AIDS: TOWARD LONG-TERM TREATMENT OPTIONS

HEARING

BEFORE THE

SUBCOMMITTEE ON HUMAN RESOURCES

OF THE

COMMITTEE ON GOVERNMENT REFORM AND OVERSIGHT HOUSE OF REPRESENTATIVES

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AIDS: TOWARD LONG-TERM TREATMENT OPTIONS

FRIDAY, FEBRUARY 20, 1998

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON HUMAN RESOURCES,
COMMITTEE ON GOVERNMENT REFORM AND OVERSIGHT,
Brooklyn, NY.

The subcommittee met, pursuant to notice, at 9:40 a.m., in the courtroom of the Borough Hall, Joralemon Street, Brooklyn, NY, Hon. Christopher Shays (chairman of the subcommittee) presiding.

Present: Representatives Shays and Towns.

Also present: Representatives Nadler and Velázquez.

Staff present: Larry Halloran, staff director and counsel; Marcia Sayer, professional staff member; Teresa Austin, assistant clerk; and Cherri Branson, minority counsel.

Mr. SHAYS. I'd like to call this hearing of the Government Reform and Oversight Committee, Human Resources Subcommittee to order.

We are a committee that oversees the Departments of Labor, Education, Veterans' Affairs, Housing, Urban Development and HHS—Health and Human Services. We're the committee that looks at programs that Government passes and makes sure the departments are performing according to the requirements of the law, makes sure that the laws make sense, and it's just a distinct pleasure for our committee to be here, and to participate in this very important hearing, looking at AIDS, the long-term treatment options.

I'm joined by, the official title is the ranking member of the subcommittee, but really he functions as co-chairman. It's not a partisan subcommittee in part, because of the ranking member I have. We work together as a team, and this is the second time we've been here, on basically the same issue. So I would just say it's great to welcome our witnesses, it's great to welcome our guests and to have two extraordinarily effective Members of Congress who have joined us, Jerrold Nadler and Nydia Velázquez, both very active and I think powerful Members of Congress because of their intellect and their work ethic.

At this time, I will make a statement and I will call on the other Members of the panel to make a statement and then we will be joined with opening words of greetings by the deputy borough president of the Borough of Brooklyn, Jeannette Gadson.

Let me just make my very short statement. The Subcommittee on Human Resources meets in Brooklyn this morning at the request of our ranking member, Mr. Towns. His long standing con-

cern and activism on behalf of people infected and affected by HIV and AIDS brings us here. We are grateful for his work and for the opportunity to listen and to learn from today's witnesses.

The AIDS virus is a determined, clever foe and as it mutates so does the reach and scope of the epidemic. Positive news about death rates should not lull us into any false sense of accomplishment or complacency. Demanding treatment regiments that are prolonging the lives of HIV-infected persons are costly and making those treatments available presents a profound challenge to current care delivery systems.

So we come here today to ask providers, advocates and community organizations how to extend the continuing care to all who need it. The testimony of our witnesses today will help us arrive at findings and recommendations to improve Federal AIDS policy.

At this time I'd like to ask for my co-chairman, Mr. Towns, who would like to comment.

Mr. TOWNS. Thank you very much, Congressman Shays. Let me begin by saying I appreciate the work that you're doing in this area as well and let me begin by welcoming you to the borough of Brooklyn. If it was a city, it would be the fourth largest city in the United States, so that's why we asked the deputy borough president of Brooklyn, Jeannette Gadson, to welcome you, because you're in Brooklyn and we do it right in Brooklyn.

The Centers for Disease Control and Prevention estimates that between 650,000 and 900,000 Americans are infected with HIV. The vast majority of the new infections occurred in people under the age of 25. About half of these new infections were in women. People of color were 40 percent of the AIDS patients in the years 1981 to 1987, but they accounted for 57 percent of cases last year.

HIV infection in America is rapidly becoming the disease of the young, poor, non-white, economically disadvantaged who do not have private health insurance. However, amidst this gloom there is some hope. Medicine has finally started to catch up to the disease and can now offer treatments that may substantially lengthen life and in some cases restore health. About 200,000 people, approximately one quarter of the people in the United States infected with HIV, are now in triple therapy. AIDS deaths across the United States dropped 44 percent in the first half of last year. In New York City, the AIDS death rate fell by 48 percent, but we still have a long, long way to go.

To date, the most important development in AIDS treatment has been the arrival of protease inhibitors, a new class of drugs that are generally used in a three-drug combination with other antiviral medications. Triple therapy can slow down viral replication to the point where the virus does not appear in the body. However, triple therapy costs up to $12,000 a year and requires a strict and accurate regimen of medications.

In addition to the costs, bringing medical care to poor people or people, the new triple therapies may be revealing the weaknesses and deficiencies in the complex mix of public and non-profit health care services used by people without health insurance. Weaving this network into a system that can bring medical advances to this population may be the greatest achievement in the battle against AIDS.

As the treatment of AIDS continues to evolve toward the management of chronic disease, services provided by nursing facilities will become increasingly important. Medicaid will be the major payer for this care. Therefore, Medicaid policies will affect the types and locations of the long-term services available to Medicaid recipients with AIDS.

The Federal Government has given the States broad discretionary powers to develop Medicaid policies for the health service available to the program recipients in their States. As a result, Medicaid policies vary widely from State to State, with recipients in some States having access to a broader range of services than in other States. Federal policy may need to be changed to allow treatment and management of AIDS.

Mr. Chairman, I believe that we can win this battle if Federal, State and local governments and local community organizations work together. I think that we have to look at what the problems are, make certain that the money goes to where the problems are and that we're able to do that and I think we will be able to bring down the numbers even lower, and I would look forward to hearing from our witnesses, and I thank my colleagues, Jerry Nadler and Nydia Velázquez, for joining us and I also appreciate their help in working with me in trying to change the formula in Washington, DC.

Mr. Chairman, I yield back.

Mr. SHAYS. Thank you. And at this time we would call on Nydia Velázquez; we welcome you to the committee.

Ms. VELÁZQUEZ. Good morning, Mr. Chairman, and Members of this panel. I would like to express my sincere thanks to Congressman Shays, the chairman of the subcommittee, and Congressman Towns, the ranking member of the subcommittee, for putting together this important hearing.

Today's hearing comes at a moment when there is much to be encouraged about in our fight against AIDS, but there is also much to be concerned about. The good news is that the death rates are falling, new treatments offer hope, and we are thinking about survival in terms of years, not months. The bad news is that the epidemic has tilted heavily toward minorities. In fact, right now AIDS is the leading cause of death among Latinos in New York City between the ages of 25 and 45. The worst part of this tragedy is that while funding for AIDS prevention and treatment has increased, the organizations that serve minority communities still lack access to funds to meet the need for services.

It is my hope that today's hearing will shed some light on how we can begin to solve these problems. This debate becomes more important in light of the great strides we're making in the fight against AIDS. We have begun to see significant advances in the treatment of this disease. AIDS survival rates are increasing dramatically. According to the Centers for Disease Control and Prevention, in 1981, the median survival rate was 9 months. By 1993, it was over 2 years. In the first half of 1997, AIDS deaths dropped by 44 percent across the country and by 50 percent in New York City alone, yet the drop was just 5 percent among Latinos. There was no improvement in blacks.

Perhaps the most significant news is the fact that we are seeing the kind of financial support for AIDS research and treatment that we have desperately fought for as the AIDS crisis deepened. This year funding for the Ryan White CARE Act has been increased to $1.15 billion. This funding represents more than mere dollars. It shows that AIDS prevention and treatment has finally made it on to the radar screens of those who have the power to direct resources for this problem.

Yet in the midst of all this hopeful information, we will hear from several of today's witnesses that not every community can share in the good news. While survival rates are increasing, alarming trends have surfaced. HIV infection in America has become a disease of poor minorities. Last year 57 percent of all AIDS patients were non-white, up from 40 percent just 10 years ago. These patients have less access to quality health care, lower levels of education, and far less political clout than people infected earlier in this epidemic. In my District alone, Bushwick accounted for nearly a third of all the new AIDS cases reported in New York in 1994. That neighborhood ranks first in AIDS cases among Hispanics and first in cases among women.

Let me take a minute to put a human face on these alarming statistics. At St. Barbara's Catholic Church in my District, 245 funerals were held in 1994. Of these, 181 were for young Latinos and Latinas who had died of AIDS. This reality is deeply alarming and troubling to me and presents an important charge to those charged with addressing the health needs of people currently infected with HIV/AIDS.

A number of factors, however, complicate our ability to treat patients from disadvantaged communities. One of these is that most current therapies are highly complicated and must be strictly followed. Some treatment requires taking four, five and even six drugs at a time, and of course, these medicines are very expensive.

We have to address these special needs on two fronts. First, we must make effective, cutting edge drugs available wherever they are needed and then we must direct funding to the kinds of organizations that will be best suited to insure that those drugs are administered properly and effectively.

For these reasons, it is extremely important that we target our funding to organizations that can best deliver such treatment to poor minority communities. These organizations have the strongest ties to the communities they serve. They have an established network of local resources to draw from. They understand the special health and social service needs of the community. They are best positioned to address the challenges presented by the makeup of the communities' population.

I have had the opportunity to see firsthand how effective community groups can be in delivering necessary services. In my district, I have been working with groups like Musica Against Drugs, which is one of the few community groups receiving training on how to successfully conduct community outreach programs. In addition, Musica has been using non-traditional approaches to combat substance abuse and provide basic services to patients with HIV/AIDS.

As today's witness will explain, these groups have been shortchanged and the communities they are serving are suffering as a

result. In the face of this reality, as we listen to testimony today, we must ask ourselves the following questions: How do we direct funding to reflect the changing needs of people with HIV? We must make sure that poor minority communities have access to the kinds of treatment and services that are the difference between life and death. As a representative of such a community, I would like to express my gratitude to today's witnesses from the community service organizations who are fighting to provide such access.

I would also like to thank the panel of city and State officials for coming today. I look forward to working with you closely to insure that these organizations are given the necessary resources to serve the people with the most desperate need.

Thank you, Mr. Chairman. This is an important issue in my community and the community of color. Thank you for allowing me to take the time to share my thoughts with you.

Mr. SHAYS. Thank you, it's wonderful to have you participate. Jerry Nadler.

Mr. NADLER. Thank you very much. Let me first express my appreciation to the chairman officiate of Connecticut for bringing this hearing to Brooklyn and particularly to Congressman Ed Towns, who took the initiative in getting this hearing brought to Brooklyn. I am participating this morning, but unfortunately, I can't stay very long. I can only come here to make an opening statement and to welcome the committee and to express my appreciation for it.

I want to say that it's very important that these hearings be held, and in particular that we're in a particular moment of change in the progress of this epidemic and our understanding of it. The introduction of the protease inhibitors and the triple therapy in the last year and a half, really, has changed everything. We now know, for example, that it is advisable or essential to begin treatment with these drugs as early as possible, as soon as we realize that a person is infected with the HIV virus, yet our laws and our programs still reflect an earlier understanding, and therefore, Medicaid funding, for example, only begins when a diagnosis of AIDS is made and does not provide funding in the earlier period that can last for years, when we know that the drugs, the treatment, ought to be initiated. So we have to study changing our laws to reflect this new understanding.

We have to begin to address needs of increasing population that will be living with AIDS on a long-term basis as the disease hopefully changes from an acute death dealing disease to a chronic disease in which people can live with it for years and maybe hopefully decades, but in which people have to be taking very severe drug regimens and expensive drug regimens this entire time period.

We have to start dealing with the needs of long-term, housing, health care and pharmaceutical needs of a population that will be living with the disease for a long time, which we haven't really addressed yet. We have to see that our Ryan White title I funding is increased sharply. The President proposed increases in ADAP funding, but only a modest increase in title I funding.

I want to say one thing, I'm sure it will come up at some point in the hearing, I'm sorry I won't be able to participate in a lively discussion, it has been in every forum that I've been at, but I believe it's essential that we promote needle exchange programs as

widely as possible, because it has been demonstrated time and time again, that needle exchange programs do not on the one hand either at all or certainly not substantially, increase drug usage, but do greatly inhibit the spread of this epidemic and could save potentially thousands and thousands of lives. So I again thank you, Mr. Chairman and Congressman Towns and Nydia for bringing this hearing here. I regret I can't stay for the rest of the hearing, but I look forward to reading all the testimony here and to the progress that will be made from this hearing. Thank you.

Mr. SHAYS. Thank you very much. It's wonderful to have you with us as well.

Now, we have with us a congressional hearing. Before it begins, Members give long statements, and now we're ready to start and to welcome you, deputy borough president of the Borough of Brooklyn, Jeannette Gadson.

STATEMENT OF JEANNETTE GADSON, DEPUTY PRESIDENT, THE BOROUGH OF BROOKLYN

Ms. GADSON. Thank you, Mr. Chairman, Congressman Towns, Congresswoman Velázquez, Congressman Nadler. It is with great privilege and pride that I take this opportunity on behalf of the people of Brooklyn and on behalf of the Honorable Howard Golden, the borough president of the borough of Brooklyn, to welcome you to Borough Hall for this very important hearing this morning, this public hearing regarding AIDS issues by the House Government Reform and Oversight Subcommittee on Human Resources.

After more than a decade of anguish, the AIDS epidemic across the Nation has shown a dramatic decrease over the past 2 years. The New York Times reported that AIDS deaths plummeted by 48 percent last year. However, New York City has been and continues to be the epicenter for this dreaded disease. With 3 percent of the Nation's population, New York has 17 percent of the country's AIDS cases, and even with the good news for 1997, on average, 7 people die each day from AIDS in New York City.

The population affected by this disease has shifted. Women and children are increasingly forming a larger percentage of the new HIV and AIDS cases. In New York City as of June 1997, women comprise 21 percent of all AIDS cases. Nearly one in four pediatric cases in the Nation have been reported in New York City. Cumulative reported AIDS cases for adolescents in New York City represent one-third of the adolescent cases nationwide. In Brooklyn, there are more women, children, adolescents and African-Americans diagnosed with AIDS, as well as more orphans as a result of parental death from AIDS, than in any other borough of the city of New York.

Thirty-three percent of the reported cases of women with AIDS in New York City live in Brooklyn; 35 percent of pediatric AIDS cases are found in Brooklyn; 86 percent of the people living with AIDS in Brooklyn are minorities, 28 percent Latino and 58 percent African-American.

Recent medical advances utilizing protease inhibiting drugs have had profound effects on not only the life span for people living with AIDS, but also on the quality of life of AIDS sufferers. Advanced drug combinations have been able to reduce the level of HIV in the

blood to undetectable levels. People living with AIDS can now for the first time make plans to live. However, while treatment may result in a reduction of viral load, severe side effects from the drugs may affect the quality of life for certain individuals.

The recent good news is changing the kinds of assistance needed by this population. Agencies designed to serve the persons living with the AIDS population must revise their services to fit this new need. Basic services such as counseling, support group, nutrition and case management will continue to be in demand. However, housing, job training and placement services will need to be expanded. Health care coverage will need to be modified to allow for sound treatment decisions based on current treatment options.

Since the early years of this epidemic, people working at local community-based organizations recognize the need for the wide array of services and support for AIDS infected patients as well as those affected by the illness. The local organizations have proven themselves successful in engaging people in treatment and prevention programs. For this reason, equitable funding under the Ryan White CARE Act is important.

Brooklyn has a large number of locally based AIDS service organizations with established records of bringing care and help to those suffering from this disease. In Brooklyn, there are three HIV care networks; Williamsburg/Greenpoint/Bushwick; East New York/Brownsville; and Bedford Stuyvesant/Crown Heights. These networks are providing culturally and linguistic appropriate services that recognize the need to provide a continuum of care to the AIDS community.

AIDS is changing, but we should not forget that it is still an urgent and unprecedented health crisis. Many people do not respond to the combination therapies. Estimates of failure are as high as 40 percent, and even those who do are still faced with the likelihood of eventual disability and a greatly shortened life.

I would like to take this time, however, to commend all who do the hard work to combat this disease. I am sure that the testimony that you are about to hear this morning will be enlightening and rewarding. And we are encouraged today in the Borough of Brooklyn that you have brought this hearing here.

I want to take this opportunity again to welcome you to Brooklyn and to thank you for the opportunity to testify before you this morning.

Mr. SHAYS. Thank you, Madam President. We thank you for your words of welcome and your very thoughtful testimony. We appreciate your testimony and extend our word of welcome. Thank you.

At this time we will hear testimony from our first panel, which is comprised of two people, Dr. Rosa Gil, special adviser to the mayor on Health Policy of New York, and Humberto Cruz, director, Division of HIV Health Care, New York State Department of Health. I would like both those individuals to come forward. Remain standing, and I'll swear you in.

[Witnesses sworn.]

Mr. SHAYS. I would like to deal with a housekeeping issue before we begin. I ask that the members of the subcommittee be permitted to place an opening statement in the record and the record remain open for that purpose. I ask further that all witnesses be

permitted to include their written statements in the record. So ordered.

Let me just explain to you. It will be green for 5 minutes, be on red for just a few seconds, and then we'll give you another round. I would like your testimony to be somewhat complete between 5 and 10 minutes, if possible, and that's our intention. We will hear from Dr. Gil, and you can open the hearing.

STATEMENTS OF ROSA GIL, SPECIAL ADVISOR TO THE MAYOR ON HEALTH POLICY, NEW YORK, NY; AND HUMBERTO CRUZ, DIRECTOR, DIVISION OF HIV HEALTH CARE, NEW YORK STATE DEPARTMENT OF HEALTH

Dr. GIL. Good morning, Congressman Shays, chairman of this subcommittee, the Honorable Congresswoman Velázquez and Congressman Towns. Thank you for the opportunity to address this subcommittee on important developments relating to new HIV therapies and the impact that they are having on HIV infected individuals in New York City.

Mr. SHAYS. I'm hearing my voice quite strongly. Would you just tap that mic? I want to know if that mic is activated. Yes, fine, thank you.

Dr. GIL. My name is Dr. Rosa Gil, I'm the special adviser to the mayor on Health Policy for New York City, and director of mayor's Office of Health Services.

In my testimony this morning, I will provide the subcommittee with data on the dramatic impact that recent HIV treatment developments are having on the epidemic in New York City, with a particular emphasis on the access to those treatments for minority populations. I will then discuss some of the implications of these treatments for the evolving nature of the disease and the need for medical and supportive services and our recommendations for the steps that the Federal Government could take to enhance access to treatment for HIV infected residents of New York City.

New York City remains the epicenter of the AIDS epidemic in the United States. Approximately 16 percent of U.S. AIDS cases have been reported from New York City, although it has only 3 percent of the Nation's population. The city has the oldest, largest and most complex AIDS epidemic in the country. More than 100,000 New York City residents have been diagnosed with AIDS since the beginning of this epidemic in 1981, and more than 65,000 of them have died; 41 percent of New York City residents living with AIDS are black, 33 percent are Hispanic, 25 percent are white, 0.76 percent are Asia/Pacific Islander and 0.04 are native Americans.

The approval of the first protease inhibitor in late 1995 has proven to be a watershed in the history of the HIV epidemic. We now have four FDA approved protease inhibitors, as well as a range of other anti-retroviral drugs. The new array of HIV therapies has dramatically improved our ability to intervene clinically to slow or in some cases even to reverse the course of the HIV infection.

In November 1997, the Department of Health and Human Services released its revised "Guidelines for the Use of Anti-retroviral Agents in HIV Infected Adults and Adolescents," which established a new standard of care incorporating these newly available medica-

tions. These medications are so new, however, that many questions remain unanswered, and even the recently released guidelines extend significant discretion to physicians in determining the best course of treatment for an individual patient. Thus, while the guidelines recommend combination anti-retroviral therapy for all patients with symptomatic HIV infection, they do not definitely establish a standard of care for asymptomatic patients, instead, encouraging physicians to discuss treatment recommendations with patients based on an array of individual considerations. The guidelines do clearly express a preference for triple combination therapy, which has become essentially the "gold standard" for HIV care, for those patients whose medical status warrants it.

The new standard of HIV therapy creates a range of opportunities and challenges for the HIV services system in New York City. For the first time, we have a demonstrable ability to prolong life for most HIV infected individuals, to improve the health status and the level of functioning for many if not for most patients, and to roll back disease progression for some who have been seriously ill.

But accomplishing these things, particularly over time, will not be easy. The new drugs are not a cure, and until another generation of drugs comes along or further research demonstrates that these drugs have the ability to clear HIV from the body or to render it harmless, the reality is that people must continue to take these drugs indefinitely. And they are not easy to take. Each of these drugs in the combination must be taken two to three times a day, on varying schedules, before, during or after meals, and often with accompanying side effects. Thus, helping people to maintain adherence to HIV treatment has become a larger challenge.

Since the time that protease inhibitors became available, and as triple combination therapy has become the standard of care for many patients, New York City has been committed to ensure access to this regimen for all HIV infected individuals for whom it is indicated. To ensure effective access, two things are necessary. First, there must be a system in place to permit patients to obtain the drugs despite their substantial cost, often $15,000 or more per year.

Second, the health care delivery system must be capable of educating patients about the availability of these drugs and providing the primary and ongoing medical care required to assess patients' needs for these drugs, to work with patients to establish a medical routine that they can follow, and to monitor the impact of medication and assess the need for change in the medical regime over time.

I would like first to discuss the publicly financed system that are in place in New York City, largely supported by the Federal funding, to make these medications and accompanying health care available to the HIV infected population. Then I would like to share the data that we have on the degree to which we are succeeding in establishing widespread access to these medications, particularly across racial and ethnic communities in New York City.

While AIDS affects people across the social economic spectrum in New York City, it has had the heaviest impact on low income individuals and so, not surprisingly, the large source of payment for

HIV care is the Medicaid program. The "Changing Environment Study" done in the fall of 1997, for the New York Ryan White Planning Council estimated that between 55 to 80 percent of HIV infected individuals in New York City rely on Medicaid for their health care. New York State's Medicaid program provides enhanced reimbursement rates for HIV primary medical care, and a broad network of institutional and individual providers in New York City participate in the Medicaid program.

The Medicaid program also had a drug formulary that covers every FDA approved anti-retroviral treatment for HIV infection. The Medicaid program is supplemented by services supported by the Ryan White CARE Act. Ryan White is designed to complement entitlement programs by filling gaps in critical services and that is precisely the role that it plays in New York City. Title I of the Ryan White CARE Act which provides funding to New York City and many other localities nationally, pays for medical care for individuals who do not have private insurance and do not qualify for Medicaid. Under Federal law, the Ryan White Planning Council determines how the title I money coming to New York City is allocated.

In recognition of the increasing prominence of medical care of HIV-infected New Yorkers, the Council this year has allocated almost $40 million to drug reimbursement and outpatient medical care, more than ever before. The Council also allocated almost $1 million for treatment education and support programs in recognition of the challenges for HIV patients in understanding their treatment options and remaining adherent to therapy.

The bulk of title I moneys for medication and health care supports two critical programs. Like every other State, New York has an AIDS Drug Assistance Program or ADAP that provides medications for the uninsured and underinsured people with HIV. Unlike any other State, however, New York has also created a unique program called ADAP Plus, which provides access to primary care services and laboratory tests for disease management. By filling the gap between private insurance and Medicaid, these programs ensure that no New Yorker is without access to HIV care and antiretroviral medications for reasons of financial need. New York State and New York City have operated in a very close partnership since the inception of the Ryan White program to make sure that these programs remain adequately funded and available to all who need them.

Let me turn now to the next important question. Are these programs working? We have recently found that the most definite answer yet to this question seems to be a resounding yes. Our surveillance data, just analyzed through 1997, shows a dramatic decrease in the rate of deaths due to AIDS and you can see attachment A to my presentation. Over the 2 years since protease inhibitors first became available, AIDS deaths in New York City dropped 63 percent from approximately 7,046 cases in 1995, to approximately 2,577 in 1997. We have not recorded so few AIDS deaths in New York City since 1986, when the epidemic was much more limited than it is today.

Equally heartening is the fact that these declines are seen across all population groups as reflected in attachment A. There were de-

clines in deaths among men and women in the Hispanic, white, black, Asian race ethnic groupings, although as was the case last year, declines were more dramatic in men. Male deaths declined 71 percent overall and ranged from 59 percent for blacks, 72 percent for Hispanics and 78 for whites and 83 for Asians. Female deaths declined 63 percent overall and ranged from 59 percent for blacks and 66 percent for Hispanic and 73 percent for white.

Overall, AIDS remains the third leading cause of death in New York City and remains the leading cause of death in those aged between 1 and 14 years of age and 25 to 49. While more analysis is necessary, these data certainly tell us that the broad access to new anti-retroviral combination therapy is making a dramatic difference in the life spans.

The clients who are served through Ryan White title I programs bear out the fact that the programs are reaching predominantly minority populations who are in great need of these services. Title I's health programs, excluding ADAP and ADAP Plus, has a total enrollment of 12,976 in calendar year 1997. During the last program year, which ended in March 1997, 7,676 new clients were enrolled in health program categories. You can see in attachment B. Of these new clients, 41.8 percent were black, 41 percent Hispanic, 10 percent white, 1.1 percent Asian/Pacific Islander. New clients in health programs are also widely distributed across the five boroughs. In fact, the four outer boroughs are represented among new clients at least in proportion to their relative percentage of live AIDS cases. See attachment C.

Looking specifically——

Mr. SHAYS. Dr. Gil, let me ask you a question. Your statement is very important, I think I'm going to have you go through all of it, but I just want to know how many pages you have left.

Dr. GIL. I can just jump——

Mr. SHAYS. I want to know how many pages you have left.

Dr. GIL. I think I have four or five pages.

Mr. TOWNS. Mr. Chairman, the entire statement is in the record.

Mr. SHAYS. Why don't you take a minute and summarize and then we'll get into some questions and anything in the end we didn't ask in the questions you need to put in the record, we'll have you comment on that.

Dr. GIL. Fine. Let me just say that the recommendations that we have for this community that we think that are very, very important——

Mr. SHAYS. I think you should go through those recommendations.

Dr. GIL. We have cited, of course, the increasing AIDS deaths that we have experienced in New York City in the past 3 years and that represents certainly a challenge, because as was mentioned before by testimony of the Congressman, that basically it will require that the infrastructure of social services will need to be changed as the life span of these individuals continue to grow.

I would like to make three specific recommendations. The first one has to do with the Ryan White CARE Act. Let me say that both Congress and Health Resources Services Administration have today been extremely supportive of our work this year. Our title I funding increased to $95 million from $92 million last year. This

enabled us to increase our services, but we would like to recommend in fiscal year 1999 the present proposal for increase in funding for the ADAP program. This is extremely important, because ADAP allows us to provide medication to the uninsured individuals, but we have to say that we'd like to see an increase in title I funding, which just reflects perhaps a 5 percent increase in the President's budget.

Second, the medication. The administration has had under discussion the possibility of allowing States to apply for a Medicaid waiver to establish Medicaid eligibility based on the diagnosis of HIV/AIDS infection rather than full blown AIDS, and a somewhat higher income than for general Medicaid. We encourage Congress to look at this recommendation.

Last, we are very concerned about the impact of changes made in the welfare and immigration law enacted by Congress in 1995 and 1996 with respect to immigrants. Approximately 9 percent of New York City AIDS cases are among foreign born residents predominantly from the Caribbean and South America. Under recently enacted changes, most new immigrants must wait until they have resided lawfully in the United States for 5 years before becoming eligible for most federally funded programs. We have recommended that Congress look at the category of PRUAL, persons residing under authority of law, which has an impact for people who are living with HIV and AIDS.

In conclusion, we would like to thank the Congress Members and chairman of this committee for allowing us to present this testimony. Thank you very much.

Mr. SHAYS. Thank you very much. It was very important testimony. I thank you.

[The prepared statement of Dr. Gil follows:]

Statement of
Dr. Rosa Gil,
Special Advisor to the Mayor on Health Policy,
New York City Office of the Mayor

to the

Subcommittee on Human Resources of the
U.S. House of Representatives
Committee on Government Reform and Oversight

February 20, 1998

Introduction

Good morning. Thank you for the opportunity to address this Subcommittee on important developments relating to new HIV therapies and the impact they are having on HIV-infected individuals in New York City. My name is Dr. Rosa Gil. I am the Special Advisor to the Mayor on Health Policy for New York City and Director of the Mayor's Office of Health Services. In my testimony this morning, I will provide the Subcommittee with data on the dramatic impact that recent HIV treatment developments are having on the epidemic in New York City, with a particular emphasis on access to those treatments for minority populations. I will then discuss some of the implications of these treatments for the evolving nature of the disease and the need for medical and supportive services, and our recommendations for steps that the federal government could take to enhance access to treatment for all HIV-infected residents of New York City.

New York City remains the epicenter of the AIDS epidemic in the United States. Approximately 16% of U.S. AIDS cases have been reported from New York City, although it has

only 3% of the nation's population. The city has the oldest, largest, and most complex AIDS epidemic in the country. More than 100,000 New York City residents have been diagnosed with AIDS since the beginning of the epidemic in 1981, and more than 65,000 of them have died. 41% percent of New York City residents living with AIDS are black, 33% are Hispanic, 25% are white, 0.76% are Asian/Pacific Islander, and 0.04% are Native American.

Dramatic advances in HIV treatment in past two years

The approval of the first protease inhibitor in late 1995 has proven to be a watershed in the history of the HIV epidemic. We now have four FDA-approved protease inhibitors, as well as a range of other anti-retroviral drugs. The new array of HIV therapies has dramatically improved our ability to intervene clinically to slow, or in some cases even to reverse, the course of HIV infection. In November 1997, the Department of Health and Human Services released its revised "Guidelines for the Use of Anti-retroviral Agents in HIV-Infected Adults and Adolescents," which established a new standard of care incorporating these newly-available medications. The medications are so new, however, that many questions remain unanswered, and even the recently-released guidelines extend significant discretion to physicians in determining the best course of treatment for an individual patient. Thus, while the guidelines recommend combination anti-retroviral therapy for all patients with symptomatic HIV infection, they do not definitively establish standards of care for asymptomatic patients, instead encouraging physicians to discuss treatment recommendations with patients based on an array of individual considerations. The guidelines do clearly express a preference for triple combination

therapy, which has become, essentially, the "gold standard" for HIV care, for those patients whose medical status warrants it.

The new standard of HIV therapy creates a range of opportunities and challenges for the HIV service system in New York City. For the first time, we have a demonstrable ability to prolong life for most HIV-infected individuals, to improve the health status and level of functioning for many if not most patients, and to roll back disease progression for some who have been seriously ill. But accomplishing these things, particularly over time, will not be easy. The new drugs are not a cure, and until another generation of drugs comes along or further research demonstrates that these drugs have the ability to clear HIV from the body or to render it harmless, the reality is that people must continue to take these drugs indefinitely. And they are not easy to take: each of the three drugs in the combination must be taken two to three times a day, on varying schedules, before, during or after meals, and often with accompanying side effects. Thus, helping people to maintain adherence to HIV treatment has become a larger challenge.

