FACTORS AND COMMUNITIES
EXCLUDING FOREIGN-BORN NIR* CASES

THROUGH APRIL 6, 1987

PRIMARY RISK FACTORY

Community (SMSA)	Homosexual or Bisexual	IV Drug Only	Heterosexual Contact	Total Cases
New York	61.4%	31.6%	2.6%	9,336
Miami	71.3%	16.0%	3.4%	800
Newark	34.7%	54.5%	5.1%	775
San Francisco	96.1%	1.4%	0.4%	3,393
Los Angeles	91.6%	2.6%	0.8%	2,981
Houston	93.7%	1.7%	0.9%	1,126

* Foreign-born NIR (no identified risk) are from countries where heterosexual transmission plays a major role in transmission.

ETHNIC DISTRIBUTION OF AIDS CASES
HOUSTON VS OTHER U.S. CASES
AUGUST 3, 1987

Ethnic Group	Houston Population	Houston Cases	U.S. Population	Other U.S. Cases
White	50%	79%	81.4%	61%
Black	27%	10%	12%	24%
Hispanic	21%	9%	6%	14%

Senator MOYNIHAN. I want to ask the three of you, who are obviously major public health officials, some questions. Dr. Haughton, you said you have a rather light caseload so far. Of the 11 children with AIDS, seven resulted from maternal transmission at risk of AIDS.

Dr. HAUGHTON. Yes.

Senator MOYNIHAN. Heterosexual transmission has thus far been limited to 12 cases?

Dr. HAUGHTON. Yes.

Senator MOYNIHAN. Is that heterosexual transmission where there is the I.V. drug factor, or is it independent of that?

Dr. HAUGHTON. Of the 12 heterosexual cases we have had, some have been the sex partners of intravenous drug users, and some have not.

Senator MOYNIHAN. And some have not? All right. I suppose it is that some who have not that worries you.

Dr. HAUGHTON. But those who have not have admitted to high risk behavior, such as sexual intercourse with prostitutes.

Senator MOYNIHAN. Oh, right.

Dr. HAUGHTON. Of those 11, some have been men, but most have been women actually. Of the 12 or so, I believe 10 have been women, and two have been men.

Senator MOYNIHAN. Is that about the way things break out for you?

Dr. SCHUNHOFF. Yes, I think so. Amongst our pediatric cases, about half are from transfusions and half are from a mother at risk.

Dr. HAUGHTON. Yes. Of our 11 children, three have been transfusions; one was hemophilliac. As you know, children in neonatal centers receive many small blood transfusions; and so, prior to 1985, they were at risk. We have not had a new case of transfusion-related AIDS since the test became available.

Senator MOYNIHAN. All right. The blood supply is cleaned up now?

Dr. BOUFFORD. Absolutely.

Senator MOYNIHAN. That turns over rather rapidly, I suppose. I know nothing about this; blood supplies must have a shelf life, if I may put it that way.

Dr. HAUGHTON. 21 days.

Dr. BOUFFORD. It is really the new method that has gone into effect; and once you have that, you don't have that kind of problem.

Dr. HAUGHTON. So, we don't expect to see any more cases of blood transfusion or hemophillia-related AIDS.

Senator MOYNIHAN. Right. But you do want this legislation? Now, you do know there are people who don't, and you know why. There are people who say: Why should we spend our money on this disease? As doctors, you don't have to distinguish between diseases or people; there are not good diseases and bad. There are behavioral-related diseases, and I suppose if the truth were but known, most of our morbidity up until now in people under 50 is behavioral related, isn't it?

Dr. HAUGHTON. Let me make one additional point, Senator, with regard to education. In my view, at least in the part of the country

where I live, it is as important for me to educate those who are not at risk of AIDS as it is for me to educate those who are.

Senator MOYNIHAN. Your testimony makes that point. You say what you don't have to worry about.

Dr. HAUGHTON. That is right because often those people are the opinion-makers in the city. Let me give you an example. Just this last spring, Surgeon General Koop came to Texas and addressed the joint session of our legislature about AIDS. Two days later, the House of Representatives voted down a very modest request of $1.5 million by our State Health Commissioner for AIDS education and services for the entire State of Texas. And their argument in turning it down was that most of the people in Texas who were getting AIDS were law-breakers because both sodomy and I.V. drug abuse are illegal in Texas. Therefore, they felt they should not spend the taxpayers' money to take care of people who were lawbreakers. So, I think it is very important for us to educate those people who make those kinds of decisions who may not be at risk of AIDS themselves.

So, we have two different levels of education that are important: our children to prevent them from exposing themselves, and the opinion-makers who make policy decisions like that.

Senator MOYNIHAN. I quite agree. This has been very precise and very helpful. Dr. Boufford, would you like to state any additional thoughts?

Dr. BOUFFORD. I would only emphasize two things. One is the linkage of AIDS and the drug abuse question, both on the prevention and treatment sides; and I think there has been a lack of drug abuse treatment facilities and resources historically that, at least in our city, we have a large number of people who are in line to get drug treatment. That obviously is a platform for counseling against the HIV virus. And secondarily, I think that the nonacute hospital options, which may be less expensive and perhaps more palatable under Medicare, is very important.

Senator MOYNIHAN. You made that point, yes.

Dr. HAUGHTON. Incidentally, the recent allocation of funds for AZT appears to be a good investment. The Chief of Infectious Diseases at Park Plaza has told me that the incidence of hospitalization has decreased from an average of two admissions per year for AIDS patients to 1.2 since he has AZT available to him.

Senator MOYNIHAN. Because it is sufficiently effective that people can be treated at home?

Dr. HAUGHTON. Right. He predicts that any investment in AZT will be a good investment because it will reduce the incidence of hospitalization.

Senator MOYNIHAN. Would you agree with that, Dr. Schunhoff?

Dr. SCHUNHOFF. Yes.

Dr. BOUFFORD. I think it is perhaps a more difficult problem without the support system. In the I.V. drug abuse population, you have more issues around housing, around more institutionally based long-term care than ambulatory care; but certainly, our experience with AZT is that it decreases the frequency of hospitalization. And to the degree we can keep I.V. drug users in the system, they are certainly doing better with that drug.

Senator MOYNIHAN. And you agree?

Dr. SCHUNHOFF. Yes, I do.

Senator MOYNIHAN. That is an important position, and we thank you very much, Doctors. Let's just hope we get lucky in the laboratory one of these days. You never can tell; it has happened, but you can't depend on it. Thank you again very much. I am sorry to hear you are leaving Texas, Dr. Haughton. You are obviously a public asset in Houston.

Now, we have kept them waiting a long time, but we are very happy to welcome a panel of Mary Boland, who is the Director of the AIDS Program in Children's Hospital of New Jersey; Dr. Andrew Wiznia, who is the Assistant Professor of Pediatrics at the Albert Einstein College of Medicine; and Phyllis Gurdin, the Director of the AIDS Specialized Foster Family Homes, Leake and Watts Children's Services, Yonkers, New York.

We welcome you all, and I would note here that there has been a change in the order of witnesses, with Ms. Boland testifying first. Fine with us. We welcome you, Ms. Boland, and you may start.

STATEMENT OF MARY BOLAND, R.N., M.S.N., DIRECTOR, AIDS PROGRAM, CHILDREN'S HOSPITAL OF NEW JERSEY, NEWARK, NJ

Ms. BOLAND. Thank you, Senator. I appreciate the opportunity to testify before you today on the subject of children, and I think also on my own experience in working in the trenches, as my friend, Dr. Haggarty, calls it.

I am the Director of the AIDS Program at Children's Hospital of New Jersey, which is located in Newark, New Jersey, northern New Jersey, and is a member of the National Association of Children's Hospitals and Related Institutions.

I will summarize my testimony briefly. Nationwide, the most conservative estimates of the numbers of children with AIDS are about 500. CDC estimates about 3,000 children are born annually and that, by 1991, they are projecting about 10,000 pediatric cases. Since the national data are still limited, I would like to focus on my experience at Children's Hospital. New Jersey ranks second in the country, following New York, in numbers of pediatric AIDS cases.

Our hospital's location in the center of Newark puts us in the epidemic area where many of the children with HIV are living. Based on our experience today, I can give you the following facts. Children's Hospital first diagnosed a child in 1982. We opened our program in 1983. Since then, we have given care to more than 150 children with HIV infection from New Jersey and New York. We are the only AIDS treatment program for children within the State; and so, therefore, we take care of almost all the children in the area. Currently, we have over 100 children below the age of 13. Only five of these children are HIV positive without symptoms of the disease. Ninety-three percent of these children are perinatally infected, that is, they are born to a woman who has a history of intravenous drug use and/or sexual contact with a male with AIDS or at risk for AIDS.

