AIDS IN THE 1990's: SERVICE DELIVERY TO EMERGING POPULATIONS

HEARING

BEFORE THE

SUBCOMMITTEE ON HUMAN RESOURCES
AND INTERGOVERNMENTAL RELATIONS

OF THE

COMMITTEE ON GOVERNMENT
REFORM AND OVERSIGHT
HOUSE OF REPRESENTATIVES

ONE HUNDRED FOURTH CONGRESS

FIRST SESSION

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AIDS IN THE 1990's: SERVICE DELIVERY TO EMERGING POPULATIONS

MONDAY, JULY 17, 1995

House of Representatives,
Subcommittee on Human Resources and
Intergovernmental Relations,
Committee on Government Reform and Oversight,
Brooklyn, NY.

The subcommittee met, pursuant to notice, at 11 a.m., in Brooklyn Borough Hall, 209 Joralemon St., Brooklyn, NY; Hon. Christopher Shays, (chairman of the subcommittee) presiding.

Present: Representative Towns.

Also present: Senator Velmanette Montgomery.

Staff present: Kate Hickey, professional staff; Thomas M. Costa, clerk; and Cheryl Phelps, minority professional staff.

Mr. Shays. If I could, I would like to call this hearing to order.

My name is Christopher Shays. I serve with Ed Towns on this subcommittee that will be conducting this hearing today and I for the record need to read in a statement to give the parameters of what this hearing is about.

STATEMENT OF HON. CHRISTOPHER SHAYS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CONNECTICUT

Mr. Shays. It is my pleasure to in fact be in Brooklyn today and to convene this hearing with my colleague, Ed Towns, the ranking member and former chairman of this committee.

The purpose of today's hearing is to review how the Department of Health and Human Services, HHS, and private providers are preparing to bring health and support services to the expanding and changing AIDS population, primarily to minorities, women and children, where infection rates are growing rapidly. The dynamic nature of the AIDS epidemic demands that those infected have access to a variety of services such as medical, dental, housing and counseling services. Programs funded by HHS and the Department of Housing and Urban Development, HUD, such as the Ryan White CARE Act and the Housing Opportunities for People With AIDS, HOPWA, are important elements of that comprehensive effort.

In the 5 years since enactment, the Ryan White CARE Act has successfully helped States and municipalities establish mechanisms to provide needed services. HOPWA has provided funding for housing projects to alleviate homelessness among infected people. I believe both Ryan White and HOPWA programs have been successful in their missions.

Besides changing demographics, one challenge facing those planning AIDS services is the changing form of government's support. Block grants can enhance local decisionmaking and program coordination, but to some they represent the frightening prospect of uncertain funding in the face of relentness need.

While I support such grants, what concerns me about the appropriations fiscal 1996 mark for the HOPWA program is the reduction in funding levels. I do not want to see this program cut when so many people are sick and need help, desperately need help. According to the Center for Disease Control, more than 440,000 Americans have AIDS and more than 1 million have HIV. As of June 1994, African-Americans and Hispanics represented 56 percent of the newly reported cases, and women represented 17 percent, more than half of whom are between the age of 13 and 19.

Critical in the fight against AIDS is the role of HHS in assisting States, municipalities and local providers to plan strategically for the changing face of AIDS in our communities. In this hearing we will hear how some State, city and private providers are being innovative in providing needed services. We will also hear how HHS is assisting AIDS service organizations to insure that their programs meet changing recipient needs.

I would like to welcome all of our witnesses here. We have 14 people who will be testifying, so Ed and I are going to try to keep our questions down. We have four separate panels and both Ed and I have votes this afternoon, so we have an incentive to be efficient with our time. Before recognizing my colleague, I again want to welcome all who are here today. This is a very important hearing, and I want to put it in this context. We have a report to make to the full committee and the committee will be taking action; but both Ed and I are, as I said earlier, going to team up to see how we can look at the fiscal year 1996 appropriations to see how we can make changes to it that while not answering all the concerns I am sure will be raised today will answer some of them.

At this time I would like to call on my colleague, Ed Towns.

STATEMENT OF HON. EDOLPHUS TOWNS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

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

Let me begin by saying I really appreciate your leadership on this issue and I also appreciate the fact that you have this field hearing in a city that has been and continues to be impacted more by this disease than any other city in America.

Overall, this Northeast region tragically continues to lead the Nation in new AIDS cases. Just as this disease begins to impact new populations, Federal programs are being subjected to major restructuring and significant funding reductions. Now more than ever there will be a need for innovative and cost-effective government interventions.

We must recognize, however, that treatment of AIDS patients and eventual cure for this disease cannot be accomplished without continuing support from the Federal Government programs.

Today's hearing will focus on how services in the 1990's can be effectively delivered to emerging populations impacted by AIDS and HIV infection. Certainly we are hopeful that a cure will be found for this disease. Unfortunately, the latest research data indicates that a cure for HIV infection is not expected any time soon. Yet questions remain about the kind of research that is currently available. The National Institute of Health has been reluctant to do research on HIV infections in women and children. While AZT offers some hope for infants, many pharmaceutical companies have halted their research into AIDS drugs. While a cure for this disease is not on the horizon, we have yet to develop an effective means of halting the rapid infection rate in these new population groups.

Given the efforts in Congress to reduce the Federal deficit and balance the budget, one issue that must be addressed is whether adequate funding resources will be available. We will also need to explore whether new preventions, methods, are needed to halt the spread of this disease. For example, if intravenous drug use is a major factor in the HIV infection rate among women, should not we seriously consider needle exchange programs? I think that is something that we need to talk about and to come up with a decision real, real soon.

Mr. Chairman, I look forward to hearing the testimony of today's witnesses, as we seek to make governmental policy responsive to the new groups affected by the AIDS crisis in the 1990's.

And again, I would like to thank you for holding this hearing and again your leadership in this issue.

Mr. SHAYS. I thank the gentleman.

The mikes here are not going to pick up our sound. These are for transcribing. I am going to ask the witnesses to talk very loudly to us so that people in the audience can hear. Can you hear in the back at this level? OK. So you cannot speak loudly enough in this room.

At this time I would like the witnesses to stand up and then I will identify them afterwards. It is the practice of this committee in every hearing to swear in our witnesses. Mr. Moran, if you are in fact going to say something you need to be sworn in.

Do you solemnly swear that the testimony you will give before the subcommittee will be the truth, the whole truth, and nothing but the truth?

[Witnesses sworn.]

For the record, I note that all our witnesses have answered in the affirmative.

I am going to ask at this time unanimous consent that all members—it will basically be the two of us, but any other member of the subcommittee be permitted to place any opening statement in the record and that the record remain open for 3 days for that purpose. Without objection, so ordered.

I also ask unanimous consent that our witnesses be permitted to include their written statements in the record and any other information you would like to submit. Without objection, so ordered.

At this time I will identify our witnesses and we will go in this order: we have Mr. George Grob, Deputy Inspector General for Evaluation and Inspections, Department of Health and Human Services based in Washington. We appreciate you coming up here. We have Mr. Mark Nadel, Associate Director of Health Policy, U.S. General Accounting Office, also in Washington as well. Dr. Eric Goosby, Director of the Office of HIV and AIDS, Office of the Assistant Secretary of Health, Department of Health and Human Resources, as well from Washington. So we thank you for coming.

I am also going to thank at this time a constituent of mine, if I may use that, Debra Katz, coming from Stamford to be here.

Gentlemen, you have been sworn in. We will take you in the order that I introduced you. We would like your testimony to be 5 minutes or less and sincerely welcome it. So we will start with Mr. Grob.

STATEMENTS OF GEORGE GROB, DEPUTY INSPECTOR GENERAL FOR EVALUATION AND INSPECTIONS, DEPARTMENT OF HEALTH AND HUMAN SERVICES; ACCOMPANIED BY WILLIAM MORAN, REGIONAL INSPECTOR GENERAL FROM CHICAGO; MARK NADEL, ASSOCIATE DIRECTOR OF HEALTH POLICY, U.S. GENERAL ACCOUNTING OFFICE; DR. ERIC GOOSBY, DIRECTOR OF THE OFFICE OF HIV/AIDS POLICY, DEPARTMENT OF HEALTH AND HUMAN SERVICES; AND DR. STEVEN BOWEN, DIRECTOR OF THE RYAN WHITE PROGRAM AT THE HEALTH RESOURCES AND SERVICES ADMINISTRATION

Mr. GROB. Thank you very much, Mr. Chairman, and Representative Towns; and I am very pleased to have with me William Moran, who is our Regional Inspector General from Chicago. He has supervised numerous studies on the Ryan White Program, including the studies that we will be talking specifically about today.

We are here to tell you about the changing face of AIDS.

Mr. SHAYS. I am just going to interrupt you a second. Can you hear or is it kind of—yes; what I am going to suggest is that I have no problem with anyone who wants to sit on this side, I have no problem with all of you moving down, because I do not think we are going to reach the back. Halfway through, could you hear, sir? So anyone who cannot hear, it is going to be difficult to have this projected. We have mikes here and we have gotten rid of them, but we are facing that way; so anybody who wants to sit up here, be my guest, or anywhere else, just move on down. I am sorry to interrupt you, Mr. Grob.

Mr. GROB. That is all right.

Mr. SHAYS. If you would really make an attempt—if you maybe take off your coat, you can speak a little louder.

Mr. GROB. I will do that.

Mr. SHAYS. And if you start to speak softly, I am going to make you put your coat back on.

Mr. GROB. Would it help if I were to turn around and face——

Mr. SHAYS. I do not even mind if you turn sideways, if you would like. No, you just speak loudly, we are going to get you to speak real loud.

Mr. GROB. OK. Well, we are here today to tell you about the changing face of AIDS, about emerging populations who are at risk of contracting the virus and of suffering and dying from AIDS, and about the emerging network of care whose framework was established under the Ryan White Act to assist people with this disease.

This concept of the network of care is quite central to my testimony and I would like to pause for a moment to define what I mean by it. Under the Act, there are planning councils at the metropolitan level, consortia at the State level; there are various service groups that receive grants from these groups, and they in turn have connections to a wide array of service providers such as people who provide Medicaid services, social services. When I use the word network of care, I am referring to the entire network, both those that are directly funded by this program as well as those that are associated with it.

We bring our report to you today directly from the front lines, from victims, service workers, coordinators and planners, from many people who see, feel, and touch the disease every day.

Legislative authority for the Ryan White Act was to have expired last year. In anticipation of that we undertook a series of studies to examine various aspects of the program, including the study of the funding formula and various reports that describe the services provided under the different titles.

The last study that we did resulted in two reports that are related to local service coordination. Those are the two that I am going to talk about today and with your permission I would like those two studies to be part of the record; we have already provided copies to your staff. The last study put us on the scene. We wanted to learn what you cannot learn in books. We wanted to see whether the network of care was actually working.

So in the summer of 1994, Bill and his team went out and visited seven cities. They visited and observed the service operations, they reviewed funding and service plans, they listened to planning councils and committee meetings, they examined minutes of the meetings they gathered onsite, they held discussions with public health officials, grant administrators, local service providers, and persons who were infected and persons who have the AIDS disease. We did this because we expected to find and to ask the service providers about problems they might have in delivering services, and our mind was very much focused on administrative problems, in other words, what are the barriers that you are facing.

What happened in conducting the interviews is that the interviewees emphasized to us something that we had heard about, but were not really very much attuned to. Now in our line of business, I call this a screamer. You go out to ask people one set of questions but they all say, "Now wait a minute, I have got to tell you about something else." It is very important—and that is what happened in these interviews.

What we found out was about this emerging population, the change in the population. I have illustrated it on the charts that you see on the right-hand side of your platform. The initial population for AIDS we had all seen were primarily homosexual men, intravenous drug users, and people who were receiving the disease through the blood supply. Now what we found out when we talked to the people on the line, they were beginning to emphasize that we were seeing a different profile here—children, children orphaned by AIDS, heterosexual partners, poor women, immigrants. And of course, these categories emphasized to us were particularly afflicting the minority populations. These statistics I think are already pretty much on the record from the opening statement and we will hear more from our other speakers on this.

This changes very much the kind of response that is needed for the disease. In the beginning, we might have talked about an emphasis of not sharing needles, of having safe sex, of securing the safety of the blood supply. Now we find ourselves with a need to say how you can take care of children who will be orphaned. We now need adoption services and foster care services. We find people who because of their immigrant status may not speak English very well, and so now suddenly we need to have translators, and so on. On the chart next to it I have written down the constant needs of care that this network needs to provide and then some of the new ones that result from the changing profile of this population.

Now this is not cut and dry, it is not as if we started here and we ended up there. This is a continuous change that is occurring. It would be very important under this kind of situation for that network of care to have to respond to these changes. Now to some extent the Ryan White Act was very successful because it built in a self-adjustment to the network. The people who are infected and people who have the disease are on the planning councils and they are in the consortia, and the people who provide the services and see it coming are also on the groups that help plan the services. So to some extent the network is self adjusting and it seems to be working in some cases.

I could give a few examples; I will just give one from New York. In a 14-month period the people serving the New York area provided services to people from 30 different nationalities, and they found 11,000 children who were orphaned by AIDS and provided adoption and other child welfare services for that kind of group. So we see that this is happening.

But the network cannot adjust itself all by itself. It does need a little help. The primary thing that the people that we interviewed said to us was they wished that there was a greater exchange of information, they wished that if they knew what worked, they could tell somebody else about it; but if there was something somebody else was doing, they would sure like to hear about it. So one of the recommendations we made to the Public Health Service was to provide for a more systematic exchange of ideas among people who are in this network of care.

Another thing is that when the program was first started, the primary goal was to establish this network, to get the funds out there, to make things operational. Now this program has matured somewhat. It has been around 5 or 6 years. Now we have to pay attention to the more mundane things. We have to make sure that we systematically gather information, that we methodically evaluate what is happening, that in fact the programs that are out there comply with the various provisions of the act. In other words, we have to deal with it now as a maturing program.

In summary then, we feel we have got to make sure that the network of care really works. We need to get the biggest bank for the buck, we need to rapidly disseminate good ideas, and we need to make sure that the response network is accessible to everybody who is infected or who has the disease.

Thank you very much.

[The prepared statement of Mr. Grob follows:]

STATEMENT BY

GEORGE GROB

DEPUTY INSPECTOR GENERAL FOR EVALUATION

AND INSPECTIONS

OFFICE OF INSPECTOR GENERAL

DEPARTMENT OF HEALTH AND HUMAN SERVICES

BEFORE THE SUBCOMMITTEE ON HUMAN RESOURCES

AND INTERGOVERNMENTAL RELATIONS

OF THE HOUSE GOVERNMENT REFORM AND OVERSIGHT COMMITTEE

THE RYAN WHITE COMPREHENSIVE AIDS EMERGENCY ACT

JULY 17 1995

Good morning, Mr. Chairman, members of the subcommittee, and to all those present. I am George Grob, Deputy Inspector General in the Department of Health and Human Services.