Programs supporting access to HIV medications in New York City

Since the time that protease inhibitors became available, and as triple combination therapy has become the standard of care for many patients, New York City has been committed to ensuring access to this regimen for all HIV-infected individuals for whom it is indicated. To ensure effective access, two things are necessary: First, there must be systems in place to permit patients to obtain the drugs despite their substantial cost, often $15,000 or more per year.

Second, the health care delivery system must be capable of educating patients about the availability of the drugs, and of providing the primary and ongoing medical care required to assess patients' need for the drugs, to work with patients to establish a medication routine they can follow, and to monitor the impact of medications and assess the need for changes in the medical regimen over time. I would like first to discuss the publicly-financed systems that are in place in New York City, largely supported by federal funding, to make these medications and accompanying health care available to the HIV-infected population. Then I would like to share the data we have on the degree to which we are succeeding in establishing widespread access to these medications, particularly across racial and ethnic communities in the city.

While AIDS affects people across the socio-economic spectrum in New York City, it has had the heaviest impact on low income individuals, and so, not surprisingly, the largest source of payment for HIV care is the Medicaid program. The "Changing Environment Study" done in the Fall of 1997 for the New York Ryan White Planning Council, estimated that between 55 and 80 percent of HIV-infected individuals in New York City rely on Medicaid for their health care. New York State's Medicaid program provides enhanced reimbursement rates for HIV primary medical care, and a broad network of institutional and individual providers in New York City participate in the Medicaid program. The Medicaid program also has a drug formulary that covers every FDA-approved anti-retroviral treatment for HIV infection.

The Medicaid program is supplemented by services supported by the Ryan White CARE Act. Ryan White is designed to complement entitlement programs by filling gaps in critical services, and that is precisely the role it plays in New York City. Title I of the Ryan White

CARE Act, which provides funding to New York City and many other localities nationally, pays for medical care for individuals who do not have private insurance and do not qualify for Medicaid. Under federal law, the Ryan White Planning Council determines how the Title I money coming to New York City is allocated. In recognition of the increasing prominence of medical care for HIV-infected New Yorkers, the Council this year has allocated almost $40 million to drug reimbursement and outpatient medical care, more than ever before. The Council also allocated almost $1 million for treatment education and support programs, in recognition of the challenges for HIV patients in understanding their treatment options and remaining adherent to therapy.

The bulk of Title I money for medications and health care supports two critical programs. Like every state, New York has an AIDS Drug Assistance Program, or ADAP, that provides medications for uninsured and underinsured people with HIV. Unlike any other state, however, New York has also created a unique program called ADAP Plus, which provides access to primary care services and laboratory tests for disease management. By filling the gap between private insurance and Medicaid, these programs ensure that no New Yorker is without access to HIV care and anti-retroviral medications for reasons of financial need. New York State and New York City have operated in a close partnership since the inception of the Ryan White program to make sure that these programs (together with the third program for the uninsured, a home care program) remain adequately funded, and available to all who need them.

Effectiveness of efforts to make HIV therapies available

Let me turn to the next important question: Are these programs working? We have recently found the most definitive answer yet to this question, and it seems to be a resounding "yes." Our surveillance data, just analyzed through 1997, show a dramatic decrease in the rate of deaths due to AIDS. (See Attachment A) Over the two years since protease inhibitors first became available, AIDS deaths in New York City dropped 63%, from approximately 7,046 in 1995 to approximately 2,577 in 1997. We have not recorded so few AIDS deaths in New York City since 1986, when the epidemic was much more limited than it is today.

Equally heartening is the fact that these declines are seen across all population groups, as reflected in Attachment A. There were declines in deaths among men and women in the Hispanic, black, white and Asian race/ethnicity groupings, although, as was the case last year, declines were most dramatic in men. Male deaths declined 71% overall and ranged from 59% for blacks to 72% for Hispanics, and 78% for whites and 83% for Asians. Female deaths declined by 63% overall and ranged from 59% for blacks to 66% for Hispanics and 73% for whites. Overall, AIDS remains the third leading cause of death in New York City, and remains the leading cause of death in those aged 1 to 14 and 25 to 49. While more analysis is necessary, these data certainly tell us that broad access to new anti-retroviral combination therapies is making a dramatic difference in life spans.

The clients who are served through our Ryan White Title I programs also bear out the fact that the programs are reaching predominantly minority populations, who are in greatest need of these services. Title I's health programs (excluding ADAP and ADAP Plus) had a total enrollment of 12,976 in calendar year 1997. During the last program year, which ended in

March 1997, 7,686 new clients were enrolled in health program categories. (See Attachment B) Of these new clients, 41.8% were black, 41% Hispanic, 10.6% white, 1.1% Asian/Pacific Islander. New clients in health programs are also widely distributed across the five boroughs. In fact, the four outer boroughs are represented among new clients at least in proportion to their relative percentages of live AIDS cases. (See Attachment C)

Looking specifically at the ADAP and ADAP Plus programs, New York City enrollment at the end of 1997 stood at approximately 13,000, of whom 73.8% were minorities, which excludes whites and other categories. (See Attachment D) Blacks and Hispanics each represent about 36% of active enrollees in these programs, whites about 24%, Asians about 1% and Native Americans 0.3%. Utilization of anti-retroviral combination therapy by ADAP participants has also grown. Approximately three-quarters of ADAP enrollees were receiving triple combination therapy of some kind in the last quarter of 1997, and the variation among racial groups is relative-ly small, from 71% for blacks, to 75% for Hispanics to 77% for whites. (See Attachment E)

Another indicator of combination therapy utilization in New York City comes from the CHAIN study, conducted by the Columbia University School of Public Health for the Ryan White Council. CHAIN is a longitudinal study, currently in its fifth year, which has been following a representative cohort of HIV-infected New York City residents over time.

The findings revealed that in June 1996, only 22% of blacks and 36% of Hispanics were taking combination therapies of any kind, compared to 55% of whites. (See Attachment F, p.1) Analysis shows that racial/ethnic disparities in the use of combination therapies seemed to be

abating by the end of 1997. By September 1997, whites and Hispanics reported almost identical levels of combination therapies use at 71% and 70%, respectively. Utilization by blacks, while still lower, had risen to 53%, almost double that of the prior period. (See Attachment F, p.2)

Our data clearly show that the programs we have in place in New York City, largely thanks to federal support through the Medicaid and Ryan White programs, have done an effective job in delivering new HIV anti-retroviral combination therapies to a broad cross-section of HIV-infected individuals. As research continues and treatment guidelines evolve, we are in a position -- provided we continue to receive adequate funding -- to make life-saving, state-of-the-art treatment available to HIV-infected New Yorkers. We look forward to a continuing partnership with Congress and the federal health agencies in delivering high-quality health care to the growing numbers of New Yorkers who continue to need it.

Challenges of new treatments to HIV service systems

Now, I will comment on the implications that these treatment developments have for the HIV service system in New York City, and make some recommendations on federal actions that would help us in New York to do a better job of reaching everyone with HIV infection with the medical care and supportive services they need to maintain their health.

I cited the dramatic decrease in AIDS deaths that we have experienced in New York City over the past two years. This is very good news indeed, but it raises one obvious implication: Many more people will be living with HIV infection and AIDS in New York City in the coming years, and they will continue to need services in order to remain as healthy as possible. This will

place even greater strains on our health care and social support systems than they are currently experiencing. I am sure you will hear later today from community-based providers who will tell you that their resources for providing all the services that people with HIV need are already fully committed. The number of people with AIDS in New York City has already been growing steadily over the past fifteen years, and now we expect that those with AIDS -- and many with HIV infection -- will be living longer as it becomes a more chronic, treatable condition. We will have to find, somewhere, the resources to provide the services they need.

A second challenge created by these new therapies has to do with medical compliance. As I mentioned, these drugs are not easy to take. Imagine swallowing 16 to 24 pills a day for the rest of your life, on a regular 8- or 12-hour rotation, some of which have serious side effects. The temptation to quit, or at least to cheat a little, can be enormous, but it is also very dangerous. HIV is not a forgiving virus, and skipping doses of anti-retroviral therapy can result in drug resistance fairly quickly. Especially for individuals who are dealing simultaneously with poverty, housing problems, drug abuse, and other ills, adding a complex HIV medical regimen to a chaotic life may simply be overwhelming. Even for middle-class individuals with steady incomes, combination therapy is not an appealing prospect. We will need to work creatively to develop new, integrated service models to support people in remaining compliant to their treatment, so that they can derive the optimum benefit from these drugs.

Third, while there will be more people needing HIV-related services, the services that many of them will need are likely to be different. We are seeing that these drugs are either halting the progression of the disease for many people, or are actually reversing it. Many of our

current HIV service programs developed around an acute, end-stage model of the disease. Those programs will still be needed, but more and more people with HIV infection are beginning to think about things like returning to work, juggling medication and employment schedules, and covering enormous medical bills into the indefinite future. Therefore, the infrastructure of our HIV service programs, most of which are delivered through community-based organizations, will have to adapt to the changing needs of their clients. Some of these needs include: chronic medical care, support for medical compliance, job training, benefits counseling and other services that will allow individuals to function in society while maintaining their health. And there continue to be many people with HIV infection who are not in the care system at all; we need to expand our outreach activities and to bring them into HIV counseling, testing and treatment.

Fourth, we cannot forget that these drugs are far from a panacea. Not only are they not a cure, but they do not work for everyone. Some people are already resistant to elements of the combinations, some cannot tolerate the side-effects, and some simply do not respond to them. For the foreseeable future, we will continue to face an epidemic in which many, many people will become seriously ill, and many will die. Thus, our service systems must, in a sense, adjust to dealing with two epidemics: the epidemic of the treatment responders, and the epidemic of the non-responders.

Finally, we cannot abandon our prevention efforts. HIV remains a very serious illness, and it is incumbent on us to make every effort possible to prevent new infections. We cannot allow a false sense of security, or an overstatement of the treatment improvements we have seen

to date, to be converted into a message that individuals at risk no longer need to take precautions. Individual prevention efforts, across all communities, remain just as vital as ever.

Recommendations for federal action

I would like to make three overall recommendations for what the federal government can do to support our efforts in New York City. The first has to do with Ryan White CARE Act funding. Let me hasten to say that both Congress and the Health Resources and Services Administration have, to date, been extremely supportive of our work: this year; our Title I funding increased to $95 million, from $92 million last year. This has enabled us to create the broad network of services that is delivering new treatments to HIV-infected individuals across New York City. But our ability to continue to do that will depend on two things: being able to pay for the drugs themselves, and having the service infrastructure to deliver them and support people in taking them.

In his FY 1999 budget, President Clinton has proposed a substantial increase in funding for the ADAP program. This is extremely important to us, because ADAP allows us to provide medication to thousands of uninsured individuals who otherwise could not afford them. But at the same time, the President has proposed only a $25 million, or 5 percent, increase in Ryan White Title I funding. Our service infrastructure is supported by Title I funds. In addition, Title I enables us to make substantial contributions to the ADAP and ADAP Plus programs which are so critical to our HIV service delivery system. I would urge the Congress to support appropriations for ADAP at least at the level proposed by the President, but also to look at increases in Title I funding that will enable us to expand our service delivery systems and

maintain our existing infrastructure to keep pace with the growing number of people needing services.

Second, the Administration has had under discussion for some time the possibility of allowing states to apply for a Medicaid waiver to establish Medicaid eligibility based upon a diagnosed HIV infection, rather than full-blown AIDS, and with somewhat higher income limits than for general Medicaid eligibility. Currently, in most states, one must receive a diagnosis of AIDS in order to qualify for Medicaid. This defeats the entire thrust of new, early treatment with combination therapies. Recent indications are that the administration has abandoned the effort to develop such a waiver program, perhaps because it believes it has been unable to meet the waiver requirement for cost-neutrality under the Medicaid program. We believe that early treatment is not only cost-effective but imperative, given the lives it would save and the productivity it would restore. We would strongly recommend that the Congress urge the Administration to give every consideration to implementing this waiver program.

Lastly, we are very concerned about the impact of the changes made in the welfare and immigration laws enacted by Congress in 1996 with respect to immigrants. Approximately nine percent of New York City's AIDS cases are among foreign-born residents, predominantly from the Caribbean, Central and South America. Under recently-enacted changes, most new immigrants must wait until they have resided lawfully in the United States for five years before becoming eligible for most federal benefit programs. More than 900,000 immigrants nationwide have already lost Food Stamp benefits, and many more will. In addition, many PRUCOL aliens (Persons Residing Under the Color of Law), who are currently receiving SSI and Medicaid

benefits, will lose these benefits by September 30, 1998. Many individuals with AIDS in New York City currently have PRUCOL status under a program called voluntary departure, and could lose their health care access due to these changes. We would urge the Congress to look closely at the impact of these changes, which we believe unfairly hurt thousands of HIV-infected New Yorkers.

Conclusion

We would, of course, be happy to discuss any of these issues further with the Committee or your staff. We very much appreciate your concern about the issues we have raised, and look forward to continuing to work with you to meet the needs of all people in New York City who are infected and affected by HIV and AIDS. Thank you again for inviting us to present this testimony to this Congressional Subcommittee.

DEPARTMENT OF HEALTH

BUREAU OF EXTERNAL AFFAIRS
125 WORTH STREET, ROOM 329
NEW YORK, N.Y. 10013
(212) 788-5290 FAX: (212) 788-4749

BENJAMIN MOJICA, M.D., M.P.H.
Acting Commissioner

FREDRIC D. WINTERS
Associate Commissioner

FOR RELEASE
Monday, February 2, 1998

Contact: Fred Winters
212-788-5290

MAYOR AND HEALTH COMMISSIONER ANNOUNCE DRAMATIC DECREASE IN DEATHS DUE TO AIDS IN NYC

AIDS DEATHS DROP ALMOST 50% IN ONE YEAR, 63% IN TWO

Today, New York City officials, speaking in New York and Chicago, announced the results of a City Health Department study that shows that deaths due to AIDS dropped precipitously in 1997. Based on the work of Dr. Mary Ann Chiasson, Acting Health Commissioner Dr. Benjamin Mojica and a team of Health Department scientists, the Mayor announced that in 1997 AIDS deaths dropped to virtually half of their 1996 level, a 48% decrease, and a full 63% decrease from their 1995 level. At the same time, in Chicago, DOH Assistant Commissioner Dr. Chiasson presented the study's findings at the 5th Conference on Retroviruses and Opportunistic Infections and at a subsequent national press conference.

The Mayor announced that based on solid preliminary figures, deaths due to AIDS had dropped to 2,577 (provisional) in 1997 from 7,046 in 1995 and 4,998 in 1996.

Mayor Giuliani said, "New York City, with 3% of the US population, has 16% of its AIDS cases. Over 100,000 people in this city have been diagnosed with AIDS since the beginning of the epidemic and 65,000 of them have died. In 1995, on average, 20 New Yorkers died from AIDS each day; in 1997, that number dropped to 7. These numbers are especially significant to the scientists and especially hopeful to all of us who have had family, friends and colleagues affected by this devastating disease.

"Further, this news is especially welcome since they are across the board, as they were last year. Men and women, young and old, black, white, Hispanic and Asian, have all shown similar improvement."

-- more --

Dr. Mojica explained, "This is the fewest number of people to have died of AIDS in this city in over a decade, since 1985. The obvious question is 'Why?' While this new data cannot give us the answer to that question, it seems equally obvious that this is directly connected to broad access to new antiviral combination therapies, including protease inhibitors, made possible by the AIDS care infrastructure we have developed in New York with the help of Ryan White funding."

In Chicago, DOH Assistant Commissioner for Disease Intervention Research Dr. Mary Ann Chiasson, presented the Health Department's findings at the 5th Conference on Retroviruses and Opportunistic Infections and answered questions at a press conference held there. Among the findings she presented were the following.

- There were declines in death in every age grouping.
- There were declines in deaths among both men and women in the Hispanic, black, white and Asian race/ethnicity groupings, although, as was the case last year, the declines were most dramatic in men.
- Male deaths declined by 71% overall and ranged from 65% for blacks to 72% for Hispanics, 78% for whites and 83% for Asians.
- Female deaths declined by 63% overall and ranged from 59% for blacks to 66% for Hispanics and 73% for whites.
- Overall, however, AIDS remains the third leading cause of death in NYC, down from second, and remains the leading cause of death in those 1-14 and those 25-49.

On Thursday at the conference, Dr. Atieno Reggy will present the results of a case-controlled study conducted in NYC which examined the relationship between deaths and antiviral therapies.

TABLE ATTACHED -- SEE PAGE THREE

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#04

AIDS Mortality
page three

Deaths from HIV/AIDS, New York City, 1983-1997

Year	All AIDS and HIV infection deaths, NYC
1983	425
1984	952
1985	1,663
1986	2,650
1987	3,192
1988	3,773
1989	4,282
1990	4,616
1991	5,228
1992	5,789
1993	6,120
1994	7,102
1995	7,046
1996	4,998
1997	2,577 (Provisional)

Prepared by NYC Department of Health

Table III-A3

New Clients by Race/Ethnicity in Health Program Categories

April 1996 - March 1997

Health Programs	White	Black	Hispanic	Asian/Pacific Islander	Native American	Other/ Unknown	Total
Air Bridge Project	5	3	311	7	0	0	326
	1.5%	*0.9%*	*95.4%*	*2.1%*	*0.0%*	*0.0%*	*100%*
Dental Care	117	874	657	2	1	121	1,772
	6.6%	*49.3%*	*37.1%*	*0.1%*	*0.1%*	*6.8%*	*100%*
Direct Observed Therapy/Preventive Therapy	5	174	63	0	1	4	247
	2.0%	*70.4%*	*25.5%*	*0.0%*	*0.4%*	*1.6%*	*100%*
Home Health Care	242	408	436	24	0	13	1,123
	21.5%	*36.3%*	*38.8%*	*2.1%*	*0.0%*	*1.2%*	*100%*
Primary Medical Care Services	102	874	621	31	0	33	1,661
	6.1%	*52.6%*	*37.4%*	*1.9%*	*0.0%*	*2.0%*	*100%*
Primary Health Care: Specialty Services	343	830	1,037	20	1	244	2,475
	13.9%	*33.5%*	*41.9%*	*0.8%*	*0.0%*	*9.9%*	*100%*
TB Service Enhancements/ HIV/TB Housing Initiative	3	50	28	1	0	0	82
	3.7%	*61.0%*	*34.1%*	*1.2%*	*0.0%*	*0.0%*	*100%*
Total	817	3,213	3,153	85	3	415	7,686
% Race/Ethnicity	*10.6%*	*41.8%*	*41.0%*	*1.1%*	*0.0%*	*5.4%*	*100.0%*

Table III-A5

Distribution of New Clients in Health Program Categories by Boroughs

April 1996 - March 1997

Health Programs	Number of Contracts	Bronx	Brooklyn	Manhattan	Queens	Staten Island	Homeless	Other/ Unknown	Total
Air Bridge Project	3	101	53	77	41	2	47	5	326
		31.0%	*16.3%*	*23.6%*	*12.6%*	*0.6%*	*14.4%*	*1.5%*	*100%*
Dental Care	6	1,016	392	161	32	152	12	7	1,772
		57.3%	*22.1%*	*9.1%*	*1.8%*	*8.6%*	*0.7%*	*0.4%*	*100.0%*
Directly Observed Therapy/ Preventive Therapy	4	38	54	137	4	0	1	13	247
		15.4%	*21.9%*	*55.5%*	*1.6%*	*0.0%*	*0.4%*	*5.3%*	*100.0%*
Home Health Care	9	192	217	429	211	55	3	16	1,123
		17.1%	*19.3%*	*38.2%*	*18.8%*	*4.9%*	*0.3%*	*1.4%*	*100.0%*
Primary Medical Care Services	20	505	657	232	191	19	34	23	1,661
		30.4%	*39.6%*	*14.0%*	*11.5%*	*1.1%*	*2.0%*	*1.4%*	*100.0%*
Primary Health Care: Specialty Services	7	638	350	391	539	17	6	534	2,475
		25.8%	*14.1%*	*15.8%*	*21.8%*	*0.7%*	*0.2%*	*21.6%*	*100.0%*
HIV/TB Service Enhancements/ HIV/TB Housing Initiative	2	17	32	28	0	1	3	1	82
		20.7%	*39.0%*	*34.1%*	*0.0%*	*1.2%*	*3.7%*	*1.2%*	*100.0%*
Total	51	2,507	1,755	1,455	1,018	246	106	599	7,686
% Borough		*32.6%*	*22.8%*	*18.9%*	*13.2%*	*3.2%*	*1.4%*	*7.8%*	*100.0%*

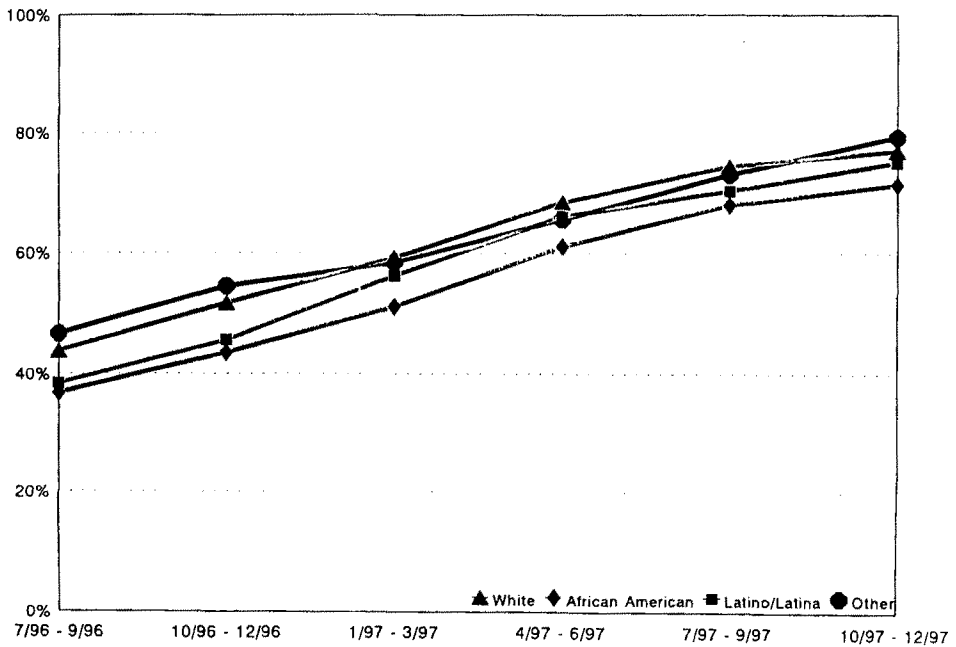
ATTACHMENT D

HIV UNINSURED CARE PROGRAM ENROLLMENT
01/01/97 - 12/31/97

New York City	ADAP Active 01/97 - 12/97 Number	ADAP Active 01/97 - 12/97 Percent	ADAP PLUS Active 01/97 - 12/97 Number	ADAP PLUS Active 01/97 - 12/97 Percent	HOME CARE Active 01/97 - 12/97 Number	HOME CARE Active 01/97 - 12/97 Percent
TOTAL ENROLLMENT	**12,976**	**100.0%**	**12,584**	**100.0%**	**433**	**100.0%**
Uninsured	3,446	26.6%	2,946	23.4%	43	9.9%
Medicaid Interim	8,747	67.4%	8,710	69.2%	348	80.4%
Insured - Partial	783	6.0%	928	7.4%	42	9.7%
CURRENT ACTIVE	**8,776**	**67.6%**	**8,383**	**66.6%**	**64**	**14.8%**
TERMINATED	**4,200**	**32.4%**	**4,201**	**33.4%**	**369**	**85.2%**
DEMOGRAPHICS						
GENDER						
Male	10,036	77.3%	9,704	77.1%	312	72.1%
Female	2,940	22.7%	2,880	22.9%	121	27.9%
AGE						
0 -23 MOS.	34	0.3%	32	0.3%	3	0.7%
2 - 12	76	0.6%	72	0.6%	1	0.2%
13 - 18	35	0.3%	35	0.3%	1	0.2%
19 - 24	320	2.5%	316	2.5%	1	0.2%
25 - 49	10,794	83.2%	10,497	83.4%	323	74.6%
> 49	1,717	13.2%	1,632	13.0%	104	24.0%
RACE/ETHNICITY						
White	3,133	24.1%	2,941	23.4%	96	22.2%
African-American	4,727	36.4%	4,614	36.7%	200	46.2%
Hispanic	4,569	35.2%	4,498	35.7%	123	28.4%
Asian	162	1.2%	154	1.2%	5	1.2%
Native American	34	0.3%	31	0.2%	0	0.0%
Unknown	351	2.7%	346	2.7%	9	2.1%
HOUSEHOLD SIZE						
1	10,849	83.6%	10,534	83.7%	340	78.5%
2	1,043	8.0%	1,005	8.0%	47	10.9%
3 +	1,084	8.4%	1,045	8.3%	46	10.6%
INCOME						
< $10,000	7,375	56.8%	7,357	58.5%	236	54.5%
10,000 - 19,999	3,133	24.1%	3,046	24.2%	124	28.6%
20,000 - 29,999	1,518	11.7%	1,410	11.2%	50	11.5%
30,000 - 39,999	685	5.3%	552	4.4%	11	2.5%
40,000 - 49,999	200	1.5%	165	1.3%	9	2.1%
50,000 +	65	0.5%	54	0.4%	3	0.7%
CLINICAL STATUS						
CDC AIDS	6,121	47.2%	5,922	47.1%	418	96.5%
HIV Symptomatic	1,979	15.3%	1,898	15.1%	5	1.2%
Asymptomatic	3,678	28.3%	3,584	28.5%	4	0.9%
Unknown	1,198	9.2%	1,180	9.4%	6	1.4%
COUNTY						
Bronx	2,548	19.6%	2,502	19.9%	74	17.1%
Kings	3,190	24.6%	3,112	24.7%	132	30.5%
Manhattan	4,715	36.3%	4,522	35.9%	138	31.9%
Queens	2,261	17.4%	2,192	17.4%	81	18.7%
Staten Island	262	2.0%	256	2.0%	8	1.8%

NYS ADAP

Combination Antiretroviral Utilization by Race / Ethnicity (Three+ ARV)



ATTACHMENT E

ATTACHMENT F

Table 6: Use of Combination Antiretroviral Therapies by Race/Ethnicity

CHAIN Interviews Conducted Between January 1996 and June 1996

Type of Antiretroviral Therapy	White	Black	Latino
(N=)	(68)	(202)	(132)
None	34%	57%	46%
Monotherapy	10%	19%	18%
2 drug Combination without a Protease Inhibitor	26%	17%	25%
1 or 2 Drug Combination with a P.I.	7%	2%	3%
3+ Drug Combination with a P.I.	22%	3%	8%
Total	100%	100%	100%

Pearson Chi Square (8)= 38.5 p<.001

CHAIN Interviews Conducted between July 1996 to December 1996

Type of Antiretroviral Therapy	White	Black	Latino
(N=)	(38)	(142)	(80)
None	34%	50%	28%
Monotherapy	5%	8%	14%
2 Drug Combination Therapy without a Protease Inhibitor	24%	22%	32%
1 or 2 Drug Combination with a P.I.	5%	6%	5%
3+ Combination with a P. I.	32%	14%	23%
Total	100%	100%	100%

Pearson Chi Square (8)=17 p<.05

TABLE 6 (Cont.) Use of Combination Antiretroviral Therapies by Race/Ethnicity

CHAIN Interviews Conducted between January 1997 to September 1997

Type of Antiretroviral Therapy	White	Black	Latino
(N=)	(54)	(183)	(120)
None	22%	35%	27%
Monotherapy	7%	13%	3%
2 Drug Combination Therapy without a Protease Inhibitor	9%	15%	22%
1 or 2 Drug Combination with a P.I.	6%	7%	13%
3+ Combination with a P. I.	56%	31%	35%
Total	100%	100%	100%

Pearson Chi Square (8)=26 p<.005

F.,P.2

Mr. CRUZ. Good morning, Mr. Chairman.

Mr. SHAYS. Good morning.

Mr. CRUZ. I'm pleased for the opportunity to present testimony on behalf——

Mr. SHAYS. Excuse me, if you could turn on the microphone, maybe. Is it long enough to put on the other side of you? Actually, there we go.

Mr. CRUZ. Can you hear me now?

Mr. SHAYS. We can hear you fine.

Mr. CRUZ. Thank you. Very rarely I'm told that I cannot be heard.

As requested in your invitation, I will discuss coordination between the State and New York City as well as current State initiatives related to the care and treatment of persons with HIV. I will provide a brief summary, 5 minutes, of our activities in these areas. More complete information is available in my written testimony.

The primary goal of the New York State Department of Health is to insure that each dollar from all sources; State CDC, New York City, et cetera, are used in a complementary fashion to provide a full continuum of all services in New York State. There is a close coordination and cooperation with New York City with regards to the allocation of funds for HIV services.

For example, AIDS Institute representatives serve on the New York City Ryan White Planning Council and participate in the decisionmaking process and in the allocation of New York City title I funds. In addition, the State and New York City have formed a unique partnership in that we jointly support initiatives through which wide range of HIV services are provided in New York City.

For example, the AIDS Institute administers service programs for the uninsured and underinsured and the city has allocated substantial title I resources to support these State-administered services for New York City residents. These programs include the ADAP program and ADAP Plus program, which Dr. Gil just recently discussed.

In recognition of the need to establish systems to educate patients and providers about the new therapies, Ryan White title I funds for New York City have been combined with the State's Ryan White title II funds to support treatment education programs for consumers and staff of community-based organizations. The State and New York City also joined to support care and service programs for HIV infected persons in New York City. These programs provide primary care services and services targeted to substance users as well as women children and adolescents. Further, there is close coordination between the city on the recent development of the Ryan White statewide coordinated statement of need.

Quality of care studies conducted by the AIDS Institute are coordinated with New York City. In regards to the State initiatives, as I say, I will briefly discuss the State initiative related to the care and treatment of patients with HIV. I have already described the State's HIV care program for the uninsured.

As Dr. Gil stated, the largest source of payment for HIV care in the city is the Medicaid program. The State Health Department has implemented programs through which enhanced Medicaid

rates are available to providers of outpatient HIV services, including private Medicare, case management services, acute and chronic care programs.

As you know, our health care system is moving away from service reimbursement to managed care system for the Medicaid population. To preserve the continuum of HIV care that New York State has developed over the past decade, the State Health Department is in the process of developing HIV special need plans better well known by SNPs, managed care plans that will be targeted specifically to meet the needs of Medicaid recipients with HIV.