Senator MOYNIHAN. Could you just help a layman here? You say only five of the HIV infected children are asymptomatic?

Ms. BOLAND. Right. These are basically infants who were born to a woman who has HIV infection. The child is born and is tested positive; it had laboratory abnormalities. We are convinced that the child has the disease; but at a year, two years, or three years of age, the child still has no symptoms.

Senator MOYNIHAN. Right.

Ms. BOLAND. But we are finding that this is a very small number of children. About 80 percent of our children come from a home where one or both parents have a history of drug use; and I would like to underscore this because, even when the woman is a heterosexual contact of a drug user, she still resides within the drug-using community and has most of the problems of a person who is a drug user.

We continue also, unfortunately, to diagnose children who have contracted their infection as a result of blood transfusion, these being transfusions given before 1985 when blood was screened, but children are still being diagnosed.

Senator MOYNIHAN. Let me just be clear on that because our previous panel said the blood supply is cleared up now.

Ms. BOLAND. Right.

Senator MOYNIHAN. This would go back, prior to a time when this was not so?

Ms. BOLAND. Right, prior to 1985.

Senator MOYNIHAN. May I ask all of you right now if you are satisfied on that issue of the blood supply?

Dr. WIZNIA. Yes.

Ms. GURDIN. Yes.

Ms. BOLAND. We have also recently begun to diagnose adolescents—12, 13, and 14 year old girls mostly—who are HIV infected as the result of drug use, sexual behavior, and often sexual abuse. So, we are starting to see adolescents as the newest population with HIV infection.

Senator MOYNIHAN. By sexual abuse, you infer something that has been imposed on a child?

Ms. BOLAND. Right. A child who has been raped essentially. Of our perinatally infected, the majority are diagnosed in the first year of life, and most of them by two years of age. Seventy-five percent of the children who meet the old CDC definition for AIDS prior to the revision do die within two years after diagnosis. However, children with milder symptoms—the children who have AIDS-related complex—are living longer. We presently have 10 children who are well enough to attend school and actually are attending in the New Jersey school system.

Fifty percent of our children are Black, 25 percent are Hispanic, and 25 percent are white. The majority live in poverty in the inner city in substandard housing with a single parent with one or more children in the family infected with HIV as well as healthy siblings. So, in addition to a parent—a mother, possibly a father—you can have one child and two children in a family. We have had one family where there were four infected children.

Our caseload has really started to increase, although our goal in treatment is to maintain the child within the home and the community. Last year, we had 600 outpatient visits for medical care. When we do hospitalize children, our length of hospitalization is

approximately 10 to 14 days. In 1986, we had a total of 99 admissions. So far for 1987, we have had over 100 admissions. What we have seen in our hospitalization, however, is that the length of admission is decreasing; and we believe this is due to the fact of our comprehensive treatment program, that we have nurses, social workers, and physicians who do comprehensive treatment and are able to provide services within the home as well as within the community. Our major problem, I think, is that we are still trying to document the extent of the problem and also the cost of responding to them.

To date, our experience is that the following areas are in need of attention. Hospitals such as Childrens' Hospital carry and will continue to carry the burden of care for children with AIDS. The resources consumed with the children with AIDS are already beginning to decrease the support available for children hospitalized with other conditions. Thus, additional assistance will be needed to support services for children with AIDS.

Because the goal is to maintain the child in the community, support is needed for respite care to back up and give relief to families caring for these children. Alternatives to the hospital care need to be identified, including day care. Foster care is needed for many children, but extra funding for these programs must be identified so that we can attract, train, and retain both parents and care providers. We believe that the costs of financing the health care are becoming a problem for all sectors of the health care system. We need to develop comprehensive programs of support that address both the medical needs of the child and the health and welfare needs of the family.

Even as we struggle to provide care for those with infection today, we must address the need for prevention for future cases tomorrow through increased support for research on drug treatment trials, collection of epidemiological data, initiation of innovative educational programs, as well as innovative models for health care delivery.

We believe our model has been successful because it relates between the Department of Health as well as the Department of Human Services; and we have had the ability to work through the community systems. We would recommend that Federal funding be provided for demonstration grants, for comprehensive pediatric AIDS treatment in epidemic areas, and also provide funding to stimulate program development in geographic regions where the number of cases is small but growing; funding for recruitment and training of care providers in respite care, day care, foster care, with special attention, I think, to the needs of developmental therapy for children.

Almost all children that have HIV infection, regardless of the severity of the other physical problems related to it, show some manifestations of encephalopathy or developmental delay. The children are often behind. In addition to routine day care, they need developmental intervention. Because of their age, the school systems are often not available to them.

In New Jersey, it is difficult to get services to children under three who are developmentally delayed. We need public and private support for programs.

Senator MOYNIHAN. What is that term "encephalopathy"?

Ms. BOLAND. Encephalopathy?

Senator MOYNIHAN. Yes.

Ms. BOLAND. What it means is that the virus causes an infection within the brain, and it manifests different ways. In some children, you can see just a severe illness where they need hospitalization; but in most of the children, what we see is more of an insidious type of a process where they just don't do as well developmentally. Instead of walking when they should at a year, they will walk at two years.

Their speech is delayed. We are thinking as they get older that they probably will not learn as well; so when they do go into school, they will need special classrooms.

I think we also need to develop the public and private insurance strategies to support the institutions who are bearing a disproportionate share of the cost of caring for these children, support the collection of epidemiological data, the implementation of drug treatment trials and the initiative of the innovative educational programs, particularly for adolescents.

I thank you for the opportunity to testify.

Senator MOYNIHAN. We thank you for everything you are doing. We are going to get back to the foster care placement question in a moment. Dr. Wiznia, you are going to speak to us as a pediatrician and as a professor.

[The prepared statement of Ms. Boland follows:]

Mary Boland
Director of the AIDS Program
Children's Hospital in Newark, N.J.

Mr. Chairman and members of the Senate Finance Subcommittee on Social Security and Family Policy, I am Mary Boland, Director of the AIDS Program, at Children's Hospital in Newark, N.J. I am pleased to join you today to share the concerns of the National Association of Children's Hospitals and Related Institutions (NACHRI) regarding providing services to children with HIV infection and Acquired Immunodeficiency Syndrome (AIDS).

NACHRI is a voluntary association dedicated to promoting the health and well-being of children. It is the only national organization of children's hospitals in the country. It represents 94 children's hospitals, virtually all of which are teaching hospitals and are involved in conducting research. Most are also regional medical centers, receiving referrals from large geographic areas.

Characteristics of Children with AIDS

Children's Hospital of New Jersey is a 135 bed Children's Hospital that has been providing care to children from the New York and New Jersey area with HIV infection since 1982. Dr. James Oleske, one of the first pediatricians to identify AIDS in children, is the medical director of our program. Because of our location in the center of Newark we find ourselves in the epidemic area where many of the children with HIV infection are living. New Jersey ranks second in the number of pediatric cases nationwide.

Since our program's inception in 1983 we have cared for over 150 children with HIV infection. At the present time we are providing services to 100 children below 13 years of age. The majority of these children have systems. Only 5 of the HIV infected children are asymptomatic.

As is true throughout the rest of the United States the majority of these children are perinatally infected. That is, they are born to a woman who has a history of intravenous drug use and/or sexual contact with a male individual who is at risk for AIDS. About 80 percent of these children come from a home where one or both parents have a history of drug abuse.

We also continue to diagnose children who have contracted their HIV infection as a result of blood transfusions, and we treat some children with hemophilia, who were infected with blood products used in their treatment

While the number of adolescents with HIV infection to date have been small, our experience in Newark is showing us that they will be the next wave of children with HIV infection. We have recently diagnosed 12, 13 and 14 year old girls who are infected with HIV as a result of sexual activity, drug use, or sexual abuse.

Approximately 50 percent of our children are black, 25 percent are Hispanic and 25 percent are white. Of those prenatally infected the majority of children became ill in the first year of life and most are diagnosed as having AIDS by 2 years of age. Seventy five (75) percent die within 2 years of diagnosis. However, many other children with milder symptoms can survive much longer. We presently follow 10 children who are well enough to attend school.

These children frequently live in the inner city in substandard housing usually in a single parent family where there may be one or more infected children as well as other healthy children. Because of problems related to drug abuse, many families are already receiving assistance from multiple health and human services agencies.

These children represent a sampling of the reported 500 children's cases in the United States. CDC estimates that 3,000 infants are born HIV infected each year. By 1991, 10,000 cases are projected.

In areas where HIV infection is epidemic, children with HIV infection and their families are straining the resources of the health care delivery systems and human services agencies. The child and family have multiple medical, social and emotional problems.

Care of Children with AIDS

In the infant and child, HIV infection can produce dysfunction of various organ systems requiring care by multiple pediatric subspecialists. Institutions such as Children's Hospitals that provide tertiary medical care are best suited to provide the range of services these children require.