I welcome the opportunity today to discuss the emerging populations affected by the HIV/AIDS epidemic and the ways some local communities respond to the increasing needs of these new populations. The Ryan White Act was created in part to provide health care to those who would not otherwise have access to health care, and to provide a comprehensive response to their needs and those of their family.

Over the past 2 years, the Inspector General's office has looked at a variety of Ryan White issues. We have previously examined the Act's funding formulas, reviewed data on expenditures, and analyzed consortia activities and special projects of national significance. These reports are of course available to the public.

After these efforts, we were most anxious to put the information in these reports in the context of how services are really delivered at the local level to those with HIV/AIDS. To gather information for our two recent reports, "The Ryan White Act: Local Implementation Issues," and "The Ryan White Act: Examples of Local Coordination," which I am submitting as part of this testimony, we went to the point of delivery of services in seven major cities across the country. We spoke with local Ryan White program administrators, public health officials, medical staff, case managers, HIV/AIDS patients, lawyers and others knowledgeable about Ryan White clients.

As a part of our visits, we reviewed funding and service plans along with progress reports, listened to issues discussed and deliberations held at planning council and committee meetings, visited and observed on-going operations at a wide variety of local providers who receive funding from a variety of sources including Ryan White, and we examined minutes of meetings and other material we collected on site.

We heard in city after city in the course of conducting our Ryan White studies that HIV and HIV/AIDS is not only a "gay, white male" disease, but emerging populations, comprised of African-Americans, Hispanics, Native

Americans, women, the young, immigrants and the non-English speaking, are more and more affected by HIV/AIDS. Recently, the Center for Disease Control and Prevention reported that minorities represent more than half the new AIDS cases in the U.S. Their report confirms what we heard.

Across the country, local government agencies, health care and social service providers told us they must reach the emerging populations afflicted by HIV/AIDS. These populations present special problems for these agencies and providers for a number of reasons:

- in minority, immigrant, and non-English speaking communities, cultural mores often discourage those who might be infected with HIV/AIDS from being tested or seeking treatment.
- women, often the primary caregivers themselves, may delay seeking treatment as they tend to their family needs first and foremost.
- overwhelming poverty of many in the emerging populations compounds the needs of those affected.
- in addition to living with HIV/AIDS, they may also suffer from substance abuse or addiction, homelessness, mental illness, or other conditions that require considerable care.

And these populations have additional needs in addition to those traditionally associated with gay, white males. As a result of the shift in the HIV/AIDS population, medical and service providers have been forced to expand from offering a basic range of services that usually included primary medical care, case management services, housing, substance abuse treatment, food banks, and transportation to various services. They still provide these services, but they must also develop and offer services geared to the emerging populations.

Other services especially needed by the emerging populations include: locating services in new neighborhoods, providing culturally sensitive services that target the emerging populations, using interpreters for non-English speaking clients, dealing with HIV/AIDS clients with multiple medical conditions, housing clients with other family members, providing day care for children of HIV/AIDS clients, and offering support services for children orphaned by AIDS.

We found examples of communities responding to each of the "increasing needs" of the emerging populations. I just want to highlight three of these responses among the many we found in our research.

In Los Angeles, a multilingual city, Ryan White funds are used to provide translators to assist a variety of non-English speaking clients with medical and social service providers. And since there can't be every type of translator at every Ryan White site, the translators travel to these offices to meet with the clients there to help them get served. One agency in particular uses translators who themselves are HIV positive, and they are also able to look out for the clients to help ensure they receive the services they need.

New Orleans, in response to the increases of infected women, and in conjunction with the Department of Housing and Urban Development, is now funding housing for families affected by HIV/AIDS. Multi-family homes are being rehabilitated to accommodate families with children. One site provides individual apartments for five adults and their children, and besides offering assistance with medications, activities of daily living and meal preparation, also offers mental health services, case management, skilled nursing, social activities, and transportation to appointments and community recreation.

And here in New York City, where some 11,000 children have been orphaned by AIDS, a model for the rest of the country was developed that provides orphan support services, including adoption services, for children of people who have died of, or are dying of AIDS. These services help prepare for and fill the gap in services experienced by children and their new guardians after the parents die. Ordinarily, no benefits would be available after death, but this program helps with transitional benefits for these children.

These are a but a few examples of how cities and providers are answering the needs of emerging populations.

Despite these and other efforts by local agencies and providers, service gaps to these clients exist. Considerable efforts must be made to bring services to clients' neighborhoods, or to provide them transportation to services at reasonable time and expense. Programs for women, minorities, young people, and the non-English speaking must attract these populations at an early stage in the disease, not only to provide them services, but to reinforce the public health message to help slow the spread of HIV/AIDS.

Clearly, much has been done, but much more remains to be done to serve all people affected by HIV/AIDS. With limited resources available, we must ensure that we are effectively targeting the use of Federal dollars. As we point out in our report, effective monitoring and evaluation can assist us in properly allocating and accounting for Ryan White funds.

Thank you for the opportunity to speak today. I will be glad to take any questions you may have for me.

Attachments:

Office of Inspector General reports

"The Ryan White Act: Local Implementation Issues" (OEI-05-93-00336)

"The Ryan White Act: Examples of Local Coordination" (OEI-05-93-00335)

CONSTANT AND CHANGING RYAN WHITE CLIENT NEEDS

Some Constant Needs	Some Increasing Needs
Basic medical care	Locating services in new neighborhoods
Case management service	Culturally sensitive services targeting emerging populations
Housing	Interpreters
Food banks	Programs for the Homeless
Substance abuse treatment	Mental Health Programs
Transportation to services	Housing for clients with multiple family members
	Day care
	Foster Care/Adoption services
	Orphan support services

CHANGES IN THE HIV/AIDS POPULATIONS

Initial Population	Emerging Populations
Homosexual Men	Children with HIV/AIDS
Intravenous Drug Users	Children orphaned by AIDS, but not infected
Blood Supply dependent groups (i.e., hemophiliacs)	Heterosexual partners
	Poor
	Women
	Immigrants

Mr. SHAYS. Thank you very much. Mr. Nadel, if you would like to speak next? I do hope you feel free to take off your jacket.

Mr. NADEL. I am fine. Thank you, Mr. Chairman.

Mr. Chairman, Mr. Towns. I appreciate the opportunity to be here today to discuss our report on access to federally funded services by women, minorities, and substance abusers and others, who have AIDS.

The AIDS epidemic is in a second decade and continues to increase at an alarming rate. In the early 1980's, communities began to address the need to provide services to people infected with HIV, and many community-based and AIDS service organizations were established to assist primarily gay white men. In 1990, the Ryan White CARE Act was enacted to improve the quality and availability of medical and support services; but with changes in the makeup of the HIV infected population and the increased availability of medical and social services through Ryan White, concerns have been raised about whether the service delivery system has been able to accommodate the needs of increasing numbers of minorities and women infected with HIV. Therefore, last year, GAO was asked to assess whether the CARE Act funding was reaching these groups.

This morning I would like to focus my comments first on who is getting services, and second, remaining barriers to care, and my comments are based on our January 1995 report. Because national data do not exist on populations served, we, like the IG, went to the localities and spent time talking to service providers. We visited Baltimore, Denver, Los Angeles, Sacramento, CA, and the Maryland suburbs of Washington, DC. In brief, we found that minorities, women and drug users generally use services at a rate that generally reflect their representation in the infected population. Nonetheless, these infected groups may have to rely on CARE Act funded services more than other subpopulations. Therefore, there still may be unmet needs for care.

Providers and advocates described barriers to care that are particularly difficult to overcome, such as homelessness, substance abuse, language and cultural differences.

I will now turn to our findings in more detail. Even as the profile of the epidemic is changing, local service delivery systems appear to be reaching increasing numbers of HIV infected minorities, women and drug abusers. This is especially important because minorities are becoming infected at a greater rate than whites. For example, African-Americans represent 12 percent of the Nation's population, but accounted for 33 percent of cumulative AIDS cases as of the end of 1994. Similarly, while Hispanics represent 9 percent of the population, they accounted for 17 percent of the cumulative AIDS cases. And these percentages, unfortunately, have been increasing.

Access to Ryan White medical and support services for minorities, women and drug users appears to be in proportion to their representation in the infected population. In our visits to the five areas, we compared the HIV infected populations with the number of clients served for certain periods as reported by the service providers. These estimates and reports identified such characteristics as race and ethnicity, gender and mode of transmission. And in my prepared statement we illustrate a figure in Baltimore which illustrates the rate of services in Baltimore, and we have a whole set of figures in our report which show the general proportionality over a range of different services.

We also asked advocates and various providers in the cities and they also affirm that the affected groups generally access services in proportion to their representation in the infected population. But these use rates of services, however, may not fully explain the need for services or access to services, although minorities, women and others, appear to receive services in proportion to the representation of the population, these groups may have to rely on Ryan White funded services even more than other groups. Minorities generally have lower incomes than whites and are much more likely to be without health insurance. Therefore, they are more likely to depend upon publicly funded services such as those funded by the Ryan White CARE Act.

I would like to turn now to some of the barriers that may limit access to services, and there are many barriers to access for HIV infected individuals that are particularly difficult to overcome. HIV infected people who are substance abusers and homeless have difficulty in seeking services because of the dysfunctional nature of their lives. For women, lack of child care limits their ability to make and keep appointments for services. Another problem in seeking services is the lack of adequate or appropriate transportation.

In some instances, the lack of knowledge about and the lack of motivation to seek services affect the extent to which people use these services. Providers said that some clients are seeking access to services only in the later stages of diseases, when much less can be done for them, because of denial of their having the disease or ignorance of the disease, or a lack of trust in the medical community. Also mentioned were cultural and language barriers. Several providers told us of people's reluctance to obtain care from providers who primarily serve a different racial or ethnic group. Some minorities and women are reluctant to obtain assistance from an organization that serves primarily a white male clientele or that is perceived as being oriented toward gays.

Providers, advocates and HIV infected persons whom we contacted acknowledged the benefits of the Ryan White CARE Act in providing services to all affected populations. However, to help in overcoming barriers to care, they also recognized the need for local outreach services, to make infected people aware of prevention, the availability of services, and the need to get medical attention early on. Such outreach services can increase the likelihood that HIV infected persons will receive needed services.

This concludes my prepared remarks and I would be pleased to respond to questions at the conclusion of the panel.

[The prepared statement of Mr. Nadel follows:]

United States General Accounting Office

GAO

Testimony

Before the Committee on Government Reform and Oversight,
Subcommittee on Human Resources and Intergovernmental
Relations, House of Representatives

For Release on Delivery
Expected at 11:00 a.m.
Monday, July 17, 1995

RYAN WHITE CARE ACT

Access to Services by Minorities, Women, and Substance Abusers

Statement of Mark V. Nadel, Associate Director
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GAO/T-HEHS-95-212

Mr. Chairman and Members of the Subcommittee:

I appreciate the opportunity to be here today to discuss our report on access to federally funded services by women, minorities, and substance abusers with the acquired immuno-deficiency syndrome (AIDS). The AIDS epidemic is in its second decade and, continues to escalate at an alarming rate. AIDS is the leading cause of death for men between 25 and 44 years old and the fourth leading cause of death for women in that age group. Recently the African-American and Hispanic communities have been particularly hard hit. And AIDS is affecting more women and injection drug users.

In the early 1980s, communities began to address the need to provide services to populations infected with the human immunodeficiency virus (HIV). Many community-based and AIDS service organizations were established to assist primarily gay, white men. In 1990, the Ryan White CARE Act (P.L. 101-381) was enacted to improve the quality and availability of medical and support services for individuals and families with HIV. But with changes in the makeup of the HIV-infected population and the increased availability of medical and social services through the CARE Act, concerns have been raised about whether the service delivery system has been able to accommodate the needs of increasing numbers of minorities and women infected with HIV. Therefore, we were asked last year to assess whether CARE Act funding was reaching these groups.

Today I would like to focus my comments on (1) who is getting services and (2) the barriers to care. My comments are based on our January 1995 report.[1] Because national data do not exist on populations served, we supplemented our information by visiting five areas--Baltimore; Denver; Los Angeles; Sacramento, California; and the Maryland suburbs of Washington, D.C.

In brief, we found that minorities, women, and injection drug users generally use services at a rate that reflect their representation in the HIV-infected population in the five areas we visited. Service providers and advocates of HIV-infected people in these communities agreed with this assessment of the patient population receiving Ryan White CARE Act-funded services. Nonetheless, these HIV-infected groups may have to rely on Ryan White CARE Act-funded services more so than other subpopulations. Therefore, there may still be unmet needs for care. Providers and advocates described barriers to care that are particularly difficult to overcome, such as homelessness, substance abuse, and language and cultural differences. Providers mentioned the importance of outreach to help overcome these barriers.

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[1] Ryan White CARE Act: Access to Services by Minorities, Women, and Substance Abusers (GAO-HEHS-95-49, Jan. 13, 1995).

BACKGROUND: RYAN WHITE CARE ACT

The Ryan White CARE Act provides federal funds to state and local areas for medical and support services for HIV-infected individuals and their families. For fiscal year 1995, 42 eligible metropolitan areas (EMA)[2] received $349.4 million under title I of the act; the 54 states and territories received $174.8 million under title II of the act.[3]

Under title I of the act, EMAs are required to establish planning councils that are made up of service providers and representatives of affected communities, among others. The councils develop a plan for service delivery and set priorities for allocating funds. The councils also provide input on which service providers receive funding. EMAs award CARE Act funds to providers of medical and support services. These providers include hospital outpatient clinics[4], community health centers, community-based organizations, and hospices, among others.

States and territories use title II funds in one or more ways. About one-half of title II funds are used to establish and operate HIV care consortia in areas most affected by HIV. These consortia--consisting of public and nonprofit private organizations that provide services to HIV-infected individuals and their families--assist in the planning, development, and delivery of medical and social services. In addition to funding consortia, states use title II funds to provide HIV-infected people with home and community-based care services; continuity of health insurance coverage; and prescription drugs, such as antiviral medications. The Division of HIV Services within the Department of Health and Human Services' Health Resources and Services Administration (HRSA) is responsible for awarding and monitoring title I and II grants.

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[2] To be eligible for funding, metropolitan areas must have more than 2,000 AIDS cases or a per capita incidence of 25 cumulative AIDS cases for every 100,000 people in the population.

[3] In addition to titles I and II, title IIIb supports outpatient early intervention HIV services for people with AIDS and HIV. For fiscal year 1994, $21.4 million was awarded to public and nonprofit private entities. Title IV provides for clinical research on therapies for pediatric patients and pregnant women with HIV and provides for health care to pediatric patients and their families. In fiscal year 1994, $46.5 million was awarded.

[4] Ryan White CARE Act funds cannot be used for in-patient care but can be used for in-patient case management services that expedite hospital discharge.