In addition to Medicaid and uninsured care programs, State initiatives include grant funded programs, grants supported by the State and Ryan White funds are directed to health care facilities and community-based organizations to provide HIV health care and supportive services.

In conclusion, the coordinated efforts of the State and the city have resulted in the development of a continuum of services for persons with HIV in New York City. All of the initiatives I have described are essential to continue the hopeful trend of declining AIDS related death, a trend we are seeing throughout New York State.

I must note that this is a time of major changes in HIV treatment and in the environment in which HIV services are delivered. Changes to the continuum may be required to meet new challenges that may be posed by new treatments, managed care and welfare reform. There is a need for increased support for therapies, as well as a need for services for increasing numbers of persons with HIV. Support will be needed to meet new challenges posed by the changing environment and we must note the need for continuing Federal support, not only for drug assistance programs, but for all the other Ryan White titles that support a service structure which insures access to primary care and supportive services. In addition, it is essential to know the importance of continued support for HIV prevention services. New infections occur every day and we do not have a cure. The headlines may imply that the epidemic is over, but we all know that it is not. HIV epidemic treatment continues to be a proponent of the continuing services.

Thank you for the opportunity to provide testimony. We look forward to working with you in insuring the provision of high quality provision of care to New York State residents affected by HIV and AIDS.

Mr. SHAYS. Thank you, Mr. Cruz. Thank both of you.

What we'd like to do is ask a few questions on the record. I want to say up front that I'd love to get into some of the more controversial issues here to help this committee sort out what is controversial and why, but I'm going to start out with Congressman Towns who can ask the question and then we'll go back and forth.

I'm sorry, let me just say, if we could get that mic back to you, Dr. Gil and if we could get—is that mic live? It didn't seem to be. Yes, OK. So the cord is long enough. Great. Super. Thank you.

Mr. TOWNS. Mr. Chairman, we're so excited about having you in Brooklyn, let me just make a special request and sort of deviate from the normal pattern, recognizing that the statements of all the witnesses will be put in the record, the entire statement, and to

say that if we could finish up here in time, that we maybe could allow 15 minutes for people from the audience. I know that's not the standard procedure, but I think that maybe out of this might come some sort of burning kind of question or burning kind of comment that they would like to make and that if we could do that, then I would certainly think that we would be able to cover a lot more. I know we have time constraints, because you have agreed to tour some facilities, things of that nature——

Mr. SHAYS. That's all right. I'll tell this to the audience, we're going to proceed with this panel. On the second panel I think we may have five witnesses, seven, so that will take a while. What we'll do is try to spend 15 minutes to a half hour. I'll ask if there is anyone who wants to speak at the end. You won't be sworn in, since you are not part of the panel, but we would like your comments, they will be on the transcript, and depending on the amount of people who want to speak, we'll determine how long, whether it's 1 minute, or 2 minutes, or 3, depending on the number who want to speak.

So those in the audience here who hear anything they agree with or disagree, whatever they want to emphasize, you will have a short opportunity in the framework to express your opinion on the record. We will be strict in the period of time. What that tells me is we'll be strict with our second panel in terms of the rule on that.

That's an excellent suggestion. We can agree with that. Why didn't I think of that? OK, you have the floor, sir.

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

Let me begin by thanking both of you for coming, and we appreciate the kind of work that you do. I had one question here that was left by Nydia Velázquez and then another one, that both of us had the same question, so I will ask it in her name and my name, the first one.

Often we find that HIV, this is one that is offered by Congresswoman Velázquez and myself. Often we find that HIV/AIDS grants are awarded to service providers that do not understand the culture or do not have the experience in the areas that they are trying to serve. How can we insure that groups from the community with an established knowledge and tremendous track record and history of providing services to the community are the ones that receive the grants?

Let me just be very specific, because I don't mean to throw curves, I believe in going right straight. You know, we have this concept in New York, citywide programs. Now, in almost every instance, and I don't have anything against Manhattan, I go there every week, almost every instance, the citywide program is based in Manhattan, and then when I look at problems that we have, Brooklyn is No. 1.

So it seems to me if there's going to be a citywide program, and I'm not discouraging citywide programs, then the citywide programs should be based in Brooklyn, that's No. 1.

And No. 2, let me tell you why I say that, because I didn't just go to bed and then wake up—I used to be the deputy borough president in Brooklyn. That's when we used to have the Board of Estimate.

Mr. SHAYS. Did you have hair, then?

Mr. TOWNS. Mr. Chairman, I had an Afro.

And what would happen is that you would have these citywide programs that would come to the Board of Estimate and finally I started doing my own research, and I found out that these citywide programs, inasmuch as they were citywide, the programs could never cross the bridge, the services could never get across the Brooklyn Bridge and I'm afraid that this might be happening now, and that's the reason why we see that the numbers in Brooklyn are much higher than they are in other places, and I just want you to respond to that.

That was a joint question between Nydia Velázquez and I.

Dr. GIL. Congressman Towns and Mr. Chairman, I want to know whether you can allow me to ask Associate Commissioner David Hansell to join me here.

Mr. SHAYS. Let me say this, I'll be swearing you in, if there's anyone else. I'm happy to do this, but is there anyone else, Mr. Cruz, do you have someone who will be joining you?

Mr. CRUZ. Dr. Chin-Loy.

[Witnesses sworn.]

Mr. SHAYS. We're going to need to help the transcriber, because this is transcribed, if you will be able to leave cards, so we can make sure of the proper spellings of your names and titles. Identify yourself for the record?

Mr. HANSELL. I'm David Hansell, associate commissioner for HIV Services, New York City Health Department.

And Congressman Towns, it's a very important question, one that we're very concerned about, I'm glad to have the opportunity to respond to it. And let me tell you what we have done to date, particularly in the context of the Ryan White program, because that's the largest source of funding that we have for community-based organizations.

Most of the Ryan White funding that we receive from the Federal Government goes out directly to community-based organizations around the city and as you know, we have just completed a redistribution of that funding under the direction of the Ryan White Planning Council, because of the structure of that program, as Congress has created it, in which the Planning Council, which is broadly representative of organizations around the city, actually tells us how to allocate the money across the various services that people with HIV and AIDS need to receive.

The Planning Council directed us actually in late 1996 that because the epidemic had changed, because the distribution of the epidemic across the city had changed and the services that people need had changed, it was time for us to look at whether the distribution of funding across the city was adequately reflecting the needs of the epidemic, and in particular, the Planning Council told us they wanted to look at three factors as we redistributed those funds. They wanted to make sure the funds were appropriately targeted to geographic communities of high need, to populations with co-morbidity factors, like, for example, tuberculosis and homelessness and poverty and mental illness that were most in need, and that we give emphasis to locally based services within the communities where people needed them.

We have just completed a redistribution. We actually expect about $46½ million will be distributed to community-based organizations beginning in March, which is when the new Ryan White program starts, a few weeks from now, and the outcome of the process shows that actually we've distributed, I think, more money to locally based community organizations than we have in the past. There is still certainly funding which is going to citywide agencies and we believe that's necessary for two reasons.

One is that there are some services which are very resource intensive, that are expensive to provide, that doesn't necessarily make sense to replicate in every community around the city and second, that we believe it's important to make sure that every HIV infected person, no matter where they live in New York City, has access to every service. It would be nice if we had enough funding to fund a provider in every service category in every neighborhood, but unfortunately we don't.

But in fact, about 75 percent of the grants we made to community organizations are to organizations that are based in neighborhoods around the city and the distribution, as we've analyzed this and we would be happy to provide this information to the subcommittee, shows that in fact the four outer boroughs, and Brooklyn in particular, are receiving a share of those awards which is actually greater than the proportion of living AIDS cases. For example, Brooklyn, which has about 24 percent of living AIDS cases in New York City right now, received approximately 32 percent of the grants that are directed to particular boroughs or to particular neighborhoods, so we feel that the distribution between the primarily locally based services that we're funding, and sort of a fallback network of citywide agencies to make sure that every part of the city is covered, is the best way of making sure that everyone in New York City has access to all the services that they need.

Mr. TOWNS. Thank you very much. Let me move very quickly to another one. I want to see what we might be able to do in Washington. How does the city of New York in HIV infections and AIDS compare to other large cities in the United States?

Mr. CRUZ. I didn't hear part of the question.

Mr. TOWNS. How does our situation compare to other large cities in the United States, the AIDS situation, for example, the amount of people that have AIDS and HIV. In other words, comparing to other cities. Let me tell you why I'm asking that. Nydia Velázquez and Jerry Nadler in particular and Congressmen Owens and Rangel were involved with me in terms of trying to change the formula, and in terms of, I think that's important, that's the reason I'm asking this question, I want to make sure that we're doing everything we can do on the Federal level as well to deal with this problem. In other words, I'm trying to be fair.

Mr. CRUZ. OK, because I represent the State, my answer would be related to changes in the formula that will impact the whole State.

In regards to the situation of New York State and the HIV/AIDS situation, we have the biggest epidemic. You heard from Dr. Gil that we have 16 percent of the cases, but we only have 2 percent of the population, and I think that's the best example that you have of the magnitude of the problem. In terms of the resources,

we felt very badly 5 years ago when we went through the Ryan White authorization because we wanted to add other factors, other co-morbidity such as substance abuse and homelessness, which were represented in the situation of New York State and New Jersey, but which were not related to other parts of the Nation.

I think that the Ryan White authorization is one of the most important areas that we have to address and I was very concerned that in any of our testimonies we never addressed that particular issue. The new formulas that are being discussed will push for live cases of HIV positive individuals and will be targeted to emphasize, meet the State's and the need of the country and culturally to where we have the greatest number of the epidemic. Therefore, we have to push continuously at the congressional level for formulas that will continue to use the factors that we already have, which is homelessness, substances abuse and the HIV cases that we have. David.

Mr. HANSELL. You made the point that I was going to make, which is that the formulas look strictly just at cases. Well, of course, New York has the largest number, but they don't reflect the fact that as Dr. Gil pointed out, we not only have the largest number of cases, we have the most complex epidemic to respond to. We have the largest number of people who are living with HIV and homelessness and tuberculosis and sexually transmitted diseases and substance abuse in the country, so it's important that the formula reflect not just the number of cases we have, but the complexity of the epidemic that we have to respond to and frankly the cost of doing that.

Mr. TOWNS. Let me ask one more question. Is my understanding that New York City only counts AIDS patients? It does not count HIV infections because of civil liberties concerns, is that my understanding?

Dr. GIL. The reporting is on the AIDS cases, correct.

Mr. TOWNS. Let me ask you this question: Would the funding to organizations change if HIV were counted along with AIDS? See, I'm concerned. You know, somewhere, some number here is just not hitting me right. I'm not sure what it is, but something, my mother can say, "Something ain't right."

Mr. SHAYS. Why am I beginning to feel like I'm in a black Baptist church?

Mr. TOWNS. You can handle it, Mr. Chairman.

Mr. SHAYS. Can you turn the mic down just a—tilt the mic down.

Mr. HANSELL. You're actually correct that actually under State law, because the States have the rules for surveillance of diseases like this, we only require reporting of AIDS cases, not HIV infection. We know there are currently about 35,000 people living with AIDS in New York City. We believe there are about 130,000 people living with HIV, but we don't know that, because we don't have reporting. It's difficult to know whether the proportions in New York City are different from what they would be in other cities, so if we had HIV reporting, certainly we would know how many people are involved. We don't know whether that would be more or less than elsewhere, but we do know there are many States in the country that already require HIV reporting.

We know that the CDC is actually shortly going to be announcing a new policy statement on that, and one of the issues I expect that Congress will have to address, in the reauthorization of Ryan White is whether the formula should continue to be based on AIDS cases or on HIV cases, which is a more complete representation of the epidemic and certainly if the direction is looking at HIV cases, we'll have to make sure that New York City and New York State are not disadvantaged by the fact that we don't currently have that information.

Mr. CRUZ. Let me add something to this. The new movement from the Federal Government is to use HIV reporting as a——

Mr. TOWNS. Can you hear him back here?

Mr. CRUZ. The new direction from the Federal Government, all the cases are that they will use as a new criteria HIV reporting. Already 26 States in the Nation are using some type of reporting for reporting to CDC. What would be the impact to New York State? Well, the impact to New York already was felt this year, because we have had increased surveillance activity, we were able to identify 2,300 cases that we had never identified previously and that made us gain some money in this year's award. However, in coming years when other States are increasing HIV reporting, potentially if we don't have a system to capture HIV and that's what the Federal Government is using, we could lose money. That's the reality.

Will we lose money or gain money? It depends on what is the system that is actually used for Ryan White authorization, but with the new treatment, the identification of HIV is critical. We need to know where they are, so they can benefit from this treatment and if they're going to be used as a measuring activity to give money, we need the resources.

Mr. TOWNS. Thank you very much. Mr. Chairman, I have no further questions. I'd like to thank the witnesses and turn it back to you.

Mr. SHAYS. Thank you very much. I'm trying to sort out the implications of new treatment on long-term policy, and I'm also trying to sort out what are the controversial issues that are still in play and what new ones will come into play. For instance, one controversial issue is needle exchange. Another issue is the cost of certain drugs and who therefore gets the benefit. Some simply are left out. There's another one that I'm struck with, and maybe you are able to comment on this and maybe not, and that is that my sense is that when you administer certain drugs, they develop, the requirement on the side of the patient, someone with AIDS, is that they make sure they take the drugs, because if they take them partially, what may develop is the consequence that they've developed some immunity, but then they don't carry it on and a stronger strain is passed on to someone else. And the implications of that are quite significant.

That would suggest that if someone isn't going to abide by the protocol and take the medicine, the drugs as they should, the question is, how do we deal with that? Should they even be taking the drug in the first place if they contribute to passing on the strain? That is a controversial issue, I would think.

First off, I spent a long time here, and one controversial area would be needle exchange, another is the cost issue and whether certain people are being shut out. The answer I guess would be yes, based on cost some aren't being treated. Another issue would be that you have to have full blown AIDS in order to get certain treatments unavailable under Medicaid when you're only HIV.

Give me a list of some other controversial issues and then I want you to deal with the last question. I just want to know what those are. I want to make sure I see the universe. You don't have to answer them, just tell me what they are.

Dr. GIL. If I may, I think the Commissioner, I think Commissioner Hansell and Mr. Cruz underscored the fact that this epidemic in New York City are characterized by individuals who have different co-morbidities, and by co-morbidities I mean other illnesses other than HIV/AIDS, for example, substance abuse, STD, mental illness. Those individuals who suffer from different co-morbidity makes the participation more complex.

It is not, many times there is an assumption here that the individual does not want to take or cannot keep up with the medical regime or the compliance. These are individuals that lead very, very complex lives. My colleagues here highlighted the issue of homelessness. If we don't have a roof over our head, I think it's difficult to think about when to take the medication, if you don't have a roof over your head. If you are a patient who suffers from TB, you are also taking medications. I don't think it's a question of either-or, because this discussion, which I agree with you, that is controversial, in a way the victims have been blamed, quote, for not being responsible for taking the medication and I think there is another story to this, which is the complexity of the lives does require case management and it does require an array of services just to help these individuals to comply with medical treatment.

I think that often to make positions on behalf of patients, at least in my practice of medical care, we're professionals, make decisions for patients without really taking into account the circumstances of their lives. So I think that this is quite a complex environment where these patients live, and indeed the community-based organizations are trying to do the best that they can, but I am giving in the President's submission to Congress, when he asked for a 35 percent increase——

Mr. SHAYS. I'm going to be a little more disciplined here. I want to cover some points. You're making some very valid points, but I want to stick with the three controversial issues; needle exchange, who gets treatment based on cost and should someone be denied treatment if they're not going to follow the treatment according to the protocol because of the possibility of developing a stronger strain and passing it on to someone else. That is controversial. Now, what would be some other controversial issues? I just want to see——

Mr. CRUZ. You mentioned three, I have six.

Mr. SHAYS. Good. What are they?

Mr. CRUZ. I think, I don't call them controversial. Those are the reality of what we're facing and the reality is new treatment and then access to new treatment. Funding for those new treatments——

Mr. SHAYS. I want you to go slow here. New treatment and funding of treatment.

Mr. CRUZ. And access to those new treatments. Then we have the issue of welfare reform and how that impacts on allocation.

Mr. SHAYS. Welfare reform?

Mr. CRUZ. Yes, as implicated by the Federal Government, it will remove Medicaid people that used to receive those services through Medicaid and now they will only have the Ryan White funding to get those services. So you have people living longer, you have new people coming to the grant because of new——

Mr. SHAYS. I got the picture.

Mr. CRUZ. Then you have the changing service delivery environment. You have funding that used to be used for certain people because they were very sick or because of the new treatment, you have to change the formula from what you provide services today for something that today they don't need it as much as before, but for which today you don't have as much funding because new activity is needed.

Mr. SHAYS. Can I put it in my words to see if I understand? Are you saying that we might have developed a formula for those who are most sick and now we're able to maintain them in a relative circumstance and therefore the formula doesn't benefit them? Is that what you said?

Mr. CRUZ. No, what I'm saying is that you have, you have developed a service delivery system to take care of people who were dying. Now you have less number of people that are dying, so you would need to provide other type of services.

Mr. SHAYS. All right.

Mr. CRUZ. The last one I have for your list is the whole changing environment fee for service structure to managed care. You're going to have many service providers who may be able to adjust to this new system of payment, but others will not. So we have a system we created for 10 years that may be impacted by this change and this is a tremendous change. We have over 100,000 people who will qualify for managed care that are receiving services in a fee for service structure, so those are the six challenges that I see from the point of view that we will have to be confronting this year and in the next 5 years.

Mr. SHAYS. That's very helpful. Yes, sir?

Dr. CHIN-LOY. Mr. Chairman, I'd just like to come back and comment——

Mr. SHAYS. Just identify your name?

Dr. CHIN-LOY. Errol Chin-Loy, I am citywide coordinator for AIDS policy, and co-chair of the Ryan White Planning Council.

I'd like to come back to your question of populations being denied treatment for a variety of reasons. The Council directed the grantee, which is the Department of Health, to insure that services go to the community and the community providers. Working in concert with our city agencies, we're insuring that no one is denied access to protease inhibitors and we have serious difficulty with anyone who would withhold treatment to patients who need it.

Mr. SHAYS. We weren't getting into the position. I guess it's important to establish your position.

Mr. HANSELL. I have one issue for your list, that is, as I think Dr. Gil and Cruz mentioned, how we aggressively address AIDS prevention programs in an environment that there's a perception, although a false perception, that the epidemic is receding.

Mr. SHAYS. I heard the word "prevention," but what was the word before that?

Mr. HANSELL. Aggressive prevention.

Mr. SHAYS. I have not heard of the whole formula issue, but it's one that stares us in the face.

Dr. GIL. Mr. Chairman, if I may, for a second, just to elaborate further on how the formula and financing of these services will change dramatically. In a fee for service environment as well as three 4 years ago, if you were to lose that number of beds in hospitals in New York City that were used for patients with AIDS who were admitted and you look at those number of beds both in the public system as well as the voluntary hospital, you will see a reduction in the number of individuals that need to be admitted into a bed in a hospital, because it was a driven hospital system, a driven financial system to support at that stage in the epidemic.

Thank God we have these new drugs, but in doing so, we shifted the financing and the formulas have to be for outpatient, for housing, for job development, for case management, so that formula needs to be looked at very carefully. Because we all were funding a hospital system base as opposed to an outpatient driven system.

Mr. SHAYS. Let me ask one more question, and that is, with new treatments where people are maintained with HIV but not AIDS, I mean, they are HIV but they are still healthy, does that suggest any new protocol in terms of notification or disclosure of who might be HIV? And is the health community debating this issue differently because of this? Do you understand my question?

Mr. HANSELL. Yes. I think both the State and the city have had partner notification programs in place.

Mr. SHAYS. What is that?

Mr. HANSELL. That is notifying the partners of the individuals who test HIV positive on a voluntary basis. I think the implication of what you're saying, which is important, as people are living longer, the place where that needs to happen is in the health care setting, because people are going to be having more ongoing relationship with their health care providers, and so incorporating partner notification into ongoing health care delivery is going to be a much more important issue.

Mr. SHAYS. I don't understand how you would enforce a partner notification. How does that work? Then we're going to try to get on the next panel. How does it work?

Dr. GIL. I'm just going to ask Commissioner Hansell to explain how we do the identification right now for AIDS and that can serve as a model for the HIV.

Mr. SHAYS. So it's notification of AIDS?

Mr. HANSELL. What we do is actually for anyone who is tested for HIV within our testing programs, when they return for their results and the result is positive, they sit down with a counselor and the counselor speaks to them about the importance of notifying their partners, encourages them to do it directly or if they need assistance in doing it, we have a program of public health advisors

who will do that. That's something that needs to be done both in the public setting and also the private.

Mr. SHAYS. So in counseling and advising, it's not necessarily in law and they haven't broken a law if they don't notify a partner?

Mr. HANSELL. That's correct.

Mr. SHAYS. I think the response to my question, I gather, would be you would use that same model, just greater encouragement but not necessarily punitive?

Mr. HANSELL. And make more of an effort to incorporate it more into the standard of care in the medical community.

Mr. SHAYS. Mr. Cruz.

Mr. CRUZ. Just as a final comment, this is a job at the congressional level. We need to maintain at the city and the State level an opportunity for more, we're concerned more and more at the Federal level they're telling us how to do things and they're trying to establish a system that may work for the system, but may not work for New York City and New York State, so we ask for your cooperation in maintaining the flexibility of the decisionmaking authority on that level.

Mr. SHAYS. One of the things I tell my fellow Republicans, we talk about local government control and State control and then we proceed to want to tell you what to do.

Any last short comment that any of you might like to make before we get to the next panel?

Dr. CHIN-LOY. One short comment, Mr. Chairman. In Dr. Gil's testimony it's outlined in terms of people of color under the law, PRUCOL, which is called voluntary departure. Those are people who are legal immigrants or granted special status, as of September 1998, those individuals will lose all benefits in the State of New York and nationwide. It's an urgent issue and they will lose all Medicaid entitlement and we approximate that in New York City alone there are about 1,500 of those individuals. It's important this issue be addressed as soon as possible.

Mr. SHAYS. Thank you. I know for the record that we had three recommendations and that was one of them. That was one of the recommendations that addressed the particular issue of health care provided for those who are here legally, but essentially denied services.

Something that we tried to support are those who have sponsored individuals in this country and in a sense assumed providing for their needs. We want to be sure they've lived up to their obligations as sponsors as the law requires. But I think the point is well taken and we need to address it in Congress. Let me do this, we need to get to the next panel.

Mr. TOWNS. I really appreciate you coming and sharing your thoughts with us, it's just so important. This is a very difficult situation and we need as much information to move forward as quickly as possible. Thank you.

Mr. SHAYS. We're going to go to the next panel. I will call the names and I will probably do great harm to some of these names. I wrote them down; Jairo Pedraza, HIV Health & Human Services Planning Council of New York City; Antonne Moore is coordinator of East New York/Brownsville HIV Care Network; Jules Levin, executive director of National HIV Advocacy Project; Adaline

DeMarrais, actually, a constituent of mine from the great State of Connecticut, I will not show undue attention; Yannick Durand and Christine Meyers, peer counselor, Shades of Lavender. Now, you're going to be accompanied by, Ms. Meyers, Yannick Durand, is that correct? Now, how many names did I screw up here, and I'll for the record say them better.

I'm sorry, Cameron Craig, the St. George Project, Interfaith Medical Center; Gwen Carter, HIV Prevention Alliance. Any others? We need more chairs.

I want all of you to be thinking right now how you're going to keep your opening statements within 5 minutes.

Mr. PEDRAZA. We're going to try as hard as the last panel did.

Mr. SHAYS. Could you all stand, please? OK, now, let's do this. Let me swear you all in.

[Witnesses sworn.]

Mr. SHAYS. Thank you, everyone responded in the affirmative for the record. Are you sitting in the order that I called you? OK. Since I may have mispronounced some names here when you gave your testimony, you can state your name again for the record and I'll listen. And we are going to be fairly strict with the 5 minutes. If the red light goes on, I'll give you a few seconds more, but not much.

STATEMENTS OF JAIRO PEDRAZA, HIV HEALTH & HUMAN SERVICES PLANNING COUNCIL OF NEW YORK CITY; ANTONNE MOORE, COORDINATOR, EAST NEW YORK/ BROWNSVILLE HIV CARE NETWORK; JULES LEVIN, EXECUTIVE DIRECTOR, NATIONAL AIDS TREATMENT ADVOCACY PROJECT; ADALINE Q. DEMARRAIS, EVERGREEN NETWORK; CHRISTINE MEYERS, SHADES OF LAVENDER PROGRAM RECIPIENT, ACCOMPANIED BY YANNICK DURAND; CAMERON CRAIG, ST. GEORGE PROJECT, INTERFAITH MEDICAL CENTER; AND GWEN CARTER, HIV PREVENTION ALLIANCE OF NEW YORK CITY

Mr. PEDRAZA. OK, buenas dias. I'm going to try to be, to stay as the other panel as strict as them and I'll try to do my best.

Mr. SHAYS. Thank you, sir.

Mr. PEDRAZA. Thank you for the opportunity to address this committee.

Mr. SHAYS. Say your name again?

Mr. PEDRAZA. My name is Jairo Pedraza. You did quite well.

Thank you for the opportunity to address the committee on the changed needs of people with HIV and AIDS due to treatment. Again my name is Jairo Pedraza and I'm the Community Co-chair——

Mr. SHAYS. I'm sorry. Some mics pick up everything. This one is that, if you don't talk into it, it doesn't pick it up. Just lower it down a little bit. Lower it even more, because you're reading.

Mr. PEDRAZA. Is that better?

Mr. SHAYS. I'm going to have you lower it more. Keep going down. You got it.

Mr. PEDRAZA. Again, my name is Jairo Pedraza and I'm the community co-chair of the New York HIV Health and Human Services Planning Council. In that capacity, I help represent the voice of the community in planning for Ryan White title I money that New

York City receives for AIDS services. I am also a person living with AIDS.

You have heard a lot of data on the impact of the new treatments are having on the epidemic in New York City. I wish to talk to you about the need to further increase access to those treatments, especially for minority populations, and the need for supportive services to ensure that people receive the maximum benefit from those treatments.

Since the time the new protease inhibitors became available, New York City's HIV Planning Council has sought ways to create access to these new HIV infected individuals. One of the biggest barriers to access is the lack of education available to people with HIV about the medications and about the treatment. Ryan White funds are vital to help the people learn about, also especially for minority communities, we are very suspicious of the medical establishment and western medication, about people helping learn about the benefits of the medications.

People also need to help to understand their treatment options and how to adhere to therapy. While this year, the HIV Planning Council has allocated a substantial portion of our grant for treatment education and support programs, it is not nearly enough. Because of the huge demands for other, immediate life saving services such as food programs, housing and counseling, we could not nearly fulfill the demand for treatment education and support. The education and support is essential for allowing people to gain access to these new drugs and to comply with their treatments.

ADAP program has also been vital to making life saving treatment available to HIV infected people, regardless of their ability to pay. Congress must greatly increase the amount of funds for ADAP in order to meet the challenge of allowing poor people with HIV greater access to both new treatment and older treatments, but it's still vital therapies, but because of the new anti-retroviral treatments, many people with HIV hope and we will live longer and we will require a host of other HIV related medications.

For example, I am now taking gancyclovir to treat a deadly HIV related infection called CMV. This medication is extremely costly and without ADAP I could never pay for it and maybe I would not be able to appear before you here today.

We are also very concerned about the impact in the welfare and immigration laws. Many of New York City's AIDS cases are among immigrants. Many immigrants have lost their benefits and are either relying on Ryan White programs or are going without treatment. It is important both to the immigrant community living with HIV and to the public sector that they are able to get treatment and services at an early stage of HIV infection, not a later stage in an emergency care setting.

Finally, it is vital that HIV services are available locally in every borough and every neighborhood of New York City, and that resources need to be allocated to where we need. People have the right to get treatment and services in our own communities. For us, people living with AIDS, the need to travel out of our area becomes more difficult due to our illness. It means taking several trains, the rush hours or even going to different services, agencies

for services becomes a burden. Having one stop services which addresses our needs would be ideal.

Also, many times going to areas we're not familiar or agencies that services specific population different than the one that we come from, could be very, very intimidating. In addition, special attention must be paid to getting underserved populations into treatment and care. Especially, especially substance users, young adults and women. Understanding their particular needs, such as child care, drug treatment, counseling.

Once again, I would like to thank you for the opportunity to be here today. For us, people living with AIDS it's extremely important that our voices as citizens be heard, but most important is that our needs are met.

I thank you, Mr. Chairman.

Mr. SHAYS. Thank you very much. Ms. Moore.

Ms. MOORE. How is this?

Mr. SHAYS. Great.

Ms. MOORE. OK. Congressman Shays, Congressman Towns, I would like to thank you for the opportunity to discuss some key issues related to access on HIV and AIDS treatment services in Brooklyn. There's an African proverb which goes, "The lion's story will never be told if the hunter is telling the tale." I am pleased to see some diversity in this panel so that people's stories can be heard today.

To give you some background, as coordinator of the East New York/Brownsville HIV CARE Network, a Ryan White title II consortium of over 90 HIV providers, people living with HIV and AIDS and community members, my purpose is to facilitate the development of plans to address service gaps and increase access to services in my community. East New York/Brownsville Brooklyn is identified as having some of the highest needs in the entire city. Yet despite the clear need, Brooklyn and communities of color continue to be the most underserved and underfunded areas of New York City. In fact, an analysis conducted by the 718 AIDS Coalition show that though the epidemic itself shifted dramatically from lower Manhattan to the outer boroughs; Brooklyn, Bronx, Staten Island and Queens, the majority of AIDS funding continues to focus on Manhattan based agencies. This is in part due to the ways in which service needs are assessed, but also because they may provide more appropriate services.

Local community-based organizations do not have access to the resources to develop the type of infrastructure which are available to other larger organizations. To date, despite the availability of more accurate data, funding agencies continue to use methods of data collection and analysis which do not present a reliable picture of the need of Brooklyn. This problem has manifested itself in the recent Ryan White title I awards. These decisions continue to leave serious gaps in communities of color which had only been partially filled by the very same funding. In fact, there remains inadequate representation from Brooklyn and the outer boroughs on the HIV Planning Council. Even in MHRA's own statistics, 17.7 percent awards were awarded to Brooklyn, whereas 27 percent went to citywide agencies, most of these based in Manhattan.

These problems directly impact on the ability to provide appropriate services, but more importantly, on the ability of people living with HIV and AIDS to access services. Ryan White is only one example. These problems arise with funding from housing opportunities for people living with AIDS and CDC as well.