While the goal of our treatment program is to maintain the child within the home and community, there are occasions when hospitalization is necessary. Of the children that we follow at any given time approximately 5 to 10 percent are hospitalized, utilizing about 10 percent of the available beds. The number of children hospitalized seems to vary with the season of the year, with more children hospitalized in the winter. In 1986, we had 99 admissions for HIV infection, and in 1987 we have already had over 100. The average length of hospitalization is 10 to 14 days, yet we have had about 3 children hospitalized for up to a year because of medical conditions that could not be treated in a home-like situation.

In addition to their medical problems, the majority of these children have developmental delays. Just as we have identified AIDS Dementia or AIDS Encephalopathy in adults, we have found

that children with HIV infection develop a brain infection. This encephalopathy results in developmental delays particularly in the area of motor skills and speech development in children.

The majority of our children are living in the community and come to the hospital once or twice a month for services. Children's Hospital of New Jersey had 600 outpatient visits in 1986 for AIDS. As the disease progresses, the child requires more extensive home care. Because of the unreliability of the families we have found that home based services such as nursing, physical therapy, and early intervention education result in better utilization of services.

Foster Care

Unlike most hospital based AIDS programs you have read about in the country, Children's Hospital of New Jersey has had no child hospitalized for a long time because of placement problems. Our program has a strong relationship with our child protective services agency, and we are able to assist them and encourage them to find speedy placement for the children.

Even prior to the diagnosis of AIDS in the child, 25 percent of the families now in the program were known to the child protective services agency and many were already in foster care. For most children, placement occurred because of unwillingness and inability of the mother to care for the child, rather than as a result of illness in child or parent. Active intravenous drug use results in the inability of the mother to provide food and shelter for the child.

Initially, many of the mothers appeared well. However, as we follow cases over time more mothers have become symptomatic, and several have died. Progressive physical illness in mothers decreases the energy available to care for the child.

Resolution of the impending death of the caretaking parent prompts our team to discuss long term care of the child with family members. While grandparents and other interested family members frequently provide care for the child, they are dealing with grief due to the loss of the parent and justified fears regarding the death of the child whose care they assume. In one family where both parents and one of two infected children have died, the maternal grandmother gave home care for the mother and child and is now caring for the surviving infected child and his well siblings.

Foster care placement is becoming a major issue as the numbers of HIV infected children increase. Most children are under the care of an extended family member, usually a grandmother or other close relative. When no family member is available, identification of a foster home can be difficult. Throughout our state there is a shortage of foster parents for all children and particularly children with medical conditions. The public fears and lack of knowledge regarding HIV infection have made the identification of foster homes much more difficult. In spite of this, New Jersey is the only state in the nation having a functioning small group home for children with AIDS. St. Claire's Home, in Elizabeth, New Jersey, provides placement in a home-like setting for 5 HIV infected children. Since it's opening in May of this year, it has been full and now has a waiting list. The majority of children who require placement are HIV positive infants abandoned at birth but whose actual HIV infection state is unclear. Unless the child is very ill, it is difficult to ascertain whether or not a young infant is infected or is demonstrating antibodies transferred from the mother, until he or she begins to develop symptoms.

Day Care

In addition to foster care, day care for young children is a major problem. Because of the diagnosis, most private and some public day care centers have been reluctant to accept young children. However, for the HIV infected child whose mother may be ill or whose foster parent may need to work, day care can be the crucial factor in obtaining and maintaining the placement of the child. We have been able to identify foster parents, often health care providers, who are willing to take the children but who do need to work during the day. We need to develop day care services for these children.

In addition, any day care services that would be developed would need to include developmental therapy as well as basic daily care. The majority of our children are under the age of 3 years of age, and school services are not available to them at this time.

Chronic Care

While acute care hospitals and medical centers are appropriate to provide services when the child is ill, there exists a need for chronic care facilities for children with severe medical problems due to HIV that preclude discharge to the home or where the child is unable to be discharged to his existing home because of his needs for medical care. At the present time there are no designated chronic care beds available for children with HIV infection. The majority of these children will remain in an acute care hospital where they do not receive any of the nursing and developmental services that are appropriate for their needs.

Some families who are willing and able to take their children home with support services do a very good job providing care to their children. Yet, there is no respite care available

for the care providers should they become tired or need a day off or in the case of a parent who becomes ill and needs to be hospitalized. We would suggest a demonstration program be funded to look at the chronic care and the respite issues related to children with HIV infection. Possibly an innovative program that combines residential care for both the mother and the child could be developed.

Financing Comprehensive Care

The costs and financing of health care for AIDS patients are rapidly becoming a problem of major concern for all sectors of the health care system. Children's Hospital of New Jersey is just beginning to look at the direct cost of providing comprehensive care to children with HIV infection. At the present time we receive grant funding which supports all our staff. Our data on cost are still preliminary, and I would be happy to provide you with the results when they are available.

For most children with AIDS in New Jersey, the primary health coverage is through Medicaid, but New Jersey, fortunately, has a comprehensive Medicaid program. Currently, we are working to contain cost by using alternatives to hospital care. New Jersey is the first state to develop a "Home and Community Based Service Model Waiver for Persons with AIDS" under the Medicaid program. Under this waiver, services such as foster care, case management, medical care, and drug abuse treatment are provided. This brings Federal matching dollars into the state for services not normally covered under Medicaid. It should be recognized that Medicaid funding, channeled to the care of AIDS patients, as needy as they may be, may detract from the routine health care funding for poor children. Supplemental funding for AIDS may be indicated.

RECOMMENDATIONS

Comprehensive Program

The morbidity and mortality resulting from HIV infection demands an approach to care that is comprehensive and coordinates care between the hospital, home and the community. The ill child must be viewed as a member of the family that however weakened or malfunctioning, has its own tasks and stages which are disrupted by illness of family members. HIV infection is a life threatening but chronic process that has the potential to destroy an entire family. The goal is to treat the illness and its symptoms while attempting to prevent further disruption of the family unit.

To provide this care, there is a need to develop and fund comprehensive pediatric AIDS treatment programs in epidemic areas of the country as well as provide funding to stimulate program development in geographic areas where the numbers of HIV infected children are still small but increasing. NACHRI recommends that the designated federal funds be made available to develop demonstration projects in the health care system as well as the human services system.

Alternative Care

The need for foster care mandates that we begin immediately to develop models to recruit, train and retain foster parents to take care of children with HIV infection. While small group homes do need to be developed and funded, the ultimate goal for children should be that the child can live in a home setting. Human service agencies within local areas who are well aware of their local situation as well as their resources could be stimulated to provide programs that would best meet the need of children in their area.

There is also a need to develop day care programs for children with HIV infection that include developmental therapy. The majority of children with HIV infection will have developmental delays ranging from mild to severe. It is important that day care services for them have an educational component. Existence of day care centers for children also reduces the burden for their foster parents as well as the ill biological parent. These types of day care and developmental services could provide access to medical care.

Financing

While increased federal funding for research and education in response to the AIDS epedimic is to be applauded and encouraged, public policy must address the financing issues related to the delivery of treatment and social services for children already infected and those who may become ill. Public and private, third party payors must develop a financing system to support institutions that are bearing a disproportionate share of the cost of caring for these children.

Prevention

The need to collect epidemiological data, the implementaion of drug treatment trials as more anti-viral agents become available, and initiation of innovative education programs that will reach out to teenagers all require the continued support of federal funding.

CONCLUSION

Children's hospitals play a crucial role in the care of children with AIDS. As the nation confronts this deadly epidemic, children's hospitals offer their expertise, service and research to meet the challenge the future holds.

As the Committee considers these recommendations, NACHRI welcomes the opportunity to work with you to explore their implementation. Thank you for providing NACHRI the opportunity to speak on this important issue.

STATEMENT OF DR. ANDREW WIZNIA, ASSISTANT PROFESSOR OF PEDIATRICS, ALBERT EINSTEIN COLLEGE OF MEDICINE, BRONX, NY

Dr. WIZNIA. Thank you, Senator Moynihan, and ladies and gentlemen. The catastrophic effects of pediatric AIDS includes the physical suffering, disability, and ultimate death of an infected child. As families cope with a terminally ill child, the explosive increase of newly diagnosed cases is exacerbating existing stresses in the medical and social institutions already struggling to care for these infants. I would like to briefly highlight a few pertinent issues depicting the magnitude and gravity of our problem.

The Public Health Service projects that in the year 1991 there will be 3,000 cases of CDC-defined pediatric AIDS, with an additional 7,000 HIV infected children. The vast majority of these cases will result from transplacental transmission of the AIDS virus from mother to infant prior to delivery.