MINORITIES, WOMEN, AND INJECTION DRUG USERS ARE RECEIVING RYAN WHITE SERVICES

Even as the profile of the AIDS epidemic is changing, local service delivery systems appear to be reaching increasing numbers of HIV-infected minorities, women, and injection drug users. This is especially important because minorities are becoming infected at a greater rate than whites. For example, African-Americans represent 12 percent of the nation's population but accounted for 33 percent of the cumulative AIDS cases as of December 1994. Similarly, while Hispanics represent 9 percent of the population, they accounted for 17 percent of the cumulative AIDS cases. Another indicator of the changing profile of the epidemic is that as of September 1989, African-Americans and Hispanics accounted for 43 percent of cumulative AIDS cases, women for 10 percent, and injection drug users for 21 percent. By 1994, the distribution of newly reported AIDS cases was 58 percent African-American and Hispanic, 17 percent women, and 32 percent injection drug users.

Access to Ryan White CARE Act-funded medical and support services for minorities, women, and drug users appears to be in proportion to their representation in the HIV-infected population. In our visits to the five areas[5] we compared the HIV-infected populations, which were estimated by the EMAs and consortia, with the number of clients served for certain periods in 1994 as reported by service providers. These estimates and reports identified such characteristics as race/ethnicity, gender, and mode of transmission.[6] To illustrate the use of services in one city, Baltimore, figure 1 shows that the use of primary care services is generally in proportion to or slightly higher than the estimated HIV-infected population. (See our Jan. 1995 report for further examples of the distribution of services among affected populations in the five areas.)

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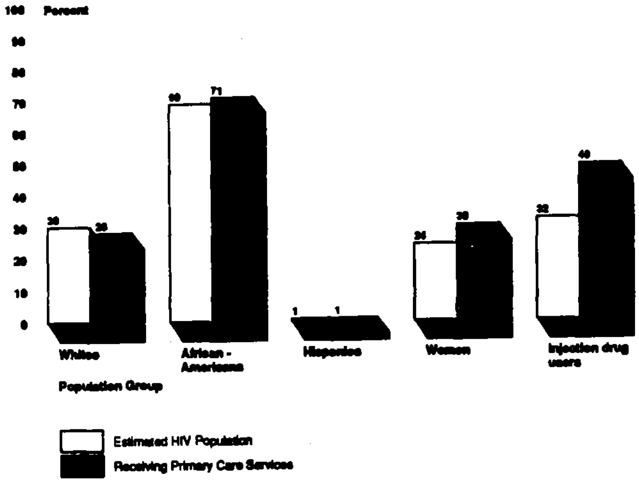
[5] We chose these areas on the basis of varying size and demographics of HIV-infected population, how long they have been receiving Ryan White CARE Act funding, and the amount of funding. We cannot generalize the results of our work to all Ryan White CARE Act-funded EMAs and consortia.

[6] At some areas, some service providers did not report one or more client characteristic, such as gender or risk group. In those areas, we could not compare all population and client characteristics.

Figure 1: Distribution of CARE Act-Funded Primary Care Services in the Baltimore EMA (Jan.-Mar. 1994)



Notes: Of the $4.6 million title I and II funds awarded in 1994, primary care services providers received 40.6 percent of the funds.

The Baltimore EMA estimates its HIV-infected population at 16,500 persons.

During the 3-month period, 839 primary care visits were conducted.

Advocates and providers we talked to affirmed that affected groups generally accessed services in proportion to their representation in the HIV-infected population. We obtained views on access from advocates and providers representing and serving various populations, including minorities, women, and injection drug users.

Use rates of CARE Act-funded services, however, may not fully explain access to or the need for services. Although minorities, women, and substance abusers appear to receive services in proportion to their representation in the population, these HIV-infected groups may have to rely on Ryan White CARE Act-funded services more so than other subpopulations. Minorities generally have lower incomes than whites and are much more likely to be without health insurance. Therefore, minorities are more likely to depend upon publicly funded services such as those funded by the Ryan White CARE Act.

BARRIERS MAY LIMIT ACCESS

Providers and advocates told us about many barriers to access for HIV-infected individuals that are particularly difficult to overcome. HIV-infected people who are substance abusers and homeless have difficulty in seeking services because of the dysfunctional nature of their lives. For women, lack of child care limits the ability to make and keep appointments for HIV-related services. Another problem in seeking services is the lack of transportation. One provider said that transportation subsidies, usually for bus fare, are provided to clients. However, some clients, such as women with small children or persons with disabilities, need other forms of transportation.

In some instances, the lack of knowledge about and lack of motivation to seek services affect the extent to which people use services. Providers said that some clients are seeking services during the later stages of infection. HIV-infected people in some cases do not seek services because of denial or ignorance of the disease and a lack of trust of the medical community. Also mentioned were cultural differences and language barriers that limit access.

Several providers told us of individuals' reluctance to obtain care from a provider of a certain racial or ethnic group or who primarily serves a different racial or ethnic group than that of the person seeking services. Some minorities and women are reluctant to obtain assistance from an organization that serves a predominately white male clientele or that is perceived as a gay white male organization.

Providers, advocates, and HIV-infected persons whom we contacted acknowledge the benefits that the Ryan White CARE Act has made in providing needed services to minorities, women, and substance abusers. However, to help in overcoming barriers to care, they also recognize the need for local outreach services to make HIV-infected people aware of prevention, the availability of services, and the need to seek medical attention early on. Such outreach services can increase the likelihood that HIV-infected persons receive needed services.

This concludes my prepared remarks. I would be pleased to respond to any questions you might have.

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This concludes my prepared remarks. I would be pleased to respond to any questions you might have.

Mr. SHAYS. Thank you very much. We have heard from the Inspector General, the GAO, and now Mr. Goosby, we welcome your comments.

Mr. GOOSBY. Thank you Mr. Chairman and Mr. Towns. I appreciate the opportunity to provide testimony on behalf of the Department of Health and Human Services.

I am Dr. Eric Goosby, Director of the Office of HIV/AIDS Policy, within the Office of the Assistant Secretary for Health. I am accompanied by Dr. Steven Bowen, the Associate Administrator for AIDS at the Health Resources and Services Administration.

Mr. SHAYS. I was wondering where he was and how he escaped getting sworn in. Feel free to come on and——

Mr. BOWEN. I will at the end.

Mr. SHAYS. I am going to ask you again, I am using your time a little bit. I would like you to really speak much louder than you are speaking.

Mr. GOOSBY. The program is a vital component of the Public Health Services' effort to combat the continuing HIV epidemic and has been highly successful in creating models of integrating Federal, State and local efforts to meet pressing needs for accessibility and access to appropriate care.

We have counted the numbers in the epidemic, but the numbers do not tell the whole story. The face of the epidemic continues to change, increasingly affecting women, children, adolescents, minority groups and other underserved populations. It is an expansion of the epidemic and not a movement from, and that all the originally identified groups that were present in 1981 continue to manifest and predominate in 1995.

A 1993 survey in several States with HIV reporting found women accounted for 54 percent of newly identified HIV infection among young youth aged 13 to 19, and 35 percent of reported HIV cases among people 20 to 24 years old. This trend brings with it greater numbers of children born with HIV infection, as we have heard, and tell the benefits of perhaps the O76 trial and the administration of AZT may help to impact on those numbers.

Minority populations have been and continue to be disproportionately affected by the HIV epidemic. Initially a disease primarily among gay white males, within a few years the proportion of cases among African-Americans and Latinos exceeded their representation in the U.S. population. In 1993 and 1994, over one-half of newly reported cases were in minority groups, although minorities account for only one-quarter of the U.S. population. In 1993, 38 percent of reported cases were African-American and 18 percent of Hispanic descent. Minority women have been particularly impacted, with three-quarters of new 1994 AIDS cases occurring among women reported within the African-American and Hispanic communities.

The changing face of AIDS also includes a greater proportion of diagnosed individuals who have no health insurance. A 1993 study showed only 26 percent of persons with AIDS had private health insurance; 62 percent were covered by some form of public insurance; and 12 percent were uninsured, reducing the likelihood they will receive cost-effective prophylactic medications and timely primary care.

The compelling public health reasons to address the HIV epidemic continue to be those characteristics of a transmissible, fatal disease which extracts a heavy price from society in loss of young, productive lives. Unlike heart disease and other chronic diseases, HIV/AIDS primarily affects young Americans and curtails their contributions.

The unique role of the Ryan White CARE Act is to provide a carefully designed program targeted to address the pressing need for accessible and appropriate care resulting from the HIV epidemic in cities and towns in our Nation. It is founded upon a strong partnership between the Federal Government and States and local communities to maximize resource allocation and distribution, and efforts at every level to coordinate responses to the epidemic.

The CARE Act has already been outlined for you, titles I through IV, so I will not repeat that. Several factors have substantial implications for the Ryan White CARE Act as a service delivery program. Increased availability of HIV counseling and testing activities have made more people knowledgeable of their HIV status, raising new demands for care. People with HIV are also living longer due to improved treatment strategies and the availability of growing cadre of health professionals who are knowledgeable in the care and treatment of HIV infected individuals from specific, unique communities. The AIDS Education and Training Center Program has been stressed in the need to expand to populations that have heretofore not developed sophisticated delivery systems for the care of HIV infected person, identifying deficits in understanding and education, and attempting to target educational interventions to the health professionals within those communities.

I want to turn briefly to the accomplishments of the Ryan White CARE Act. We have essentially seen a marked increase in access to care. Three hundred and twenty-five thousand people with HIV disease conservatively estimated having received health care and support services from the Ryan White CARE Act. We are in a position to say without doubt that the systems that have been orchestrated to deliver a continuum of medical services to HIV infected individuals have been most effective because of the ability to develop support services that keep and retain individuals in the continuum of care. The services provided through the Ryan White CARE Act cover a broad range of services, and I will not outline them for you; I have submitted this in writing to you.

Throughout the Ryan White CARE Act, programs have been emphasizing the development of these continuums of care, but have been less effective in dealing with multiply diagnosed individuals—individuals who bring to the health care delivery system not only a diagnosis of HIV but a diagnosis of tuberculosis, sexually transmitted diseases, serious mental illness, as well as homelessness and other social issues that can impede the ability to deliver effective medical services.

The Ryan White CARE Act has also increased the provider base. Hundreds to thousands of HIV infected individuals entering delivery systems throughout our country have precipitated an expansion of the awareness of how to diagnose and treat this disease within our health professional communities. The Federal, State and local partnership is also unique. I believe in keeping with the current trends in Congress, we have from the beginning tried to identify and maximize State and local responsibilities, not only for identifying needs, but more importantly for specifically targeting allocation decisions to those needs. Once targeted, the allocation decisions remain within the local environment for reaction to and adjustment of the targeting mechanisms. There has been a cost-effectiveness within all of the Ryan White programs; I believe that there is data that is currently available and will be expanded over the next 2 years to show specific movement away from emergency room use, and movement away from longer hospitalizations.

I want to briefly turn now——

Mr. SHAYS. Let me just—you are trying very hard to summarize for us——

Mr. GOOSBY. Yes.

Mr. SHAYS [continuing]. I appreciate it. I think if you could just try to wrap up in 1 minute; I think it would be unfair given the task you have.

Mr. GOOSBY. What have we seen and learned from the Ryan White CARE Act? We have learned a lot and we have attempted to incorporate the information that we have identified as problematic in our recommendations for reauthorization of the CARE Act. The program experience has demonstrated that service delivery in the early years of the grant is compromised by the need to prepare or revise inadequately developed existing plans for the coordination and delivery of HIV care services.

We want to strengthen local autonomy and decisionmaking and insure the response of the epidemic from region to region. The Department has recommended that private for-profit entities also be available for Ryan White funding to fill the gaps where private nonprofits do not exist. We also recommend that the legislation to reauthorize the CARE Act allow up to 10 percent for title I funds to be used for in-patient use.

There are several proposals that have been recommended to strengthen the participation of relevant stakeholders in local planning and priority settings. This is one of our main priorities. For title I of the legislation, the Department is requesting that a required minimum of 25 percent of the planning council membership be composed of persons with HIV and AIDS.

I will close now with the message that the Ryan White CARE Act has worked. It has worked because of the ability for multiple levels of government to define and identify specific needs within their populations and to target specific resources to those needs. And I might add that the perpetuation of this focused targeting, the authority being attained in the allocating body, is the key to an expanding and responsive delivery system. Thank you very much.

Mr. SHAYS. Doctor, thank you. I know you had a lot more in your statement and it will be submitted for the record and will be covered.

I am going to ask Mr. Towns if he has a question, I will have one question, then we will get on to our next panel.

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

Let me just make certain that I understood you clearly, Doctor, that you said that in 1994 that 56 percent of the new cases were blacks and Hispanics?

Mr. GOOSBY. That is correct.

Mr. TOWNS. What special concern should we have about these new population groups' access to treatment? Can you share with us some of the various treatment that these groups might face?

Mr. GOOSBY. Congressman, you bring up, I think, a very important issue. Minority populations in this country historically have not had access to medical services. That deals with any disease, looking at any group in any geographic area. The reason for that is multifactorial; but the bottom line of it is that our minority populations have more difficulty entering care and being retained in care. This is true for HIV infected minority populations as well. It is also true that the epidemiology of the epidemic, focusing and beginning with gay white men initially, had delivery systems that were responsive to the needs of that population, and I might add appropriately so.

As the expansion of the epidemic continued and as we began to see greater movement into minority populations, women and children, adolescents in particular, we attempted to identify this trend, this expansion, and move the awareness of the planning bodies toward responding to the specific needs of these populations. Grounding the decision-process and the definition of the needs of the population has been the key to linking resource allocation with service expansion to serve different populations that were not originally identified.

I think that this work is not done yet. And with continued vigilance and continued support through technical assistance, as well as the identification of effective models to increase access and delivery points of care with mechanisms and systems that support the individual and keeping them in care, I believe that we will continue to have an impact on those numbers.

Mr. TOWNS. One last question, Mr. Chairman.

There has been a lot of discussion about needle exchange and of course here in this city there has been an ongoing debate. Can I get your views on that?

Mr. SHAYS. The short version.

Mr. GOOSBY. The short version?

Mr. SHAYS. The bottom line.

Mr. GOOSBY. This is a very difficult issue. I believe you are correct once again to bring it up as something that needs to have ongoing discussion.

Currently we are constrained by a mandate from Senator Helms that puts the impetus on the Assistant Secretary of Health to identify research that shows that the use of needles does not increase drug use within the needle exchange population, those using the needle exchange program; and second, that it does not increase drug paraphernalia present in the community in and around the needle exchange program, and that it does indeed decrease the actual sharing of needles within the IV drug using population that utilizes the program.

There have been a number of studies that have shown—that have shed light—that is positive on this issue, and there have been a number of studies that have shown that these questions have not been met. The Assistant Secretary continues to monitor the literature, both published and unpublished, to try to get to the point where we can answer that honestly, with a degree of assurity that is acceptable to the Assistant Secretary, and the Surgeon General, before going ahead and opening up Federal funding for needle exchange support. Currently States and cities, if their laws so allow, can put their resources into needle exchange programs.