In Brooklyn, the greatest risk factor for HIV infection is injection drug use. However, not only injection drug users are at risk in this category, but also their partners and children. As one of the mandates of the Ryan White legislation, the East New York/Brownsville HIV CARE Network completed a service delivery plan, which assessed the need and provided recommendations on addressing them. This document identified substances users as one of the most difficult populations to regain services and substance use interventions as one of the three highest needs.

Engaging individuals into services becomes more complicated by HIV and AIDS, which is still viewed negatively in communities of color. The combined stigma of substance abuse and HIV magnifies the individual's reluctance to enter into the service delivery system. This is seen when out of necessity of individual enters the system only to be denigrated, humiliated and ignored.

In recent years, early access to new more effective treatments has become more important than ever. The fact that the highest risk population is not accessing services presents a major public health concern, including increased HIV infections, hepatitis A and B, tuberculosis and other related illnesses.

There have been several studies indicating that one of the best gateways for injection drug users to services has been needle exchange programs. There are only two needle exchange programs available in all of Brooklyn. Nevertheless, these have experienced great success with engaging injection drug users into services. They have the unique ability to increase knowledge and access to service, because they become a liaison between the injection drug user and the service provider. Often they will attend appointments with the individual to provide better transition. This is what early intervention is all about.

The issue of needle exchange is not a simple one. Nevertheless, needle exchange programs work, they save lives and increase access to treatments and services.

Access to services for people of color and difficult to reach populations is critical. In truth, I, like most of us here today am appalled by the way in which drugs and the violence which can result has impacted individuals families and our society as a whole. I am disheartened every time I feel like my voice and the voice of people living with and infected by HIV and AIDS are not heard when we request assistance in stemming the epidemic by increasing necessary resources.

Today I have testified before you as a coordinator, a person paid to do this work, but I am also here as a woman of color, a resident of the community devastated by combined diseases of poverty, HIV and substance use. I am also a person who is proud to be a resident of Brooklyn and who is part of a network and PLWHA Advisory Board full of wonderful, committed and knowledgeable individuals who have some pretty good ideas about how to improve the condi-

tion of people living with HIV and AIDS. One of the ways is to implement innovative methods of increasing access to needle services.

As such, on behalf of the East New York/Brownsville HIV CARE network, I humbly request that when you, Congressman Shays and Congressman Towns, return to your colleagues in the subcommittee, too, that you encourage increasing the amount of money allocated for Ryan White and HIV/AIDS prevention, insuring that communities with the highest need also have the greatest access to resources.

Additionally, ensuring that the Secretary of Health and Human Services maintains the authority to lift the ban on needle exchange.

Thank you once again for allowing me to address you on this very important issue, due to the fact of people living with HIV and AIDS.

[The prepared statement of Ms. Moore follows:]

Testimony Presented to Subcommittee on Human Resources

Friday, February 20, 1998
Brooklyn Borough Hall
209 Joralemon Street, Brooklyn, NY

Presented by: Antonne Moore, Coordinator
East New York/Brownsville HIV CARE Network

Congressman Shays and Congressman Towns, I would like to thank you for the opportunity to testify on HIV/AIDS in Brooklyn. As you know, the issue of AIDS in New York City, and Brooklyn in particular, is much more complex than can fully be discussed in this forum. Nevertheless, I am honored to be able to discuss some key issues related to accessing HIV/AIDS treatment and services in Brooklyn.

As Coordinator of the East New York/Brownsville HIV CARE Network - a Ryan White Title II Consortium of more than 90 HIV providers, people living with HIV/AIDS and community members - my purpose is to facilitate the development of plans to address service gaps and increase access to services in my community. East New York/Brownsville, Brooklyn is identified as having some of the highest needs in the entire City. These communities combined represent 11% of the total Brooklyn population, but 19% of those living with AIDS. A study conducted by the Federation of Protestant Welfare Agencies estimated that by the year 2,000, there will be 16,000 motherless orphans in Brooklyn alone, the highest of any other borough. In 1995, the former Health Services Agency estimated that one in thirty-seven individuals in Central Brooklyn is HIV positive. The NYC AIDS Surveillance Report shows that East New York has the highest number of women living with AIDS in Brooklyn.

Yet, despite the clear need, Brooklyn and communities of color, continue to be the most underserved and underfunded areas in New York City. In fact, an analysis conducted by the *"718" AIDS Coalition* showed that, though the epidemic itself has shifted dramatically from Lower Manhattan to the outerboroughs - with 70% of all new AIDS cases - the majority of AIDS related funding continues to focus on Manhattan-based agencies. This is, in part, due to the ways in which service needs are assessed. But

also because, though they may provide services more effectively to people of color, local community-based organizations do not have access to the resources to develop the type of infrastructure which are available to other larger organizations.

To date, despite the availability of more accurate data, funding agencies continue to utilize methods of data collection and analysis which do not present a reliable picture of the need in Brooklyn. This problem has manifested itself in the recent Ryan White Title I awards which blatantly ignored the HIV Health and Human Services Planning Council and the 1990 Ryan White Legislation mandates to focus on both demographic and geographic high need areas. These award decisions left serious gaps in communities of color which were only partially filled by the very same funding in previous years. Some corrective efforts have been made, mainly as a result of an increase in New York City's Title I award. thanks to a letter from Congressman Towns. However, these efforts have not completely rectified the gaps left by these decisions nor addressed the underlying problems - the lack of adequate resources and the continued use of inappropriate data regarding need.

These problems directly impact on the ability to provide appropriate services, but more importantly on the ability of People Living with HIV/AIDS to access services. In reality, it is not simply a matter of inadequate disbursement of funds, but also a matter of increasing Ryan White Funding in New York City. Though the number of people dying from AIDS in New York City has decreased, they remain higher among people of color. In fact, one of our neighborhood Hospitals has noticed an increase in AIDS admissions. These differences are particularly clear for women with 88% of AIDS cases being among women of color. The decline in AIDS deaths for African-American women was 59% as compared to their White counterparts at 73%. If services are not targeted to these communities, we will not see a change.

In Brooklyn, the greatest risk factor for HIV infection is injection drug use. However, not only injection drug users are at-risk under this category, but also their partners and children. According to the New York City AIDS Surveillance Report, in East New York/Brownsville, injection drug use represents 61% of reported AIDS cases. As one of the mandates of the Ryan White legislation, the East New York/Brownsville HIV CARE Network completed a Service Delivery Plan, which assessed the needs and provided recommendations on addressing them. This document identified substance users as one of the most difficult populations to engage in services and substance use interventions as one of the three highest needs.

Engaging individuals into services becomes more complicated by HIV/AIDS, which is still viewed negatively in communities of color. The combined stigma of substance use and HIV magnifies the individual's reluctance to enter into the service delivery system. This is particularly true, when out of necessity the individual enters the system only to be denigrated, humiliated and ignored. In recent years, early access to new, more effective treatment has become more important than ever. The fact that the highest risk population is not accessing services presents major public health concerns, including increased HIV infections, Hepatitis A & B, tuberculosis and other related illnesses.

There have been several studies indicating that one of the best gateways for injection drug users to services has been Needle Exchange Programs. Needle Exchange Programs in New York City conduct more than simple exchanges. They utilize a harm reduction model which promotes access to drug treatment, provides much needed referrals, and most important, access to individuals who would not normally enter HIV-related treatment. Not only are these programs better able to engage this difficult to reach population, they are one of the most effective prevention mechanisms for injection drug users against HIV and other blood-born diseases.

There are only two needle exchange programs available in all of Brooklyn. Nevertheless, these have experienced great success with engaging injection drug users into services. They have the unique ability to increase knowledge and access to service because they become a form of liaison between the injection drug user and the service provider. Often they will attend appointments with the individual to provide better transition. This is what early intervention is all about. Lifting the federal ban on needle exchange would provide communities such as Brooklyn with the resources to expand this preventive, effective, and innovative work.

The issue of Needle Exchange is not a simple one. Nevertheless, it is an issue of public health and science. Studies conducted throughout the Nation, by the U.S. General Accounting Office, Center for Disease Control and Prevention and the National Research Council and Institute of Medicine, have shown that these programs help in the prevention of HIV and other blood-borne diseases. According to a poll conducted by the Kaiser Family Foundation 61% of Americans favor allowing state and local governments to use federal funds for needle exchange programs. In a study in Connecticut, the rate of needle sharing was reduced from 71% to 15% in three years without increasing drug use. In a study conducted by the City, syringe exchange/harm reduction programs could reduce 5,000 new HIV infections by the year 2,000. Needle Exchange Programs work, they save lives and increase access to treatments and services.

Access to services for people of color and difficult to reach populations is critical. In truth I, like most of us here today, am appalled by the way in which drugs and the violence which can result has impacted individuals, families and our society as a whole. I am disheartened every time I feel like my voice and the voice of people living with and affected by HIV/AIDS are not heard when we request assistance in stemming the epidemic by increasing necessary resources.

Today, I have testified before you as a Coordinator - a person paid to do this work. But I am also here as a woman of color and a resident of a community devastated by the combined diseases of poverty, HIV and substance use. I am also a person who is proud to be a resident of Brooklyn and who is part of a Network and PLWHA Advisory Board full of committed and knowledgeable individuals who have some pretty good ideas about how to improve the condition of people living with HIV/AIDS. One of the ways is to implement innovative methods of increasing access to needed services.

As such, on behalf of the East New York/Brownsville HIV CARE Network, I humbly request that when you Congressman Shays and Congressman Towns, return to your colleagues in the Subcommittee that you encourage increasing the amount of money allocated for Ryan White and HIV/AIDS prevention, ensuring that communities with the highest need also have the greatest access to resources. Additionally, ensuring that the Secretary of Health and Human Services maintains the authority to lift the ban on needle exchange.

Thank you once again for allowing me to address you on these very important issues which will impact people living with and affected by HIV/AIDS in Brooklyn

Mr. SHAYS. Thank you, Ms. Moore.

Mr. Levin.

Mr. LEVIN. I'm glad to be here and have this opportunity to address this panel and Congressmen here today about some very important issues. I particularly want to thank Congressman Towns, the good Congressman Towns, for inviting me to speak here and for his support of some of the important issues that I have here outlined here today by some of the people.

I have to tell you that it is my belief that the important information you can get will come from the community people at this panel. The Government people have something to say, but I'm not quite sure they can say the things in the way that the community people here can say it and I don't think they did. I'm not sure they addressed some of your questions regarding the importance of adherence.

Let me tell you that in line with what Jairo said, education, treatment education, equals access and compliance equals treatment access and equals treatment compliance and there is not adequate treatment education in the minority communities. Let me tell you that I, my organization for which I'm the executive director is a member of the ADAP working group. I'm sure you're familiar with our workings in Washington, and I myself am a treatment writer, we publish a newsletter and have a web site on the Internet where we disseminate treatment information all over the world and we have highly scientific treatment information which we disseminate to doctors and to patients, and I interact with leaders from the communities in all the different cities in the United States, mostly leaders in the gay white male community.

I live in Brooklyn, my organization is in lower Manhattan, and due to the good work of the AIDS Institute, we are one of the organizations that is funded to do treatment education in Brooklyn, and I think Jairo mentioned this, and so we bring treatment education due to that funding to seven or eight ASO's in Brooklyn, some of them are here today, Life Force, Brooklyn AIDS Task Force, Musica Against Drugs, as Congresswoman Velázquez mentioned, and some of the biggest organizations in Brooklyn.

I want to tell you I am stunned, I've been bringing treatment education to Brooklyn since about a year ago. I am stunned in the difference in knowledge of treatment education over that short bridge between Manhattan and Brooklyn. There is a tremendous gap and I'm not sure I believe the city government when they say they are putting enough funding into treatment education for minority populations in Brooklyn. Lack of treatment education equals lack of access, because people don't know what the treatments are, they don't know what their choices are, they don't know if their doctor is leading them astray or not and I will mention again to that and they don't know what future strategies will be, and they don't know why they should be compliant.

Education frequently helps with compliance. It's not alone making somebody compliant, but it helps, and with regards to adherence, we need proper support for adherence programs. Adherence is maybe the biggest, non-adherence is maybe the biggest factor for treatment failure in the United States today. So just to say that ASO's in the outer boroughs are doing their best as one of the gov-

ernment officials speaking today to address adherence, that's not good enough. We need programs, we need money to do the programs and you need good people setting up the program and there is none of that going around today in New York City in Brooklyn that I know of for sure, and in fact throughout the city.

One of the—we bring in seven sessions to each organization over 6 months. One of the sessions we will be getting to is adherence and we will do our best to discuss and work with agencies on improving adherence for their clients, but it's a very complicated issue that needs to be addressed comprehensively. Let me try to run through some of my points today.

Mr. SHAYS. Let me say, you've got about 6 minutes total. You've done such a good job not even looking at your statement. You can feel free to paraphrase; it will be helpful.

Mr. LEVIN. OK. Some important points. First of all, primary care, too often, for HIV does not reach the appropriate standard of care, doctors in Manhattan, in the big clinics may know more about how to use these treatments, but I tell you that the doctors in Brooklyn do not, and as a result, we need better treatment education, not just for the patients, because it's the history of HIV is that the patients are the ones who are the activists or caused all the changes do better in educating themselves and treating themselves. They need treatment education, but I tell you that the doctors need treatment education.

The triple drug therapy is going by the wayside. Within a year we're going to have double protease therapies, we'll have four drug therapies. I think a lot of doctors in Brooklyn don't know how to adequately use triple drug therapy, which is why we've had a wave of resistance in the last year and we'll probably have more resistance.

Let me also say that you need to fully fund ADAP. The ADAP working group will be meeting with you in Washington over the course of the next several months. I know we've been visiting with you over the last few months. We are very thankful that you have been increasing funding several hundred million dollars in the last several years, that's terrific, but there are people falling in between the cracks because it's not fully funded. I tell you after spending hundreds of millions of dollars to help develop these drugs through the NIH, it's amazing to me that Congress doesn't want to fully fund access to everybody. I just find that unbelievable.

Let me say that needle exchange is extremely important. I am HIV positive. I contracted HIV 13 years ago through using needles. I will tell you that if clean needles were available then, I don't think I would have HIV and it would not make somebody use drugs who never used drugs, because they can get a clean needle. It will not increase drug abuse.

Let me just finally say that adequate funding really needs to go—I am active with organizations all over the country, the bigger ones mostly and the smaller ones. APLA in Los Angeles, GMHC in New York City, San Francisco AIDS Foundation because of my treatment education work, I work with all of them, and I will tell you that as Jairo said in my work and going into all the little organizations in the Borough of Brooklyn, there are many, many people who never cross the bridge into Manhattan for any services. They

are comfortable in their community, working with their local organization, and there must be improved linkages for services and improved funding for these little organizations, because many of these individuals don't take treatments because they don't understand them or they're not adherent because they don't understand that they should be adherent and many other reasons besides that. I think, thank you very much.

[The prepared statement of Mr. Levin follows:]

written testimony and CV for:

Congressional Sub-Committee on Human Resources
Committee on Government Reform and Oversight

Hearing-
"AIDS: Toward Long Term Treatment Options"
Friday, February 20, 1998
9:30 am at Borough Hall, 209 Joralemon St, Brooklyn NY

from:

Mr. Jules Levin
Executive Director, National AIDS Treatment Advocacy Project (NATAP)
72 Orange St #3C
Brooklyn, NY 11201
ph: 718 624-8541

I am pleased and honored to have this opportunity to express my feeling about some subjects of great importance to me and to people with HIV. I want to thank the good Congressman, Edolphus Towns, for inviting me to address this hearing. I also appreciate that this committee is taking the time to explore and learn about this subject. Improving treatment options for patients with HIV is crucial to the lives of people with HIV and towards stemming the tide of this health epidemic.

Today, I will discuss subjects about which I am the most intimately involved with and therefore have the most knowledge about, ones that I feel the most strongly about. These subjects are ones that are extremely crucial to stemming the incidence of HIV, to extending the survival of people with HIV and to improving their health.

We have therapies capable of extending survival for people with HIV by greatly suppressing the levels of HIV in a person's body. Today, I am going to talk about several important issues related to trying to maximize this capacity -

- Too often, primary medical care for HIV does not reach the appropriate standard of care
- There is a lack of adequate education and consequent knowledge about treatment (among doctors, patients and other related supportive professionals) causing this inadequate care which leads to inappropriate and suboptimal treatment
- HIV is a unique disease. It is the only one where the patients have been so empowered to take care of their own treatment. Additional patient education is crucial
- There is a need to increase funding for ADAP

- Compliance or adherence to HIV treatment regimens are crucial in the success of therapy. Non-compliance or adherence to the demanding requirements for taking the HIV treatment regimens has played a major role in treatment failures

- Supportive local community or neighborhood centered services for people with HIV are required for these individuals to survive and to benefit from adequate medical care and treatment

- Properly designed and supported needle exchange programs can have a large impact on the incidence of HIV overall. Particularly because the current trend in the USA is that a larger proportion than ever of HIV incidence is coming from among individuals who use IV drugs or individuals who have sex with them.

Clearly New York City is the epicenter for HIV disease in the USA. Amazingly there are doctors in this city who recommend suboptimal treatment for their patients with HIV. If this occurs in NYC can you imagine the scope of the problem elsewhere. I hear reports of doctors in NYC still treating HIV with AZT monotherapy or other suboptimal treatment regimens. Treating any individual for primary HIV requires due consideration of many factors. A doctor must consider planning a regimen that at once is capable of accomplishing a properly chosen goal of therapy which is usually lowering HIV plasma viral load to undetectable levels by the available diagnostic tools. In composing this regimen he or she must also consider future treatment strategies. The ultimate goal is to lower viral load to an acceptable pre-planned level, to sustain the durability of that achievement and to plan for future strategies to continue that achievement and maintain the person's health and survival.

Although there are a good number of doctors in NYC and elsewhere who are capable of accomplishing this, there are many who have insufficient knowledge to accomplish this. I personally know many doctors who know how to treat HIV and have the knowledge to do so and I applaud the efforts they take to educate themselves and to give good care to their patients. However, I think the number of such doctors is way exceeded by the number of those who do not have adequate knowledge about the pathogenesis of HIV, about the drugs used now and in the future to treat HIV, and how to properly design treatment strategies. In many cases doctors don't or are unable to take the time to adequately assess a patient's situation and put together an appropriate regimen. Some patients receive a regimen that is not appropriate for them. When this occurs the patient is more likely to fail that regimen more quickly. Due to resistance and cross resistance a person failing such a first line regimen may not be responsive to additional therapy.

Another reason for treatment failure is non-adherence or non-compliance with the sometimes very demanding requirements for taking the medication. Non-adherence to a drug regimen is common among all individuals with any number of medical syndromes. Non-adherence is a human problem. But, non-adherence is preventable. Measures can be taken to improve adherence to HIV medications. Only very recently have efforts to improve adherence been started. Much more widespread effective programs to support adherence are required. The delay in imlementing adherence or compliance programs has resulted in the first wave of treatment failure from which some individuals will never recover. An adherence support mechanism must be at once simple, individually tailored

to the needs of that person, and comprehensive enough in scope to support success of therapy.

A number of smaller adherence projects are in development but this problem must be well recognized and addressed to prevent treatment failure due to this one cause. A comprehensive effort is required to address this crucial problem which broadly impedes successful treatment.

Usually, a person fails a treatment regimen because resistance develops to the protease inhibitor. Non-adherence can cause resistance to drugs to develop. Once resistance to a protease inhibitor occurs the person is cross resistant to other protease inhibitors. The person is not likely to benefit well from a next regimen or protease inhibitor. This is why it is so crucial that doctors and patients be so well educated about choosing treatments. Improper treatment regimen design can cause permanant treatment failure. Non-compliant behavior such as missing doses, not taking full doses, or eating when taking certaindrugs for which you are not supposed to eat with also is a major cause for resistance to drugs.

I think we can do something about these problems of below standard care for HIV and non-adherence. We can improve medical care and adherence by first fully recognizing the problem, having the resolution to improve the situation, and then implementing programs to accomplish the goals. These problems, however, need immediate attention. We have already had too many treatment failures due to these problems. It is important to remember the consequences of treatment failure. They can lead to declining health, death and additional transmission of HIV. These consequences also effect our economy. Death and declining heath prevents young capable people from working and contributing to our overall economy.

The latest data from the CDC (Center for Disease Control) indicate that the incidence of HIV in minority communities is a major driving force in the overall rate of incidence for HIV. Special attention needs to be paid to the unique needs of these communities in order to stem the epidemic of AIDS. Some of the problems include inadequate housing, substance abuse treatment, inadequate HIV treatment education, inadequate medical care, and other special needs.

People with HIV are unique from individuals with any other disease. They are the only ones empowered as much as they are. There is a history and tradition for people with HIV to have this empowerment. Many of us have traditionally directed a large part of our own treatment and treatment education. It is this movement that has played a large role in improving governmental activities and funding with regards to HIV. This is one of the important reasons that direct consumer education is key to successful treatment. Traditionally such empowerment has existed in the gay white community, but it is inadequate in minority communities. It is important to extend this empowerment to the minority communities through treatment education.

What can be done to address these problems?
The American Medical Association or Congress can require that like cancer and other specialty areas of medicine, physicians who treat HIV should be required to meet certain

standards. Doctors treating HIV should be required to have a certain board certification that they are specialists in that field.

Physicians and patients need improved education about treating HIV. Other professionals who are involved in the care of PWAs should also receive such education--nurses, home health care attendents, social workers, case managers, etc. We need broad based comprehensive programs designed to reach and well educate all HIV treating physicians and patients. It is with the knowledge obtained through such programs that a patient can participate in their care. Armed with adequate knowledge a patient can assess if their doctor is knowledgable. Armed with this knowledge a patient can hold their doctor accountable for good care. Armed with adequate treatment knowledge a person can select their own treatment regimen.

My organization, NATAP, has two missions: (1) advocacy for those with HIV and their affected others with drug companies, the FDA, NIH, other Federal entities; (2) dissemination of comprehensive and up-to-date treatment information to doctors, patients, and other professionals in NYC, other parts of the USA, and internationally. We do this through our treatment newsletter, NATAP Reports, our internationally read web site, and our live in-person forums or seminars. Our in-person free seminars draw more attendants than any other such events. Our 1998 January 17 forum at NYU drew 1500 registrants and 800 attendents. All of our forums get this amount of attendance. We bring in leading scientists and researchers to bridge the gap between the science and the doctors and patients. In October '97, we held a treatment education forum for 600 case managers right here in Brooklyn. There is a hunger for treatment information if you meet the need in an appropriate way, which NATAP is capable of doing.

This is an important point I'd like to make with you. NATAP is now receiving a grant from the NYS AIDS Institute for conducting a 7-month HIV treatment education program with 7 community AIDS service organizations in Brooklyn. These organizations include Lifeforce (a women's organization), Musica Against Drugs (primarily Hispanic individuals), Brownsville Multi Services Center (provides medical care and case mngt services for afro-american and hispanic individuals), Bedford-Stuyvesant Family Health Care Center, St Nicholas Scattered Site Housing, People of Color in Crisis, and Brooklyn AIDS Task Force. Our program consists of visiting each organization once per month for 6-7 months. The audience consists of staff and clients. Our program takes then from soup to nuts about treatment for HIV. Our subject matter includes-HIV Pathogenesis, current and future HIV treatments, perinatal transmission and treatment, pediatric treatment, adherence, improving doctor/patient relationships and case manager/client relationships. I do some of the presentations and we bring in doctors and researchers to present some of the information. We are very well received by the organizations. They are anxious to receive the trainings.

I have encountered a situation where many clents and case managers have grossly inadequate knowledge about HIV and treatment. To address this, in some cases we've had to slow down our pace. 7 months is inadequate to accomplish our goal. Our goal is ambitious--everyone who comes to our sessions will obtain a good understanding of HIV and treatment. The funding for this program ends in June '98. Our program is being very successful and should be continued but the funding is not available.

The Federal government through Ryan White Title's I or II should mandate that each state spend a specified percentage of funding on direct consumer or patient education. My opinion is that this type of education is key to an individual empowering themselves to make sure they receive the best treatment possible. Additionally, all too frequently patients don't trust treatment advise from their doctors but may be more receptive to information from an organization such as NATAP.

We at NATAP receive continuing requests from hospitals, doctors and AIDS service organizations to provide them with educational programs. The only thing preventing me from conducting more educational efforts are limited financial resources. Support for such efforts from Congress would be helpful.

ADAP- NATAP is a member of the ADAP Working Group located in Washington DC. I am the representative for NATAP in that group. I think you may be well acquainted with the Working Group's goals and activities. Without adequate funding for all state ADAP programs, many individuals get no treatment or receive suboptimal treatment. It is unconscionable that the PHS and NIH would document the standard of care for HIV and that the state ADAP programs would not be required and duly funded to meet these standards. You have probably heard about the states where there are waiting lists to receive drugs, where program eligibility criteria are prohibitively restrictive, and where their drug formularies are too limited. In some states ADAP programs have closed and reopened because of inadequate funding.

It is unconscionable that such a situation is still ongoing 2 years after the FDA approval and availability of protease inhibitors. Granted, the situation has improved as Congress and the Administration have supported significant funding increases over recent years. But, *everyone* with HIV who needs treatment should have access to such treatment. The hopes of stemming the tide of this epidemic requires proper treatment. Over the course of the last 10-13 years, the Federal government has spent hundreds of millions of dollars for research for drugs. Now that we have those drugs, it is bewildering to me why access to them is limited.

Continued Support for Small Community Based Service Organizations. The organizations, such as the ones NATAP visits to deliver our educational programs are meeting and fighting HIV on the front lines of the battle. They are providing irreplacable services to the people with HIV: primary medical care, case management services such as providing resources for housing, food, treatment education, etc. All the successes and problems faced in the HIV crises are present in the everyday affairs of these organizations. Additional and continued support for these organizations is crucial. Some may tell you that the sickness and death is waning because of the new therapies. But, the prevalence of incidence for HIV is switching to minority communities. In these communities, problems continue unabated: inadequate treatment information and access, inadequate medical care, higher rates of non-adherence, inadequate sustance abuse services. Funding increases are required to assist these organizations in coping and making progress. As mentioned earlier, NATAP provides treatment education to such organizations. Without continued funding we will have to stop providing these services. But these are only 7 organizations. IN New York City, there are many more organizations not receiving any the type of trainings that we deliver.

Neighborhood Linkages. In my experience in dealing with these aforementioned organizations and others like them, they are vital connections to the people with HIV in their neighborhoods. These AIDS service organizations (ASOs) have an irreplacable relationship with their clients. Their clients feel comfortable in their neighborhood ASO and are not likely to travel to St Vincent's Medical Center or New York Hospital in Manhattan for treatment or treatment education. NATAP visits these ASOs once a month during the 7 month project to deliver treatment education. This linkage between my organization and the neighborhood ASO is crucial in that it may be the only way to reach some individuals with life saving treatment education.

Needle Exchange. It is clear to me that well designed needle exchange programs will lower the incidence of HIV among IV drug users and individuals who have sexual contact with them. It is also clear to me that such programs would not increase the use of IV drugs but would probably increase the number of individuals seeking substance abuse treatment. But, this is not a subject people like to talk about. It is not a pretty subject. But, as a person who contracted HIV because I shared needles for IV drug abuse, I can tell you in no uncertain terms that the availability of clean needles to me would have probably prevented me from contracting HIV.

There are many needle exchange programs in a number of cities throughout the USA supported by state or local funding. They have been documented to show that decreases in transmission of HIV occur when a well designed program is implemented. Congress commissioned its own committee to research this question and this committee returned a document saying that needle exchange prpgrams can decrease HIV transmission. This document has been presented to Secretary Shalala and to Congress. It is way past the time where we should have Federal support for needle exchange programs. Support should consist not just for funding but also with assistance in designing and implementing programs in collaboration with local government and private entities.

In summary, there are several points I want to make:

- With the availability of successful treatments for HIV, too many doctors and patients are not well educated enough on how to use them. Support from the Federal government can help improve treatment education

- ADAP needs adequate support. No person with HIV should be denied access to adequate treatment

- Small neighborhood based organizations providing basic services are crucial to minority communities. It is the main source of services for many individuals living in those high incidence neighborhoods. Continued and additional support is needed from the Federal government

Needle exchange programs can decrease HIV incidence. They do NOT encourage IV drug use. Needle exchange needs Federal support

Jules Levin
Executive Director, National AIDS Treatment Advocacy Project (NATAP)
72 Orange Street #3C
Brooklyn, New York 11201
ph: 718 624-8541, fx: 718 624-8399

I was born and raised in New York City where I received my undergraduate degree from New York University in 1971. I spent several years in graduate degree programs for law and business and worked in several different fields of business including securities trading and real estate. I have been married to my wife Elissa for 15 years and found out that I am HIV positive about 10 years ago. I have been taking a 4-drug regimen for the past 18 months and it has been successful to date.

There are two main missions for NATAP: (1) advocacy for people with HIV with drug companies, the FDA, the NIH and other governmental entities; I frequently meet with drug companies to consult about planning drug development including clinical trials; (2) dissemination of HIV treatment information and education about treatment.

About 6 years ago I merely happened to become involved in AIDS treatment advocacy. My initial involvement, which lasted about 1 year, was to organize efforts on a national scale to lobby the manufactuers of protease inhibitors to provide drug to individuals in desperate need prior to FDA approval. This type of drug supply is officially called Expanded Access. Merck and Abbott were unwilling to offer expanded access programs so we had to negotiate with them.

Subsequently, upon realizing the importance of treatment education unique to this new era of treating HIV with the availability of protease inhibitors, I decided to focus on treatment education. I founded NATAP and we were the first to conduct treatment education forums in 1996 on protease inhibitors in New York City and Los Angeles. The size of the crowds registering for our forums were unprecedented. In each of these first two forums about 1,000 people registered. NATAP continued to develop. I started a newsletter for which I do all the writing and was one of the first to conduct treatment education through a web site on the internet. I continued conducting free treatment seminars for the community and large crowds continued to attend. In the last 15 months, NATAP has increased from 1 employee (me) to 4 and we conducted 3 very well attended important forums in 1997. At each of our forums I select topics that are the most cutting edge for treatment. We bring in some of the most knowledgable scientists to discuss these issues. Usually we prepare reproductions of the discussions and distribute them by mail and through our web site.

Most of our forums are conducted at New York University Medical Center as they generously assist NATAP in holding the events. In May 1997, our treatment forum for the community drew 800 registrants. Usually a wide variety of individuals attend our forums including doctors, researchers, scientists, patients, nurses, etc. In October 1997 we conducted two large forums. For the first time we conducted a forum strictly for case managers from community AIDS organizations in New York City. Amazingly, over 600 people attended. In that same month we held a forum at NYU Medical Center on resistance and cross resistance to HIV drugs for which 500 people attended. In January

1998 again at NYU we held our best forum to date on selected special topics of great interest and 1,500 people registered to attend. For the first time we offered continuing medical education (CMEs) credits to doctors and nurses for attending the forum. This was a success as we attracted over 150 doctors and nurses for these credits. We are expanding into educating doctors as well as patients. We are currently planning for the first time to conduct a forum just for doctors in Brooklyn, NY in March 1998. This is a specialized forum just for doctors who are not very knowledgable about treating HIV.