Initial data from multiple prospective pregnancy studies of HIV infected women indicate a transmission incidence of about 40 to 60 percent. It is estimated that in 1987, some 3,000 to 5,000 HIV seropositive women will complete pregnancies resulting in between 1,500 and 2,500 HIV infected babies.

At the Albert Einstein College of Medicine, we have cared for over 200 HIV infected children over the past six years. An alarming epidemiologic change in maternal HIV infection has occurred over the past two years. Intravenous drug abusing mothers were responsible for 95 percent of infected infants born prior to 1985, whereas 35 percent of infected babies born in the past two years were mothered by women infected through heterosexual contact with infected men.

Senator MOYNIHAN. They were not themselves——

Dr. WIZNIA. They were not themselves intravenous drug abusers. In the majority of those cases, the women didn't even know that their sexual partners had engaged in high-risk activity. In general, the disease course for the human immunodeficiency virus is more aggressive in the pediatric population than in adults. I would like to discuss the clinical ramifications of pediatric AIDS on a more human level, as we the caretakers encounter it on a day-to-day basis.

Approximately four years ago, a seven month old infant was admitted to the hospital in severe respiratory distress. This infant's mother, an intravenous drug abuser, with nine previous children in foster care placement, abandoned this child; and New York City Special Services for Children assumed legal responsibility. The baby's medical course over the next two months consisted of an open lung biopsy, continuous intravenous infusions, chronic oxygen dependency, and the detection of the presence of the AIDS virus.

Subsequently, his mother died of pneumocystis carinii pneumonia, and his father—also an intravenous drug abuser—stated that he was incapable of caring for this child. For the next 18 months, Tony lived on a pediatric floor of the hospital. His friends and family included the physicians, nurses, social workers, volunteers, and even the other pediatric patients. The elevator operators wore

masks when transporting the adult AIDS patients, but they hugged and played with him.

Medically, his 18 months were relatively benign for an HIV infected child. He experienced one episode of meningitis, had four separate episodes of salmonella infection in his intestines and in his blood, was chronically treated for thrush, and required multiple courses of intravenous antibiotics. In addition, a repeat open lung biopsy demonstrated the presence of pulmonary lymphoid hyperplasia, which is a chronic inflammatory process found in pediatric AIDS patients, which casues respiratory difficulty.

Although developmentally delayed, as is typical of HIV infected children, he was able to overcome adversity and became an adorable toddler. A pediatric staff nurse married his father in order to gain joint custody of Tony. He finally left the hospital at age 25 months. For the next two years, he required four emergency hospital admissions, in addition to elective biweekly admissions for intravenous gamma globulin.

Nine months ago, he experienced a 10-minute generalized seizure, the first of many, as a result of the neurological involvement by the AIDS virus. As time passed, his neurological status deteriorated to the level where he required a walker to ambulate, and his language regressed to nonsensical babbling. Five months ago, he developed pneumocystis carinii pneumonia, an opportunistic infection.

He succumbed to his illness after three weeks on a respirator. At Tony's wake, his father asked my opinion about a rash that the father had for the past three weeks. It was shingles, a clinical manifestation of an immunodeficiency. Three weeks later the father was diagnosed as having pneumocystis carinii pneumonia. His adoptive mother, not infected by the human immunodeficiency virus, has just recently returned to her duties as a pediatric nurse.

This account is the reality of pediatric AIDS. It affects every facet of an infant's life. It includes pain and suffering and eventually death. It leaves a child homeless for 18 months in a hospital. It is straining the medical and social institutions struggling with this reality.

As a pediatrician and child advocate, I find our response inadequate. These children need comprehensive care programs, as Ms. Boland addressed. They need medical, developmental, and social problems to be addressed.

Society needs to know that these children are not outcasts, and we must learn effectively how to prevent additional cases of pediatric AIDS.

Senator MOYNIHAN. Why don't we hear from Ms. Gurdin, and then we can talk?

[The prepared statement of Dr. Wiznia follows:]

Andrew Wiznia, M.D.
Assistant Professor of Pediatrics
Albert Einstein College of Medicine
Bronx, New York 10461

Pediatric AIDS is an illness with catastrophic effects transcending the boundaries of typical Pediatric diseases. The physical suffering, disability, and eventual death of an infected child is only part of the devastating consequences of Pediatric HIV infection. These infants are the passive recipients of the AIDS virus, either via contaminated blood products or more often prenatal or perinatal congenital transmission from HIV infected indigent, inner city, minority, single women. Additionally, the explosive increase in newly diagnosed cases is exacerbating existing remarkable deficiencies (wide gaps) in the medical and social institutions that have been struggling to care for these infants for the past 6 years.

The U.S. Public Health Services projects that by the year 1991 there will be 3000 cases of CDC defined Pediatric AIDS with an additional 7000 HIV infected children. The vast majority of cases will result from transplacental transmission of the AIDS virus from mother to infant prior to delivery. Additional transmission via contaminated blood products will be negligible in the future due to widespread screening of blood products. Initial data from multiple prospective pregnancy studies of HIV infected women indicate a transmission incidence of 40-60%. It is estimated that in 1987 some 3000-5000 HIV seropositive women will complete pregnancies resulting in 1500-2500 HIV infected babies. In our pregnancy study which provides extensive family planning and psychosocial support, most infected women have not opted for elective abortions. Additionally, mothering one infected child has not dissuaded subsequent pregnancies in a number of these mothers.

At the Albert Einstein College of Medicine we have cared for over 200 HIV infected children over the past six years. An alarming epidemiologic trend in maternal HIV infection has occurred over the past two years. Intravenous drug abusing mothers were responsible for 95% of infected infants born prior to 1985. However, in the past 2 years only 65% of infected infants were offspring of intravenous drug abusing women. The remaining 35% were born to women whose risk factor for HIV was heterosexual contact with an infected male. Furthermore, one half of these women had no knowledge of their sexual partner's high risk activity and it is not unusual to diagnose maternal HIV infection only after detecting a problem in the infant.

The diagnosis of Pediatric HIV infection within the first year of life is quite difficult. The presence of HIV antibodies in an adult indicates an individual's exposure to the virus. Detecting HIV antibodies in an infant less than 12 months of age may reflect either transfer of maternal HIV antibodies to her infant in a passive manner or true HIV infection in that baby. N.Y.C. hospitals are frequently confronted with an HIV seropositive newborn abandoned by its HIV infected seropositive intravenous drug abusing mother. Foster home placement for this infant is frequently dependent upon determining whether the child is actually infected, a chore that is expensive and technically difficult. This dilemma only compounds the difficult social services situation in many inner city hospitals which may have 30-40 "boarder babies" utilizing valuable and expensive hospital beds for months while awaiting placement into foster homes.

In general, the disease course for the human immunodeficiency virus is more aggressive in the Pediatric population than in adults. The average incubation period for developing AIDS in children (ages newborn-4) infected by blood transfusion is 1.9 years as opposed to 7 years in the adult population. Most infants infected in utero can demonstrate symptoms consistent with an immunodeficiency as early as age 2 months. HIV infected children suffer from many of the same illnesses and symptoms as adult patients. Fevers, weight loss, recurrent diarrhea, oral candidiasis (thrush), unexplained lymphodenopathy, and chronic viral infections, are part of the day to day existence for these infants. As their immunodeficiency worsens, they are more likely to contract an opportunistic infections, ie: pneumocystis carinii pneumonia (approximately 30% survive their first episode), atypical mycobacterium infections (for which there is no effective therapy), disseminated fungal infections, and even lymphomas. Approximately, 90% of children will die within 12 months of their opportunistic infection. It is currently estimated that the medical cost of meeting one HIV infected infant is $100,000/year.

Certain characteristics of HIV infection are unique to the Pediatric population. Bacterial infections of the blood, central nervous system (meningitis), soft tissue and bone are common and recurrent resulting in prolonged hospitalizations and possible residual sequelae (ie: deafness from meningitis). Many institutions are giving intravenous gammaglobulin (antibodies) infusions to HIV infected infants in an attempt to prevent these bacterial infections thereby decreasing morbility, mortality, hospitalizations, and medical costs.

Approximately 1/3 of HIV infected infants suffer from Pulmonary Lymphoid Hyperplasia (PLH), a chronic inflammatory process occurring in the lungs. This malady causes chronic hypoxia (low oxygen levels in the blood), recurrent pneumonias, frequent hospitalizations, and severely limits the exercise tolerance of the children. It has been successfully treated with chronic steroid administration which themselves have additional adverse side effects.

I consider the central nervous system complications of Pediatric HIV infection the most devastating aspect of this disease. Only 8% of HIV infected infants perform at age appropriate levels on standardized developmental tests. As the children age, some will attain new, albeit delayed developmental milestones, whereas other infants will suffer from progressive neurologic deterioration, becoming demented and encepholopothic. As HIV progresses in these children many regress developmentally for instance from a 2 year old who is able to walk, talk, and feed themselves, to a 4 year old who can only crawl, babble, and is once again bottle dependent.