[The prepared statement of Dr. Goosby follows:]

WRITTEN TESTIMONY
AIDS IN THE '90'S; SERVICES DELIVERY TO EMERGING POPULATIONS
BEFORE
THE HOUSE SUBCOMMITTEE
ON HUMAN RESOURCES AND INTERGOVERNMENTAL RELATIONS
OF THE COMMITTEE ON GOVERNMENT REFORM AND OVERSIGHT

July 17, 1995

Submitted by Eric P. Goosby, M.D.
Director, Office of HIV/AIDS Policy
Office of the Assistant Secretary for Health
United States Public Health Service
Department of Health and Human Services

Mr. Chairman and Members of the committee, thank you for the opportunity to provide testimony on behalf of the Department of Health and Human Services in addressing "AIDS in the 90's; Services Delivery to Emerging Populations." I am Dr. Eric Goosby, Director of the Office of HIV/AIDS Policy within the Office of the Assistant Secretary for Health and I am accompanied by Dr. Steven Bowen, the Director of the Ryan White program at the Health Resources and Services Administration. We are here to discuss the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 and its impact and potential for providing essential health care and support services for individuals and communities affected by HIV disease. This program is a vital component of the Public Health Service's effort to combat the continuing HIV epidemic, and has been a highly successful model of integrating Federal, State and local efforts to meet pressing needs for accessible and appropriate care.

When the Ryan White CARE Act was passed by a bipartisan majority in Congress and signed by President Bush five years ago, it was the first targeted Federal response to address the urgent health care delivery needs resulting from the HIV epidemic. In some urban areas, the health care crisis had reached emergency proportions, far exceeding the ability of local health departments, emergency rooms, community-based providers and hospitals to respond to the increasing need for care. Today, because of the Ryan White CARE Act program, these cities are able to keep open the doors of community clinics which offer hope and care to people living with AIDS, and to provide care at home instead of in high cost hospitals. To people living with HIV/AIDS, the Ryan White CARE Act program has been a lifeline of care and compassion--enabling them to live longer, more productive lives while researchers continue the search for a cure to give them back their futures.

The Face of the Epidemic

In terms of sheer numbers, the HIV epidemic remains one of the top public health problems facing the nation today. AIDS is now the leading cause of death among Americans between the ages of 25 to 44 years, representing a tremendous loss to society of productive individuals in their prime. Over 440,000 cases of AIDS have been reported to the Centers for Disease Control and Prevention (CDC), and almost a quarter of a million have died of AIDS since the first case was recognized 13 years ago. It is estimated that approximately one million Americans carry the virus, with an estimated minimum 43,000 new HIV infections expected annually by the CDC in the next few years.

Numbers alone do not tell the whole story. The face of the epidemic continues to change, increasingly affecting women, children, adolescents, minority groups and other underserved populations. The spread of HIV among women has increased dramatically and shows no signs of abating. Cases among women are increasing by roughly 17 percent a year, and growing numbers of women are contracting HIV through heterosexual contact. In 1994, women accounted for 18 percent of the new cases among adults. A 1993 survey in several States with HIV reporting found women accounted for 54 percent of newly identified HIV infections among youth aged 13-19, and 35 percent of reported HIV cases among people 20-24 years old. This trend brings with it greater numbers of children born with HIV infection, until the benefits of the AIDS Clinical Trials Group (ACTG) 076 trial are more widely available. The ACTG 076 trial demonstrated that perinatal transmission of HIV could be reduced in a specific cohort of HIV infected women by two-thirds.

Minority populations have been and continue to be disproportionately affected by the HIV epidemic. Initially a disease among gay white males, within a few years the proportion of cases among African Americans and Latinos exceeded their representation in the U.S. population. In 1993 and 1994, over one-half of newly reported AIDS cases were in minority groups, although minorities account for only one-quarter of the U.S. population. In 1993, 38 percent of reported cases were African American and 18 percent of Hispanic descent. Minority women have been particularly impacted, with three-quarters of new 1994 AIDS cases among women reported within the African American and Hispanic communities.

The epidemic has also spread geographically and now confronts health and support service providers and families in all parts of the country. The rising rate of growth of cases in rural and small urban areas poses new demands in communities confronting HIV infection for the first time. Concurrently, the epidemic is not shifting out of the highly impacted urban epicenters, as over two-thirds of new cases were still reported in high incidence cities between July 1992 and June 1994.

The changing face of AIDS also includes a greater proportion of diagnosed individuals who have no health insurance. A 1993 study showed only 26 percent of persons with AIDS had private health insurance; 62 percent were covered by some form of public insurance; and 12 percent were uninsured (Fleishman and Mor), reducing the likelihood they will receive cost-effective prophylactic medications and timely primary care.

The compelling public health reasons to address the HIV epidemic continue to be those characteristics of a transmissible, fatal disease which exacts a heavy price from society in loss of young, productive lives. Unlike heart disease and other chronic illnesses, HIV/AIDS primarily affects young Americans and curtails their work contributions. The growing number of persons with HIV requiring care continues to place a heavy burden on health care delivery systems, particularly on those public health entities that are already struggling to meet high volumes of uncompensated care. By diagnosing and treating young people with HIV disease, their productive years are lengthened and their need for publicly funded care reduced. Through proactive planning and providing a continuum of care for persons with HIV, significant savings in both economic and human terms can be gained, and efforts to contain the epidemic strengthened. Our strong resolve to address this epidemic in a coordinated, comprehensive manner now maximizes our investment for a healthy America tomorrow.

The Role of the Ryan White CARE Act

The Ryan White CARE Act is a carefully designed program targeted to address the pressing need for accessible and appropriate care resulting from the HIV epidemic in cities and towns across the country. It is founded upon a strong partnership between the Federal government and States and local communities, to maximize resources and efforts at every level for a coordinated response to the epidemic.

The purposes of the four Ryan White CARE Act titles differ somewhat as they target specific aspects of the epidemic. Title I is intended to provide substantial resources to cities facing high HIV/AIDS caseloads, to sustain and develop systems of care that emphasize a continuum of services and reduce inpatient burdens. Title II enables States to improve the quality, availability and organization of health and support services for individuals with HIV disease and their families more broadly throughout each State. Title III(b) provides primary medical care and other services through health centers in underserved areas which face an increasing demand for HIV care. Title IV combines the goals of pediatric HIV research with family-centered health and support services to meet the unique needs of adolescents, children and their mothers for HIV care. Together the titles function to put in place a strong national/State partnership to respond to the effects of the epidemic.

The Ryan White CARE Act supports the development of systems of care which are responsive to local needs and resources. Health and support services are too often fragmented, overwhelmed in high incidence areas, and nonexistent in others so that access to cost-effective care is jeopardized. Through a structure of locally determined needs assessments and funding decisions, the Ryan White CARE Act provides the backbone for communities to address gaps in services and enable people with HIV to access and stay in care. The Ryan White CARE Act has also assisted States and communities to plan ahead for service delivery needs in areas where the number of HIV/AIDS cases may still be low.

Several factors have substantial implications for the Ryan White CARE Act as a service delivery program. Increasing availability of HIV counseling and testing activities have made more people knowledgeable of their HIV status, raising demand for care. People with HIV are also living longer due to improved treatment strategies and the availability of a growing cadre of health professionals knowledgeable in the care of HIV disease, which were supported by the Ryan White CARE Act and the AIDS Education and Training Center Program. This rising demand, along with the increasing impact of HIV in communities and populations with unique and multiple needs for access and care, significantly affect the background in which the Ryan White CARE Act is placed.

Accomplishments of the Ryan White CARE Act

Increased Access to Care

The Ryan White CARE Act has made a broad range of health care and support services available to increasing numbers of people with HIV/AIDS. By a conservative estimate, over 300,000 people with HIV disease have received health care and support services under the Ryan White CARE Act since 1991. Many who would have died are now alive and leading productive lives. An estimated 75,000 people with HIV disease have received medications that prolong and improve the quality of their lives through the Title II option for pharmaceuticals; more than 200,000 have received health care and support services through coordinated consortias of care since 1991. Title III(b) grantees provide primary medical care and other needed services to 40,000 people with or at risk for HIV disease, and Title IV serves 11,900 HIV positive or affected women and children. The following are examples of increased access to services in various community settings:

Houston: The number of patients being served by the Thomas Street Clinic has grown from 765 in 1991 to more than 3,500 in 1994.

Kansas City: As the result of one year of Title I funding,the number of people in care grew from 250 in late 1993 to over 1,100 in 1994, and the total number of physician visits increased from 346 to 15,246 in that same period.

Chicago: The Chicago Department of Health's Early Intervention Program has increased five-fold in roughly two years, growing from 60 to over 527 the number of people entering care between 1992 and 1994.

Philadelphia: The number of people receiving comprehensive care services was doubled at five Public Health District health centers located in neighborhoods with the highest incidence of HIV and the least number of residents with health insurance.

Ft. Lauderdale: The number of children receiving care through the Comprehensive Pediatric AIDS Project grew from 70 in 1991 to an active caseload of over 400 in 1994, for a total of 860 clients in three years.

Atlanta: The number of patients receiving outpatient primary care through Grady Memorial Hospital, the only public hospital serving metropolitan Atlanta, grew from 969 adults and 166 children in 1991 to over 5,000 adults and 400 children in 1994.

Missouri: The Ryan White CARE Act funds enabled the State to develop through its consortia a network of 116 primary care health professionals providing care to people living in rural areas. It includes family practitioners, internists, infectious disease specialists, ophthalmologists, oncologists and psychiatrists. Uninsured patients are able to receive timely medical care for a lesser cost than if they had to travel long distances to an urban center. In the first year (1993) 92 patients were served; in the first 6 months of 1994, over 100 patients received care.

Pennsylvania: A seven State funded consortia served 4,600 patients with HIV in 1992 and 5,884 patients in 1993, providing both primary medical care and dental care, home health care, substance abuse treatment and related support services.

Florida: Before Title II funding was available, the HIV clinic in Pensacola operated one day per week and served 70 patients. The clinic is now open five days a week and serves over 500 active patients. The Sun Coast AIDS Network which previously provided care to 462 patients each quarter now serves of 1000 patients in that time. Recent approval to purchase a van for a mobile HIV clinic will make it possible to deliver medical care to HIV/AIDS patients living in rural areas of northwest Florida who otherwise would have to travel over two hours for routine medical care and treatment.

While these examples highlight the success of increasing the number of people able to access care, there are still critical shortages in the availability of services. More primary care providers are needed in both rural and urban underserved areas, and many individuals are not yet able to receive needed services due to insufficient resources. A particular challenge that is being addressed by Ryan White CARE Act grantees is developing strategies and service capabilities to respond to the changing demographics of HIV which increasingly affect minority populations, injection drug users, and poor women and children. Many of these individuals are uninsured and face substantial barriers to entering and staying in a system of care. In a January 1995 report, the General Accounting Office documented the effectiveness of the Ryan White CARE Act in reaching out to serve these emerging populations, while noting that cultural and social barriers continue to make this an important focus.

Services Provided Through the Ryan White CARE Act

The Ryan White CARE Act has made a broad range of health care and support services available to people with HIV/AIDS, including primary medical care, prescription drugs, home health care and hospice care, dental care, drug abuse treatment, HIV prevention counseling, case management, and linkages with housing assistance and transportation to enable people to access and remain in care. Services for members of minority groups and other special needs populations such as women and children, adolescents, and the homeless are increasing and becoming more appropriate and accessible. Programs have also expanded services for persons with HIV/AIDS who are also substance abusers or who have TB. Because of differing local demographics of the epidemic, and varying gaps in local health care delivery systems, the funding priorities and services provided through the Ryan White CARE Act vary among grantees in accordance with local planning council and State consortia allocation decisions.

Throughout the Ryan White CARE Act programs there has been an emphasis on developing a continuum of care to provide alternatives to costly inpatient care. Studies have shown that provision of adequate primary health care significantly delays or prevents the onset of disabling opportunistic infections, and as a result reduces unnecessary hospitalizations. Individuals with HIV enrolled in primary care are less likely to use emergency rooms or be hospitalized for Pneumocystis carinii pneumonia (PCP), tuberculosis (TB), and other bacterial infections. This produces cost savings in both the public and private sectors. One case of prolonged hospitalization for multiple-drug resistant TB can cost more than $100,000; for each case in which PCP hospitalization is prevented, $14,000 is saved.

A key component of the continuum of care has been the development of case managers who facilitate timely access to needed services, reduce emergency room and acute care hospital use, maximize efficient use of all available benefits, and promote coordination of health and social services creating a "system of care" for individuals. Under Title I, the services most frequently funded to achieve this continuum include primary medical care, case management, mental health treatment, substance abuse treatment, and housing. As an example, Baltimore, Maryland increased the number of agencies providing ambulatory medical and support services from 51 to 85 between 1991 and 1993. Within Title II, in addition to pharmaceuticals and insurance continuation programs, services funded most frequently are primary medical care, home health care, case management, mental health services, and dental care. Under Title III(b), critical services added or expanded include increased access to early intervention primary care services, outreach, HIV pre- and post-test counseling, TB testing, and support services such as food assistance and linkages to housing. Title IV grantees have supported increased outreach, counseling and testing activities, and provision of AZT to mothers and infants to reduce transmission of HIV. Throughout each Ryan White CARE Act Title, it is clear that Federal resources are to be used as a last resort when services are not reimbursable through other Federal, State or local programs.

The Special Projects of National Significance (SPNS) grant program has provided a unique opportunity to develop innovative models of care for specific populations. Several of the projects have been funded in low incidence areas, where traditional models of service delivery are unavailable or do not work. Groups such as rural populations, American Indians/Alaska Natives, adolescents, and women and children present special challenges in the delivery and range of services needed. To date seventy-four projects have been funded. Many new challenges lie ahead such as examining the effects of managed care on HIV service delivery systems.

Increasing the Provider Base

A key feature of building expanded service capacity has been supporting the development of a larger number of providers willing and able to serve persons with HIV/AIDS. Under Title I, more than 1700 providers now deliver a comprehensive range of medical care and related services to persons with HIV disease living in 42 major metropolitan areas. Under Title II, HIV care consortia have contracted with over 1500 providers to ensure the availability of care statewide. There are more than 130 providers of primary care and prevention services funded under Title III(b), serving a high proportion of women and minority people living in urban and rural areas. Through Title IV, services for women and children are available through 199 affiliated clinical sites located throughout 26 States.

The activities of the AIDS Education and Training Center (AETC) Program have provided critical support in developing and sustaining a broad-based network of providers trained in HIV care. Through a wide range of activities, including regional workshops, conferences, direct and telephone consultation services for physicians and other health professionals, AETCs have supported the goals of providing up-to-date information on the treatment and care of people with HIV/AIDS. These activities have had a significant effect in increasing services for persons with HIV, and the Department recommends that this program be formally linked as an integral component of the Ryan White CARE Act.

Federal, State, and Local Partnerships

A major hallmark of the Ryan White CARE Act has been the successful partnerships developed between the Federal government and State and local HIV planning councils and consortia. In a time of limited resources, the need to effectively target and coordinate efforts to address the HIV epidemic is increasingly urgent. Through the Ryan White CARE Act, Federal resources are provided to States and localities to assess their needs and design effective strategies to meet them. Because the characteristics of HIV and its impact differ widely from city to city and State to State, local flexibility has been essential to use resources most efficiently. A unique feature of the Ryan White CARE Act has been the participation of those groups most affected by HIV--persons living with HIV and the providers who serve them--in the comprehensive needs assessment and planning processes, including setting local priorities and making funding allocation decisions among them.