In the meantime our newsletter, NATAP Reports, is distributed worldwide and our newly designed web site is also read worldwide. Our treatment information is well received by both doctors and patients. I will bring copies of the current 40-page double issue of NATAP Reports to the hearing in Brooklyn so that you can see the type of information we provide. And of course you can read our web site, <http://www.natap.org>. I believe our web site supplies the most comprehensive, up-to-date and accurate treatment information on the internet.

I hope I haven't bored you with this endless description of NATAP's activities but I was asked to describe who I am and the work that we do. I think that the work I do does in fact allow me to have certain insights into the needs of the HIV community and so a description of my work allows you to see where I get my insights.

Financial Disclosure. In accordance with your request I am disclosing that in 1997, NATAP received a financial grant from the New York State AIDS Institute for about $74,000 to conduct our 7-month treatment education program in Brooklyn, New York. It is not a direct grant from the Federal government but I assume some of the funding comes from Ryan White. This is the only government funding NATAP receives.

Mr. SHAYS. Let me just tell you, your entire statement is put in the record. Our staff goes over all the statements with a fine tooth comb in preparation for the legislation and recommendations we developed, so be assured that it is not just stuck in the record. Your testimony as you gave it was quite helpful, so I thank you very much.

Mr. LEVIN. I hope so. Thank you.

Mr. SHAYS. Thank you. Adaline DeMarrais. Am I saying your name right?

Ms. DEMARRAIS. Adaline. Thank you.

Congressman Shays, Congressman Towns, thank you very much for this opportunity to share with you some concerns I have about current and future psychosocial medical response to people infected and affected by HIV disease.

As a founder and director of Evergreen Network, which is a social service agency in Bridgeport, CT, that primarily serves economically marginalized families and individuals touched by HIV/AIDS in southern Connecticut, I work with over 150 infected adults and children and 200 affected children and their families and I'm proud today to be the first speaker today to speak about children.

Children are a critical issue in this disease. In 1985, I was among the first in the United States to realize that large numbers of children were being orphaned by this disease and were not being recognized or provided for by social service programs at any level. For the past 12 years, I have worked with children and families as their parents died from this disease. Today because of the new drug therapies we are starting to see longevity for these people. However, stemming from my years of experience in this field, I have many significant concerns about gaps in service, continued access to treatment, lack of coordination of care among community, city and Federal providers.

The issues that I have identified are; the affected children in these families must have a system of temporary guardianship and mental health services for them available for them and social service provision must not stop with the death of a parent. Even with improved prognosis, their parents will still require occasional hospitalization and/or bed rest because of their fragile health systems. The children in affected families need to be assured of continuous uninterrupted care and supervision during these times of acute parental illness or death.

In addition, I have recently seen that the stress and trauma of their parents illness and possible death necessitates a need for mental health services to these children. And these mental health services need to be available for extended periods of time and for multiple periods of treatment. We know this clinically; children grieve and resolve trauma developmentally. That means that what is resolved at age 6 needs to be redealt with again at least in middle school and again in high school at the very least. The numbers of these children are significant. Here in New York City, the New York Times reported over 30,000 children and those numbers are extrapolated to Connecticut, because we have this close affinity with New York. We share many wonderful things with New York but also the tremendous increase in this disease.

No. 2, I'd like to talk about infected women who are being impacted with the new welfare to work regulations. For many women their partners have already died and they're the sole support of their families. Even with the new medication, these women's health systems are more vulnerable to general infection and complications resulting in absenteeism and subsequently they're at greater risk for job loss.

We need to redefine disability qualifications. In addition to fragile impaired health systems, these clients often experience a general malaise, exhibiting chronic tiredness, nauseousness and overall weakness as side effects from the medications they are taking. These maladies cause them to be poor candidates for good work attendance, not through any fault of their own.

Another interest or issue for me is medical coverage as a critical need for this population. For those clients who are able to return to work, they need guaranteed low cost medical coverage. Why is the Government carrying the full burden of medical costs for these clients? Medical insurance companies need to accept part of the coverage for these clients and the Government needs to use its buying power to buy low cost medical insurance and then partially subsidize the coverage to make it readily available to this population. A critical aspect of care for this population is also the need for drug treatment programs. Significant numbers of these patients do very well on the new medication, medical treatments, but their prior lifestyles of drug use puts them at continued risk for medical problems and legal correctional problems. And there is a continuing lack of drug treatment for women, especially women with children.

Another new issue, this is very, very new, some subtle drug failure is now apparent with the new treatment medications and NIH has verified this with me. I am seeing some patients who are exhibiting neuropsychiatric symptoms, although they're having very good physical response to the medication. There appears to be chronic psychiatric impairment with specific neurological symptomatology, such as loss of decisionmaking ability, loss of acute and cognitive function and memory impairment.

In addition, people are living longer with this disease, and their fragile health systems will experience the additional burden of normal health care issues inherent in aging, and we need to look ahead and have the vision to propose future responses for these challenges.

In response to these concerns I in the record have the model of service provision that Evergreen has provided and I'd like to share that, if you'll look through the record. Thank you very much.

[The prepared statement of Ms. Demarrais follows:]

Friends Through the Seasons

February 20, 1998

Congressman Shays, and Committee Members, thank you for this opportunity to share with you some concerns that I have about the **current and future** psychosocial/medical response to people infected and affected by HIV/AIDS.

As the founder and director of the **Evergreen Network, Inc.**, a social service agency in Bridgeport, Connecticut that primarily serves economically maginalized families and individuals touched by HIV/AIDS in the southern Connecticut, I work with over 150 infected adults, 200 affected children and their families

In 1985 I was among the first in U.S. to realize that large numbers of children were being orphaned by this disease and were not being recognized or provided for by social service programs at any level. For the past 12 years I have worked with children and families as their parents died from this disease. Today because of the new drug therapies, we are starting to see longevity for these people, however stemming from my years of experience in this field, I have many significant concerns about the gaps in service, continued access to treatment and the lack of coordination of care among community, city, state and federal providers.

The issues that I have identified are:

1. The affected children in these families must have a system of temporary guardianship and mental health services available for them and **social service provision must not stop with the death of the parent**. Even with improved prognosis, their parents will still require occasional hospitalization and/or bed rest because of their fragile health systems. The children in affected families need to be assured of continuous, uninterrupted care and supervision during these times of acute parental illness or death. In addition, I have repeatedly seen that the stress and trauma of their parents' illness and possible death necessitates the need for mental health services for these children. And these mental health services need to be available for extended periods of time and for multiple periods of treatment. Children grieve and resolve trauma developmentally. What is resolved at age six needs to be dealt with again in middle school and high school at the very least. The numbers of these children are significant - over 30,000 in NYC alone, as reported by *The New York Times*. If we have any hope of these children becoming contributing members to our communities, we must provide these services.

2. Infected women are being impacted with the new "welfare to work" regulations. For many women, their partners have already died and they are the sole support of their families. Even with the new medications, these women's health systems are more vulnerable to general infections and complications resulting in absenteeism, and subsequently are at greater risk for job loss. Under the current guidelines, after 21 months they will then be unable to access public assistance again. In addition to fragile/impaired health systems, these clients often experience a general malise, exhibiting chronic tiredness, nauseousness and overall weakness as side effects from the medications. These maladies cause them to be poor candidates for good work attendance.

3. Medical coverage is a critical need for this population. If these clients are able to return to work they will need guaranteed low cost medical coverage. **Why is the government carrying the full burden of the medical costs for these clients?** Medical insurance companies need to accept part of the coverage for these clients. The government needs to use its buying power to buy low cost medical insurance and then **partially** subsidize the coverage to make it readily available to this population.

4. Some subtle drug failure is now apparent with the new treatment medications. I am seeing some patients who are exhibiting neuro-psychiatric symptoms although they are having a very good physical response to the medications. There appears to be chronic psychiatric impairment with specific neurological symptomatology such as loss of decision-making ability, loss of acuity in cognitive function and memory impairment. Case managers are reporting more mental health issues for some clients who have a good physical response to the drugs, but continue to show psychological symptoms. The need for mental health services is acute with special need for long term mental health care for this chronic condition.

5. As people with this disease live longer, their fragile health system will face the additional burden of the normal health care issues inherent in aging. We need to see ahead and have a vision to propose potential future responses for these challenges.

6. For all of these concerns we need a more encompassing network of care for both the infected and affected people touched by this disease.

In response to these concerns I would like to share the model of service provision that **Evergreen Network, Inc.** has developed. Our program for affected children was the first in the country and has become a model for Yale Child Center's program as well as for many other agencies. We provide case management for affected children as well as a weekly support group that incorporates the use of therapists and college student volunteers to work with the children in an often one-to-one ratio to provide therapy and peer models. Each child's birthday is celebrated as well as report cards and seasonal holidays. Extensive use of resiliency factors has been incorporated into the program. In addition, there is a "Big Friend, Little Friend Program with other college students for

additional one-to-one peer mentoring. **Service provision does not stop with the death of the parent.** This is a critical part of this therapeutic intervention.

Currently, Evergreen is the only agency that provides case management services for the infected and affected children. Unfortunately, the systems set up to protect and aid these children often do not adequately respond to their needs. The role of the case manager is to go into the schools, courts, clinics and other state agencies and advocate for the basic academic, psychological, legal and health needs of these children.

The Evergreen Network, Inc. fills a service gap by providing the majority of psychosocial services in the Greater Bridgeport Area as well as case management. Evergreen, through the help of professional therapists and over 150 community volunteers, provides practical and accurate information about local services available, as well as step-by-step guidance in how to access those services. More importantly, by creating separate support groups for those whose lives have been permanently altered by HIV/AIDS, Evergreen helps to combat the isolation and searing stigma that still surrounds this disease.

The psychosocial support groups that are now being offered include:

* a weekly evening group for HIV+ men and women.

* a weekly luncheon group for HIV+ women.

* a weekly "Sunshine Kids" group for children who have a family member infected by HIV/AIDS.

* a monthly group for grandparents raising children orphaned by AIDS

* a monthly group for caretakers raising HIV- children.

* a monthly group for significant others of persons with HIV/AIDS

* a quarterly Bereavement Group for anyone who has experienced the death of significant person in their life due to AIDS.

These support groups are provided free of charge. Since transportation to and from these groups is often prohibitive and unavailable to its participants, The Evergreen Network has developed a voucher program with a local taxi company to provide regular, safe and dependable transportation.

Case Management - and more

In addition to support group services, each client receives assistance in navigating the complicated systems of the courts, medical providers and the departments of Social Security, State Health, State Housing and Income Maintenance. Clients are also encouraged to participate in a weekly G.E.D. tutoring program that assists them in getting

their high school equivalency. At several of the groups, clothing, food, household goods and a nutritious meal are provided. This is often the participants only well balanced meal of the week.

As its name implies, The Evergreen Network, Inc. seeks to send a message of hope and connection to those who know only despair and isolation as a result of HIV/AIDS. People served by Evergreen know that they are not alone. We strive to offer information, hope and relief from unremitting isolation, one of the disease's most devastating side effects. A non-judgmental, caring environment is offered to help relieve the stigma of AIDS, as we attempt to bear the heavy burden the disease imposes together. It is our hope that ongoing weekly, support groups, tailored to the needs of individuals touched in diverse ways by the disease will provide renewed strength and hope.

A History of Firsts . . .

Support Groups for Children and Grandparents and Women

The Evergreen Network, Inc. was the first agency in the country to identify the trauma for affected children and form a support group for these children, "The Sunshine Kids." In addition, Evergreen was the first agency in Connecticut to recognize the stress for grandparents raising grandchildren orphaned by this disease. For these older family members, anxiety over their declining health and the pain experienced from the loss of their own daughter or son is coupled with the stress of caring for an orphaned grandchild.

Evergreen was also one of the first agencies to recognize the unique needs of HIV+ women and start the first support group in Connecticut where these women could address such issues as how to tell their children they are HIV+ and how to plan for the future guardianship of their children.

The Evergreen Network was one of the first agencies in the U.S. to recognize that families and partners continue to need assistance after the death of the infected person. Although most agencies end service provision with the client's death, it is clinically recognized that people experience normal grief reaction for up to seven years following the death, and children re-grieve their loss through each developmental stage. Also, many families are economically marginalized, and now with the loss of a primary caretaker they face even more severe burdens. It is critical after the death of one or both caretakers to encourage the preservation of the family unit and therefore, Evergreen continues to provide the extra assistance that these families need. This psychological, legal and financial support often prevents the orphaned children from being placed in the foster care system. Currently Evergreen is the only agency in Greater Bridgeport Area that continues to work with the family members after the death of the infected person.

An Advocacy Role

The Evergreen Network has been and continues to be in the forefront of both identifying and implementing program strategies to respond to this pandemic both locally and statewide. These past 5 years we have been building a foundation based on the appropriate response to the needs as defined by the clients and the therapists. We have continually advocated for the rights of persons both infected and affected. In that capacity, The Evergreen Network was the lead agency in requesting a legal precedent from the Probate Administrative Court regarding temporary guardianship of children whose parents have a medical crisis (e.g., hospitalization). As of October 1, 1994, the State Legislature passed Public Act 94-207 that permits a parent to designate a standby guardian of a minor. In addition, Evergreen was instrumental in the pursuance of a Mental Health subcommittee on the State-wide Consortium. Evergreen initiated the dialogue and after extensive meeting with State agency directors, this working group has become reality.

Additionally, The Evergreen Network initiated the development of a sub-committee on children/adolescents in the local consortium to address the specific needs of this population. Recognizing that Evergreen cannot presently respond to the needs of the nearly 1,000 children affected by HIV Disease/AIDS in this catchment area, Evergreen has drawn other child-responsive agencies into this sub-committee in an attempt to expand the services available to this population.

Mr. SHAYS. Just in your second page outline you said there are psychological support groups that are not being offered. What's the point of that in your statement?

Ms. DEMARRAIS. The variety which are offered, that are critical to the issues themselves and these help with drug compliance medication compliance. Clients come in, they share with us, "I don't want to take this, I'm having a tough time," and they encourage one another at the support group meetings. We find we're having much better drug or medication compliance because of this encouragement of one another, "I'm in the same boat as you are, but I'm taking, I want to be alive for my children" is what they're saying, "I want to be alive next year." It's a good system. Life to life.

Mr. SHAYS. We'll cover more in our questions. Thank you.

Ms. MEYERS. I'm Christine Meyers, I'm 21 and I'm a peer educator of Shades of Lavender, which is funded by Brooklyn AIDS Task Force.

I lost my cousin to AIDS before I started volunteering and as time progressed more and more of my friends died from AIDS or became infected with HIV. It wasn't a question for them of being safe, it was a lack of information that they needed to know. No one talked to me about the dangers of unsafe sex, they were not given a choice about safer sex.

I talk to young women about how to use dental dams and condoms, young women who are bisexual and lesbian, I show them safe sex is important. The young women I teach this to actually take this information and use it wisely. Youth listen to youth, as opposed to youth listening to adults. My group is small and we form a rapport before we start talking about sex. I make them feel comfortable enough to ask questions about sex. My peers now bring up safe sex with their partners. I give explicit safe sex information which they can use to negotiate their own safer choices.

At first I was a participant at Shades of Lavender and then became a volunteer as well. Shades of Lavender is a Brooklyn-based organization that does AIDS outreach services in Brooklyn. Anyone is welcome to come to Shades of Lavender. I have been a participant at Shades of Lavender for 2 years. Shades is geared toward women in general and lesbian and bisexual women. I feel personally that lesbians are considered the lowest risk group for people infected with HIV or AIDS. I think we should be considered as much a risk as anyone else. BBLYS, which is Brooklyn Bisexual Lesbian Youth Sisters, is a program with Shades of Lavender, which introduces the idea that lesbians too need to think about, practice and negotiate safer sex when they have sex with women or men.

Most of the young women who come to Shades or BBLYS, actually are between 15 and 19 and are already sexually active or at a loss as to what to do. Most of the young women have questions about whether they need to practice safer sex. I do not insist on safer sex because I don't want to force on them my opinion about it. Instead I show them how to practice safer sex if they want to.

BBLYS is administered by a professional Shades of Lavender staff member. As the youth participant gains more experience with the group, they become more involved.

I think that some young people are naive to the fact of the AIDS epidemic. They know that the disease is there, but there is a lack of specific information about sex and AIDS. They either don't know about safe sex or don't know how to go about learning about it. We need more AIDS education geared toward youth to show them the consequences of not practicing safer sex.

Many young people think that AIDS is over because it's not in the media anymore. You can blame whoever you want to, but if you want to live a long, healthy life you yourself have to go out and seek this information. This is why AIDS outreach to youth is more important now. Most of the young women that come though BBLYS are in school and get some information about AIDS there, mainly about how to practice safe sex and about AIDS. The young women who come to BBLYS still seem to be lacking assurance about AIDS. I think the participants feel that the information they get from us is good because we're part of a youth organization and they seem to know that what we're telling them is fact and in general there are a lot of youth who don't trust information from adults, so they don't trust AIDS information from adults. They trust information from us because it's coming from professional people and some of the young people there are involved on a volunteer levels which makes them feel more comfortable.

Young people not having sex is out of the question for them. This leads us to only one thing, showing young people how to practice safer sex. The Federal Government's attitude toward safer sex leaves young people with a lack of funds, programs and opportunities for safer sex education. Safe sex education does not make me or anyone else want to have more sex. It simply teaches us to be safe. We're not looking to be sexually active to the point of having sex with everybody. We just want to know that we could be safe if we do have sex.

The Federal Government needs to have funds geared specifically toward youth and HIV/AIDS education. A national knowledge of AIDS and HIV education is a must for youth especially. We should not just look at science to find a cure. We also have the power to slow the spread even further if we practice safer sex.

I don't think there's research on the possibility of HIV transmission in lesbian sex, but I cannot say anything definite because no one has told us any definite answers. There should be Federal AIDS research specifically on the transmission of HIV between women. This research would benefit everyone who has sex. Once we know if it's possible to get HIV from another woman, that information affects all lesbians, all bisexual women and all women and men who have sex with each other. It also would give everyone who wants to practice safer sex more information and more choices on how to do so.

In conclusion, I would ask Congress how can the youth of today be the adults of tomorrow if we're not being told what HIV and AIDS really mean? Ignorance equals death just as well as silence does. Thank you.

[The prepared statement of Ms. Meyers follows:]

Testimony for the Congress of the United States

Subcommittee on Human Resources

February 20, 1998

Testimony given by: Christine Meyers

Accompanied by Dr. Yannick Durand

Shades of Lavender

470 Bergen Street

Brooklyn, N.Y. 11217

Hi, I'm Christine Meyers, and I am a peer educator and youth volunteer at Shades of Lavender, which is funded by Brooklyn AIDS Task Force. I am twenty one years old. I have been a volunteer in different places since I have been 15, simply because I did not see youth such as myself listening to anything that the adults had to say. I though I might benefit myself, as well as benefit other youth, if I started speaking to other youth about AIDS.

I lost my cousin to AIDS before I started volunteering. As time progressed,

more and more of my friends, people my age, either died from AIDS or became infected with HIV. It wasn't a question for them of being safe, it was a lack of information that they needed to know. No one taught them about the dangers of unsafe sex. They were not given a choice about safer sex. They were simply thrown a condom, and it was expected that they would know what to do with it, and how to tell others what they wanted to do with it.

As a peer educator, I help educate other youth on AIDS education. I talk to young women about how to use dental dams and condoms. I show them that safe sex is important. The women I teach this to actually take this information and use it wisely. Youth listen to youth, as opposed to youth listening to adults. My group is small, and we form a rapport before we start talking about sex. I make them feel comfortable enough to ask questions about sex. My peers who participate in the program have told me that after they have participated in Shades of Lavender program, they now bring up safer sex with their partners. We have spoken specifically about bringing up safer sex, condoms and dental dams with their partners. I give explicit safer sex information, which youth can use to negotiate their own safer choices.

At first, I was a participant at Shades of Lavender. I then became a volunteer as well. Shades of Lavender is a Brooklyn-based organization that does AIDS outreach services in Brooklyn. Anyone is welcome to come to Shades of Lavender. I have been a participant at Shades of Lavender for two years. Shades is geared towards women in general, and specifically lesbian and bisexual women. Women need a safe space to be a part of in order to share their experiences with other women.

Lesbians are considered the lowest risk group for people infected with HIV and AIDS. I think we should be considered as much risk as anyone else. We can not say for sure if lesbians sexually transmit HIV or not. No one has done research on the sexual transmission of the virus between women. One out of every five lesbians that I meet think that they are immune to HIV. The other four simply don't practice safer sex. The fact of the matter is, no one knows if lesbian sex can transmit HIV or not.

Shades of Lavender aims to address that problem. Shades distributes flyers

at youth groups and lesbian youth groups to come to Shades and talk about HIV prevention. Once there, the Shades youth group introduces the idea that lesbians, too, need to think about, practice and negotiate safer sex when they have sex with women or men. Most of the young women who come to Shades are between 15 and 19, and are already sexually active. Most of the young women have questions about whether they need to practice safer sex. I do not insist on safer sex because I don't want to force on them my opinion about safer sex. Instead, I show them how to practice safer sex, if they want to.

The youth group is administered by a professional Shades of Lavender staff member. As the youth participants gain more experience with the group, they become more involved in suggesting discussion topics, doing outreach, responding to each other, answering each other's questions when they know the answer.

Shades is one of two or three groups that I know about that is specifically geared towards young lesbian or bi-sexual women. It is one of the only places in New York City that such women can come to ask questions about HIV prevention

specifically for lesbians. It is a place that feels safe. It is confidential. It is a safe place for young women to talk to other young women without their business being spilled out into the street.

As a youth educator, I think that young people are naive. They know that the disease is there, but there is a lack of specific information about sex and AIDS. They know that AIDS is there, but they either don't know to practice safer sex, or they still choose not to. We need more education aimed towards youth, and more AIDS education geared towards youth to show them the consequences of not practicing safer sex. Many young people think that AIDS is over because it is not in the media anymore. You can blame whoever you want to, but if you want to live a long, healthy life, you have to go out and seek information. This is why AIDS outreach for youth is important. Most of the AIDS outreach - the pamphlets and the flyers - are mostly found in gay youth organizations, or gay organizations. I have been to a few straight youth organizations, but they do not have the same level of outreach as they gay youth organizations.

Some of the participants in Shades' youth group talk to their parents about

sex. But few young people talk about AIDS. Some of the gay youth talk to their parents about being gay, and their parents are okay with that. But few parents talk about the AIDS factor. Most of the young women who come to Shades are in school, and get some information about AIDS in school. Mainly, how to practice safe sex, and probably about AIDS. The young women that come to Shades still seem to be lacking assurance about AIDS. I think the participants at Shades of Lavender feel that the information that they get from Shades of Lavender is good because it is an AIDS organization. They trust the information from Shades better than the information at school. In general, there are a lot of youth who don't trust information from adults, and so they don't trust AIDS information from adults. They trust information from Shades because it is staffed by young professional people, and that there are young people involved on the volunteer level.

Young people not having sex is out of the question. This leads us to only one thing: showing young people how to practice safer sex.

The Federal Government's attitude towards teens having sex leaves young people with a lack of funds, programs and opportunities for safer sex education.

Most young people want to be adults, so they will not abstain from sex. Safe sex information does not make me, or my friends, go out and want to have more sex. It simply teaches us to be safe. We are not looking to be sexually active to the point of having sex with everyone in the world. We just want to know that we can be safe if we do have sex. I think all youth want to control their own lives. Safer sex fits into that need for control quite naturally. For youth, sex is the most powerful thing that they can control.

The federal government needs to have funds geared specially towards youth and HIV/AIDS education. A national knowledge of AIDS and HIV education is a must for youth. It is our turn to be educated. No one really likes to talk about sex, whether you are a youth or an adult. I think that if there are enough people who got together who actually want to talk about it, maybe more people would get involved. We should not just look at the science to find a cure; we have the power to control the disease if we practice safer sex. Prevention is the only vaccine that we currently have for HIV.

There is no research on the possibility of HIV transmission in lesbian sex.

At Shades, I can give clients the best possible answer about HIV transmission and lesbians, but I can not say anything definite because no one has told us any definitive answers. There should be federal AIDS research done specifically on the transmission of HIV between women. This research would benefit everyone who has sex. Once we know if it is possible for a women to get HIV from another women, that information affects all lesbians, all bisexual women, and all women and men who have sex with each other. It would also give everyone who wants to practice safer sex more information, more tools, and more choices in how to do so.

In conclusion, I would ask Congress: how can the youth of today be adults of tomorrow if we are not being told what HIV/AIDS really means? Ignorance equals death just as silence does.

Mr. SHAYS. Thank you very much. Mr. Craig. Dr. Durand. I'm sorry, we will be having his comments after, thank you.

Mr. Craig, I think we're going to have to get that mic closer. I know it's inconvenient, because it doesn't have a long stem.

Mr. CRAIG. Congressman Shays, Congressman Towns, my name is Cameron Craig. I'm HIV positive, I was diagnosed in 1996. Like I said, I'd like to express my deepest sorrow and my sincere wishes to the family and friends of three of my members in the Interfaith Hospital who just recently passed away due to the AIDS virus.

My therapist suggested that I go to St. George in order to participate in counseling services, and with the help of the group counseling services that I participated in, I am now able to educate my peers in my community about the dangers of high risk sex behavior in the Borough of Brooklyn. As Dr. Levin said, Brooklyn to me seems to be still considered the second class borough when it comes to services that are needed in this city. In my peer education talks that I do around this borough and in the prisons, I find that ignorance and denial are still rampant in Brooklyn. We're providing our young adults and teenage population; there are many who consider AIDS as I'm not going to get it, I can't get it, as long as she's a virgin, she can't give it to me or I can't give it to her.

I find that in participating in group counseling services, members of the group counseling groups are empowered to speak to one another, they find out what each other is going through, they find out that they're not alone, they make better choices in medication and in asking questions of doctors as far as what the medications are. It seems to me that it's just that there's not enough done as far as supportive counseling is concerned.

It is very apparent that when you have someone else to talk to that has been in your position as far as being affected and infected by the virus, you make better choices. You find that you're not alone, you're not isolated. You don't have, you don't go through periods of thinking about suicide, thinking about going back to drug use. Having the virus, you find that there are other things that can lead to you not adhering to your drug regimen as far as stress, social discrimination, alienation from family and friends, and just being scared to talk to people because you're infected with the virus.

Once you join these programs, you find that you enjoy life a lot better, you find that you're able to deal with the fact that there are other people out there like you, who are infected who are living longer lives, happier lives, and if you're into drug abuse, cleaner lives, because now you know you're doing drugs, doing drugs will not allow you to live a longer life, because they're interacting with the drugs you're taking to make you live longer.

In conclusion, to me, there are ways Congress could legislate funds to support new counseling services in Brooklyn especially, so that as Mr. Levin said, I shouldn't be required to go all the way in Manhattan to find a service since I live here in Brooklyn, since Brooklyn has the highest population in the city, of New York City.

So thank you very much.

[The prepared statement of Mr. Craig follows:]

Cameron Craig
St. George Project
c/o Interfaith Medical Hospital
555 Prospect Place
Brooklyn, N.Y. 11238

Testimony for the Subcommittee on Human Resources
Brooklyn Borough Hall
February 20, 1998

Congressman Shays, Congressman Towns, my name is Cameron Craig, and I am here today to give testimony about the role of supportive counseling in the treatment of HIV positive people.

I want to tell you today about the some of the reasons I believe my health has benefited from participating in a group counseling program for HIV positive people. I am also representing the St. George Project at Interfaith Medical Hospital, and I will talk about the impact of the St. George project on my health as well.

I was diagnosed with the virus in September of 1996. Presently, the virus is undetectable in my blood, and I have a t-cell count of 500, which is up from 123 at the time I was hospitalized and diagnosed with HIV.

Cameron Craig
St. George Project
c/o Interfaith Medical Hospital
555 Prospect Place
Brooklyn, N.Y. 11238

In participating in supportive counseling, I am enabled to educate those who have not infected. It has become apparent in doing peer education and outreach that not enough is being done to stem the tide of this epidemic in Brooklyn. There is still a lot of ignorance and denial about the transmission of HIV among our young adult and teenage population. Government-funded supportive counseling groups not only benefit those already infected, but they also help to prevent HIV infection, because participants in supportive counseling groups are empowered to go out into the community, and speak with their peers about AIDS education, thus, preventing others from becoming infected.

I am one of those success stories. I am someone who has benefited from the supportive counseling program at St. George, which received Ryan White Title I funds. Through my work in the counseling program, I now feel comfortable talking to teenagers and young people about the specific ways which HIV is transmitted. President Clinton spoke about community involvement when he was

Cameron Craig
St. George Project
c/o Interfaith Medical Hospital
555 Prospect Place
Brooklyn, N.Y. 11238

running for president, and he said "Each one , teach one." Mrs. Clinton has spoken a great deal about how it takes a village to raise a child. Both sentiments hold true with regards to HIV treatment and prevention.

I am someone living with HIV, and it is my responsibility to tell others both about how they can live long lives with HIV infection, and how they can avoid getting it in the first place. I would not have been able to help others if I did not get the support that I did through a counseling program. I firmly believe that my outreach to the HIV community has extended and saved lives. I also believe that many of the young people that I have spoken to will think twice before engaging in high risk sexual behavior.

When I talk to teens about AIDS prevention, I talk mostly about ways to have safer sex. As someone who sees everyday the front lines of the epidemic, I can tell you in my opinion, that I see AIDS being transmitted primarily through unsafe sex, and not through dirty needles or blood transfusions. I want to add that the needle exchange

Cameron Craig
St. George Project
c/o Interfaith Medical Hospital
555 Prospect Place
Brooklyn, N.Y. 11238

program has greatly reduced the chances of becoming infected through shared needles.

AIDS to me is a manageable illness. The correct lifestyle and medications will enable you to live a long and comfortable life. Unlike cancer, AIDS is a disease that you keep for life. Once diagnosed, there are many opportunistic infections that can make you sick that wouldn't normally do so because of your compromised immune system. This is why the correct and holistic response to AIDS is to empower people with HIV to make informed choices about their health. Supportive counseling is one such tool that is necessary to transition AIDS from a fatal illness to a chronic illness.