Pediatric HIV infection encompasses the entire gamut of child health care and requires a comprehensive, multidisciplinary approach to medical and psychosocial issues. Their medical condition requires extensive evaluations by general pediatricians and those with subspecialty training in immunology, infectious diseases, neurology, and child development. Malnutrition, common in these patients, is known to cause or exacerbate immunodeficiencies and must be addressed through supplemental nutrients. Neurological sequelae require early and extensive physical and speech therapy intervention. Adequate dental care has been difficult, at best, to obtain. Medical costs will increase as the population of HIV infected infants grows requiring recurrent hospitalization, and more intensive care. For example, 10% of Pediatric hospital beds at the Bronx Lebanon Hospital at any given time are occupied by HIV infected children and up to 50% of Pediatric intensive care beds in the Bronx occupied with our patients.

An HIV infected infant typically comes from a household where an average of 2.7 other family members are similarly infected. Many of their parents are incapacitated by their disease or are deceased which requires other family members, foster parents or hospitals to serve a parental role. Adequate housing and basic essentials for daily living are oftentimes not available for these children and their families. The psychological inpact on these chronically ill children as well as their family members and caretakers is profound and will be longlasting.

Schooling is an issue that has generated much public debate in the news media and in communities where an infected child is of school age. In multiple prospective studies casual spread of HIV from infected infants and children to uninfected family members has not occurred. Therefore, an infected child who is toilet trained, without a bleeding disorder and has not demonstrated agressive behavior represents an insignificant health risk to classmates. To the contrary, these children are themselves at risk for infections. In N.Y.C. a multidisciplinary team including physicians, social workers and the Board of Education review each child's school application individually. If qualified, the child attends school anonymously as any other child with the Board of Education informing the physicians of any outbreak of infectious diseases.

A small number of preschool children have been enrolled in a Pediatric AIDS day care center at Bronx Municipal Hospital Center. Lack of toilet training, biting tendencies, etc. have mandated this unique format. In addition to infectious disease problems, these children have special educational and psychosocial needs not normally handled in routine day care settings. At present, facilities for only 25 children exist in New York City.

The problems confronting HIV infected infants and children are difficult, complex, and escalating at an alarming rate. The needs of these children and their families will best be met by a coordinated multidisciplinary approach involving the medical community, psychosocial intervention, and government support.

STATEMENT OF PHYLLIS GURDIN, DIRECTOR, AIDS SPECIALIZED FOSTER FAMILY HOMES, LEAKE & WATTS CHILDREN'S SERVICES, YONKERS, NY

Ms. GURDIN. Thank you, Senator Moynihan. I thank you for the opportunity to testify here. I think I am going to end this on a little better and happier note because my story is a little more optimistic at the moment.

Senator MOYNIHAN. Good.

Ms. GURDIN. Leake and Watts is an agency that has a history of 156 years of caring for children.

Senator MOYNIHAN. A long, long time. It may even be the original.

Ms. GURDIN. At this point, we service 1,200 children in various programs, ranging from foster care to residential treatment to preventive services and day care. We do the whole gamut of services for children. Our AIDS program is the smallest and newest program for the agency.

Foster care has always done a pretty good job of looking after the needs of children. It has cared for the neglected, the sexually abused, the developmentally delayed, the retarded child. When AIDS came along, it was felt that AIDS children would be able to be cared for by foster care.

But the foster care system in 1984 and 1985 did not seem to be able to recruit homes for these children. In October of 1985, the AIDS Institute, State of New York, funded Leake and Watts with a startup grant to see if it would be possible to recruit foster homes for AIDS children.

At that time, there were 10 children in New York City hospitals who did not require medical care on an inpatient basis and were merely hospital boarders. We started the program, and the aim was to place 10 children within approximately a year. The program went better and faster than we hoped, and by June of 1986, we had placed 10 children. As of this point, we have placed 23 children; one child died. Our goal is to place 30 children in foster home care within this year.

The program has shown many things that are typical of the foster care field. The people who came forward to take these children were very similar to people who are foster parents in general, and foster parents have had a lot of bad press. Let me tell you: They are great people, and they really should be honored much more than they are by our society. It is a very difficult job.

The people who take these children really have the most difficult of jobs. We found them to come from Black, White, and Hispanic; they will take children across racial lines. We have placed across racial lines because our great concern is to get a child a home as fast as possible. We have found them to be single women very often. We haven't taken families with young children; we were afraid of cross-infection problems. So, the youngest child in any of our foster homes is nine years old.

Senator MOYNIHAN. I see.

Ms. GURDIN. They also receive many entitlement programs, such as Social Security, for some of our parents are over 65. And sometimes they get public assistance. The two factors that are different

about these people that we found in general foster care, although our numbers are small—we have 15 foster homes at the moment—is that most of our foster parents have some medical training. They have been nurse's attendants; they have been LPNs; they have been trained by the entitlement programs through the Department of Social Services often to be a home attendant.

In addition to this, they all came to us with some knowledge of AIDS. They had read about it; they were interested in television material on AIDS, and they were knowledgeable. And they weren't fearful of transmission.

The other factor was they had all had some experience with death. Either they had been involved in having cancer or a heart condition. Some of them had lost spouses from cancer. And all of them had the attitude: Yes, the child might die, but my job is to provide the best quality of life today. And that is what we focus on. What can we do for this child today while he is here? And I believe this is one of the problems in servicing AIDS children. Everybody has the feeling they are going to die; so why do anything for them?

At this point, we are servicing 22 children. They range in age from 14 months to seven years. They were all hospital boarders. The children had lived in hospitals anywhere from approximately 14 months to five years before they came into foster care. They are Black, Hispanic, and white. Our heaviest number is in the minorities group; they are equally divided between Hispanic and Black.

They are all children of I.V. drug users. The disease was acquired intrauterine. They are all developmentally delayed, some of them very severely. One little boy has severe cerebral palsy; some of them are just three or four months behind. We do believe all these children will continue to have problems with learning and development.

We are trying to address these problems with professional help. The children do get sick fairly often, and they are in and out of hospitals. We try to keep the amount of time in hospitals to the minimum. In addition to providing an amount to the foster parent, we provide medical health aids for them; and therefore, we can very often take a child out of the hospital, put him back in the home when he isn't completely well, because the foster mother has someone to help her. So, the child can get care 24 hours around the clock. We feel this is very important.

It is a cheaper way of caring for children, and also a much better way of caring for children. Our foster parents receive the highest rate that New York City pays or New York State pays for foster children. They receive $134.00 a month per child. The agency receives approximately $100.00 a day per child; $37.00 is passed through to the foster parent.

When this is seen against $300.00 to $1,200.00 a day for care for a child in the hospital, it is a very economical program.

In addition to the amount the foster parent receives, they receive health aid monies because you can't leave an AIDS child with a neighbor. You have to keep it confidential; otherwise, you do have a great deal of problems.

They also receive 24-hours a day support. There is someone on staff always available, 24 hours a day, seven days a week, 365 days a year, to these people. We have found this to be a successful way

of caring for children. The children have done well developmentally. They have stayed relatively healthy physically.

We don't know what will happen to them as they grow older. Our oldest child is seven years old at this point, but at this point, the quality of care for these children is excellent, and the cost to the taxpayers is far less than keeping them in hospitals. We do believe that every child who can go home to his natural parent should, that programs should be increased to help these families so that they can care for their own children. There will always be a residue of these children who need to be in foster care. This program should be enlarged, and I believe that one of the ways we can get more homes is even by paying the foster parents more than we are paying.

I think foster care for AIDS children has to be viewed as a job, not as an avocation, as it has always been viewed. People who are trained as LPNs, nurse's aides will stay home and care for children if we provide adequate money for them. Many of them prefer this, and I think this is a very profitable way for the taxpayer to handle this problem.

In addition, I believe we will need a certain number of small group congregate facilities for these children because of the fact that we will never have enough foster homes available at the moment we need them, the way the numbers are increasing, especially in New York.

Also, there will be children who will continue to get sick, as I believe Ms. Boland and Dr. Wiznia described. Many of these children will not need acute hospitalization, but they will need more care than a foster parent can give them.

In addition, I believe you need to educate more. We need to provide incentive payments for people who live and work with AIDS. We could have placed many more children this year. Staffing has been an enormous problem. We have done something which we believe is innovative in the field of social work. We are now paying a $3,000.00 a year incentive in our agency for anyone who is willing to work with AIDS. We followed the military model because we must have staffs to care for children.

Also, we had a new problem that reared its ugly head as I left the office yesterday, and I would like to make mention of it because I think it will be a problem to come for all of us. Our insurance company informed us, as of January 1988, they will no longer cover liability for any AIDS program.