Under Title I, local planning councils have emphasized the vitally important participation of people with HIV disease in these local processes. Among the 34 Title I planning councils in Fiscal Year (FY) 1994, the mean and median percentage of council members who reported having HIV/AIDS was 20 percent. Representation from minority communities is also vital as these communities bear a disproportionate burden of new

AIDS cases. In FY 1994, the mean percentage of council members who were African American was 25 percent; persons of Hispanic descent comprised 10 percent of planning council membership (excluding Puerto Rico).

State consortia funded under Title II have also sought diverse representation from local public health agencies and health care providers, bringing mental health and substance abuse agencies together with social service agencies, community based organizations, and people with HIV/AIDS. The vast majority (92%) of consortia reported they had participated in the development of State HIV/AIDS plans, thereby ensuring a unified and coordinated approach to services throughout the State.

Cost-Effectiveness of Care

Delivery of health care services to persons with HIV in the setting most appropriate to their needs has been a goal within the Ryan White CARE Act. By emphasizing a continuum of care services, Ryan White CARE Act grantees have been able to report numerous examples of cost savings made possible through Ryan White CARE Act funded activities. The following are examples of cost-effectiveness identified in local programs:

Reno, Nevada: The Washoe County District Health Department's Early Intervention Clinic funded under Title III(b) has a caseload of 225 to 275 HIV positive clients. An analysis of calls received on the after-hours call line showed that nurses were able to prevent 90 unnecessary emergency room visits by prescribing medications or arranging for clinic visits the following day. This success rate so impressed two Reno hospitals that they each provided $50,000 grants to the clinic in 1993 to support HIV-related direct patient care.

Massachusetts: Massachusetts measured the rate of hospitalization, and the number of at-home deaths versus in-hospital deaths as an indicator of the impact of Title II funds. Acknowledging other variables, the State found that the average length of hospitalization for people with AIDS decreased from 11.9 to 9.4 days pre- and post- implementation of the Ryan White CARE Act. During this same period, the average length of stay for all other diagnoses increased from 6.6 to 7.0 days. Hospital discharges of persons with AIDS who had a referral to a home care agency increased from 8.9% to 13.7%. The percentage of people with AIDS who have died at home has increased from 10.8% to 24%.

Georgia: A study within the State found that people with AIDS who received case management lived significantly longer between HIV diagnosis and death, and had significantly lower hospital-based charges.

New York: A study of New York State Medicaid recipients found that patients who took AZT were hospitalized fewer days per month and had reduced Medicaid expenditures. Receipt of AZT therapy, in turn, was related to having a primary care provider or specialist care. In another study it was found that the average length of hospital stay in New York State for HIV/AIDS patients declined from 19.8 to 16.1 days from 1990 to 1993. Further, clients who had access to Ryan White CARE Act funded outpatient services also had better survival rates than those who did not; 88 percent of HIV/AIDS patients (all stages) survived two years with Ryan White CARE Act services versus 55 percent for those without.

New Jersey: In 1993, the pediatric AIDS Clinic at Children's Hospital of New Jersey supported under Title IV reported that outpatient care had decreased hospital admission by 33 percent, and decreased mean duration of hospitalization by almost 50 percent compared to data collected 2-3 years earlier.

In addition, evidence from four States--Florida, Hawaii, Minnesota and Wisconsin--suggests that Title II health insurance continuation programs (HICP) have resulted in significant cost savings. When these States compared the estimated costs of care for all HICP-eligible clients with the total costs of their health insurance continuation programs, they found savings of $1.3 million over one year, or $9384 per HICP client each year. The larger the percentage of clients with late stage HIV disease who would otherwise receive publicly funded care, the greater the cost advantages. Title II funded health insurance continuation programs also allow people with HIV to maintain employment with reduced hours or part-time work without loss of insurance; the cost of their health insurance premiums are at least partially offset by the taxes they pay. Under the HICP provisions of Title II, twenty States reported serving 2,828 clients, making premium payments for 20,492 client months in 1993.

Delivery of Care in Rural Settings

The Ryan White CARE Act has played an essential role in increasing access to HIV-related care and services in rural areas. In many States, Title II is the only source of funding for these services. Rural or statewide consortia have been vital in linking people with HIV with primary health care and case management services, as well as pharmaceutical and health insurance programs. Forty one States have developed consortia, which serve multi-county regions or an entire State. The following are examples of improved access to care among rural residents:

New Mexico: New Mexico has improved rural services through a Statewide case management system, implemented through home health agencies, and addition of a mail service delivery option in the State's drug assistance program, which ensures delivery of medications within 2 days of a physician's prescription. In the last 2 years, New Mexico has experienced a four-fold increase in clients, and in 1994 served more than 700 clients.

Missouri: Missouri has developed a network of 116 primary care physician providers to serve rural patients. Patients who do not have private insurance or Medicaid are able to receive medical care, with services provided closer to their homes. Through a SPNS grant, 15 rural resource centers were established, each of which has trained and activated a large corps of volunteers. The centers also operate telephone support groups designed to overcome barriers of distance and poor health.

North Carolina: North Carolina has emphasized the development and support of HIV task forces in local counties to assure adequate assessment of service needs and the provision of appropriate resources. All 100 counties now have access to HIV care services through 15 regional consortia.

In addition, twenty-four American Indian tribes have benefited from Ryan White CARE Act funding of a nearby major service provider, enabling clients with AIDS to remain at home in rural or reservation settings instead of traveling to urban centers for care.

Planning for the Future

When the Ryan White CARE Act was enacted five years ago, it represented the first serious targeted Federal effort to support local and State care for persons living with HIV. Over the past four years, this process has led to the extraordinary development and enhancement of systems of care to provide comprehensive services to persons living with HIV disease. The Ryan White CARE Act works. It combines targeting of resources, local planning and flexibility in directing funds to newly impacted areas and emerging populations. It has substantially increased the number of people in care while saving money. The basic structure has been successful, requiring only limited changes.

The Department's experience in administering the program and reviews by external organizations have identified several issues that this reauthorization process will provide the opportunity to address. These include questions ranging from appropriate funding formulas to the need for more program evaluation at the local and national level.

The Department has been working, in collaboration with grantees, national organizations, providers, and people living with HIV disease, on these and other program implementation and improvement issues. Progress has been made and the work continues to both streamline processes and administrative requirements and retain and strengthen accountability for service delivery.

From deliberations regarding reauthorization of the Ryan White CARE Act the Department has developed specific recommendations to address these issues and meet the challenges the Department foresees in the next five years of the epidemic. These issues and recommendations are summarized below.

Program experience has demonstrated that service delivery in the early years of a Title I grant is compromised by the need to prepare or revise inadequately developed existing plans for the coordination and delivery of HIV services. The creation of a local planning and decision-making process, and the coordination of resources with other Title XXVI programs, pose critical challenges for the communities which are about to become eligible metropolitan areas (EMA). First year grants under Title I would be utilized more effectively in realizing the emergency provisions of the legislation if new EMAs were awarded small, one-time planning grants to complete the essential groundwork of the HIV Planning Council. The Department recommends making one-time planning grants available to EMAs expected to qualify in the next funding cycle, to assist them in complying with the expedited funding allocation process required of Title I grantees.

Ongoing challenges for all grantees include developing and implementing methodologies to achieve community-based comprehensive needs assessment and planning, and to integrate these activities within a broader statewide assessment of need. Technical assistance is often sought by grantees to assist them in these efforts and the development of specific service systems, such as case management, primary/specialty medical care, community-based home care, and transportation. The Department recommends making technical assistance more readily available to all grantees.

To maintain and build upon the service delivery systems that have been put in place with Ryan White CARE Act funding, the Department recommends that localities funded through Title I have a maintenance of effort provision similar to that in Title II, requiring continuation of HIV-related care services from one year to the next. Maintenance of effort requirements are important for ensuring the mandate that Ryan White funds be used to supplement, not supplant, existing local expenditures for HIV-related care services.

Strengthening local autonomy and decision-making will ensure responsiveness to the epidemic from region to region. To enhance local autonomy the Department recommends private for-profit entities to be permitted to contract for the delivery of services, when they provide the only available or highest quality of HIV care. For many grantees, for-profit entities are important components in the continuum of care for people with and at risk of HIV. The current language that restricts contract funding to public and private non-profit entities in which we believe negatively affects the development of such care, and limits HIV care options for these populations.

We also recommend that the legislation to reauthorize the Ryan White CARE Act allow up to 10 percent of Title I funds to be used for inpatient hospital costs under a capitated care model. Capitated systems of care are being used more and more by the public and private health sectors as a cost effective way to provide health care services. Because the current Ryan White CARE Act legislation does not provide for use of Title I funds for inpatient care, grantees have not been able to use a capitated systems option for persons with HIV/AIDS.

To increase accountability for quality of care the Department recommends the establishment of performance measures that are mutually negotiated between the Federal government and grantees. Treatment regimens for HIV disease have become more firmly established over time, yet they continue to change as new medical advances are incorporated into practice. Providers in community-based settings, especially those in rural or remote areas or those with low HIV caseloads, would benefit from a coordinated effort to provide current information on quality of care standards. The Department recommends a provision for allowing the Secretary to establish, in consultation with State grantees, providers, and affected communities, recommendations for a minimum drug formulary. State drug formularies currently range from one drug - AZT - to all Food and Drug Administration approved drugs for HIV and opportunistic infections, creating an issue of inequitable access to HIV treatment based on residence. Establishment of a recommended minimum drug formulary will provide States with a standard by which they can compare their treatment program. Finally, the Department proposes that all grantees be required to implement quality assurance procedures based on quality of care indicators developed through a collaborative process between the Department, professional associations, national organizations and representatives of HIV service organizations, and grantees funded under the Ryan White CARE Act.

The Department also recommends that the legislation explicitly identify substance abuse treatment and programs as eligible uses of funds. Because the legislation does not specifically identify substance abuse treatment as a fundable service, some local jurisdictions may believe they cannot use Ryan White CARE Act funds for this purpose. Legislative revisions to the Ryan White CARE Act would clarify that funds may be used to address the unmet substance abuse treatment needs of persons with HIV disease, as it directly affects the ability to retain such persons in HIV treatment.

Several proposals are being recommended by the Department to strengthen the participation of all relevant stakeholders in local planning and priority setting processes. For Title I of the legislation, the Department is requesting that a required minimum of 25 percent of the Planning Council membership be composed of persons with HIV/AIDS, and that such membership be reflective of the demographics of the HIV epidemic in the EMA. Further, the Department recommends that the required membership of the Planning Councils be revised to enhance representation.

The Department is also recommending proposals to streamline the Ryan White CARE Act by increasing coordinated planning among all Federal HIV-related programs. In addition to expanded representation on Title I Planning Councils, increased coordination for planning is being proposed through the establishment of a State-level assessment of HIV-related needs and resources. A more comprehensive array of entities and other grantees funded under the Ryan White CARE Act within the State would be included in the development of a State-level assessment of need. The requested requirement for a State-level assessment of HIV-related needs and resources would ensure that the needs of people with HIV are identified and addressed in a more comprehensive and consistent manner, and that scarce resources are used more efficiently and are not duplicated in providing services to people living with HIV disease.

Finally, the Department also recommends changing the formalized date a metropolitan area may become eligible for Title I assistance. Under current law, a metropolitan area qualifies for Title I assistance if it has more than 2,000 cumulative cases of AIDS or a .0025 per capita incidence of cumulative cases reported to the CDC as of March 31st of the most recent fiscal year. This provision makes it very difficult for the Department to accurately project how many cities may qualify for Title I funds in the coming fiscal year when preparing the President's budget.

The Department recommends moving this qualifying date up by three months to December 31st of the preceding year. In other words, FY 1996 eligibility would be based on CDC AIDS surveillance data reported on December 31, 1994. This would allow the Department to more precisely project the number of new metropolitan areas that will qualify for Title I assistance in the fiscal year.

The Department also recommends increasing the minimum formula award to States under Title II from $100,000 to $250,000. The requested $250,000 minimum allotment would provide the support necessary for States with low numbers of reported AIDS cases to develop a better coordinated and more effective statewide program of services for individuals with HIV disease, and carry out the Statewide assessment of need described above.

An example is the State of Missouri. Ryan White CARE Act Title II funds have enabled the State through its consortia to develop a network of 116 primary care physicians to provide care to patients living in rural areas. It includes family practitioners, internists, infectious disease specialists, ophthalmologists, psychiatrists and oncologist. In first year, 92 patients were served while in the first six months of 1994, over 110 received care. This effort was coordinated by the State health officer who also coordinates sexually transmitted diseases, and tuberculosis. With an increase in the minimum award the State would be able to dedicate a larger portion of the officers time to HIV service development.

The Department also recommends a single application and single award for Title I to streamline the formula and application process. By combining applications for the formula and supplemental awards, grantees would be able to redirect time and effort now spent on the application process to improving the delivery of services to individuals with HIV disease quickly and efficiently.

The Department also seeks giving the Secretary the authority to use unexpended and uncancelled formula funds for Titles I and II after the end of a fiscal year to offset a future grant award to the grantee. This responds to the urgent need to make funds available to the areas of greatest need where they can be quickly utilized for the delivery of services.

The Department is also recommending the option of a waiver from the requirement that States use 15 percent of its award to provide health and support services to infants, children, adolescents, and women. Under this proposal, the Secretary would be given authority to grant waivers for this requirement to States with low incidences of HIV in these populations. The States, however, must demonstrate that there is an existing system of care to meet the needs of these populations.

The Department recommends a statutory limitation to clarify that eligible cities for Title I funds must be metropolitan areas of at least 500,000 with at least 2,000 cumulative cases of AIDS reported to CDC. The 0.0025 cumulative rate factor for Title I eligibility increasingly confers eligibility for funding on small and medium-sized communities with relatively small numbers of AIDS cases. Funding these communities diverts funds from major urban areas that are experiencing an emergency in health/support services delivery for people living with HIV.

The Department recommends that two new Ryan White CARE Act titles be established that would authorize the Special Projects of National Significance (SPNS) and AIDS Education and Training Center Program (AETC) programs as separate grant programs. The SPNS program represents a critically important vehicle for identifying, evaluating, and disseminating innovative models for providing care more effectively to people living with HIV. Funding the program as a set aside of the total Ryan White CARE Act appropriation would recognize SPNS' contribution to Ryan White CARE Act programs as a whole. It would remove the entire financial obligation for the SPNS program from Title II and share responsibility for support proportionately across all the Ryan White CARE Act programs. The reauthorization of the AETC program is necessary due to the continuing spread of the HIV epidemic, which has resulted in increased training needs for health care providers in government-funded settings and in the private sector. We believe the AETC program should be moved to Title XXVI because the location of the current authority in Title VII does not reflect appropriately the linkage between the AETC program and the Ryan White programs under Title XXVI. Moving the AETC program to the Ryan White CARE Act would maximize the linkage of training to the Ryan White service programs, and would serve to increase coordination and collaboration among the programs.