With AIDS, there is a still a lot of social discrimination being done that doesn't happen with cancer. The social stigma that is apparent can be treated through supportive counseling. Those in the most dire need of supportive counseling are often the most difficult to get to attend supporting counseling groups in the first place. It helps if

Cameron Craig
St. George Project
c/o Interfaith Medical Hospital
555 Prospect Place
Brooklyn, N.Y. 11238

such groups are located in communities that they are familiar with, because that familiarity decreases the anxiety about getting counseling. As a Brooklynite, I feel that I should not be required to go to Manhattan to get services. There are some of us who are not well enough to go to Manhattan, and others who really don't know Manhattan - geographically or culturally - that well. I recommend to you as Congress members that the Federal government should legislate that there be equitable distribution of block grants, based on the geographic distribution of AIDS cases within the area receiving the block grant.

One of the reasons I have benefited from the St. George project is that it is in close proximity to be my home. The St. George project is a community based organization, based in Interfaith Hospital, in the Bedford-Stuyvesant/ Crown Heights area of Brooklyn. This program was set up to educate and empower consumers who are HIV positive. The programs within the St. George project include the political action group, community action counsel, focus group, drug and relapse prevention group, and HIV positive

Cameron Craig
St. George Project
c/o Interfaith Medical Hospital
555 Prospect Place
Brooklyn, N.Y. 11238

support group. Excluding the community action counsel, which is administered entirely by clients, each group is facilitated by a medical staff member of St. George. The commitment and work of these professional members enable us as clients to resolve our issues about HIV/AIDS.

My therapist recommended that I go to St. George in order to meet people like myself who were infected with the virus. This is necessary so that isolation does not become routine. In being with other members, you begin to enjoy life again, and you see things clearer. This sense of validation helped to prioritize my life. I was able to clear away non-essential anxieties (we call it something else at the St. George Project, but I won't use the cow-chips word at a congressional hearing), and focus on making better choices about my health.

In this way, the supportive counseling program at St. George enables members to live healthier lives. In fact, supportive counseling becomes a type of medical treatment that can lead, as did in my case, to medically significant

Cameron Craig
St. George Project
c/o Interfaith Medical Hospital
555 Prospect Place
Brooklyn, N.Y. 11238

results, and more importantly, to longer lives for those who are HIV positive.

The Federal government should fund more post-HIV counseling to reduce noncompliance of drug regimens and suicide. As these new drug therapies come on-line, and turn AIDS into a chronic illness, the government needs to do more about the mental state of clients or consumers taking these drugs. In fact, more research into the relationship between mental health, stress, and chronic diseases, particularly immune diseases, could help not only AIDS patients, but a wide variety of people affected by other stress-inducing illnesses. Researching the impact of stress, and ways to reduce it, is less expensive than treating the diseases that stress aggravates.

Those of us who are HIV positive have many issues deciding how we adhere to the drug therapies, when and if to disclose to family and friends, maintaining or finding employment, and issues in our personal life. The stress level that we maintain in facing these issues contribute to

Cameron Craig
St. George Project
c/o Interfaith Medical Hospital
555 Prospect Place
Brooklyn, N.Y. 11238

the success or failure rate of the drug regimen. Ultimately, with maintaining a healthy diet, along with your vitamins and your medication, you should lead a long a healthy life. Supportive counseling enables you to come to grips with the fact that you have an illness, and then expands your horizons on life. A lot of members of the St. George project thought they had a death sentence when they were told that they were HIV positive. Because of supportive counseling, HIV is now a manageable illness for those members.

In conclusion, I would like to describe an exercise done in our focus group at St. George, called the mirror exercise. Each member was asked to look at themselves in the mirror and observe the person looking back at them. In the beginning, most of our clients could not look at themselves because of the way they appeared. With the help of supportive counseling, we now can look at our reflection, and admire the person that we have become. We came into supportive counseling with a death sentence, but we leave with a life sentence. Looking in the mirror, we see a smile reflected.

Mr. SHAYS. Can I ask you in your testimony, if you have to go to Manhattan for some services?

Mr. CRAIG. My services that I go to are in Brooklyn. I feel that all the best services are in Manhattan. I don't feel I should go to Manhattan to get adequate services.

Mr. SHAYS. The services are somewhat essential, but it's your feeling the better programs are in this community, is that——

Mr. CRAIG. Yes.

Mr. SHAYS. Thank you for your testimony.

Mr. LEVIN. Could I just comment on this?

Mr. SHAYS. Yes, very quickly.

Mr. LEVIN. Funding has been so disproportionate for so long, for Manhattan-based facilities, that even if you increase funding for Brooklyn, you need a more proportional increase to make up for that.

Mr. SHAYS. I understand that. I believe the city believes they are more proportional, but your point is that there's a bit of makeup needed.

Mr. LEVIN. A big makeup. Years.

Mr. SHAYS. Thank you for sharing that.

Ms. Carter.

Ms. CARTER. Good morning.

Mr. SHAYS. Good morning. I'm going to have you talk a little louder here. I want to make sure that we hear you. And it's important for others to hear you as well.

Ms. CARTER. Thank you, Congressman Towns, Chairman Shays. Thank you for the opportunity to testify before the subcommittee.

It's heartening that you have recognized the importance of coming to Brooklyn to hear from some of us who are on the front line in the fight against HIV in the city that has the dubious distinction of being the epicenter of the AIDS epidemic.

I'm Gwen Carter, executive director of Life Force for Fighting AIDS, Inc., a community-based organization located in Brooklyn and serving residents throughout the borough. The primary populations that we target are HIV infected and affected women and their families, in other words, everyone. Life Force is one of the first organizations in the country to train and employ HIV positive women as peer outreach workers and educators. Most of our peer educators are black and Latina and they live and work in the Brooklyn communities where they battle to protect other women like themselves from becoming HIV infected.

Although peer-delivered prevention services, linked to concrete supportive services, are at the foundation of Life Force's model of service delivery. We know that fostering long-term behavior change in at-risk populations requires more than just the provision of information alone. Indeed, effective prevention strategies across all ethnic populations, including women, substance users or men who have sex with men, require that a continuum of prevention services be available.

Effective HIV prevention strategies must include HIV counseling and testing, and comprehensive behavior change interventions. They will be delivered in community-based settings and they will be linked to proper medical services. For example, the good news that is being held out about new treatment options——

Mr. SHAYS. Let me interrupt you, because I want to be helpful to you. You have an 11-page statement that will take you a long time to go through if you intend to read it all. I just want to tell you now, because I don't want you to go through half of it and then spend 30 seconds summarizing the last half.

Ms. CARTER. I'll do some paraphrasing, thank you.

Mr. SHAYS. Thank you. Sorry to interrupt you. Feel free, you have a little bit more time because of my interruption.

Ms. CARTER. OK.

Sophisticated medical treatments and access to new medical advances seem to be more of a privilege for a certain class of individuals who more often than not live outside of Brooklyn and who are frequently not black or Latina. This is the very issue that I would like to discuss today.

Fundamentally, I'd like to direct my remarks to the role of the Federal, State and local governments in responding to HIV/AIDS in New York City black community with a specific emphasis on the role of community-based AIDS providers rooted in the community.

Today I'm representing the HIV Prevention Alliance of New York City, acronym HPA. The HIV Prevention Alliance of New York City is a collaborative development among black AIDS service providers. HPA provides technical assistance to these HIV prevention service providers in developing organizational capacity, needs assessment and strategic planning to perform analysis, service planning and infrastructure development. The critical role played by the black community-based organizations in this epidemic has also been ignored.

All of the agencies involved in the coalition of boards of directors, executive directors and staff are predominantly black and all have experience and exceptional track records in delivering HIV prevention services. Each of the patients is most assured that ours is the type of organization that needs to be supported, not only by the public, but also provided funding to combat the transmission of HIV in our communities. HPA has five member organizations based in Brooklyn. In addition to Life Force, they include Caribbean Women's Health Association, Haitian Women's Program, Greater Brownsville Youth Agency and People of Color in Crisis. These organizations all deliver HIV prevention strategies that are created and delivered in community-based settings whose leadership and staff reflects the target population.

When we first came together, our main concern was the exclusion of agencies like ours from Federal HIV prevention funding and other city, State and Federal resources. Significant developments are progressing without serious thought or consideration of the role of our type of organization in the fight against HIV/AIDS in African-American communities. Public health strategies will fail in black communities unless respected community representatives are engaged in the design and implementation of new programs.

Today's hearing is a monumental undertaking, in that it speaks to the importance of coordinating a strategic response among community, State and city providers to improve prevention, care and treatment options in Brooklyn. Life Force participates in HPA because HPA offers a model to stimulate just such an opportunity for coordination and partnership across sectors. HPA focuses on im-

proving the organizational capacity of black AIDS service organizations to better deliver HIV prevention services. However, we believe the model will prove instructive for coordinating care and treatment programs not only in Brooklyn, but also citywide. Thank you.

[The prepared statement of Ms. Carter follows:]

Good morning, Mr. Chairman. Thank you for the opportunity to testify before the subcommittee. It is heartening that you have recognized the importance of coming to Brooklyn to hear from some of us who are on the front line in the fight against HIV in the city that has the dubious distinction of being the epicenter of the AIDS epidemic.

I am Gwen Carter, Executive Director of Life Force: Women Fighting AIDS, a community-based organizations located in Brooklyn and serving residents throughout the borough. The primary populations that Life Force targets are HIV infected and affected women and their families. Life Force was one of the first organizations in the country to train and employ HIV positive women as peer outreach workers and educators. Most of Life Force's women peer educators are Black and Latina, and they live and work in the Brooklyn communities where they battle to protect other women like them from becoming infected with HIV.

Although peer-delivered prevention services, linked to concrete supportive services, are at the foundation of Life Force's model of service delivery, we know that fostering long-term behavior change in at-risk populations requires more that just the provision of information alone. Indeed, an effective prevention strategy across all at risk populations, including women, substance users and men who have sex with men, requires that a continuum of prevention services be available. Effective HIV prevention strategies will include HIV counseling and testing, and

comprehensive behavior change interventions; they will be delivered in community-based settings; and they will be linked to proper medical services. For example, the good news that is being heralded about new treatment options, from protease inhibitors and the success of combination therapy, is of little consequence for people living in poor and under served Brooklyn communities where access to basic primary care services is woefully constrained. Sophisticated medical treatments and access to new medical advances seem to be more of a privilege for a certain class of individuals, who more often than not live outside of Brooklyn, and who are frequently not Black or Latino.

This is the very issue that I would like to discuss today. Fundamentally, I would like to direct my remarks to the role of the federal, state and local governments in responding to HIV/AIDS in New York City's Black community, with specific emphasis on the role of community-based AIDS service providers rooted in this community. Local epidemiological data underscore the need to focus attention on the city's African-American, Caribbean and African populations. Recent AIDS surveillance data showed that although Blacks make up only 25% of the city's population, they represent 40% of all adult AIDS cases reported from April 1, 1995 to March 31, 1997. During this period, Blacks accounted for the highest proportion of adult male and female cases among racial/ethnic groups, at 37% and 53%

respectively.[1] The epidemic in New York City is now clearly located in communities of color, with Blacks being most heavily impacted.

Today I am here representing the HIV Prevention Alliance of New York City (HPA). The HIV Prevention Alliance of New York City is a collaborative development among Black AIDS service providers citywide. HPA provides technical assistance to these HIV prevention service providers in developing organizational capacity; and needs assessment and strategic planning to inform gaps analyses, service planning and infrastructure development. Beginning in the Spring of 1997, the Executive Directors of HPA's twelve organization came together, under the leadership of the Harlem Directors Group, an alliance of community based providers in Greater Harlem and Upper Manhattan, to highlight what was then a glaring disregard by federal funders of the HIV prevention needs of Black people in high prevalence communities. The critical role played by Black community-based organizations in this epidemic had also been ignored. Common among all the agencies involved in the coalition were boards of directors, executive directors and staff that were predominately Black, and they all had experience and exceptional track records in delivering HIV prevention services. Each of the agencies also

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[1]Bureau of Disease Intervention Research, New York City Department of Health. Epidemiologic Profile of HIV/AIDS in New York City. September 1997. p. 2.

shared the same belief that ours were just the type of organizations that needed to be supported by not only public, but also private funding, to combat the transmission of HIV in their communities. HPA has five member organizations that are based in Brooklyn. In addition to Life Force, those agencies are Caribbean Women's Health Association, Haitian Women's Program, Greater Brownsville Youth Agency and People of Color In Crisis. These organization all deliver HIV prevention strategies that are created and delivered in community-based settings whose leadership and staff reflect the target populations.

When we first came together, the coalition partners were gravely concerned that the exclusion of agencies like ours from federal HIV prevention funding and from other city, state and federal resources, would bode poorly for HIV prevention and care efforts in African-American communities. Essentially the concern was this: no matter what the development, from an HIV vaccine, more advancements in interrupting maternal-pediatric HIV transmission, combination drug therapies to prolong and improve the quality of life for people with AIDS and HIV infection or syringe exchange programs, the strategy for reaching the most heavily impacted communities must necessarily involve the front-line AIDS service providers in organizations like ours. Significant developments are progressing without serious thought about or consideration of the role of our type of organizations in the fight against HIV/AIDS in African-American communities. What is certain is that pubic

health strategies will fail in Black communities unless respected community representatives are engaged in the design and implementation of new programs. Ensuring that Black community-based organizations not only have a voice in policy development, but that they also have the capacity to provide quality services, is the reason that HPA came together. Let me be clear. This is no easy task. It involves careful coordination across all levels of government, and among governmental agencies with varied responsibilities. Partnerships between the community and public sectors must be crafted and sustained if we are to get a handle on the epidemic in the most at-risk communities. Today's hearing is a monumental undertaking, in that it speaks to the importance of coordinating a strategic response among community, state and city providers to improve prevention, care and treatment options in Brooklyn. Life Force participates in HPA because HPA offers a model to stimulate just such an opportunity for coordination and partnership across sectors. HPA focuses on improving the organizational capacity of Black AIDS service organizations to better deliver HIV prevention services. However, we believe the model will prove instructive for coordinating care and treatment programs not only in Brooklyn, but also citywide.

I would like to spend the remainder of my time talking specifically about two aspects of HPA, an example of a creative partnership between community and government, aimed at reducing HIV transmission in the New York City's Black

population. First, I would like to describe the overall goal of HPA, which is to expand the capacity of Black service providers to deliver effective HIV prevention services. Second, I will discuss the potential that HPA has to serve as a model for promoting public health in at-risk communities.

HPA: Addressing Capacity Building Needs in Black AIDS Organizations, Coordinating Services and Eliminating Service Gaps

Organizations like the twelve that comprise HPA are credible community resources that offer the infrastructure through which any serious initiative that addresses HIV/AIDS related needs in our communities should be provided. However, the ability of our agencies to provide depends on our capacity to provide. Today, I offer the perspective of many community based providers and urge your attention and leadership on this frequently overlooked but critical component of meeting HIV-related needs of Black communities in Brooklyn, and throughout New York City.

Capacity building is often discussed among HIV prevention program developers and policy makers. Unfortunately, public discussion has always focused more on finding a cure or treatment, rather that health promotion and disease prevention. If we are able to re-orient this public mind set, we will be taking the first steps toward eradicating HIV in Black communities. There is a critical need for building the organizational and community capacity to change individual and

community norms and behavior around sex and drug taking.

The mission of HPA is to do just this. With funding from the Centers for Disease Control and Prevention, the New York State Department of Health, AIDS Institute, was able to enter into a contract with the Harlem Directors Group to develop the collaboration of twelve Black organizations - now called the HIV Prevention Alliance of New York City. Consistent with the notion of stimulating partnership between government agencies and community based providers, the New York State Department of Health's AIDS Institute played a critical role in moving HPA from a concept to reality, by drawing down federal resources to support a local need in a new and innovative way.

As a consortium of twelve organizations, HPA will undertake three activities to address the capacity building needs of its member organizations. These steps are organizational needs assessment of each agency; a strategic planning process to develop long range goals and objectives for collectively addressing the epidemic in the city's Black community; and the development of an evaluation plan to determine the viability of the model and whether it can be replicated for other at-risk communities.

Based on the outcome of the organizational development needs assessment of each agency, technical assistance will be provided to each to address identified needs. This process will help us to better define organizational and community

capacity needs in a manner that has not been achieved to date. It is anticipated that the needs assessment will uncover needs which we will not be able to address in the first year of the project. Addressing these needs will become project priorities in the second year of the project. In addition, the strategic planning process will use findings of the needs assessment process to develop plans for encouraging service collaboration, identifying funding opportunities and addressing gaps in service delivery. These too will be core activities in the second year of the project.

HPA: Longterm Strategies for Promoting Public Health in Vulnerable Communities

We believe that the model that is being developed and tested for Black communities by HPA may be replicable for other racial and ethnic communities and for other jurisdictions throughout the United States. With a strong commitment to evaluating the project, specific measures will be designed and reported against. Over the next few years, we will be in the position to propose strategies for building organizational and community capacity for delivering a wide range of HIV prevention and care related services for other vulnerable communities.

Yet this project has many additional potential benefits. With the collaboration of twelve major agencies that serve a population that increasingly shows significant concentration of HIV disease, a greater capacity to engage in strategic coordinated deployment of services will emerge. Until now, the resources necessary to collect and analyze data on neighborhood level needs, existing service delivery systems and potential synergistic relationships among agencies serving Black communities, has not existed.

The project model also offers opportunities to advance the health status of populations at risk for a variety of preventable disease and conditions by offering avenues to reach individuals who are not accessing traditional health care delivery systems of public health services. Individuals being served by HPA agencies are at risk for various vaccine preventable diseases, tuberculosis, asthma, diabetes,

cardiovascular disease, substance use, and injuries, including domestic violence. The project has the potential to develop a new model of meeting a variety of needs of populations with multifactorial risks in a way that may have significant public health, social and economic benefits.

Now, let me return to the key topic of today's hearing, long-term treatment options. Treatment options for the city's Black community, indeed any at risk community, cannot be considered in a vacuum. Community-based providers who are knowledgeable of the behaviors and norms of at-risk communities, and have access to these communities, must be involved in the design and implementation of strategies to make treatments accessible to those most in need. Prevention, treatment education, adherence and compliance programs, case management and coordination of care must all be delivered by community-based organizations that reflect the target population. Otherwise, all strategies are doomed to failure. Our community-based agencies must be prepared for the role that they are going to have to play in a coordinated approach to combating the epidemic in the Black community, and other vulnerable populations. Organizational capacity and community capacity must be developed and expanded to meet the task. We at HPA are pleased that we have this opportunity to take some initial steps in the right direction. We respectfully request that you join us in our efforts.

Thank you.

ABOUT THE HIV PREVENTION ALLIANCE OF NEW YORK CITY

The HIV Prevention Alliance of New York City is coordinated by the Harlem Directors Group (HDG). HDG is a collective of decision-makers representing Harlem based community agencies and institutions that provide HIV related services to individuals and families. The HDG advocates for a fair and equitable distribution of resources based on community need, and works to establish and maintain a coordinated HIV-related service system that effectively meets the needs of Upper Manhattan residents.

The following organizations are members of HPA:

Caribbean Women's Health Association	Brooklyn
Gay Men of African Decent	Manhattan
Greater Brownsville Youth Council	Brooklyn
Haitian Women's Program	Brooklyn
Harlem-Dowling Westside Center for Children and Families	Manhattan
Harlem United Community AIDS Center	Manhattan
Life Force: Women Fighting AIDS	Brooklyn
Minority Task Force on AIDS	Manhattan
New York Council of Smaller Churches	Manhattan
People of Color in Crisis	Brooklyn
Southeast Queens Clergy for Community Improvement	Queens
Sub-Sahara AIDS Rescue	Staten Island/Brooklyn

For information about the HIV Prevention Alliance of New York City, contact Leo Rennie, Project Director, at the Harlem Directors Group, 2090 Adam Clayton Powell Jr., Blvd., Room 111A, New York, N.Y. 10027. (212) 531-0049 [phone]/ (212) 531-4405 [fax]

Mr. SHAYS. Thank you very much. Your statement includes a lot more so it will be part of the record. And I thank you for speaking.

Mr. TOWNS. Thank you very much, Mr. Chairman. Can I just deviate for a moment, we have someone in the room I'd like to introduce? We have with us the senior member of the New York State Assembly; the Assistant Speaker of the Assembly, Assemblyman Edward Griffith, is with us.

I see you personally in Brooklyn. Nice to have you with us.

Mr. SHAYS. How many years in the State house?

Mr. GRIFFITH. Twenty-six years.

Mr. TOWNS. I think he should know his way around, right? No question about that.

Mr. SHAYS. It's wonderful that you're here.

Mr. GRIFFITH. Thank you, Congressman Shays.

Mr. SHAYS. If you would like to come here, I'd love to have you do that, if you have a question you'd like to ask, we'd love to have you.

Mr. TOWNS. Thank you so much.

Let me begin by saying to all of you, thank you so much for your testimony, and I listened very carefully to things that you said. I want to ask you, do you anticipate, based on your views, your feelings, your work and the kinds of things you're doing, the number of HIV and AIDS cases in New York City over the next decade will go down or up? If so, they will go down, I want to know why, if it will go up, I would like to know why, and let me briefly run down the line and ask all of you very quickly, I'm going to leave you out of this, I'm going to make this a New York thing.

Mr. SHAYS. Don't worry.

Mr. TOWNS. I'd like to run down, I'd like to know if you think it's going to decrease, why, if you think it's going to increase, I would like to know why.

Mr. PEDRAZA. Well, unfortunately, I hate to be the pessimistic point of view, but I think in our community it's going to go high. In the Latino and African-American it's going to go high. I live in Harlem and there's hardly any prevention we can identify with. Everything is written in very hard to understand material, so prevention messages are not given clear to me, they're not done to address my needs or my questions, so unfortunately I would say that we are heading to high levels of HIV.

Ms. MOORE. I think I would disagree with higher up. I think we're going to see a continued rise, particularly in communities of color, not only because literature is not made in languages which most people can understand who are not professionals, but also because we see a decline in funding for prevention services and services for people living with HIV and AIDS in communities of color.

In fact, we've already seen some rise in AIDS in our communities, one of our neighborhood hospitals has seen an increase in AIDS admissions in their hospital. In fact, not only are people living with HIV and AIDS going to be affected, but their children will be as well. Recent studies show that in Brooklyn, there will be the highest number of orphans, motherless orphans by the year 2000, 16,000 motherless orphans in Brooklyn. So I think the numbers will continue to go up.

Mr. LEVIN. Well, the point I'd like to make is that I think there's a mischaracterization of all the accomplishments that the new therapies have, that has occurred as a result of that. Because I think the drugs weren't used properly as soon as protease inhibitors were approved in March 1996, there was a tremendous wave of resistance that developed to the therapies. Doctors were frequently adding on protease inhibitor, onto current nucleotide therapy, and that was not the way to use the drugs. Some of them didn't know that at the time.

So as a result, many people became resistant to the therapies back then and today are struggling with trying to find new therapies that may work for them. Sometimes it's transient. Most of the time they have found transient help. I think what's going to occur here is if we don't have adequate treatment education for doctors and for patients on how to use the drugs properly today, you're going to have more and more waves of resistance occurring, where people are going to be failing therapies. We're already failing therapies all over the place and we have not been able to find followup therapies yet.

I think there's a hope in the near future that the new therapies, some protease inhibitors that may work against a resistant virus and some other types of drugs that may not be cross resistant with protease and we're hopeful of that, but I think you will find that resistance will develop to the therapies in increasing amounts over the next several years and I think that's going to cause a big problem.

Dr. DURAND. I think not only has AIDS education funding been reduced, but also because of overmedia use of new treatment and in terms of ethnicity, a lot of people are also under the impression that it doesn't matter, you don't need to prevent it anymore, because if you're infected, you can live with it. So in young people and in a lot of people that we're dealing with at the new Task Force on Prevention, there's less anxiety, there is less worry, because, I think the media kind of paralyzed the new treatment and therefore people are comfortable with the idea of being infected and being able to live with it, the same reason why certain notification, and new behavior, you can live with the medication.

So what we're seeing and what I think should be emphasized is not only education in terms of treatment education, which is a very focused and time limited intervention, but a more multidisciplinary approach, because we're also talking about renotification, when we're talking about renotification, we're talking about a long-term process and we're talking about the involvement of the support system of the family of the person involved, so it requires actually I think a procedure approach to education, including treatment education, but not focusing only on treatment education.

Mr. CRAIG. Yes, I see this increase in myself. I agree with her with the fact that the media in a way has downplayed the effects of the virus, especially with people becoming undetectable. A lot of my peers and a lot of 13 seem to feel that if you say that you're undetectable then you have no more virus in your blood, that's not true. You still carry the virus, it's just not replicating, and they are under the impression that they could still have unprotected sex

and they're not going to get infected, because I'm undetectable, I can't pass it to you.

And I also think you're going to be seeing an increase in the Caribbean section of Brooklyn in particular because of, just because of the culture. When I try to do peer education and outreach there, that community is not as open as, I would say as the African-American community is. They're not open to speak about sex education in particular, about wearing condoms in particular, about just sex in general.

Ms. CARTER. I think that the number of AIDS cases will definitely increase, just because in our work we find that there are a lot of people who don't have the courage yet to get tested. So there are a lot more HIV positive people who are not counted within the numbers and as they get the courage and the education to get tested, the numbers are logically then going to go up.

We come into contact with people who have found out recently that they were positive, and know that they were positive for like 13 years and they just found out. So as these people get educated and go to get tested, you're going to see the numbers go up, and if we don't get enough money to do the kinds of work that all of these agencies at this table do and the people who are here involved in to provide prevention education to people, that's the key, that's the key to making the numbers go down.

Mr. TOWNS. Thank you very, very much, and let me just sort of say that I would like to ask you to give me your views for the record, not now, but if you would be kind enough to give me your views on needle exchange. Don't do it today, but if you could just give it to me, let me put it into the record afterwards, but I would like very much, Mr. Chairman, if we could just get that from all of them in terms of their views.

Mr. SHAYS. Let me just ask you this if you would just lift up your hand if you support needle exchange in this panel here.

Ms. DEMARRAIS. We were the first program.

Mr. SHAYS. The issue is you all support it.

Mr. TOWNS. I guess that solves the problem. That's the consensus of the group, Mr. Chairman. They've been reading a lot of material. Thank you very much.

Mr. SHAYS. Let me use that as a segue into explaining the needle exchange—you said you were the first?

Ms. DEMARRAIS. I don't know if we were actually the first State, but I know we were one of the first States to have it, and we have found that No. 1, it works in helping to prevent infection, and we know that it does not increase drug use. It is an effective program, it's a program that the governments and the States need to look at very seriously.

Mr. SHAYS. Let me use this as an opportunity to tell you that one of the reasons we invited you was that we wanted to make sure there was a focus on young children, and let me ask you first your background, how you got into this issue?

Ms. DEMARRAIS. I'm a psychotherapist or psychologist. In any case, I've worked with children for 30 years and I worked with children's parents who are incarcerated, their parents 12 years ago were dying of AIDS, so I started support groups for the children not knowing, then the children revealed to me, so I started a sup-

port group in 1987 for the affected children, and I've been working with those children ever since.

Mr. SHAYS. Since 1987.

Ms. DEMARRAIS. Yes.

Mr. SHAYS. 1987 is when Stewart McKinney, my predecessor, died of AIDS. One of the most unbelievable stories in my judgment is how his wife made a determination that she would devote her life to helping people who were affected by AIDS, and she opened homes for individuals who were HIV positive. She also opened a facility in Washington, DC, Stuart McKinney House, which basically was a home in which mothers who die of AIDS are with their children, are providing the transition for their children to meet their new mom and the mother and the new mother and the children live together. It's a very touching and moving program, and it's the kind of part of this story that doesn't quite get told what happens to the children whose parents have died of AIDS.

Ms. DEMARRAIS. That's why we need guardianship issues. Guardianship issues are critical to be looked at. I've worked with the probate court in Connecticut, the administrative court, probate court to set up guardianship programs so that parents can do advanced planning, can identify a guardian, and also temporary guardianship while they are alive and may need help caring for the children.

So guardianship is a critical issue for children whose parents have this disease, that there is continued supervision, guardianship. A child cannot survive in our society without a guardian. You can't get medical care, can't go to school unless you have a guardian. When a parent dies, I've had children refused medical care because their parent died a few weeks before. They were now sick themselves and the doctor would not treat the child.

Mr. SHAYS. I would hope you would contact my office in every instance that that happens, and I'm really embarrassed that I haven't come by to see your program. How many young children are you helping right now?

Ms. DEMARRAIS. Approximately 200 children.

Mr. SHAYS. Did you ever suspect it would increase up to that level?

Ms. DEMARRAIS. No, I had no idea. And in fact I've been telling people within the State of Connecticut that I knew the numbers were growing rapidly, because I had women coming to the support group saying, and the women were saying I have 3 children, 2 children, 4 children and we were doing Easter baskets for 100 children, so I knew we had huge numbers and when I turn around and say to State officials, if I have this many and I'm only working with part of the children in Bridgeport, I know that there are 2,000 children in the city of Bridgeport alone, within the State of Connecticut, we're looking at 10,000 children orphaned already.

Mr. SHAYS. I'll get back to the children, but how many programs like yours are duplicated in the State of Connecticut?

Ms. DEMARRAIS. We're starting to see a few come. Yale has started one. As far as I know, there are three or four now.

Mr. SHAYS. I'd like to ask about all of you, but Jairo, I'll come to you if you want to make a comment if you're aware of programs

similar to this, to tell me what they might be. Jairo, you wanted to make a comment? Sorry for the mic back and forth, here.

Mr. PEDRAZA. I'm sorry, I just want to use the problem to a question that was asked of a panel previous to us, that was HIV surveillance, documenting HIV as compared to documenting AIDS cases.

Mr. SHAYS. Before you ask, answer this, can any of you point out a program in this area that might be somewhat similar?

Ms. MOORE. There's a few programs that are somewhat similar that probably cover some areas of it, though maybe not as complementary. I know SUNY Downstate has a program where they have support groups of children who are survivors of parents who have died of AIDS or who are HIV positive themselves. Normally the children need to know their parents are HIV positive.

Mr. SHAYS. The bottom line, it's not very comprehensive. The program may be, but it's not covered in a lot of areas, so Brooklyn per se or Harlem doesn't necessarily, you're not aware of a citywide program like that?

Ms. MOORE. Not in the outer boroughs, nothing.

Mr. SHAYS. You make a mistake. You can't call it outer boroughs, that's the first mistake. Outer borough sounds like it's not as important as the inner borough. I'm being a little facetious.

Mr. TOWNS. But you've been accurate, Mr. Chairman.

Mr. LEVIN. On my board of St. Vincent's Services, which is two blocks from here, it's a social services organization, under the guidance of the Catholic church here in Brooklyn, and they have a somewhat comprehensive program for children, they deal with adoption and foster care and they have a program for children or foster care and adoption who have HIV——

Mr. SHAYS. Do they provide services for the children while their parents are still alive or are they basically picking up after the parents have died?