Senator MOYNIHAN. Could you write us a letter on that?

Ms. GURDIN. We certainly will.

[The prepared statement of Ms. Gurdin follows:]

Phyllis Gurdin

Director AIDS-Specialized Foster Family Homes
Leake and Watts Children's Services
Yonkers, New York

Mr. Chairman and members of the Subcommittee, my name is Phyllis Gurdin and I am the Director of AIDS-Specialized Foster Family Homes for Leake and Watts Children's Services, Yonkers, New York. I want to thank you for the opportunity to testify this morning regarding foster care for children infected with the HIV virus.

Leake and Watts Children's Services is a multiservice child welfare agency servicing children for last 156 years. We service approximately 1200 children in programs such as day care, preventive services, foster care, group home care, and residential treatment. AIDS is the newest and smallest program within the agency; at this point we are servicing 22 children in foster family homes.

Foster care has a long history of caring for children with multiple and serious problems. Over the years, children who have been abandoned, abused, or neglected, and children who are developmentally or physically disabled or mentally ill have been served in foster homes. With the coming of the deadly Acquired Immune Deficiency Syndrome (AIDS), however, a new demand is being made on the foster care system. Hundreds of young children have been infected with a virus that seriously suppresses the human immune system, and an increasing number of these infants come from families who are unwilling or unable to care for them. As a result, many young children, whose infection was usually contracted intrauterine, need placement in foster homes.

The initial placement for many children with AIDS or related complexes has been a hospital setting. This placement has made sense when a child was acutely ill but it is not a long-term setting for the quality care of children. The child welfare system has been increasingly asked to provide homes for children with the AIDS virus. Some children have been placed in foster homes without careful planning and without the knowledge that they had AIDS or an AIDS Related Complex (ARC). Once the disease is diagnosed, foster parents are often unwilling to care for them. The child welfare system was unable to place these children through its regular foster care programs.

In the New York City metropolitan are, one of the country's first foster care programs specializing in serving children with Aids or ARC has been established. In October 1985, Leake and Watts Children's Home, a 156-year-old New York City multiservice child caring agency, began a foster home program for children with Aids.

Transmission

Children do not "catch AIDS" as they might catch influenza or chicken pox. For children, the disease is acquired only though direct exposure to the contaminated blood of a person in a high-risk group for AIDS (typically due to blood transfusions using blood products attributed to infected intravenous drug users or homosexual men) or in utero. The largest number of children infected are children of intravenous drug users (or their sexual partners) who are infected with the disease or are carriers of the disease; the virus is transmitted to the children in utero. All research on the transmission of the disease concludes that it cannot be transmitted by casual contact, which is defined as living in the same household with an infected person, casual kissing, or swimming with an infected person.

AIDS is a blood-borne disease, transmitted sexually, or by sharing contaminated needles, or in utero, and has not been proven to be spread by casual contact. No nurse, doctor, foster parent, teacher, or peer has ever contracted the HIV virus from an infected child. The fact that AIDS is not a disease of casual contact is of

great importance to the child welfare system. Children carrying the HIV virus can be placed in foster care without jeopardizing the foster parents or their family.

TREATMENT

There is no cure for AIDS at the present time. Medical researchers are experimenting with a variety of antiviral agents and immune system stimulators. These attempts to either kill or render the virus harmless, or bolster or restore the body's immune system, have shown promising signs, but none has demonstrated the ability to stop the disease. But the treatment is increasing the life span of these infected children.

AIDS Project

In October 1985, New York, New York City reported 87 cases of children with Aids. It was estimated that there were five times as many children with ARC. Of these children, at least 15 children with Aids or ARC were identified as abandoned by their parents and consequently in need of foster placement. Some children were hospitalized "boarders" for periods of two month to two years; they were not in need of inpatient medical care. The child welfare agencies of the city were unable to find foster homes for them.

In the fall of 1985, Leake and Watts Children's Home was funded for nine months by the AIDS Institute of the Health Department of the State of New York to recruit and establish foster homes for children with AIDS or ARC. If this initial step was successful--if foster parents could be found who were willing to care for children with the AIDS virus--the New York State Department of Social Services and New York City Department of Special Services for Children would provide the funds to establish and maintain a model pilot foster home program.

It was recognized that finding a sufficient number of qualified foster parents capable of meeting the needs of these children would be the most difficult phase of this program. To carry out the AIDS Foster Care Project, the agency employed a project director and a foster parent recruiter. The director had worked in child welfare for over 20 years and was familiar with all aspects of foster care and adoption. The recruiter, a psychology doctoral candidate studying AIDS, was well informed concerning the disease and knew many members of the network of New York agencies serving AIDS patients.

The project began with this two-member team establishing working relationships with the AIDS network (which primarily served a homosexual clientele). The team developed associations with all agencies serving AIDS victims, including the Department of Health, the Visiting Nurse Service, the AIDS Institute, Gay Men Health Crisis, and medical and social work staffs of city hospitals. This activity enabled the team to: 1) keep abreast of new knowledge about the disease, as new finding were being reported almost daily; 2) alert city agencies and community groups to the existence of the project; and 3) identify potential resources for the children and foster parents who would eventually be recruited.

Recruiting Foster Parents

Personal contacts were established with community groups, including church groups, religious orders, nursing associations, hospice organizations, and groups serving the gay and lesbian community. These contacts resulted in invitations to speak at public meetings where the director or recruiter might then identify potential foster parents.

The project originally identified the Bronx as a catchment area for recruitment. Geographic limitation would facilitate supervision of the foster homes and assure access to medical and relevant programs. The Bronx was selected primarily because it is

the location of the Albert Einstein Medical Center, where pediatric immunologists were active in medical research on pediatric AIDS and had developed comprehensive medical services for the children. In addition to this medical expertise, The Bronx Municipal Hospital was in the process of developing a pioneering day care and educational facility for children with AIDS. This would be an important resource for foster parents, because New York City had decreed that no child with the HIV virus could attend city day care or Head Start programs.

In actuality, the plan for a catchment area had to be abandoned because it was not possible to recruit a sufficient number of homes in the Bronx to serve all the children. In addition, as the number of children with the virus increased, it became possible to locate medical and social services for the children throughout the metropolitan area.

Before the establishment of the project, the public child welfare agency had been unsuccessful in attempts to recruit foster parents through a mass media approach. Personal networking was therefore preferred in the project. This involved the director's seeing a selected group of foster parents who had faithfully served children through their affiliation with the agency, and giving them a detailed description of the disease, the needs of the children, and the programs's supports for foster parents. Foster parents who responded positively to the presentation were asked to help recruit homes through their friends, relatives, and community affiliations. This initiative was successful, and the first foster home to be approved was referred by a Leake and Watt's foster parent.

Community networking was also successful. Organizations and hospitals publicized the program through their publications. New York State's Department of Social Services and New York City's Special Services for Children publicized the project. In addition, positive, informed newspaper coverage resulted in a number of referrals. The director undertook a vigorous schedule of speaking engagements to a wide variety of audiences. These community contacts resulted in the recruitment of five qualified foster homes.

In summary, the project was publicized both officially and by word of mouth whenever possible from October 1985 through June 1986. During this nine-month span there were approximately thirty inquiries. Six homes were approved and ten children were placed. The goal of the pilot project had been achieved. The number of children needing foster care placement has continued to grow. As of September 1, 1987, twenty-two children are placed in fifteen foster homes (twenty-three children were placed since January 1986, one child died). At this point in time there are at least thirty children awaiting foster care placement in New York City Hospitals. The referral of prospective foster parents continues but at a very slow pace.

Selecting Foster Parents

Among the criteria for screening the appropriateness of a potential foster parent for an AIDS child were the following: 1) accepting married or single adults; 2) not accepting a home with a child under the age of ten, to protect the AIDS or ARC child from potential exposure to infections that could be introduced by a younger child; and 3) accepting parents who were informed concerning AIDS and who expressed confidence in handling the child and had little fear of transmission.

A maximum of two children were placed in each household; whenever possible, two children close in age were placed together to reduce the isolation of each foster child by providing a peer relationship in the home. It was also believed that placing two children would not overwhelm the foster parents and might help them cope with separation and grief should one of the children become too ill to be maintained in the home.

Description of Foster Parents

With only fifteen foster parents it is not possible to establish a definite profile of foster parents willing to care for a child with the HIV virus. Twelve of the fifteen foster parents are single women. Seven are black, six are Hispanic, and two are white. The foster parents range in age from thirty-two to seventy. Only two work outside the home. One is a social worker for the Department of Social Services; the other is a L.P.N working on a medical staff of a large hospital. In eight instance, the family has a minimal income based on various entitlement programs. In most instances, the major part of the family income is derived from foster care payments. Each family receives a special rate of $13,608 yearly, ($1134 monthly), per child in care. Foster parents have biological children living in the home; none is younger than age ten.