Considerable discussion has occurred regarding whether, and how, funding formulas under Title I and Title II should be modified. The Department does not have a specific position or recommendation on this issue. However, if any changes should be made to the formulas for allocating Ryan White CARE Act funds, the Department would urge that deliberations be guided by the following principles. First, ensure that substantial targeted resources are available to those communities whose public health infrastructure is most heavily affected by providing services to people living with HIV disease. Secondly, that any alteration in funding distribution take care to ensure that those service delivery systems put in place with Ryan White CARE Act funds over the last four years not face catastrophic disruption. Diminishing the capacity of existing service delivery systems which are providing essential care is not in best interest of an effective response to the HIV epidemic.

The Department recommends that the legislation include a provision allowing the Secretary to utilize supplemental funds from Title I to ensure that no EMA will receive less formula funds in FY 1996 than they received in FY 1995. In subsequent years, the Secretary would be given discretion to use supplemental funds to ensure that formula awards for adversely impacted communities would remain at no less than 90 percent of their previous year award.

Conclusion

The Ryan White CARE Act works--a strong and healthy partnership between the Federal government, States and local communities. And the Ryan White CARE Act must continue, as the HIV epidemic has not abated. The epidemic is now expanding to affect new areas of the country as well as continuing to batter the health delivery systems of urban epicenters. From the public health perspective, until there is a cure for AIDS our best defense is to offer and sustain people living with HIV in a coordinated system of care.

The Ryan White CARE Act emphasizes the appropriate relationship between the Federal, State, and local governments and links local autonomy with retention of accountability. The HIV epidemic is a national public health priority, but strategies to support the delivery of health and support services are best designed locally. The Ryan White CARE Act is currently in the reauthorization process and we look forward to working with members of Congress to strengthen it while retaining its capacity to be responsive to the evolving nature of this epidemic. I am pleased to respond to any questions you may have.

Mr. TOWNS. Mr. Chairman, I yield back; but before I yield back, I would like to say that I think that you really make a case in terms when you talk about access to care for Federal presence, I really think that it is still important that we are involved in it, and to say to you that we need to find a way to make certain that the funding flow follows the problem. Because if you really wanted to address this situation and do it effectively, then we have to find a way that the dollars go to where the problems are, and I think that in some instances that might not be the case. So I am concerned about that, Mr. Chairman, and I think we need to continue to look to make certain that we do address that issue. And I yield back.

Mr. SHAYS. Thank you, gentlemen.

I know all of you have traveled a bit, and so this is kind of quick and we should take more of your time, but the message comes through, and I want to ask you this. Do any of you disagree with anything that has been said by anyone else in this table? To me it is a remarkably consistent message. Is it fair to use this chart, or others, Mr. Nadel? Is this chart pretty accurate?

Mr. NADEL. That is entirely consistent with our findings.

Mr. SHAYS. And we are going to call this the Screaming what?

Mr. NADEL. The Screaming Issue, perhaps.

Mr. SHAYS. The Screaming Issue. OK, it is an unexpected issue that in the course of your investigation became very obvious to you.

Mr. NADEL. Yes.

Mr. SHAYS. You were asking one question, you were getting a different answer, and this was the answer you were getting.

Mr. NADEL. Yes.

Mr. SHAYS. And that opens up the purpose for this hearing. So basically you all have served the ball, it is in play now. We are going to ask your next panel to start to respond to it.

I just want to thank each and every one of you, and you do not need to stay if you do not want to, and thank you for being here. I have been told, having been a quasi-New Yorker since I live 30 miles away, that New Yorkers are not bashful, and if you are having trouble hearing, you can literally take your chair and put it in front of us here and around. So if you cannot hear, it is your own fault. I believe in accountability.

We are going to ask our next witnesses to come, and that is Dr. Benjamin Mojica, who is the acting commissioner of Health, New York City Department of Health; we are going to have Mr. Ronald Johnson, city-wide coordinator, Office of the Mayor AIDS Policy Office; and Dr. Nilsa Gutierrez, director of the AIDS Institute, New York State Title II Grantee; and then Mrs. Debra Katz, AIDS program coordinator, in the great city, the great city of Stamford, my home town.

If all of you would come—do not sit down because we are going to swear you in. And we need new names up front here too.

If you would raise your right hand please? Do you solemnly swear that the testimony you will give before this subcommittee will be the truth, the whole truth, and nothing but the truth?

[Witnesses sworn.]

For the record, all have answered in the affirmative. Quietly, though all did.

We will start with Dr. Mojica, if you would begin.

STATEMENTS OF DR. BENJAMIN MOJICA, ACTING COMMISSIONER, NEW YORK CITY DEPARTMENT OF HEALTH; ACCOMPANIED BY DR. NILSA GUTIERREZ, DIRECTOR OF THE AIDS INSTITUTE, NEW YORK STATE TITLE II GRANTEE; AND DEBRA KATZ, AIDS PROGRAM COORDINATOR, STAMFORD DEPARTMENT OF HEALTH, STATE OF CONNECTICUT TITLE II GRANTEE

Mr. MOJICA. Good morning. Thank you, Mr. Chairman.

Mr. SHAYS. Good morning. I will again remind you to speak very loudly. I am going to be a little more strict on the 5-minute rule here and I will try not to interrupt you.

Mr. MOJICA. I will do that. I have never been known to raise my voice but I will try to now.

Mr. SHAYS. It is not loud enough.

Mr. MOJICA. Good morning. Mr. Chairman, Mr. Towns, I have brought along with me assistant commissioner Mitchell Netburn, for the Ryan White CARE Services, the city of New York.

I am Ben Mojica, I am acting commissioner for the city of New York, the City Health Department. Thank you for inviting us to testify today on the topic of service delivery to emerging populations affected by the AIDS epidemic.

Every week, close to 200 new AIDS cases are reported in New York City and approximately 130 people die of this illness. New York City, one of the first areas in the Nation to be struck by AIDS, continues to be the center of this tragic epidemic, with a total of 17 percent of all AIDS cases in the United States, although we just have 3 percent of the U.S. population.

The epidemic remains tragically dynamic with an increasing number of cases and some dramatic changes in the population affected. Since the beginning of this decade, intravenous drug use, as a risk activity, has been increasing and, indeed, has surpassed sex between men as the leading cause of transmission for men. There has also been a steady increase in AIDS cases among women with transmission attributed to substance abuse and sex with infected male partners. Infants born with HIV are the tragic outcome of women with HIV infection.

Minorities have been disproportionately affected by the epidemic. Black and Latino New Yorkers make up, respectively, 25 percent and 24 percent of the city population, but over the course of the epidemic, 39 percent of people reported with AIDS have been black and 30 percent Latino. Whites constitute 43 percent of the population but only 30 percent of the AIDS cases. Additionally, women of color are much more likely than white women to have AIDS. Black women have accounted for 53 percent and Latino women for 33 percent of all cases reported among women in New York City. The impact of AIDS is not limited only to those populations, however; 444 cases have been reported among Asian/Pacific Islanders and 22 among Native Americans and Native Alaskans since the beginning of the epidemic.

Women now constitute 23 percent of all cumulative AIDS cases in New York's eligible metropolitan area, as defined by the Ryan White CARE Act. More than half of these HIV infected women appear to be concentrated in three poor, largely black and Hispanic communities—the South Bronx, Central Brooklyn and Upper Manhattan—where the health care and social service infrastructure requires continuing and increased support.

Also, many HIV infected women are single parents, often with HIV infected children. Therefore, effective service delivery to this population must not only encompass their immediate medical needs, but also provide services such as day care or home attendants which enable women to access the medical and social services they so desperately require. It is also important to stress the toll of AIDS on the lives of the uninfected. In 1993, the Orphan Project, a not-for-profit organization, found that in New York City alone, AIDS had orphaned 5,400 children under 12 years and 5,400 children between 13 and 17 years old.

This changing face of the epidemic, the comorbidity of HIV with tuberculosis, sexually transmitted diseases, and mental illness, and the presence of social problems including homelessness, have served to complicate delivery of vital health services and prevention activities. The HIV/AIDS epidemic in New York City, therefore, presents unique challenges to service delivery. It has become a continuing challenge, indeed, to provide accessible, effective, and affordable services to these various communities with their own specific needs.

The Ryan White CARE Act has funded critically needed AIDS service programs within and outside the city of New York and the Health Department. Ryan White moneys support innovative and effective programs that address the very complex needs of a sometimes difficult to reach population—programs which would disappear without this crucial funding, leaving these communities cruelly underserved. Unlike Medicaid and other local entitlements, title I gives us the flexibility to respond quickly to the shifting needs created by the HIV/AIDS emergency.

Although title I funds are used for services to HIV infected people and not for prevention, we believe that the title I program has helped to curtail the spread of the epidemic as well, since participation in services motivates people to adopt safer practices that reduce the likelihood of transmission. As the AIDS epidemic increasingly affects women, adolescents and young adults, and new minority groups composed of recent immigrants, it is even more crucial to link prevention and education efforts with direct services. We are supportive of the increased emphasis being placed by the Federal Government on linking prevention and service delivery.

Consistent with this linkage, another critical component of effective AIDS service delivery is local community participation in the planning process. Under title I of the Ryan White CARE Act, New York City has created the HIV Health and Human Services Planning Council which sets the priorities and allocation of the Ryan White funds. New York City has also formed the HIV Community Prevention Planning Group which is funded by the Centers for Disease Control and Prevention, and like the Ryan White Planning Council is composed of community service providers, elected officials, and government agencies.

I would now describe to you selected programs administered through the Department of Health.

Mr. SHAYS. I am going to have to ask you to summarize, Doctor. I am sorry.

Mr. **Mojica.** I will summarize what we have said.

Mr. **Shays.** We have let everyone know that their testimony was to be 5 minutes, so if you could just end.

Mr. **Mojica.** We have said that there is an emerging population in New York City that has been since affected by the AIDS epidemic and that we need to provide to them accessible and affordable health services for all. I will now be happy to answer questions.

[The prepared statement of Dr. Mojica follows:]

TESTIMONY BY
BENJAMIN MOJICA, M.D., M.P.H.
ACTING COMMISSIONER
CITY OF NEW YORK
DEPARTMENT OF HEALTH
BEFORE THE
SUBCOMMITTEE ON HUMAN RESOURCES
AND INTERGOVERNMENTAL RELATIONS
"AIDS in the '90s: Service Delivery to Emerging Populations"
JULY 17, 1995

Good Morning. Thank you for inviting me to testify today on the topic of service delivery to emerging populations affected by the AIDS epidemic.

Every week, close to 200 new AIDS cases are reported in New York City and approximately 130 people die of this illness. New York City, one of the first areas in the nation to be struck by AIDS, continues to be the center of this tragic epidemic, with a total of 17% of all AIDS cases in the United States, although we have just 3% of the U.S. population.

The epidemic remains tragically dynamic with an increasing number of cases and some dramatic changes in the population affected. Since the beginning of this decade, intravenous drug use, as a risk activity, has been increasing and, indeed, has surpassed sex between men as the leading cause of transmission for men. There has also been a steady increase in AIDS cases among women with transmission attributed to substance abuse and sex with infected male partners. Infants born with HIV are the tragic outcome of women with HIV infection.

Minorities have been disproportionately affected by the epidemic. Black and Latino New Yorkers make up, respectively, 25% and 24% of the City population, but over the course of the epidemic, 39% of people reported with AIDS have been Black and 30% Latino. Whites constitute 43% of the population but only 30% of the AIDS cases. Additionally, women of color are much more likely than white women to have AIDS. Black women have accounted for 53% and Latina women for 33% of all cases reported among women in New York City. The impact of AIDS is not limited only to those populations, however: 444 cases have been reported among Asian/Pacific Islanders and 22 among Native Americans and Native Alaskans since the beginning of the epidemic.

Women now constitute 23% of all cumulative AIDS cases in New York's Eligible Metropolitan Area as defined by the Ryan White CARE Act. More than half of these HIV-infected women appear to be concentrated in three poor, largely Black and Hispanic, communities -- the South Bronx, Central Brooklyn, and Upper Manhattan -- where the health care and social service infrastructure requires continuing and increased support. Also, many HIV-infected women are single parents, often with HIV-infected children. Therefore, effective service delivery to this population must not only encompass their immediate medical needs but also provide services such as day care or home attendants which enable women to access the medical and social services they so desperately require. It is also important to stress the toll AIDS takes on the lives of the uninfected. In 1993, the Orphan Project, a not-for-profit organization, found that in New York City alone, AIDS had orphaned 5,400 children under 12 and 5,400 children between 13 and 17.

This changing face of the epidemic, the co-morbidity of HIV with tuberculosis, sexually transmitted diseases, and mental illness, and the presence of social problems including homelessness have served to complicate delivery of vital health services and prevention activities. The HIV/AIDS epidemic in New York City, therefore, presents unique challenges to service delivery. It has become a continuing challenge, indeed, to provide accessible, effective, and affordable services to these various communities with their own specific needs.

The Ryan White CARE Act has funded critically needed AIDS service programs within and outside of the Department of Health. Ryan White monies support innovative and effective programs that address the very complex needs of a sometimes difficult to reach population - programs which would disappear without this crucial funding, leaving these communities cruelly under served. Unlike Medicaid and other local entitlement programs, Title I gives us the flexibility to respond quickly to the shifting needs created by the HIV/AIDS emergency. Although Title I funds are used for services to HIV-infected people and not for prevention, we believe that the Title I program has helped to curtail the spread of the epidemic, since participation in services motivates people to adopt safer practices that reduce the likelihood of transmission. As the AIDS epidemic increasingly affects women, adolescents and young adults, and new minority groups composed of recent immigrants, it is even more crucial to link prevention and education efforts with direct services. We are supportive of the increased emphasis being placed by the federal government on linking prevention and service delivery.

Consistent with this linkage, another critical component of effective AIDS services delivery is local community participation in the planning process. Under Title I of the Ryan White CARE Act, New York City has created the HIV Health and Human Services Planning Council which sets the priorities and allocation of the Ryan White funds. New York City has also formed the HIV Community PreventionPlanning Group (PPG) which is funded by the Centers for Disease Control and Prevention, and like the Ryan White Planning Council is composed of community service providers, elected officials, and governmental agencies. The PPG serves to identify new needs and articulate policies in areas of HIV prevention services. New York City's AIDS Policy Coordinator, who is appointed by the Mayor, serves on both panels, and our Departmental staff work closely with both groups to assure a coordinated and comprehensive approach in planning for both prevention and service delivery programs.

I would now like to describe to you selected programs administered through the Department of Health with federal support which provide direct services to emerging populations, notably women and minorities affected by AIDS.

Services to Women

Women represent nearly one in every four HIV-infected adults in our metropolitan area. Seventeen percent ofall pregnant women in New York City receive late or no prenatal care, while 50% of all births in New York City are covered by Medicaid. These statistics emphasize the barriers to care that so many women and their children in New York City face. Because HIV-infected women have increased health needs that differ from men's, and are often single parents with limited mobility, special initiatives are needed to assure that they obtain essential services. Ryan White Title I funding has been especially critical in meeting the needs of these women.