Mr. LEVIN. Frankly, I don't know the details of all their programs, I hear about it when she comes home at night, they have a program here, and it sounds comprehensive, they have nurses and social workers who deal with it and they come to our forum, so I know they have supportive staff there.

Mr. SHAYS. Let me ask, is anyone else aware of such a program?

Ms. CARTER. I'd like to say that last year Life Force and Brooklyn Legal Services were funded to do a joint venture to address just this issue, of parenting planning, what we did was combine an attorney with the Life Force peer educator we know out in the community to places where women who might have that situation would be and inform them of their rights from a legal standpoint and most of the women who were involved in the program from our point of view were women who have been through that and were able to tell them what to expect and to help them through it on an emotional level, how to plan for the future of their children. So there are limited programs.

Mr. SHAYS. I would come to the conclusion that there's really an outstanding need to focus attention on this area, and this is not a criticism of Brooklyn or Manhattan or Connecticut, but if this is clearly one of the centers where you have a challenge with HIV and AIDS, and you can't quickly name some of these programs and you

all are very active in the field, it tells me that Ms. DeMarrais, you are kind of on the cutting edge of a program that we need to see expanded to other parts of our State and the country.

Let's get on your topic.

Mr. PEDRAZA. It was about AIDS reporting and HIV reporting, that's the issue that you asked the previous panel.

Yes, I understand very much the view from the State and the city level for getting more funding to the city and the State, but it's a very, very controversial issue in the community, especially because name reporting, I assure you, will deter people from getting tested. Youths will not test if they have to submit their names. Immigrants will not test if they have to submit their name, because they're in fear of INS. There are many fears in our community.

Mr. SHAYS. Fair enough.

Mr. PEDRAZA. And I think that needs to have a lot more time to be addressed so we can all give our points of view on the issue of HIV. I know the need for our city to receive more money, yes, more money is needed, but at what price.

Mr. SHAYS. I notice sometimes in restaurants in Connecticut I'm introduced to some of the workers and all of a sudden they disappear. If they do it just based on meeting a Member of Congress, I'm sure they don't want to have their names written down.

Let me pursue that thought, a question where you were responding earlier to the panel. Was there any comment made in the previous panel that you want to take issue with or reinforce? Yes?

Ms. MOORE. Actually, yes, now that you ask.

I think that in the panel before, I think there's a misunderstanding of the proportion of funding that's actually within Brooklyn. As I stated in my oral testimony, in fact, only 17 percent of the awards were funded to Brooklyn, whereas 27 percent were funded citywide, and as you've heard from other testimony, citywide services do not work in Brooklyn.

People, most of the time these citywide services are based in Manhattan, people are forced to go, people living with HIV and AIDS are forced to travel across the bridge, however they do so, to go into the Manhattan based agency to receive those services. They do not work and yet they continue to be funded by these programs, and I think that's a very big issue, particularly with regard to access to services. So I wanted to point that out.

Mr. SHAYS. When you say citywide service, do you mean a citywide service based in Manhattan?

Ms. MOORE. Most of them are, yes.

Mr. SHAYS. You want a service to be universal in all the boroughs, even in the outer boroughs like Manhattan?

Ms. MOORE. There are some services which can be implemented throughout the city. Sometimes, there is some success with actual delivery of food services, let's say, but you can't, to use this example of food services, within the community, my community, food services wasn't funded, and that's a big problem with the community, because the food and nutrition services in our community were congregate, which meant that people who were homeless, people who lived in a shelter could go there to congregate with other folks, but also more importantly, they could receive other services.

Mr. SHAYS. You're basically saying you want a borough controlled service. In other words, you want a particular service to be available to everyone in New York City, but are you saying you want that service to be borough controlled. I won't spend much more time on this. Obviously you all understand this.

Ms. MOORE. What I'm trying to say is that a greater proportion of citywide services are unsuccessful and this issue of consolidating and having one service be distributed amongst the various boroughs is ineffective. It's been proven to be ineffective.

Mr. SHAYS. I think I understand what you're saying.

Mr. PEDRAZA. Even though the upper Manhattan is not part of the outer borough, but anything past 72nd Street or 96th Street is an outer borough in itself. Harlem is disproportionate in receiving services, most of the services are located in a certain area in Manhattan. I myself as a person with AIDS, I have to go to services downtown. It's a burden. We talk about Manhattan, it's a very large island in itself, so I agree the boroughs out of Manhattan need to have their own services, but there are also areas in Manhattan that are considered outer boroughs as well.

Mr. SHAYS. Fair enough. I'll let you guys wrestle with this one. It's a very valid point and one that won't be readily resolved, but needs to be looked at.

I'm going to just say, I'm going to do a lot of questions and I'm going to ask the deputy speaker if he has a quick comment or question he wants to ask the panel. Then what we'll do—as long as you don't get interested in running for Congress here——

Mr. TOWNS. He's my friend.

Mr. SHAYS. I'd like all of you to speak to this real question of whether you would disagree or agree with the earlier panel's comment and then we'll go to the Deputy Speaker.

Mr. LEVIN. I think I have one brief comment, I think it will be covered very well by the other speakers, and that is it seems to me that the adequacy of the medical providers and the services they provide in Manhattan is sort of not on an equal basis with what you see in Brooklyn.

You have probably from 59th Street to 23rd Street or 14th Street, east and west side, maybe five or six, almost every 10 blocks you have a major HIV clinic. You have the newly formed St. Luke's Roosevelt on 59th Street, you have the new GMHC clinic on 24th Street, you have Bellevue, then you have St. Vincent's, then you have Gouvenere has something in the East Village and I'm probably missing one or two. There's St. Clare's. And in most of those centers you have very knowledgeable docs.

I don't think you see that on a par in Brooklyn in the centers. There aren't enough centers, there aren't enough doctors and they're not well educated.

What frequently happens is many of the people in Brooklyn know that those centers are good and they travel to those centers to get their medical care, St. Vincent's in particular and Bellevue and those are great places, but they shouldn't have to travel to go there to get those kind of services if they don't want to.

Mr. SHAYS. I understand. Thank you.

Ms. DEMARRAIS. The one issue that was not addressed by the panel before is medication for children. The drug companies have

provided these new medications, but because there are fewer numbers of children infected than adults, they're not willing to implement the change in medication dosage for children and we really need to push the drug companies so that these medications are truly available for the children.

Mr. SHAYS. What I appreciate you doing is if you would write the subcommittee a short, one page or two-page letter, what we'll do is we will pursue that issue. One of the powers this subcommittee has is to oversee the FDA, CDC, Institutes of Health and sometimes we accomplish as much by a nice letter suggesting that we're happy to have a hearing if they don't think it's very important. That seems to have an impact. Any other comments, Dr. Durand, did you?

Dr. DURAND. Yes, actually, the previous panel stated that there has been funding directed toward Brooklyn and the outer boroughs. However, I want to raise the issue of the reality of the funding, like when they give funding for programs without taking into account the reality of the people we are serving, it kind of defeats the purpose.

If you have funds to service women and you don't have any funding to provide child care or token reimbursement, most of the time you have one or two staff funded to work on that project, and you're servicing hundreds of people, how efficient can you be in reaching any population and hopefully having them come back?

The women cannot come because they cannot find somebody to take care of their kids. I mean, when you weigh it, they're not going to come if you cannot have somebody to look after their children, or if they have to pay two fare zones to come to your program. No matter how much they like a program, if they don't have the $6 for transportation they're not going to come.

Mr. SHAYS. Mr. Craig.

Mr. CRAIG. I'd like to add on something that Dr. Levin said, especially when it comes to the drug medications. You can take an armload of medication for this virus and it won't do a hill of beans unless your mental health is in tune with that medication. I find that, I know for me in particular, until I decided, until I got straight mentally, the medicines would have never worked. In talking to my peers and talking to people on the street, they're under the impression, well, if I get the virus I can take this medication and I'll get better. They don't know anything about the side effects, and there are a whole lot of side effects, a host of side effects, too many even to name and it's more than just the normal ones that you see on the boxes.

Mr. SHAYS. It's your point that out in the street people are becoming less concerned about HIV and AIDS because they think now there are drugs that might meet their needs and sustain them if they become infected?

Mr. CRAIG. Yes, that part, and they also don't know anything about the mental stress that taking the medication can put you through. Once you find out you're HIV positive, there are a lot of mind games your head plays with that. Until you get that straight, medication won't work.

Mr. SHAYS. Ms. Carter, do you have any issue that the previous panel——

Ms. CARTER. They both give me money. I don't think I should——

Mr. SHAYS. Listen, let me say something to you. That was probably the most cogent comment made today. But all of your comments were done in good taste, so I don't think anybody would be offended by your disagreement with the previous panel and, frankly, they may want to come back and tell you why they were here.

Any comment you want to make, then we'll get into some comments that people want to make. Let me say before the Speaker makes a comment, who in the audience would like to address the panel? We have eight. OK, if we can get through, just about eight, we can have a nice dialog. So Mr. Speaker?

Mr. GRIFFITH. Thank you very much, Chairman Shays, Congressman Towns. I certainly commend you on all these hearings here today in Brooklyn. The AIDS epidemic is a critical one, not only in New York, but throughout the Nation. However, because we represent this area, we are genuinely concerned about the services and the funding of programs in New York State. I notice that we had Rosa Gil and Dr. Cruz speak this morning. Now, I serve as a member of the AIDS Institute so I'm familiar with a number of the issues that are there. I know most groups normally come up during the budget year to ask for additional funding. The AIDS epidemic is of such concern to this State that we have attempted to make every effort to provide what we consider adequate funding. It doesn't necessarily mean that we do that, but that we try to do it.

This year I think that the funding is a little bit less than anticipated and I think many of the AIDS groups have called that to our attention. We're trying to take a look at that, but the one issue that concerns me is the one raised by Mr. Levin as it relates to doctors not being adequately prepared for treating or counseling AIDS programs in Brooklyn and I think that's a very serious point that you raised, and I would like to pursue that a bit further with the AIDS Institute, if you would provide me and my office with some sort of background and support documentation as it relates to training of doctors and service offered by doctors in Brooklyn as opposed to service offered in Manhattan.

I know that Manhattan receives quite a bit of funding only because there's one group of specialists who were sort of pioneers in the area, and they received the largest amount of funding. I don't want to begin naming groups, because I don't think that would help. I know that this is one of the largest coalitions in Manhattan. However, that doesn't mean we should stay away from Brooklyn, and since I'm from Brooklyn and I have concerns about that and Congressman Towns has some concerns about it and I'm sure Chairman Shays has concerns as well, we want to be sure that some kind of equity is perceived by the constituents and clients in Brooklyn.

So I would ask you to either call my office or write me a letter documenting exactly what you think has not been done, what is lacking in terms of doctors.

I'm very concerned about this. People go into hospitals, they go into clinics and do not receive adequate medical care. The doctors are just not being as serious as they could possibly be because of the kinds of clients they're serving. Take these other doctors, put

them in other areas, and the quality of service goes up. They take some clients for granted and others don't.

So if you could provide that to me in writing, I'll set up a meeting with you and the AIDS people and the chairman of the health committee and we'll try to get this into the record. That's the reason why I'm down here this morning. Congressman Towns has invited me to a meeting and I got advance word from my staff on this, and I said I'll make it down here because this is a serious issue. People think it doesn't affect you; it affects us all.

You go to the hospital, there's confusion, and what confusion with the AIDS virus. If you're not gay or lesbian, you pick it up anyway, so we're all at risk. Anybody is at risk. This disease does not show itself for maybe 5 to 10 years, so you can have it today and not realize you have it for another few years. So I think this is one of the greatest dangers that we face today, and I think that again, Chairman Shays, I commend you for coming here today and focusing our attention on this.

Mr. SHAYS. Thank you. This is the second hearing we've had here for this very reason.

Let me do this, I'm sure it's more than all of you can say. I am going to ask that we clear this table. And I'll wait. I would like those who are in the audience to stand up if they would like to speak because it's easier for me to count. I have 10. OK, let's do this. My staff is going to kill me, because they say if I allow you to sit down with the mic we'll never end this, but I would like to have you come and sit down and I would like whoever is extra to sit just beyond, we'll see how many we have, and could we confine it to those who are here. Let me try to figure out how much time we have here.

Here's what we're going to do. We're going to have everyone sign in and start at that end. What I'd like is your full name. We're not swearing you in, but we have to have your name for the record because you will be on the transcript. The only difference is that you weren't sworn in, and I'll want you to give your name and I want you to give what your background might be and I am going to limit you to 2 minutes.

We're not going to ask questions, we're going to hear you, and so two politicians up here are going to shut up, and we're going to hear you. Two minutes. Can we do the timing for 2 minutes? And I'm going to hold you to the 2 minutes. I was a big fraud previous, but I'm going to be tough. Because we do have to be other places as well. So we're going to start this way. Your name, your concern and your comment. You've got 2 minutes.

Ms. CRANDLES. My name is Sheila Crandles, I'm a social worker at SUNY-Downstate that Antonia Moore mentioned before. My statement is that I have ran two title I programs since 1991, I think, and 1992. I'm a little nervous.

Mr. SHAYS. Don't be nervous.

Ms. CRANDLES. The two programs are a supportive counseling program for adults with HIV needs and a program called Project Hope. We work with teens whose parents are HIV. We work more with the kids before their parents get sick and die to help the child with the transition and to help the child with all of their feelings,

to try to help them with the psychological challenges that they have.

I want to make one comment. I wanted to speak before you and thank you for coming and I really want to thank Congressman Towns and our Brooklyn congressional representatives for really taking an interest. We lost our funding back in November after providing services to, well, currently we had 250 clients, but we had many more over the years, and if it wasn't for Congressman Towns, if it wasn't for the clients themselves, if it wasn't for the various HIV care networks in Brooklyn, we wouldn't be able to say right now that we're going to be funded. We have been refunded, we don't know what level, but we have been told we would be refunded in HRA.

My concern is that in programs like ours, we assumed we would be refunded. Our numbers, when I drew them up in the reports, our percentages, are above our projections by 140 percent. I never thought we would be at risk for being cut and many other Brooklyn programs are in the same position and I would just like to find out if there's some way that programs that are providing services shouldn't be in jeopardy, or else we should be told ahead of time so we can have adequate time to prepare. These last 3 months have been so devastating to staff, to clients, I think, and we're so grateful we're going to be around, but I think something needs to be done to prevent this from happening in the future and that's my comment.

Thank you for coming.

Mr. SHAYS. Why don't you stay after the hearing so we can touch base.

Mr. TOWNS. Actually, we're going to SUNY Downstate immediately after the hearing.

Ms. KERSAINT. My name is Gabrielle Kersaint, and I'm director of the Haitian Women's Program in Brooklyn. Thank you, Congressmen Towns and Shays.

I'm here to speak about the Haitian community in Brooklyn. My program provides health management and health education programs to Haitian refugees and immigrants. We are the program that was providing case management services to Cubans. We are working with 120 refugees and children for the last 3 years and we were also shocked that we were not funded and we had very little time to refer clients to other services.

We deal with people who cannot speak English, who cannot read and write, who still suffer from severe trauma, and we developed some expertise in terms of dealing with immigrant issues. We assist our clients in understanding how to take the new drugs and now if we have to just discharge clients with no planning, our funding runs out next Friday, I think the result people are going to be homeless. A lot of our clients have been cutoff food stamps, they're having problems just maintaining basic services.

So I think in terms of future decisions for funding, especially in Brooklyn, you really have to look at community-based programs and what they do. We're a very small program but we provide quality services. Out of all the, there's about 500,000 Haitian immigrants in Brooklyn, in New York City. In Brooklyn, 71 percent of the Haitian immigrants live in Brooklyn. Out of all the foreign

born immigrants with AIDS, Haitians constitute 71 percent, so it's a very large number. Yet when the first allocation of Ryan White funding, not one Haitian agency got refunded for case management services. There were four programs, not one got refunded.

After some advocacy efforts, one agency said OK, they will get refunded, but for the most part most of us have not been refunded and I'm very concerned about that, because a lot of people are going to suffer.

[The prepared statement of Ms. Kersaint follows:]

FACT SHEET REGARDING THE IMPACT OF LOSS OF RYAN WHITE FUNDING ON HAITIAN WOMEN'S PROGRAM CASE MANAGEMENT SERVICES

I. Problem Statement:

Haitian Women's Program, (HWP), a not for profit community based organization was established in 1981. HWP currently provides comprehensive case management to a total of 140 HIV positive Haitian refugees and immigrants residing in Brooklyn. Recent Ryan White funding cuts have left Haitians with virtually no case management services that are culturally sensitive and linguistically appropriate in Brooklyn. Ryan White funding has not been awarded to any not for profit community based organizations in Brooklyn for case management services. Four Haitian organizations did not get refunded for case management services in Brooklyn: Haitian Centers Council, Haitian Community Health, Information and Referral Program, (Lakou Lakay), and Kings County Hospital. HWP was the largest of these Haitian funded programs employing four case managers and a social worker. In addition, HWP is the only Haitian agency that also has other related AIDS services program such as Housing, Education and Tuberculosis screening to complement its existing case management services. Ryan White funding constituted one-third of our agency's budget. The recent discontinuation of Ryan White funding will not permit HWP to adequately provide the clients with the following services:

- Permanent housing search and placement
- Assistance with applying for medical coverage
- Assistance with immigrant issues
- Escorting clients to medical appointments
- Conducting Home and hospital visits
- Advocacy for client rights
- Intervene when clients are being discriminated against because of HIV status, culture, color, lack of language
- Assistance with permanency planning, living wills and health care proxy
- Provide clinical crisis intervention and referral to mental health providers
- Education on ESL and literacy
- Education clients on service systems; HIV prevention; tenants's laws and rights
- Escort/translation services through our Buddy volunteer program

II. Demographic Data Supporting Need for Services:

According to the 1990 census data, there are approximately 500,000 documented Haitian immigrants in the New York City area. However, is estimated that there are one million Haitians in the entire city when accounting for those who are undocumented, and under reporting errors. Brooklyn has 73.54% of Haitian immigrants settling in New York between 1983-1989. Of this group, there are individuals who are HIV positive and are in desperate need of assistance. In Brooklyn, 71% of the immigrant AIDS cases are from Haitians.

According to the World Health Organization (1990), Haiti ranks amongst the highest countries with reported AIDS cases in comparison to other reported AIDS cases in the Caribbean.

There are also several barriers which impedes Haitian's access to AIDS treatment and prevention services. They are:

Welfare Reform/ Immigration Laws:

The new welfare reform and immigration laws greatly hinder access to services for Haitians and other immigrants. HWP staff has acquired a great deal of expertise in linking clients to immigration attorneys and advocating for services on their behalf despite the new laws.

Socio-Political:

Haitians were inappropriately included as a high risk group for HIV/AIDS and barred from donating blood by the Food and Drug Administration in 1983. Coupled with this fact and the heighten anti-immigrant sentiments, Haitians are reluctant to receiving appropriate services due to these past experiences. At Haitian Women's Program, clients receive culturally sensitive, linguistically appropriate information.

Culture, Language and Literacy:

The Haitian Community is one which perceives itself to be very different from other Caribbean or African American communities. Haitians have encountered barriers in health care due to AIDS discrimination. In addition, many Haitians will try to cure an ailment through traditional medicine before seeking medical treatment by a doctor, until the illness is at its tertiary states. Many Haitians do not seek out the appropriate services due to language barriers and poor communication. Diligent efforts are made by staff of Haitian Women's Program to dispel these myths, encouraging clients to seek, obtain and utilize the needed services.

III. Possible Impact on Client Services if Funding is Not Restored:

If Ryan White funding is no longer received by not for profit community based Haitian organizations, the following problems are destined to develop:

- Premature deaths of clients due to lack of services
- Increased spread of HIV infection and reinfection
- Inability to understand and access necessary life saving treatment and adherence to necessary drug regimen
- Threat of deportation to countries where there is no medical treatment available to poor people who are HIV infected.
- Communication barriers will increase the incidence of lack of comprehension and knowledge of available services, therefore clients will be falling through the cracks and not getting the needed services.
- Difficulty in negotiating systems such as food pantry, entitlement benefits such as DAS, food stamps, Medicaid, SSI public assistance, and housing.
- Increased isolation and depression due to the absence of culturally sensitive and linguistically appropriate services.
- Clients will not be empowered to make informed decisions which may place them at risk for progression of disease which ends in death.

Mr. SHAYS. Thank you very much. I appreciate both you being under 2 minutes.

Ms. PAGE. My name is Darlene Page, AIDS ministry coordinator, Church of the Open Door, located here in Brooklyn, 901 Gold Street, Dr. Mark P.C. Taylor. We're familiar with Ed Towns and I want to thank you, Congressman Shays, for having us.

The ministry just started at the end of last year and just in getting some background information putting together referral services, I found that we couldn't locate many Brooklyn services. When we had to refer people, most of the time we referred them to a Manhattan source or service. Even things like they had mentioned earlier; the food program. There are really not any food programs in Brooklyn where a person can come and get a hot meal or they can bring their family to get a hot meal. There were a lot of other things that I found that they had in Manhattan and didn't have in Brooklyn. And so when my pastor's secretary faxed me your invitation today I came to see who is in Brooklyn and I'd like to know how do we get together and how do we network and I would like to leave my name and get the names of other people who are in the services of helping people with HIV and AIDS. Our service provides spiritual support, education on the disease and prevention, fellowship with people who have HIV and their families and referrals. So thank you very much.

Mr. SHAYS. Thank you very much.

Mr. BETHEA. Good afternoon, Chairman Shays, Congressman Towns. My name is Michael Bethea, I'm program coordinator with Exponents/ARRIVE. I want to give a historical perspective of syringe exchange. I'm a native Brooklynite, I lived in Bridgeport for 4 years.

Mr. SHAYS. Those had to be the best years of your life.

Mr. BETHEA. What happened in 1985, there was an agency, ADAP, and a gallant woman who passed away 2 years ago, Yolanda Serrano, we were involved in implementing needle exchanges in New York City and there was a pilot program that happened in 1985 and 1986. There was some good data that came from that program and that data was studied in Yale, New Haven, so actually the first syringe exchange programs started in New York City, and it was housed in the New York City Department of Health. So that's where it actually began. Then you started having underground programs that went on from that point.

But the data that came out of Yale, New Haven proved and showed most effectively that syringe exchange did in fact work. What it in fact showed is that it linked people who were using the syringe exchange programs to other services, and I think that's the most important thing that we need to know about syringe exchange, is that it's basically a bridge to services. You know, when we start hearing about needle exchange, we start thinking about giving junkies needles and in fact that's not what it's about at all. In fact, what it is about is linking people to a variety of services. That's why I think the people here that have testified today are adamant about getting those services in Brooklyn, specifically because there are two syringe exchange programs in Brooklyn, and I believe there's another one getting ready to start.

OK, thank you very much.

Mr. SHAYS. Let me just tell you, it's very important that you made that point, because while it's obvious, that that would be the case, now that you've said it I would never have put it in that perspective. I really appreciate that. I appreciate all your comments, but that one particularly.

Ms. SACCONE. Good afternoon, thank you for the opportunity to speak before you. My name is Denise Saccone, I'm a social worker and a creative arts therapist at Interfaith Medical Center, formerly over the St. George Project. I say "formerly" because the St. George Project was not refunded for 1998.

You heard testimony from Cameron Craig, who was a product of that program. It was a very innovative program, the first and only psycho-social, psychoeducational program in Brooklyn for people living with HIV and AIDS. We, as the woman from SUNY Downstate mentioned, were devastated back in November when we found we were not being refunded. We scrambled in vain to find additional funding.

The hospital is a very poor hospital and could not find funding within itself to refinance us and keep us open. Losing the funding at St. George was not only devastating for staff, but also, obviously for the clients. We couldn't find them replacement services. We had a discharge planning day where we invited different agencies to come in. There was no other agency that provided the services in the way that we provided them for us to discharge our clients to.

The closest we came was the Jewish Board AIDS Day Program. However, you have to have an AIDS diagnosis to belong to that program, whereas at St. George, HIV infection was all that was required.

The additional plight of Interfaith Medical Center is that it is a federally designated AIDS Medical Center and now finds itself in the year 1998 only able to provide medical services through their primary AIDS service and through their TB clinic. All other support services were defunded; the HIV/AIDS Women Health Initiative, the St. George Project, and the day treatment program that dealt with the substance abuse issue. Other panelists have clarified how important it is to address all the needs of these clients. Thank you.

Mr. SHAYS. Thank you.

Mr. TAVERAS. Good afternoon, I'd like to first thank the committee for allowing the public to speak. My name is Frank Toveras, I'm a coordinator for the FACT Program, by substance users, for substance users, a product of Exponents, Inc., of the Bronx.

I'll make my statement now. My statement says that HIV and AIDS and substance abuse go hand in hand. New York City, New York State and the United States. Because of the fact that peer oriented, peer delivered services have been frowned upon, funding has gone away from that. This is a total disgrace to the fact that HIV and AIDS was first fought by peers, by people living with HIV and AIDS.

We need to go back because the community has to take part in the rebuilding of itself. Professionals can come in and teach, but the community, the people in the community, are the ones that are ultimately responsible for building that community back and need to play a critical part. And third is that this whole system of sub-

stance abuse and HIV and AIDS and peer oriented services is part of harm reduction. Harm reduction is not just a needle exchange. Harm reduction is non-judgmental, it is low threshold and it is the only prescription that is necessary. It's the most crucial description on my part necessary to combat HIV and AIDS in New York City, New York State and the United States.

If I may say so, one piece that was brought up was clinical trials for substance users. More studies need to be done with people who are using substances and are accessing medications. That is not being done.

Someone mentioned children. Of the cumulative AIDS cases in children under AIDS, which is 1,195 in New York City, 68 percent resulted from mothers who were infected through their own injected drug use or through the sexual contact with an injecting drug user. This population is driving this epidemic and because of moral, social issues that are not being addressed.

Last, I'd like to say that we need to have the voice of experience, the people who have the experience within the community, as part of planning bodies and Community Boards. This voice is adamantly needed. Professionals are needed, but we need to have the voice of the community in there, and that means the guy who is still using drugs, the guy who is recovering from drugs. I am a recovering substance user and alcoholic and I'm here today because of my experiences, giving a sense of responsibility for what I have to do to make myself and my community better.

Thank you.

Mr. SHAYS. Thank you very much.

Ms. BROWN. Good afternoon. I'm the grandmom of four little girls with HIV/AIDS.

Mr. SHAYS. And your name is?

Ms. BROWN. Roberta Brown.

Mr. SHAYS. Roberta Brown. Thank you, Roberta.

Ms. BROWN. I heard the doctors, social workers and everybody, and they're absolutely true that you have to travel from Brooklyn to New York for the better medical treatment. I said that's not good, but I found that New York doctors do have better experience than some of the medicine in cases that we deal with, such as those that I have been taking care of; the oldest one since 1987 when she was first diagnosed. We were going through a crisis at the time.

We didn't go through within the home most of the time. SUNY Downstate as the young lady said before, has started a child support group and it's very, very good, but the problem is, when you come out, what is there for her to do? There is no place for these children to go to be with. They have to speak. There is nothing there for them up here in Brooklyn, no outlet for them, no other children to play with and they're in the homes all day. This is my main concern. To have something there for them besides the four walls, and better treatment where we don't have to go hunt for the better medical advice.

And I have one more comment. The mother of these girls is my niece. She's been hospitalized four times and each time she's hospitalized, she leaves the hospital with about 12 medications. Because she doesn't have any income and she's not on social service, she can't get the medicine, so she comes out of the hospital, and

she has to go right back in, because there's no medication for her to get.

Mr. SHAYS. In other words, all she gets is inside? She gets it in the hospital?

Ms. BROWN. She's always committed.

Mr. SHAYS. If she's committed, she gets the service; if she's out on the street, she doesn't.

Ms. BROWN. She can't even get the medication filled.

Mr. SHAYS. Thank you, Ms. Brown.

Ms. BROWN. Thank you.

Ms. PETERKIN. Good afternoon, Mr. Shays, Mr. Towns. My name is Betty Peterkin and I'm from Brooklyn/East New York. I'm also here today because I'm a product of this disease. This disease is very insidious as I know for myself. Recently the New Year's came and I started out in Brookdale Hospital. I almost lost my life, but came out two times. I was introduced to this aftercare center right here, Black Veterans, 210 Hart Street. I was diagnosed in 1991, so I had lived with it. I had learned to accept it, but to be fully acknowledged and have someone acknowledged enough to give me the education and thought and loving care; I didn't get that until I walked into 210 Hart Street. Just Wednesday, going to a meeting, I heard that they're going to close it down because there's no money to fund me and a lot of other people. There are people out there like myself that want help. There are people out there that could get help because they haven't been in to the right places yet and it's people like those that work with people like us, that want us. Sometimes we can't just want it ourselves and it takes a lot of other people to help us. To be a living product of this insidious disease and to say, living in Brooklyn, that nobody has enough money to furnish me, just to cultivate me and help me live with this disease, is very sad when they can send people to the moon, you know, it's real sad. I want to thank you.

Mr. TOWNS. Thank you.

Mr. ROYAL. Mr. Chairman, my beloved friend, Congressman Towns, Assemblyman Griffith, to all of you in this room. I hadn't intended to speak. I intended to come as an observer, but I'm compelled to speak.

First, quickly responding to your question, Congressman Towns, is it going to go up or down? The answer, it's going to go up. It's going to go up because of the socioeconomics in the communities that I travel in, which are mostly black folks and Latinos. Unemployment is high, drug use is on the run, therefore it's going to go up.

Assemblyman Griffith, who was very kind and gracious, said I don't want to go into name-calling, but I'm a preacher, I got to tell it like it is. You can't keep on giving money to the Gay Men's Alliance, which has not really seriously committed itself to the black and Latino population of New York City. They get all the money and we in Brooklyn and Harlem and everywhere else, we got to fight for scraps. That's what's going on in New York City. Now, we talk about it, but nobody wants to bring it up front. I'm here to tell you, it ought to be brought up front and I'm doing it today.

No. 2, very quickly, there is an attitude problem among the so-called missionary folks that run programs which are basically

mostly Caucasian. The folks that are not only affected by it, most times are dealing with folks that don't understand their culture, don't understand their economic situation, don't understand their housing conditions. And so they're miles apart from what we have to deal with. There is no coordinated, serious coordinating effort between the city, State and Federal agencies dealing with these agencies.

You had a number of experts. I've listened to it, good Congressmen, this morning here. All of these good folks testifying about what they've been doing. The agencies as a whole have not really responded to the needs of the community. And then let me just do this very quickly. What's happening in Brooklyn is happening not only here, it's happening all over America in the inner cities, where they take one organization and pit it up against another and when you look around again, we're fighting each other. And this is leading to the demise. This is part of the problem.