The project staff has assumed that the foster parents are similar to those who care for "normal" children. However, certain traits are common to all or most of these six families:

Knowledge: the foster parents were very well informed concerning AIDS before contacting the agency. They had read news articles and followed special television presentations on the disease.

Confidence: they were convinced that they were not endangering themselves or their families by caring for an infected child. This was discussed many times during the home study and if anyone expressed fears or doubts about the transmission of the disease they were not accepted.

Medical Training: in eight of the fifteen homes, the foster parents had formal training as a nurse or nursing attendant. All eight had nursed patients with contagious diseases and had experienced the death of at least one patient they had nursed. In each case they had mourned the loss of the patient but had been able to continue in their vocation.

Illness History: in nine of the fifteen home, the foster parents had personally experience severe illness--in seven cases the spouse had died of cancer or heart disease, in two cases the foster parent or spouse had survived cancer.

All of the approved foster parents said that they had given a great deal of thought to death, but their basic life view was very "present day." They recognized that seventy percent of AIDS children die and that there was no cure for the illness. They said they could accept this prognosis. Rather than trying to save the child, they saw their goals in terms of providing a good quality of life for as long as the child's health would permit. Although all were offered a "normal" foster child in place of a child with AIDS or ARC, they preferred to care for a child with the disease. Their choice was significantly influenced by the special payment rate and the accompanying support services, but they were reluctant to discuss these considerations because they feared that their motivation would be questioned. The increased rate for AIDS children is justified by the nature of the demands and challenges for the foster parent.

Description of Children

As of September 1987, twenty-two children are placed in foster homes. Fifteen are male, seven female. Seven are hispanic, fourteen are black, and one is white. They range in age from fourteen months to seven years.

The children were all placed from hospitals. These children had been hospitalized any where from five months to five years for no medical reasons. Twelve children had never lived any where else. The other ten had lived either in foster homes or with parents. In five of these cases the children were abandoned after their foster parents or their own parents learned of their condition. Five children were removed from their parents by the court because they were neglecting them.

All the children were born to intravenous drug users and had contracted the disease intrauterine. Fourteen children were diagnosed as ARC and seven were diagnosed as meeting the CDC criteria for AIDS. The children have all suffered a number of illnesses such as pneumonia, severe ear infections, frequent bouts of diarrhea, severe skin conditions, and failure to thrive. They have evidenced some degree of developmental delay ranging from mental retardation with cerebral palsy to a developmental lag of six months. In addition, five children exhibit hyperactivity, sleep disorders, and aggressive-destructive behavior. It has not been possible so far to consider the relative sources of these delays and disturbances, the disease itself, the child's past environment, or the parents' drug addiction. The children are making progress in reaching new developmental milestones but the prognosis for continued gains is unknown.

At the time of placement the location of twenty-one natural mothers was unknown. Since then, eight mothers have been located; seven have AIDS or ARC and the eighth died of AIDS. Only two mothers have expressed any interest in seeing their children; one has three other children living with her. Two of these children are older than the foster child and do not have AIDS. A younger sibling has been tested but the results were inconclusive; doctors suspect the infant will develop the disease later. The other has grown children. In all twenty cased the placed children have siblings. These siblings are in the care of relatives, with other agencies, or their location is unknown. Two siblings have died of AIDS. It appears that none of the mothers is able to care for her placed children.

Services for Foster Families

The foster families are provided a special rate, financial aid, insurance, and professional support services. They receive $1134 per month per child, the highest foster care rate paid by New York State. In addition the foster family receives payment for approximately thirty-two hours a week for health aides for respite care. The agency supplies all equipment (carriages, cribs, play equipment) and extra clothes, including, if necessary, washing machines, to avoid criticism from neighbors if the foster parent had to use a public laundry and the child's disease became common knowledge. Funds for recreation are provided. If foster families have no source for medical insurance the agency covers the cost of medical insurance premiums. Foster parents continue to receive payment if a child needs brief hospitalization. The agency receives an average of $100 per day per child to cover all costs.

Another source of assistance to the foster parents and children has been the project staff. In addition to the director and psychologist-foster parent recruiter, a registered nurse and a social worker were hired. Help is available to the foster parent twenty-four hours, seven days a week.

Summary

Recruiting foster parents is a difficult task that requires a multifaceted strategy using both formal and informal networks; media announcements generate a high volume of interest but the most appropriate candidates have been located through foster parent and community networking.

2. Successful recruitment depends upon finding foster parents who are well informed concerning the disease, are not afraid of contagion, and, it would appear, have some medical background/experience in caring for ill people.

3. Recruiting and keeping foster parents are made possible at our present level of knowledge about and treatment of AIDS by offering an exceptional boarding home reimbursement rate (even at this rate one month of foster care is less expensive than two days in the hospital!) with continued financial assistance during hospitalizations. Maintaining foster homes also requires intensive medical and psychological support services.

4. Because assisting foster parents and children places strong demands on staff members for support, information, and guidance, caseload size must be small.

Conclusion

Whenever possible HIV infected children should remain with their families. Adequate social and medical support must be available to families. This should include decent housing, home care and respite care.

Individual foster care represents the best alternative for the child who cannot be cared for within his/her family. Increased funding for foster parents, additional social and practical support such as day care, home care and professional support will help recruit badly needed foster parents.

Innovative small group homes should be established. This would service the population of children, for whom as yet there is no individual foster parent available. In addition, it will service a group of children who are too ill to be cared for by foster parents but who do not need an acute hospital facility.

There is an acute shortage of social workers, nurses, and teachers who are willing to work with these children. There must be increased education and financial incentives to work with HIV infected children.

Senator MOYNIHAN. First of all, on the subject of care for children—and you, Dr. Wiznia and Ms. Boland, probably can answer this well—a child can be born with the HIV virus, but isn't there a trigger mechanism that puts this virus into action?

Dr. WIZNIA. Basically, it is a continuum.

Senator MOYNIHAN. A continuum?

Dr. WIZNIA. A continuum of an infection. At first, you get infected; you get exposed to the virus. The virus infects certain cells, certain parts of your body; and it can remain latent for an unknown period of time. It seems to be more aggressive in children. The best studies are in people who received the virus through blood transfusion. It takes a child about two years to develop full-blown CDC-defined AIDS, which means that their immune system during that two-year period of time has become more and more debilitated until they cannot mount an immune response against normal pathogens that you and I get exposed to that do not cause illness.

So, there is a continuum over that two-year period of time during which their system is becoming worse and worse as a result of the virus. In an adult, that can take about seven or eight years from the time they get a——

Senator MOYNIHAN. Wait, now, I am hearing something, and you will understand that I am a layman in these things.

Dr. WIZNIA. Yes.

Senator MOYNIHAN. There are viruses which can be acquired and which stay latent forever, are there not?

Dr. WIZNIA. Right, there are.

Senator MOYNIHAN. Can you tell me about one?

Dr. WIZNIA. One example would be Epstein bar virus, which in adolescents, in middle-class neighborhoods, causes mononucleosis. Okay?

Senator MOYNIHAN. Yes.

Dr. WIZNIA. That virus in an African population is usually infective in an age group of about four or five years of age. By the age of about 20, those children who were previously infected, can develop different types of lymphomas and other different types of cancers, as a result of their virus infection 15 years prior to that. So, there are viruses actually that can remain latent in our genes; basically, they remain latent incorporated in our DNA. But with time, there may be a triggering mechanism; there may be other viral infections that they become exposed to. In those children, one of the things I would think that happens is that many of them become malnourished.

There have been a number of studies on patients who are malnourished and being immunosuppressed as a result directly of their malnutrition. Okay? So, you basically have a virus which sits in our immune system to remain latent and, as other viral infections—malnutrition, unknown cofactors——

Senator MOYNIHAN. Malnutrition is independent——

Dr. WIZNIA. It may be socioeconomically dependent, and it may be dependent on one of the symptoms of HIV infection, which is chronic diarrhea, which can cause that.

Senator MOYNIHAN. These may induce it?

Dr. WIZNIA. That is right. And it is sort of a cycle. Every time they get an additional infection, the virus which lives in the

immune system replicates more aggressively. You get more of a virus load, of the AIDS virus load in the body; and then, that sets up a person for an additional viral infection. So, you have a cycle.

Senator MOYNIHAN. So, my little notion of the mechanism of a trigger is not correct?

Dr. WIZNIA. There is a continuum. You don't get infected one day, remain clinically well for two years, and bang, there you have it. It is more of a course like the child I described to you, who was admitted to the hospital, had one infection, and then over the next two years, had multiple infections.

Senator MOYNIHAN. So, any child born with HIV is likely to succumb to full-scale AIDS?