A mobile van is now reaching HIV-infected women in under served areas in Central Brooklyn. The van provides, in addition to primary care, gynecological, prenatal, and nutritional counseling services. In cooperation with social services agencies, social services are provided to the women who obtain health care from the van.

A community site that is convenient to where many HIV-infected women live now offers a new program that includes substance use counseling, case management, 12-step groups that specialize in drug and alcohol problems, psychological counseling, and training in parenting skills. The agency carries on intensive coordination and follow-up to assure that HIV-infected women in the program obtain the primary health care and other social services they need.

In a collaborative effort with the New York State AIDS Institute, we have identified six facilities in poor New York City neighborhoods with high numbers of HIV-infected women as new or expanded sites for HIV primary care. The programs now being organized at these sites are expected to serve more than 700 HIV-infected persons, of whom a large proportion will be women.

Services to Minority Communities

The Early Intervention Program (EIP) establishes links between health care providers and the HIV-infected individual whose treatment can be enhanced with early medical care and social services. This link is intended to eliminate or reduce social, psychological, and economic problems. Located in Brooklyn, the EIP program provides services to approximately 1000 HIV positive clients annually from African-American, Caribbean and Spanish-speaking cultures.

Immigrants, both legal and undocumented, are included in many minority communities. The Department is deeply concerned about the proposed restriction of immigrants' access to health care services as part of the House and Senate welfare reform proposals. The federal proposals currently under discussion would eliminate the availability of numerous benefits essential to the health of immigrants residing in the United States. The Prevention Planning Group is especially concerned that the denial of preventive services to immigrants is penny-wise and pound foolish. This denial will result in a higher number of people relying on emergency care, which is in fact, a more costly and less effective method of care.

I have described these services to emphasize the very real ways in which collaborative work between the federal agencies (HHS and CDC) and localities (DOH) can provide vital and specialized services to those most in need. I will now be happy to answer any questions you may have.

Mr. SHAYS. We will have some questions. I thank you.

Dr. Gutierrez, that is a mike that does not project; it is just for the transcriber. You have no mike, that is why you have to speak loudly. There is no mike on the table. You have a beautiful, loud voice, and you can project it. We have taken our mikes away too, so we can be on equal footing here.

Dr. GUTIERREZ. Thank you for your compliment. I am Dr. Gutierrez, I am the director of the AIDS Institute——

Mr. SHAYS. You had a harder time saying your name that I did.

Dr. GUTIERREZ [continuing]. Yes. I am the director of the AIDS Institute for the Department of Health, and we are responsible for tracking the HIV epidemic throughout New York State and that tracking guides us with statewide planning in the areas of prevention, care and support services. So I appreciate the opportunity being here.

As you have heard, and you know, New York State leads the Nation in AIDS cases and we certainly have the greater proportion of injection drug users, that is, 50 percent versus 31 percent for the Nation. We have many more women, 20 percent versus 13 percent for the Nation, and people of color, 68 percent versus 50 percent.

There are approximately 28,000 people in New York living with AIDS, with an estimated 250,000 persons with HIV infection. We expect this to grow over 4 years, up to about 130,000 people, and as you know it continues to be the leading cause of death in New York among males the ages between 30 and 49, and women between the ages of 25 and 39. Approximately 80 percent of New York's AIDS cases are found in New York City.

So while everyone knows that the epidemic is alive and well and still in the gay community, HIV infection in minority communities amongst women and drug users was well established as far back as 1987, when AIDS was the leading cause of death in the black community amongst women. So this is a very, very old story. If we want to get a sense of the magnitude of the problem over time, New York cases reported in 1994 reflect the following trend: 75 percent were among minorities, up from 62 percent in 1990; 25 percent were among women, up from 18 percent in 1990——

Mr. SHAYS. I am sorry, just so I am following you—is this 75 percent of new cases?

Dr. GUTIERREZ. Correct, reported in 1994.

Mr. SHAYS. In the city?

Dr. GUTIERREZ. In New York State, of which the majority are in the city. And 54 percent were among IV drug users, up from 48 percent in 1990.

As you also know, the HIV epidemic is not identical in all communities, and so if you look at neighborhood-based information, you can see that for example amongst women the case rate may be as high as 35, 40 percent. That is important. So what we do, what the Institute does, is to develop programs and services with both State and Federal dollars that really strives to establish health and support services within communities with significant caseloads with particular needs.

With funds from the Ryan White CARE Act, New York has created three reimbursement pools that provide free medications, home care and primary health care to persons with HIV infection that lack insurance. And then to assist us in targeting title II funds to populations with special needs, we have established a statewide AIDS service delivery consortium made up of care providers, persons with HIV, and other individuals qualified to offer guidance on our efforts to serve these populations.

With over $12 million of State funding we created a program called the Multiple Service Agency Initiative which really looks to establish comprehensive HIV care programs run by organizations that are native to those communities, and we specifically selected minority communities throughout the State. These comprehensive one-stop shopping programs are established so that neighborhoods, communities, can take ownership of this issue and of the problem, and we have also established community development programs that look to provide African-American, Latino, Asian and Pacific Islander and Native American communities with the means to identify the needs and expand service delivery. This is with State dollars.

In addition to these grant-funded programs, the Institute has utilized an HIV-specific Medicaid reimbursement rate, clinical training, and a unique quality improvement program to New York, to insure that health care services are widely available and of the highest quality, and that they are standardized.

The Medicaid system, as you know, in New York is under transition to managed care on a statewide basis. For emerging populations in the AIDS epidemic and for those where the epidemic is well-established, this transition is particularly important as the great majority of them rely on Medicaid for their health services.

Before the State began to shift to managed care, New York DOH recognized the need to enhance the understanding of managed care systems and the implications of this transition for services to people with HIV, and with this in mind we secured a SPNS grant under the Ryan White CARE Act to look at cost, quality, and access data on patients with HIV, under a managed care system, as well as fee for service. This information will be used to establish actuarial rates, monitor the quality of access to care under managed care, evaluate utilization thresholds, and monitor changes in delivery systems that result in the shift to managed care.

This project has the potential to serve as a national model to develop HIV specific services within a managed care setting.

Mr. SHAYS. Can I ask you to summarize?

Dr. GUTIERREZ. OK, this is very difficult, but let me tell you——

Mr. SHAYS. I understand it is, I apologize.

Dr. GUTIERREZ. I understand.

Mr. SHAYS. We would just like an opportunity for questions as well.

Dr. GUTIERREZ. I guess I would say this: that we are working very hard under the New York State waiver. There is a specific charge to the AIDS Institute to develop something called a special needs plan for people with HIV infection and the purpose is to do a couple of things, to ensure that the current HIV care providers, both medical and community-based, remain an integral part of that service delivery system, that we insure quality by applying our quality of care program to those managed care programs, as well as to the special needs plans for people with HIV, to insure that case finding occurs aggressively and in an aggressive way, and that we support particular things like permanency planning, which you may be familiar with, that case management as we know it retains its character and quality, whether it be in traditional HIV care providers or in a managed care environment.

[The prepared statement of Dr. Gutierrez follows:]

TESTIMONY BY

DR. NILSA GUTIERREZ

DIRECTOR, AIDS INSTITUTE

NEW YORK STATE DEPARTMENT OF HEALTH

BEFORE THE

HOUSE SUBCOMMITTEE ON HUMAN RESOURCES AND INTERGOVERNMENTAL RELATIONS

MONDAY, JULY 17, 1995

BROOKLYN BOROUGH HALL

NEW YORK, NEW YORK

Good morning. My name is Dr. Nilsa Gutierrez, and I am Director of the AIDS Institute, the office in the New York State Department of Health responsible for HIV-related prevention and health care programs. I appreciate the opportunity to come before you this morning to address the needs of emerging populations in the AIDS epidemic.

New York State leads the nation in cumulative AIDS incidence, accounting for 20% of the total and has a significantly different profile from that of the rest of the country. New York State has a greater proportion of injection drug users (50% vs. 31%), women (20% vs. 13%) and people of color (68% vs. 50%).

There are approximately 28,000 New Yorkers living with AIDS and an estimated 250,000 with HIV infection. AIDS cases in New York are expected to grow by 65% in the next four years, to a cumulative total of over 130,000. AIDS continues to be the leading cause of death among New York males age 30-49 and females age 25-39. Approximately 80% of New York's AIDS cases are found in New York City.

While the epidemic continues to heavily impact the gay community, in New York and in other states, AIDS is increasingly an epidemic of minorities, women, and injection drug users. New York cases reported in 1994 reflect this trend: 75% were among minorities, up from 62% in 1990; 25% were among women, up from 18% in 1990; and 54% were among IV drug users, up from 48% in 1990.

Because the HIV epidemic across communities is not identical, the AIDS Institute has developed programs and services, with both state and federal dollars, that strive to establish health and social services within communities and regions with significant caseloads.

With funds from the Ryan White CARE Act, New York has created three "reimbursement pools" that provide free medications, home care, and primary health care to persons with HIV/AIDS that lack insurance. To assist us in the targeting of other Title II funding to emerging and special needs populations, we established a Statewide AIDS Service Delivery Consortium made up of care providers, persons with AIDS, and other individuals qualified to offer guidance on our efforts to serve these populations.

With over $12 million in state funding, we have created Multiple Service Agencies (MSAs), which are programs located in, run by, and providing services to minority communities across the state. These are "one-stop" comprehensive programs, offering a range of services including prevention education, case management and supportive counseling. We have also established "community development" programs to provide African-American, Latino, Asian/Pacific Islander and Native American communities with the means to identify needs and expand service capacity.

In addition to these grant-funded programs, the Institute has utilized HIV-specific Medicaid reimbursement rates, clinical training, and quality improvement activities to ensure that health care services are widely available and of the highest quality. These efforts are particularly important in addressing the HIV-related needs of persons in emerging populations, many of whom reside in areas characterized by a shortage of appropriate primary health care services, let alone the kind of sophisticated care persons with AIDS require.

As you know, the Medicaid system in New York has begun a transition to managed care on a statewide basis. For emerging populations in the AIDS epidemic--minorities, women, and intravenous drug users--this transition is particularly important as the great majority of them rely on Medicaid for their health care services.

Before the State began the shift to managed care, the New York State Department of Health recognized the need to enhance its understanding of managed care systems and the implications of this transition for services to persons with AIDS. With this in mind, the AIDS Institute secured a Special Projects of National Significance (SPNS) grant under the Ryan White CARE Act to provide us with cost, quality, and access data on patients with HIV in both managed care and fee-for-service systems. This information will be used to help establish actuarial rates, monitor the quality of and access to care under managed care, evaluate utilization thresholds, and monitor changes in service delivery systems that result from the shift to managed care.

This project has the potential to serve as a national model for the development of HIV-specific managed care programs due to the large pool of managed care enrollees and the variety of service delivery sites involved. It will provide answers to the most critical questions associated with HIV managed care, including how capitated reimbursement can support the current standard of comprehensive HIV care and the feasibility of developing a comprehensive and effective quality monitoring and improvement system.

This information is particularly important during New York's transition to statewide Medicaid managed care. New York plans to develop managed care Special Needs Plans (SNPs) specifically designed for persons with HIV disease. These plans will maximize integration of the existing, well-developed and coordinated networks of comprehensive HIV care, ensuring access to quality care provided by experts in the delivery of HIV medical and supportive care. Existing HIV care networks will evolve into formal legal entities that will be licensed as Managed Care Special Needs Plans. The SNPs will include medical and supportive services including case management, outreach, and day care provided by medical and community-based organizations. We will expect SNPs to conform to established clinical quality of care guidelines and all SNPs will be monitored.

The maintenance of existing grant-funded programs and a smooth transition to Medicaid managed care are essential to the delivery of services to emerging HIV-infected populations. In particular, we will ensure that the State's emerging plan for health care financing addresses the uninsured population -- including the homeless, immigrants, migrants and substance users, many of whom are at high risk of HIV infection. Additional needs related to emerging HIV positive populations include the following:

- ensuring there is primary care service capacity to meet ongoing caseload increases;
- improving access to drug treatment and harm reduction programs;
- facilitating access to coordinated, family-centered care, including linkages with hospitals and community-based providers;
- improving outreach to high-need populations, including pregnant women and substance abusers to link them to HIV counseling, testing and care;
- ensuring access to housing for low-income and Medicaid-eligible persons with HIV/AIDS; and
- expanding the availability of permanency planning services to assist persons with HIV/AIDS and their families in making legal arrangements for the care of surviving children and in

coping with loss.

Finally, I'd like to briefly mention the importance of re-authorizing the Ryan White CARE Act this year. The CARE Act delivers nearly $140 million to New York for HIV-related health and supportive services, and the loss of this funding would decimate the HIV health care infrastructure in New York. As such, it is imperative that Congress act quickly to reauthorize the CARE Act.

I appreciate the opportunity to present this testimony, and would be glad to respond to any questions you may have.

Mr. SHAYS. Thank you, Doctor.

Mrs. Katz.

Mrs. KATZ. Thank you, Chairman, and Congressman Towns for having me here. I am particularly honored as your constituent. I will be speaking primarily today on some Stamford initiatives, although they are widespread throughout Connecticut along with many other initiatives in that State. I also would like to say that the State of Connecticut Legislature does fund six needle exchange programs in the State of Connecticut, Stamford has one. They will not be talked about in this presentation since I am focusing on Ryan White.

In the State of Connecticut the devastating impact of the AIDS epidemic on racial minorities and women has long been evident and a response to address this issue has already begun. More specifically, as AIDS program coordinator for the city of Stamford, I can testify that our local statistics have for many years been increasingly demonstrating the toll AIDS is having on Latino and African-American communities and women. Presently 68 percent of AIDS cases in Stamford are minority and the rate of AIDS cases in the last 2 years has increased by 130 percent in women.

Stamford received its first Ryan White title II grant in November 1993, and its first Ryan White title I grant in April 1995, so initiatives discussed in this testimony are fairly new. Initiatives also involved both funding from Ryan White title I and title II.

The Stamford Ryan White Program is based on an HIV case management model. Case management clients for the Stamford Ryan White Program already reflect the impact HIV is having on both minority communities and women. Eighty percent of the clients served are minority; 43 percent are women. The breakdown of transmission risk of Stamford's Ryan White clients also dramatically represents the changing nature of the AIDS epidemic; 9 percent are homosexual/bisexual, 40 percent intravenous drug users; 27 percent resulting from heterosexual transmission, and 14 percent perinatal.

Our HIV case managers must be and are culturally and linguistically diverse to enable us to optimally serve minority communities. Language and culture can be barriers to care and we must make services diverse.

Services must also be available and provided in areas that reach women and minority communities. In Stamford, the HIV primary care medical clinic is located at the Stamford Community Health Center. The Stamford Community Health Center is located in a building that offers many antipoverty community services, and therefore, the location is both familiar and convenient for many women and many members of the minority communities.

In addition, due to Ryan White funding, those uninsured or underinsured have not been restricted in any way from receiving vital HIV care. To serve women and racial minorities it is crucial that lack of health insurance not provide a barrier to care. Many persons with HIV infection work full- or part-time with poor if any health insurance and are often not eligible for Medicaid or Medicare.