What do we do? You've heard my protest. What do we do? I've listened to some of these folks sitting here. I'm thankful to God that at the last juncture you said let the public speak. What some of these folks need to do is go to the back of the room when this meeting is over and say "let's stop playing games with each other, let's sit down and figure out how we can pull it together. Let's call on some of our so-called celebrities," and I'm talking about black stars, "the basketball stars, the entertainers and give some benefits like they do for them other organizations and raise some money. Let's go to Washington and set up a meeting with Congressman Towns and Congressman Shays and talk to the CDC," which does not make site visits like they ought to. They don't know what's going on.

Now, I've done it. I am the national chapter for the 369 Veterans Association. I'm also the past chairman for Harlem Hospital's Community Board, so I know from whence I speak and very quickly——

Mr. SHAYS. Let me just say, my mother told me never to interrupt a preacher, and especially a veteran, but we do need to move along.

Mr. ROYAL. I'm ready to bow out, but I just want to say this for the benefit of Assemblyman Griffith. Somebody hit it right. Many of these hospitals because of the rotation system, Congressman Towns, you've seen it in our own hospital, you got a lot of doctors there, residents, interns, rather, who have not come prepared, who not only don't speak your language, but 9 out of 10 times are not working under attending supervision, attending physician supervision, so the end result is that when you go into the emergency room for triage, 9 out of 10 times you're going to end up getting what is known in common vernacular as the shaft. And that's why we have the problem.

I thank you both for the hearing today and I pray God that sooner or later that you'll take this hearing all over this city, because it's not only needed in Brooklyn. Everywhere.

Mr. SHAYS. Thank you very much.

Ms. MCFARLANE. Hi, my name is Rosa McFarlane. I am an intake counselor for Black Veterans for Social Justice and HOPA program, Housing Opportunity for People with AIDS. We just recently lost our funding, and, I'm going to try not to cry like a baby, but

we lost or funding and it's scary because we have over 300 clients on our caseload, and we have to house them. We not only house our clients, we followup on them after they're housed, and a lot of them are saying, "well, what's going to happen to me," because, as long as we are backing them, the landlords treat them well, make sure they have heat and hot water.

We had to stop our intake and it's just really scary. What are we going to do? We will have to refer clients out, but we don't exactly know yet where we're going to have to refer those clients. We have clients that are housed and they're not used to living by themselves, so they would come in and just talk. We touched a lot of their lives and they have touched mine. I know that I will have to get another job because I have to pay bills, but—I'm so sorry. This field, my heart is in this field. Thank you.

Mr. SHAYS. Thank you.

Mr. BRIDGES. Good afternoon. My name is Vincent Bridges, I'm the housing specialist for Black Veterans for Social Justice, HOPA program, Housing Opportunity for People with AIDS. To add on to what Ms. Peterkin as well as McFarland has said, we recently found out last week, I believe, that our program is going to be cut. For what reasons, we don't know. Earlier this week, earlier this week we received a phone call from another agency who is receiving funding, and they're in Manhattan, and they called us and told us they were referred to us by the Ryan White program because we provided good services for our clients. My question is, if we provided that much good service to our clients, why are we being closed and why are they being open?

Mr. SHAYS. We are going to adjourn this hearing. You asked some very important questions. I know that Mr. Towns in particular and his staff are going to followup on some of the why's in the full committee.

I do need to end this hearing now, and just tell you that I learned a lot and our committee is not a committee that just learns a lot. We followup. We've seen a lot of our hearings result in legislation and appropriations, so I thank all of you, our first panel, our second panel, and our third panel, and those of you who are in the audience, and God bless each and every one of you.

This hearing is now adjourned.

[Whereupon, at 1:04 p.m., the subcommittee was adjourned.]

[Additional information submitted for the hearing record follows:]

Statement of
Derek Link
Director of Federal Affairs

GMHC welcomes the opportunity to present written testimony to the subcommittee. We would like to discuss the need for an increased understanding of HIV infection trends in Brooklyn and indeed in all of New York City. While primary responsibility for monitoring the epidemic rests with New York City and with New York State, the federal government should make increased resources available for local jurisdictions to fight the epidemic at the community level.

After seventeen years and more than 400,000 deaths, AIDS seems almost unrecognizable from its earliest and darkest days. When the epidemic began, there was little hope for infected individuals. Today, our nation's investment has begun to yield impressive dividends. New drugs, better medical care, physicians trained in HIV disease, and an effective community-based infrastructure have transformed the management of HIV. Thousands of infected individuals are now living longer and healthier lives, and perinatal transmission has been dramatically reduced.

These advances pose a fundamental challenge to the system used to monitor and track the epidemic. They have, in fact, brought us full-circle, back to the beginning, when no one understood the direction, magnitude and gruesome toll of the epidemic. Since 1981, the system for monitoring the epidemic has relied on counting individuals who have AIDS. In the absence of effective treatment, AIDS surveillance was a reasonable surrogate for HIV trends. However, the wide-spread introduction of combination therapies and greater access to medical care have helped thousands remain healthy and AIDS-free for longer periods of time. The current AIDS-based surveillance system is no longer an effective measure of the true extent of the epidemic. Today, as in 1981, we know little about HIV infection trends, and this lack of information is endangering lives and undermining our efforts to fight the epidemic.

Surveillance data play a crucial role in battling the epidemic. Surveillance data help answer vital public health questions, such as the number of infected individuals in the United States, behavioral risk factors for infection, and emerging trends among individuals with newly acquired infection. Surveillance data can also help assess the course of disease among the infected by monitoring health care usage, disease severity, number of deaths, and characteristics of those for whom treatment fails. Surveillance data are also crucial for the design, conduct and evaluation of HIV prevention programs. Surveillance data can be used to allocate resources to hard-hit regions and communities.

Recommendations

1. GMHC calls on New York to implement a system for monitoring HIV infections. A new surveillance system for the epidemic should count the number of people who are infected with HIV in addition to the number of people who have AIDS. HIV surveillance should be designed

to generate accurate, useful, complete and timely data on infection trends, and should inform our efforts to battle HIV. The implementation of a new HIV surveillance system must include the following:

- **Involve affected communities in the development of a new surveillance system.** New York must seek the participation of all communities fighting the epidemic in this process.

- **Assure strong privacy safeguards.** New York's strongest confidentiality protections, which now shield the AIDS-based surveillance system, must be applied to HIV data collected by public health officials. New York's AIDS surveillance system has operated without breaches of confidentiality for almost two decades. A new HIV-based surveillance system must be protected in a similar manner.

- **Evaluate and implement a "unique identifier" system.** An anonymous, coded system of unique identifiers should be developed for HIV surveillance because it will offer the strongest protections for patients' privacy. New York already uses unique identifiers for monitoring other conditions. Maryland and Texas have unique identifier systems for monitoring HIV infections. These models should be examined to develop an appropriate system for HIV surveillance in New York.

- **Re-evaluate the type of data collected by New York's public health officials.** The current surveillance system provides limited data on the populations most at risk. A new surveillance system should be enhanced to collect better data on more people so programs can be targeted to communities that need the most help.

- **Oppose linking HIV surveillance to non-surveillance activities.** HIV surveillance is a research activity conducted by epidemiologists. Linking surveillance to non-surveillance activities, such as mandatory partner notification, contact tracing, and the criminal justice system will jeopardize the implementation of a new surveillance system and will drive infected individuals away from HIV counseling and testing.

- **Preserve free, publicly-funded anonymous testing.** Anonymous testing is an important vehicle for some people to receive counseling and testing, enter medical care, and prevent further transmission. Anonymous testing is an important adjunct to surveillance, because lack of this option leads some people to delay testing, donate blood as a means to be tested anonymously, and give false information at confidential testing sites.

2. GMHC calls on New York City, New York State and the federal government to enhance their funding and commitment to ending this health crisis. Monitoring HIV infections will benefit people infected with HIV only when it is linked with appropriate medical and human services.

- **Guarantee health care to all people who are infected with HIV.** Government must assure that Medicaid, AIDS Drug Assistance Programs, and private health insurers offer comprehensive health care to all infected individuals, in accordance with the new Public Health Service's HIV treatment guidelines.

- **Expand HIV prevention efforts and target high-risk populations.** HIV prevention is our only weapon against this epidemic. Yet, for most of the epidemic, government-funded prevention programs have not targeted the populations most at risk. In fact, federal funding for prevention targeted to gay men was illegal until 1992, and federal funding for needle exchange remains illegal today. Adolescents, young gay males, people of color, women, and injection drug users have been ignored by government-funded prevention programs, and the cost of this ignorance is stark and shameful.

- **Promote HIV testing.** Since HIV testing is the crucial first step for an infected individual to begin taking charge of his/her health, government at all levels must aggressively promote HIV testing to communities at highest risk through print, radio, television, and community-based programs. Promotion of HIV testing should include information on the value of testing, the different testing options available, including anonymous testing, and the confidentiality protections afforded HIV test results.

- **Enact federal and state confidentiality protections for medical records.** Although public health data, such as AIDS and HIV surveillance, are protected by state and federal statutes, medical records are widely shared such that today private medical information is too easily available. Individuals must be assured that their private health information will be held in the strictest confidence.

Summary

Recognizing the important role HIV surveillance can play in our national strategy against the epidemic, GMHC strongly urges New York to implement HIV surveillance. GMHC calls for a compassionate and considered process for implementing HIV surveillance. GMHC believes this is an opportunity for all communities to make stronger their commitments in battling this health crisis, and calls on all levels of government to increase their funding and commitment.

TESTIMONY
Presented to the Subcommittee on Human Resources
of the Committee on Government Reform and Oversight
"AIDS: Toward Long-Term Treatment Options"
Friday, February 20, 1998
Borough Hall
Brooklyn, NY

It is with deep appreciation that I thank both Congressman Shays and Congressman Towns for scheduling hearings on an issue which has affected Brooklyn residents in such a profound way, and for conducting these hearings in Brooklyn. Brooklyn may now have the dubious distinction of having the largest population of people living with HIV/AIDS in the United States--and by every indication this epidemic is still growing in communities of color throughout the Borough.

Appropriate Medical Care Including Long Term Treatment Options Must Be Made Accessible to Every Person Living with HIV/AIDS

As the supervisor of HIV/AIDS legal services for Brooklyn Legal Services Corporation A for the past six years, I have witnessed the rapid increase in HIV transmission among the most fragile members of our society – women of childbearing age living in poverty, children, adolescents, and individuals already sick with tuberculosis, substance abuse, or mental illness. Fear of discrimination, stigma and shame still accompany transmission causing the newly infected to take desperate measures to hid their illness. While the epidemic has been increasing in Brooklyn's low-income communities of color, access to medical care and new treatments, food and nutrition programs, substance abuse services, income support, and supportive services is becoming more difficult.

This growing lack of access to appropriate, adequate and competent medical care, treatment and treatment options as well as subsidies for food and nutritional services, transportation, and nonhazardous housing/shelter is the focus of my testimony today. Without access to these life-sustaining subsidies and health-related services people living with HIV will continue to develop debilitating HIV illness and AIDS, rendering "long-term

treatment options" meaningless.

Lack of access to these life-saving services is caused by a number of factors, including the most obvious -- poverty, hopelessness, stigma, fear of discrimination, and becoming too ill to "take care of business". Welfare reform, new rent laws in New York City, immigration reform, and managed care have all added extra layers of regulation complexity in a system where access to services is already replete with "land mines" of complicated and intricate rules used to determine and maintain eligibility for services -- rules so complicated that legal aid/services attorneys practicing Medicaid and welfare law for many years, cannot understand them.

Add to these factors a lack of neighborhood-based resources for care and service in the hardest to reach low-income communities of color, and the result is a continuing escalation of HIV transmission, serious illness requiring lengthy hospitalizations and nursing home care, more AIDS orphans with deep emotional and psychological injuries, and the skyrocketing costs of "emergency room" medical care as the medical care of last resort.

What is to be Done?

While many approaches are needed to improve access to desperately needed services, and in particular for special populations and communities historically under served through inadequate allocation of resources, two will be presented through this Testimony for the Subcommittee's consideration.

Move Away from the Trend Toward Consolidation of Care and Services: Place Medical Care and HIV-related Services in Underserved Communities of High Need

Placing services and care in locations where they are most needed seems a rational and simple solution. Unfortunately, in what is described as a "cost-containment" measure, just the opposite is happening in New York City, and there are disturbing indications that "consolidation" may be a national trend. A look at recent New York City Ryan White Title I funding decisions serves to illustrate this point.

That the epidemic has reached a critical stage in Brooklyn due to even increasing

transmission among special populations combined with a shocking paucity of HIV-related services based in Brooklyn was confirmed in a recent study commissioned by the New York City Department of Health.[1] Citing only a few of the many examples, Bushwick has the highest number of people coinfected with HIV and TB in New York City; East New York has the highest number women infected with HIV; Bedford-Stuyvesant and Bushwick, the highest need for custody planning legal and social services; Williamsburg and Bushwick, the highest number of Latino/as living with HIV; East New York, Brownsville and Bedford-Stuyvesant the highest numbers of African-Americans living with HIV; Williamsburg, the highest number of children infected with HIV; and Brownsville has the highest need for client advocacy services in the City of New York.

Brooklyn will have 16,000 AIDS orphans in 2001 -- more than half the number predicted for all of New York City. Clearly, these poor communities of very high need must have access to medical care and HIV-related services. Because of cultural and linguistic considerations, the fear of traveling much beyond neighborhood boundaries, and the fear associated with HIV-status disclosure, people living with HIV and AIDS in these communities are much more likely to access neighborhood services than services offered in unfamiliar surroundings long distances from home.

Yet, recent Ryan White Title I funding decisions resulted in 75% of the locally based care and services being taken out of Brooklyn communities and placed in large City-wide providers of services located, for the most part, in Lower Manhattan. Although many examples can be provided as to the devastating affect this will have on Brooklyn communities, one serves as very compelling.

In Brownsville, a community of the highest needs for virtually every HIV related service, and with the highest numbers of African-Americans and women living with AIDS, a food and nutrition program has been serving hot meals in a congregate setting for five years. Although designed and funded to serve 50 people living with HIV for each meal, as many as 95 - 100 were served each meal. At each mealtime, guest speakers provided

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[1] *HIGH NEEDS INDEX FOR RYAN WHITE TITLE I PRIORITY SERVICES*

information on new HIV treatments, the proper protocol for taking protease inhibitors and other potent HIV-related medications, gave cooking and shopping lessons, assisted people with benefits advocacy, and served as a gathering place for the exchange of HIV/AIDS information in a supportive atmosphere.

Many came to these meals having no other source of food, while others came for referrals to health care centers, supportive counseling and substance abuse treatment programs. This was the only provider of hot meals and nutrition counseling for the communities of Brownsville, East New York, and Bedford Stuyvesant.

This provider recently lost all of its Ryan White Title I funding which supported these services, and on March 1, 1998 will close its kitchen and layoff its staff. Funds from this program were shifted to programs in Lower Manhattan who claim they will serve these communities. Historically, however, City-wide programs have been able to reach very few Brooklyn residents and most go without where services are located in Manhattan. Manhattan, with its wonderful decline in new AIDS cases, now has seven (7) food and nutrition program while Brooklyn, with the largest HIV/AIDS population in the City has one located in Williamsburg whose capacity is 35.

The lost of this food program many predict will result in much higher emergency medical costs for those who no longer have access to good nutritious meals and referrals for critically needed services. Consolidation may be "penny-wise" but it is certainly "pound-foolish".

Increased Need for Client Advocacy/Legal Services by Attorneys and Advocates With Expertise in HIV Legal Issues and Health Care Delivery Systems

The second approach to ensuring access to appropriate HIV-related medical care, benefits and supportive services is to increased dramatically the number of trained legal staff available to communities of high need. While funding for attorneys is not the most popular or easy to sell request, the critical need for increased numbers of legal staff with

expertise in HIV-related issues has been well documented. Two recent studies[2] conclude that changes in welfare, Medicaid, social security, immigration and health care delivery systems have created an emergency need increased client advocacy/legal services for people living with HIV/AIDS. A report prepared for the NYC HIV Health and Human Services Planning Council entitled ***The Changing Environment*** states: "there is an immediate need for increased...client advocacy for the Majority of Title I recipients"(p.104). **Table 8** of ***The Changing Environment*** projects that 26,640 - 35,880 HIV+ clients will need client advocacy services in 1998 – an increase of over 7 times the number of clients (4132) in 1996.

The kinds of legal issues faced by people living with HIV are the same as any poor family might face in a crisis, except for HIV/AIDS phobia and discrimination. Because of HIV stigma and discrimination, skilled attorneys with experience in HIV discrimination are necessary to handle these matters competently. Parents living with HIV/AIDS are encouraged to make legal custodial arrangements for their children in the event of chronic debilitation, long-term hospitalization or death, which require the assistance of an attorney. New guardians or caretakers of AIDS orphans often have difficulty obtaining benefits and services for these children, and need a skilled advocate. Parents living with HIV are sometimes threatened by child welfare agencies with removal of the children from their homes where neglect due to illness is suspected, or based on a belief that HIV is contagious through touch.

Often these cases are complicated and labor intensive: a few examples from our practice –

●HIV+ children who are orphaned and live with a relative caretaker who speaks no English, and does not have legal custody and the legal authority to consent to treatment;

●AIDS orphans residing in public housing with no adult in residence facing eviction and loss of benefits unless the 17 year old is found competent by Family Court to become

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[2] *HIGH NEEDS INDEX FOR RYAN WHITE TITLE I PRIORITY SERVICES*

6 Testimony,

the guardian of her siblings;

●a 21 year old man with a T-Cell count of 10 who Medicaid case has been closed by mistake and is unable to purchase the protease inhibitors he has been taking, which can create a life-threatening condition unless medication is obtained immediately;

●a mother with full-blown AIDS whose welfare case including food stamps, Medicaid, and rent payments is closed because she was hospitalized at the time she was to recertify at the welfare office;

● the sole surviving child also HIV+ whose mother, father, grandparents on both sides, and mother's siblings all died of AIDS, and who is unable to obtain HIV related treatment because his caretaker has no legal custody or authority to consent to treatment.

While Brownsville Brooklyn ranks "number one" in need of client advocacy services throughout New York City, our Legal Services program, the sole provider of free legal services to the communities of North Brooklyn including Brownsville, receives only $200,000 in HIV/AIDS funding to serve all of North Brooklyn. Our staff ratio to HIV-infected North Brooklyn resident is approximately 1 staff attorney or paralegal to every 4000 infected residents. With our two attorneys and two paralegals we are able to assist only 20% of the HIV+ individuals who seek our representation.

Conclusion

"Long Term Treatment Options" will not become a reality for many living with HIV unless and until access to appropriate medical care and treatment, and other HIV-related care and services is addressed. By locating medical care and services in the neighborhoods of high need for these services, and by greatly increasing the number of trained legal advocacy staff available to people living with HIV, major barriers preventing access will be reduced significantly, if not eliminated.

Respectfully submitted,

Carol Horwitz, Director
Comprehensive Rights Unit (HIV/AIDS legal advocacy)
Brooklyn Legal Services Corporation A
Brooklyn, NY

**TESTIMONY TO THE SUBCOMMITTEE ON HUMAN RESOURCES
OF THE
U.S. HOUSE OF REPRESENTATIVES
COMMITTEE ON GOVERNMENT REFORM AND OVERSIGHT**

Presented by: Gabrielle Kersaint, Executive Director

**Haitian Women's Program
464-466 Bergen Street
Brooklyn, N.Y. 11217
(718) 399-0200**

Congressman Shays and Congressman Towns, thank you for the opportunity to share with you several critical issues that will severely impact the needs of the Haitian, Caribbean, African French Speaking, and African American communities infected/affected with HIV/AIDS that reside in Brooklyn. My name is Gabrielle Kersaint, Executive Director of the Haitian Women's Program (HWP) and I will begin by presenting information about the Haitian Women's Program and the decision made by the Mayors Office and the HIV Planning Council to cut funding for HWP's Case Management Services previously funded by Ryan White Title I.

I. Problem Statement:
Haitian Women's Program, (HWP), a not for profit community based organization was established in 1981. HWP currently provides comprehensive case management to a total of 140 HIV positive Haitian refugees and immigrants residing in Brooklyn. Recent Ryan White funding budget cuts have left Haitians with virtually no case management services that are culturally sensitive and linguistically appropriate in Brooklyn. Ryan White funding was only awarded to one not for profit community based organizations in Brooklyn for case management services. Two organizations that serve Haitian immigrants did not get refunded in Brooklyn: Haitian Women's Program, and Haitian Community Health, Information and Referral Program, (Lakou Lakay). HWP was the largest of these Haitian funded programs employing four case managers and a social worker. In addition, HWP is the only Haitian agency that also has other related AIDS services program such as Housing, Education and Tuberculosis screening to complement its existing case management services. Ryan White funding constituted one-third of our agency's budget. The recent discontinuation of Ryan White funding will not permit HWP to adequately provide the clients with the following services:

- Permanent housing search and placement
- Assistance with applying for medical coverage
- Assistance with immigrant issues
- Escorting clients to medical appointments

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- Conducting Home and hospital visits
- Advocacy for client rights
- Advocacy and legal intervention when clients are being discriminated against because of HIV status, culture, color, lack of language
- Assistance with permanency planning, living wills and health care proxy
- Clinical crisis intervention and referral to mental health providers
- ESL and literacy education
- Educating clients on service systems; HIV prevention; tenants's laws and rights
- Escort/translation services through our Buddy volunteer program

II. Demographic Data Supporting Need for Services:
According to the 1990 census data, there are approximately 500,000 documented Haitian immigrants in the New York City area. However, is estimated that there are one million Haitians in the entire city when accounting for those who are undocumented, and under reporting errors. Brooklyn has 73.54% of Haitian immigrants settling in New York between 1983-1989. Of this group, there are individuals who are HIV positive and are in desperate need of assistance. In Brooklyn, 71% of the AIDS cases are Haitian immigrants.

According to the World Health Organization (1990), Haiti ranks amongst the highest countries with reported AIDS cases in comparison to other reported AIDS cases in the Caribbean.

There are also several barriers which impedes Haitian's access to AIDS treatment and prevention services. They are:

Welfare Reform/ Immigration Laws:
The new welfare reform and immigration laws greatly hinder access to services for Haitians and other immigrants. HWP staff has acquired a great deal of expertise in linking clients to immigration attorneys and advocating for services on their behalf despite the new laws.

Socio-Political:
Haitians were inappropriately included as a high risk group for HIV/AIDS and barred from donating blood by the Food and Drug Administration in 1983. Because of this past and current anti-immigrant sentiments, Haitians do not trust government funded services and are reluctant to receive services from any programs. At the Haitian Women's Program, trust is established and clients receive culturally sensitive, linguistically appropriate services that pertained to their specific needs.

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Culture, Language and Literacy:
The Haitian Community is one which perceives itself to be very different from other Caribbean or African American communities. Haitians have encountered barriers in health care due to AIDS discrimination. In addition, many Haitians will try to cure an ailment through traditional medicine before seeking medical treatment by a doctor, until the illness is at its tertiary stage. Many Haitians do not seek out the appropriate services due to language barriers and poor communication. Diligent efforts are made by staff of Haitian Women's Program to dispel these myths, encouraging clients to seek, obtain and utilize the needed services.

III. Possible Impact on Client Services if Funding is Not Restored:
If Ryan White funding is no longer received by not for profit community based Haitian organizations, the following problems are destined to develop:

- Premature deaths of clients due to lack of services
- Increased spread of HIV infection and reinfection
- Inability to understand and access necessary life saving treatment and adherence to necessary drug regimen
- Threat of deportation to countries where there is no medical treatment available to poor people who are HIV infected.
- Communication barriers will increase the incidence of lack of comprehension and knowledge of available services, therefore clients will be falling through the cracks and not getting the needed services.
- Difficulty in negotiating systems such as food pantry, entitlement benefits such as DAS, food stamps, Medicaid, SSI public assistance, and housing.
- Increased isolation and depression due to the absence of culturally sensitive and linguistically appropriate services.
- Clients will not be empowered to make informed decisions which may place them at risk for progression of disease which ends in death.

Haitian Women's Program thanks you for your time and consideration about these critical issues that will impact the community served. I appreciate the oportunity you have provided in allowing me to make these points known.

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PASA

Kathy Dee Zasloff
Executive Director

Prevention through Education and Training

Testimony for Human Resources
and Intergovernmental Relations Subcommittee
Field Hearing on AIDS: February 20, 1998

My name is Kathy Dee Zasloff and I am the Executive Director of People Against Sexual Abuse (PASA), a community-based organization (CBO) in Brooklyn that provides education and training to eliminate all forms of sexual violence. As Executive Director of PASA, I design and field-test the youth and adult trainings that PASA offers locally and internationally. I am also an active member in a variety of local, state and international networks of CBOs that focus on youth empowerment, community development and violence prevention. I am a member of the NYS Department of Health's, Aids Prevention Planning Group (PPG) and co-chair the PPGs emerging issues committee.

Thus, I am pleased to submit my testimony as: an advocate for innovative youth programs; someone who has developed youth programs in collaboration with young people; someone who is involved in interpreting the data and trends of HIV infection; someone who interacts with both AIDS and youth service organizations in Brooklyn and other boroughs; and as a health educator that has a finger on the pulse of emerging issues facing youth and AIDS programming today.

As someone involved in health services as opposed to health care, I submit to you that the health service response is AIDS and HIV is, properly, concentrating on taking care of those already infect 'd, and preventing others from becoming so. This is in contrast to the medical community's response to AIDS, which is finding a cure for AIDS, and finding a vaccine. The only protection we have in the health service sector is education on how not to become infected and that means helping people to make healthy choices.

People Against Sexual Abuse, Inc.
57 Front Street 4th Floor
Brooklyn, NY 11201
(718) 834-9467 voice
(718) 834-0018 fax
(718) 934-1033 TTY
e-mail: info@pasa.org

PASA's programs teach people to recognize and internalize the state of being empowered so that they practice making healthy choices as a daily activity. Ideally, this practice should be the approach to HIV prevention, particularly for young people, in our country.

I am submitting my testimony for two reasons. First to make recommendations about tracking the epidemic's changing path and second, to inform the discussion about adolescents who have been infected since birth. Frequently, the government and the government's advisors, are too quick to make recommendations without studying the issues in depth. I think that the government, and the legislators that comprise it, need to reflect on changing practices, and practicing change.

The two topics about which I write today are ones that are developing in the Brooklyn community. One focus is the discussion about the controversial issue of HIV surveillance and tracking who is becoming infected with HIV. Currently, we are only tracking who is dying of AIDS. The other issue is about programs designed to serve young people who have been infected with HIV since birth, young people who are now entering adolescence.

There are two recommendations that I would make on the controversy surrounding HIV surveillance. First, I strongly recommend that we focus on the real issue: tracking the epidemic. In order to adequately track the changing pathways of HIV infection, we will need to commit resources to HIV surveillance and widen the collection net for information. Second, I strongly urge that legislators not be distracted by the debate of names reporting versus unique identifiers. This controversy clouds the necessity of changing our response to HIV infection and AIDS as the disease transitions into a chronic and manageable illness. We have the tools, technology and know how. Let's not be distracted from our goal: to keep people living healthy lives.

I think it is meaningful to consider the importance of HIV surveillance. We have done our job well and people with AIDS are now living longer. The reporting of AIDS diagnosis tracks who is dying of the disease. HIV surveillance tracks who is becoming infected with HIV. In terms of prevention and disease management, it is important to know who is becoming infected with HIV because early intervention is life saving.

As we broaden the collection of data in the information net, we see an emerging population: young people infected with HIV since birth. As we speak, community AIDS service providers are just beginning to see a generation of teenagers come of age who were born HIV positive. Some of the teenagers know that they have HIV, but some do not. Many teens find out they are HIV positive when they themselves become pregnant, or when their newborn infant is tested. While there is an effort made to trace these teen-age moms' sexual partners to identity how they got infected, many of them in fact, have been HIV positive since birth, and have never been told their diagnosis. Many of them are now having their own children, who are also HIV positive.

It is important to address the three separate service sectors of congenitally infected young people, and to recognize their differences in terms of health and health services needs. The oldest cohort is adolescents who are currently 15-20 years of age. These young people have been infected for almost 20 years, and have had medical intervention only recently, a maximum of perhaps 10 years. These adolescents were not expected to live this long. Thus, they have a variety of serious educational, social and physical limitations because the effects of their illness and the lack of medical interventions. Also, there was an underlying presumption by their parents that their children would die of AIDS before they would become teenagers. To further complicate these young peoples lives, many of their parents died of AIDS and the surviving guardians also never expected these young people to live long lives. These young people, some of whom may still not know that they are HIV positive, are now of child-bearing years, and many are probably at high risk of becoming teen parents.

The second cohort is young people who are now 9-15 years of age. These children have received more medical interventions, and are more educationally, socially and health-wise capable because of the emerging therapies of the last 10 years. These children are living with a changing reality, although they were not expected to live either when they were born. Many of these children are now sexually active. Again, some of them know they are HIV positive, some do not. Safer sex education for this group is critical! Not only to protect the health of other teens who are not yet infected, but to protect the lives of the unborn.

The third cohort is 0-9 years old. Some of these children may live perfectly "normal" lives; we have the medical technology and the infrastructure, created by Title IV of the Ryan White CARE Act, to make it possible for these children to live healthy lives. But, we must ensure equal access to the new therapies and to new support systems, support systems that empower these children to live, and not treat them as if they will die.

There are several contextually logical reasons why the oldest and second oldest cohort of congenitally infected adolescent were not informed of their HIV status. First and foremost, these children were not expected to live long enough to be at risk of infecting others through sexual contact or through needle-sharing. The parents of these children often died, and the guardians who took over their care were ill-equipped to deal with notification issues and the consequences. The Ryan White CARE Act was born out of Ryan's experience with AIDS discrimination. No parent or guardian would ever want their child to go through what Ryan did, and might take every precaution, including telling no one of their child's HIV status, to prevent that experience. But today, children who are born HIV positive will most probably live healthy lives, and we need to address this issue of a young person's right to know their HIV status.

I am an advocate for youth, and particularly youth empowerment. I believe children have a right to know about their own health, and a right to take whatever steps necessary to promote their good health. And so, I think that children have a right to know about their HIV status. But I think that if that notification were to be codified into law, legislators must think about how children are told that they are HIV positive. Most HIV positive children will have an HIV positive parent who may or may not be alive when it is age appropriate to tell the children about his or her status.

I would suggest, of course, that HIV positive youth and their parents engage in a discussion. The government and the AIDS service providers have a role to play in encouraging such discussions, particularly for children and parents who would not otherwise engage in such conversations.

In conclusion, I offer these comments to provoke thoughtful reflection and to help you stay on track. I recognize that congress members are called upon to quickly become experts in many areas, a daunting task. I have been building expertise for almost 15 years in identifying what is missing in service systems and in personal empowerment issues. I hope you will use the logic of my testimony to think through the legislative issues affecting HIV and AIDS.