Dr. WIZNIA. I am told now the answer to that is yes. Hopefully, in a few weeks, we will be starting AZT trials in the pediatric population in New York. There have been some pilot studies done; but I would like to mention that the drug was hurried very aggressively through the FDA and through different committees for treatment in adults, and it seems to have lagged in getting clearance for treatment in the pediatric population.

Senator MOYNIHAN. Right, but for good methodological reasons, I assume. It is not that people just haven't got around to it; or are you not sure?

Dr. WIZNIA. I am not sure. [Laughter.]

I know Dr. Oleske, whom Mary works with, has been a very avid and very vocal advocator of treatment and in the delay of getting it to children.

Senator MOYNIHAN. Oh, yes?

Ms. BOLAND. Yes.

Senator MOYNIHAN. I am sure the argument is being heard.

Ms. BOLAND. I think I would like to go back to your comment about children being born. I don't think we know enough yet about the whole population of children who are born infected. What they have been seeing and what we have been seeing are the sick children; but until the prospective national history studies, which are now in progress, have a couple of years behind them, I don't think we will get a sense of what the scope is because our experience recently has been that we are starting to diagnose eight and nine-year-old children who are perinatally infected, who have all the manifestations, have an infected parent, and they are being found when the parent dies and someone says should we go and look at the children? So, those children may have been there and actually been surviving for a long time.

Senator MOYNIHAN. I hear you saying you are now finding nine-year-old children who were obviously born with this?

Ms. BOLAND. Right, were born with the infection.

Senator MOYNIHAN. So, there is a nine-year stretch?

Ms. BOLAND. Right. So, I don't think we or anyone knows yet what the full picture is.

Senator MOYNIHAN. There are 450,000 people in New York City who have the virus, and only 15,000 have died. Is it your feeling that in 1,000 cases there are going to be——

Dr. WIZNIA. The longest cohort studies are out of San Francisco in gay men, and it is patients studied from the time they are infected and they are carried out seven years. Thirty percent have devel-

oped AIDS; an additional 40 percent will develop AIDS-related complex, which is a pre-AIDS syndrome, meaning that those patients are sick. And only 30 percent will remain asymptomatic. So, in seven years, 70 percent will have symptoms consistent with the disease, with an estimate of anywhere from two to eight percent of clinically well patients each year becoming clinically symptomatic.

There are people who think that everyone who is infected with this virus will become ill at some time.

Senator MOYNIHAN. So, in your profession, some people think 80 percent and some think 100 percent.

Dr. WIZNIA. That is right.

Senator MOYNIHAN. There are people coming into this system all the time, if you want to call it a system, so we need to find a direct approach.

Dr. WIZNIA. Definitely a hospital system.

Senator MOYNIHAN. Kevin Cahill called me in about 1982 and said that something was going on here; and we ought to do something about it. Of course, I hope we get lucky in the laboratory.

Dr. WIZNIA. Maybe. Hopefully.

Ms. BOLAND. Right.

Senator MOYNIHAN. We have not. We can describe what is going on. Look how long it took us to know what syphillis was. I remember movies I was shown in the Navy in 1944. I don't think it ever got quite so population-specific, but we don't really know. You are just getting cohort studies, about seven years in all?

Dr. WIZNIA. Right. Those are the adults. And I am sure you have a cohort study, Mary?

Ms. BOLAND. On children, a cohort study. Yes.

Senator MOYNIHAN. All right.

Dr. WIZNIA. I would like to make one additional point.

Senator MOYNIHAN. You surely may.

Dr. WIZNIA. All right. One of the problems in diagnosing pediatric AIDS is that there are a number of children born in city hospitals whose mothers are intravenous drug abusers. We extrapolate their mothers, 50 percent of the drug abusers in New York City, on an average, are HIV positive, meaning that they have antibodies against the disease. A newborn's antibodies come from their mothers; there is an internal transport of antibodies through the placenta to the baby.

That means that any child who is born to a mother who is antibody positive, which is what the screening tasts look for—any child who is born to a mother who is antibody positive will be born antibody positive. So, you have babies now being born in New York City hospitals who are antibody positive.

Not all of these children who are antibody positive will go on to develop—actual infection with this virus——

Senator MOYNIHAN. Oh, they have the antibodies?

Dr. WIZNIA. They have the antibodies but may not have the virus.

Senator MOYNIHAN. Yes.

Dr. WIZNIA. At a newborn level, it is very difficult to make a determination whether or not these children are actually infected. It is costly, there are technical difficulties in determining this. So,

what happens with these children is that they remain in hospitals as boarder patients.

Senator MOYNIHAN. Nobody wants them.

Dr. WIZNIA. Nobody wants them because—do they or do they not have AIDS? And in certain hospitals, there are 30 to 40 babies.

Senator MOYNIHAN. The degrees of fear escalate as you go down the ladder, as I said. We have to think about this whole question of being in foster care, and we certainly will, and we want to hear from you. We are going to hear from you about the insurance?

Ms. GURDIN. Yes, right.

Senator MOYNIHAN. There is the question about how effective this legislation will be if it is disease-specific. And I think I am beginning to learn that the less you speak of this subject and the more you speak about waiving the 24-month waiting period with a disease that is surely fatal in a short period, that is the way to talk about it. But, on the other hand, this is going to be a real test of this civilization. It is not just one of those marginal costs of being highly industrial or urban and so forth. Those costs—like deaths due to automobile collisions—you can get around. But not in this case.

This is dreadful. You have that combination of welfare, drugs, AIDS in the inner cities. That has the potention for great gulfs of fear.

Thank you, Ms. Boland. Thank you, Ms. Gurdin. Thank you, Dr. Wiznia. You have been very generous with your time and are doing extraordinary things with your lives. The hearing is now adjourned.

[Whereupon, at 12:58 p.m., the hearing was adjourned.]

September 8, 1987

Department of Health
Herman Kiefer Health Complex
1151 Taylor
Detroit, Michigan 48202

Coleman A. Young, Mayor
City of Detroit

TESTIMONY FOR THE SENATE SUBCOMMITTEE ON SOCIAL SECURITY AND FAMILY POLICY

ON

ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS)

Subject: AIDS in Detroit as of September 8, 1987

The City of Detroit has been a part of the State Health Department Reporting Program since 1981. Michigan, as of August 31, 1987, had 887 reported AIDS cases and 242 deaths. The City of Detroit has had 163 cases or 42% of the State's total cases. Thus far this year (1987), we in Detroit have had 50 cases (as of 8/27/87) -- compared to 35 this time last year.

Gender

94% of the State's AIDS cases are male and 6% are female. The risk group with the highest percentage is male, homosexual/bisexual - 64%; male, homosexual/bisexual who are also IVDA (intravenous drug abusers) - 8%; or 72% have some homosexual involvement. Whereas, 15% of all the State cases involve the IVDA risk group.

Risk Group

A look at the Detroit City drug abuse risk group in April, 1987, showed an increase in the IVDA AIDS cases (from 12.5% in 1983 to 38.9% in 1987). There was a corresponding decrease in the homosexual/bisexual males. The unique demographic feature of the Detroit cases is that 50% are IVDA and/or IVDA and Homosexual/bisexual as compared to the State rate of 15%. In terms of the most cases in Detroit, IVDA stands out.

Race

57% of Michigan cases are White
41% of Michigan cases are Black
1% of Michigan cases are Hispanic
1% of Michigan cases are Other

A look at the Detroit AIDS cases by risk group as of September 10, 1987:

Risk Group	Number	Percent
Homosexual/Bisexual, Male	92	56.1
IV User, Male	28	17.1
IV User, Female	11	6.7
Homosexual/IV User, Male	17	10.4
Hemophilia, Male	1	.6
Sexual Contact, Female	2	1.2
Haitian, Male	1	.6
Other Unknown, Male	8	4.9
Other Unknown, Female	1	.6
Mother IV User, Female Child	2	1.2
Mother Sexual Contact, Female Child	1	.6
TOTAL	164	100.0

(Source: Detroit Health Department, Office of Epidemiology & Biostatistics.)

Detroit does not operate a public hospital. About 96% of the patients hospitalized are at either Detroit Receiving or Henry Ford Hospitals, both private, non-profit. Data on payment for AIDS public versus private may be obtained from these two (2) facilities.

SUMMARY

AIDS is epidemic in Detroit. The State of Michigan has 1% of the total AIDS cases in the United States and Detroit has 42% of the State's cases. The predominate gender is male (94%) and the predominate risk group is male IVDA (17.8%) and male homosexual/bisexual who are also IVDA (10.3%).

Two (2) major hospitals treat most of the cases. They are, as indicated above, Detroit Receiving and Henry Ford Hospitals.

Respectfully submitted,

George D. Gaines, Jr.
Deputy Director

GG/et