Transportation to HIV services also becomes a critical obstacle in serving HIV impacted communities where financial resources are limited. To address this issue, the Stamford Program has been able to arrange an account with a taxi company, purchase bus tokens, and acquire car seats for all HIV case managers' cars. When transporting women with HIV infection to services, one must take into account that young children will also often be present.

The dramatic increase in HIV infection in women has and will continue to significantly impact on the rates of pediatric AIDS due to perinatal transmission. Ryan White funds are used in Stamford to support our first Pediatric AIDS Care Program located at Stamford Hospital. HIV infected children in Stamford can now receive their specialty care near their home where previously they had to travel to New York or New Haven.

For families, the burden of traveling at least 2 hours roundtrip to get their HIV infected children medical specialty care has now become unnecessary and the local availability of this care has increased medical compliance. In addition to medical care, the Stamford Ryan White Program offers both HIV case management and mental health services at the same location and at the same time as the Pediatric Clinic. This one stop service enables family members, specifically mothers who are also infected, to easily access other vital support services.

The Clients Special Needs Fund is a critical part of the Stamford Ryan White Program. The strained financial resources of many of our clients often requires the use of emergency funds for medications, lab tests, home health care, dental, et cetera.

The provision of home health care and respite care is vital to many individuals who are HIV infected. Without home health care, clients' ability to remain in their homes could often not even be considered an option. For HIV infected women with children, the provision of home health care may be the only way these mothers can continue to remain with their children when they are sick.

A special fundraiser was held in Stamford by a private day care to begin the first child care scholarship fund for children who are HIV infected or children who have HIV infected caretakers. This scholarship fund is small but is a beginning to filling a major gap. The cost exacerbated by limited space for child care is further complicated for families impacted by HIV. As the rate of HIV infection for women and children continues to increase, child care is a necessity. For the HIV infected mother or father who must get to medical appointments or is too sick or weak to care for their child all day long, providing child care can enhance their ability to continue to take care of their children.

The initiatives highlighted in this testimony are only a few of the services needed and I am just going to quickly summarize some of the others. We need to provide funding for outreach efforts. In serving women and minority communities, we cannot just afford to sit and wait for those in need to find the service. For many, HIV infection is only one of many stresses in their lives; when one is worrying about feeding their family or finding shelter they do not worry about one's health.

In improving service to HIV infected women and community members we must offer one-stop service. All services that can possibly be located in one spot must be, including substance use, legal services, and mental health. In working with women and HIV infected children, we must provide mental health and legal counseling because of issues of guardianship and placement.

Finally, family members that can no longer work often jeopardize their housing. They may not be able to get limited housing subsidies, and therefore, homelessness often looms dangerously close for most of them.

Ryan White funds are critical to the delivery of emergency services. The funding is even more vital since the AIDS epidemic continues to shift to women and minority communities who have far fewer resources available. To serve these communities, we must continue to provide Ryan White services. The cost of not providing HIV services is great—society will pay at some point—and the delivery of Ryan White funded services is cost-effective and compassionate. Without this service, hundreds in Stamford would receive no care at all and nationally more than I could count would receive no services.

[The prepared statement of Mrs. Katz follows:]

Testimony: *"AIDS in the 90's - Service Delivery to Emerging Populations"*

Hearing: **Subcommittee on Human Resources and Intergovernmental Relations**

Location: **Brooklyn Borough Hall, New York**

Date: **Monday July 17, 1995**

Testimony by: **Debra Katz, MSW, CISW**
AIDS Program Coordinator City of Stamford
President, Stamford CARES Inc.
(Coalition for AIDS Resources Education and Services)

In the State of Connecticut the devastating impact of the AIDS epidemic on racial minorities and women has long been evident and a response to begin to address this critical issue has already begun. More specifically as AIDS Program Coordinator for the City of Stamford, I can testify that our local statistics have for many years been increasingly demonstrating the toll AIDS is having on Latino and African American communities and women. Presently 68% of AIDS cases in Stamford are minority. The rate of AIDS cases in women in Stamford has increased by 130% in the past two years.

Stamford received its first Ryan White Title II allocation in November 1993 and the first Ryan White Title I funding in April 1994. Initiatives discussed in this testimony are primarily funded through both Ryan White Title II and Title I funds. The Stamford Ryan White Program is based on an HIV case management model. The client and HIV case manager in partnership complete a needs assessment, develop a plan and access resources as needed. Case management clients for the Stamford Ryan White Program already reflect the impact of HIV on both minority communities and women. 80% of the clients are minority and 43% are women. The breakdown of transmission risk of Stamford's Ryan White clients also dramatically represents the changing nature of the AIDS epidemic; 9% homosexual/bisexual, 40% intravenous drug user, 27% heterosexual and 14% perinatal.

Our HIV case managers are culturally and linguistically diverse to enable us to optimally serve minority communities. Language and culture can be barriers to accessing services for members of minority communities and priority must be given to accommodating this diversity to assure quality service.

Services must also be available and provided in areas that reach women and minority communities. In Stamford the HIV primary care clinic funded by Ryan White is located at the Stamford Community Health Center. This health center is located in a building with many other anti poverty community services which routinely serve women as well as many minority community residents . The familiarity and convenience of this location for many of the communities at risk for HIV has helped to enhance our ability to link primary medical HIV care with those individuals in need of this service. In addition due to Ryan White funding those uninsured or underinsured have not been restricted in any way from receiving vital HIV care. To serve women and racial minorities it is crucial that lack of health insurance not provide a barrier to care. Many persons with HIV infection work full or part time with poor if any health care insurance and are often not eligible for Medicaid or Medicare.

Transportation to HIV services also becomes a critical obstacle in serving HIV impacted communities where financial resources are often extremely limited. To address this issue the Stamford Program has been able to arrange an account with a taxi program, purchase bus tokens and acquire car seats in all HIV case managers cars. When transporting women with HIV infection to services one must always take into account that young children might also be present requiring safe transport in car seats.

The dramatic increase in HIV infection in women has and will continue to significantly impact on the rates of pediatric AIDS due to perinatal transmission. Ryan White funds are used in Stamford to support our first Pediatric AIDS Care Program located at Stamford Hospital. HIV infected children in Stamford can now receive their specialty care near their home without having to travel to New York City or Yale Hospital in New Haven. For families the burden of traveling at least two hours round trip to get their HIV infected children medical specialty care has now become unnecessary and the local availability of this care has increased compliance with medical appointments. In addition to medical care, the Stamford Ryan White Program offers both HIV case management and mental health services at the same location and at the same time as the Pediatric Clinic. This one stop service enables family members specifically mothers who are also infected to easily access other vital support services along with their child's medical care. The Client Special Needs Fund is a critical part of the Stamford Ryan White Program. The strained financial resources of many of our clients often requires the use of emergency funds to help pay for their medical care, laboratory tests, medications, home health care, dental care, mental health counseling and other vital services when no other available resources can be found to fund this service.

The provision of home health care and respite care is vital to many individuals who are HIV infected who have no extended family or support system to help care for them. Without home health care, clients ability to remain in their homes could often not even be considered an option. For HIV infected women with children, the provision of home health care may be the only way these mothers can continue to remain with their children when they are sick.

A special fund-raiser was held in Stamford by a private day care agency who helped to begin the first Child Care Scholarship in Stamford for children with HIV infection or for children affected by HIV because their caretaker is HIV infected. This scholarship fund is small but will begin to fill a major service need. The cost, exacerbated by limited space for child care, is further complicated for families impacted by HIV. As the rate of HIV infection for woman and children continues to increase child care arrangements often become a necessity for many families. For the HIV infected mother or father who may need to get to medical appointments or is too ill to care for their child all day long, child care may assist them in being able to continue to care for their children yet also attend to their own health needs . Child care may not even be an option if there is no form of available subsidy of scholarship.

The initiatives highlighted in this testimony are only a few of the services needed to address the increasing impact of HIV on women and minority communities. Outreach efforts are needed to bring these affected communities into the service delivery system. This system offenunfamiliar and scary to many can be an obstacle to care if aggressive steps are not taken to reach out to those individuals in need of the services. As the demographics of the AIDS epidemic shifts so does the needs of the client. We cannot afford to sit and wait for those in need to find the service. For many, HIV infection is only one of many severe stresses in their lives and often there is just no time to worry about one's health when feeding one's family and finding shelter are more urgent needs.

In improving service to HIV infected women and minority community members it is vital that we offer one stop service whenever possible. To negotiate a complicated service delivery system is both overwhelming and time consuming. HIV infected women need to get their medical care at the same time and location as their HIV infected children. The cost of this not occurring is that women will often neglect and ignore their own health care because of lack of time or child care. HIV health care should include; mental health counseling, support groups, HIV case management, nutrition counseling, financial assistance, substance use counseling, legal guidance and other services and should be linked to one's medical care so we can attend to the needs of the whole person.

In working with women with HIV infection their children must also be served. Both mental health counseling and legal counseling become priority services as issues of guardianship and placement become critical. Families impacted by HIV infection where one or more family members are infected must be supported in staying together as long as possible.

As family members can no longer work because of their health, the payment of their rent or mortgage is often jeopardized due to limited or lack of housing subsidies. Homelessness often looms dangerously close for many of these families.

Ryan White funds are critical to the delivery of emergency services for persons with HIV infection. This funding is even more vital as the AIDS epidemic continues to shift to women and minority communities who have far fewer available resources of their own. To serve these communities with diminishing resources is impossible. As more and more cities and towns become eligible for Ryan White grants, level or diminished congressional funding will result in less funds to go around and therefore decreased services.

The cost of not providing HIV services is great. Society will pay this cost at some point. The delivery of Ryan White funded services is both cost effective and compassionate. Without the initiatives funded by Ryan White Title I and Title II in Stamford there are hundreds of persons with HIV infection who would receive no care at all. Nationally, more HIV infected individuals than we can begin to count, would be left without any life prolonging AIDS services if there is not Congressional re-authorization and refunding of the Ryan White Act.

Mr. SHAYS. Thank you very much. I appreciate the audience giving me the opportunity to let my colleague have a little more time. Let me ask first this general question: Did you all agree with the presentation of the first panel? If you have any qualifications to the presentation of the first panel, I would like to know.

Mr. MOJICA. I do agree.

Mr. SHAYS. You do agree.

Mr. MOJICA. Yes.

Mr. SHAYS. Do any of you disagree with what your colleagues on the same panel have said or wish to emphasize something slightly different?

Mr. MOJICA. I do not have any disagreement.

Dr. GUTIERREZ. No, no.

Mr. SHAYS. Doctor, you said in the beginning that the African-American population was 24 percent in the city and you said 23 percent—did I get that correct?

Dr. GUTIERREZ. Our data reflects New York State data; his is New York City. So they are discussing 80 percent of the cases; we are discussing total cases in the State.

Mr. SHAYS. It is interesting when you get into these numbers, you are talking averages——

Dr. GUTIERREZ. Right.

Mr. MOJICA. Right.

Mr. SHAYS [continuing]. And averages can be very different; I mean we all have different shoe sizes and we cannot say that everyone wears a size 8. So clearly in New York City, but New York State as well, what is being said here is you are affirming what is being said here and quite strongly it seems to me.

Mr. MOJICA. Correct.

Dr. GUTIERREZ. Absolutely. I think that the most important thing is that it is not a problem of 1995. This was well-established in the late 1980's. The epidemic—tracking the epidemic in New York City was essentially this same profile. It is the relative numbers over time and the relative rates over time that is changing. So when emerging is discussed, it means relative rates of change.

Similarly if you look at five communities and three boroughs you will get five different profiles with respect to people affected and how the problems manifest themselves. So once again, there is no single formula to respond to very, very complex problems. And as you know, infection of the gay community and within a family of gay partners is a very different scenario than that of a family where you have three generations of substance abuse and multiple persons in each of those generations infected. The issue of permanency planning foster care, guardianship, all that comes up in a way that does not occur in other things. So that is different.

Mr. SHAYS. In public life there are correct words to use and incorrect words, and we do not refer to people who are HIV positive, people with AIDS as victims, and it is an interesting dialog as to why we do not, because we do not want them to think that they cannot do something for themselves to deal with the crisis that is facing them.

But Debra, your comment about when people do not have food or housing, the fact that they are HIV, it becomes an extraordinarily dominant issue, but it is not the issue of the moment. This is not the forum to get into this issue, but we have to deal with the allocation of resources for combating the disease within the structure of services, housing, and research. Do any of you care to just make a short comment as to the priorities of those three? And if you are not willing to say something of some significance, I would just as soon not even get into the issue; but if you have any passion about this issue, I would like to hear it.

They all are needed?

Dr. GUTIERREZ. What issue?

Mr. SHAYS. The issue is where you set your priority in those three—which gets first attention?

Dr. GUTIERREZ. Well, the moment that you set yourself up to establishing a priority for a State, as an example, you shortchange other communities. It is impossible to do. So what we try, what we do is to essentially look at regions and subregions and look to see what are the relative—what has relative importance for each of those communities, and then establish an initiative or a project that responds to that need. It is impossible to do otherwise. You shortchange people.

Mr. SHAYS. Mr. Towns.

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

Dr. Gutierrez, you mentioned about a special needs plan. Is that dependent on Federal funds?

Dr. GUTIERREZ. No, the special needs plan is part of the State's waiver to establish managed care in the State of New York—mandatory managed care in the State of New York—and in order to responsibly care for people with HIV infection, we determined that a special needs plan would be the way to establish the vehicle necessary, the organization necessary to include those HIV care providers that have the experience, that have been involved in HIV care and support services over the course of the epidemic and become active players in providing continual care and treatment for people with HIV, even in a managed care environment.

Obviously the mainstream managed care plans have some experience in HIV care. It is not uniform and it has been difficult for the AIDS Institute to determine how much each plan has. But irrespective of what the health maintenance organizations have or do not have, we believe that it was fundamentally important to provide a system of care that would be different for people with HIV infection because there was already a care infrastructure in place supported by State and Ryan White CARE dollars.

Mr. TOWNS. Right. Emerging populations are more diverse and not as well organized as the earlier population infected by the AIDS virus. In your experience, what initiatives could we promote on the Federal level to enhance service delivery to these patients? What can we do? Because I think that we have to address it. We just cannot continue to ignore it. We look at the numbers you are talking about and we see in terms of how they are changing; but at the same time we are not changing, and whether we do—also, what do I need to do? I do not have a problem asking you that either.

Dr. GUTIERREZ. Do you want to answer that?

Mr. NETBURN. I think part of it in the new Ryan White legislation that is proposed there is——

Mr. SHAYS. Could you just identify your name again?

Mr. NETBURN. Yes, Mitchell Netburn, the assistant commissioner for the Ryan White Program at the City Health Department.

Mr. SHAYS. Does that mean you are in charge of the program?

Mr. NETBURN. Correct.

Mr. SHAYS. Whenever I hear the word assistant I usually assume they are in charge.

Mr. NETBURN. In the proposed new language for the Ryan White CARE Act there is a greater emphasis placed on the planning council's having membership that is reflective of some of the emerging populations. I think one of the unique things about the Ryan White legislation is that it has allowed for some of those local controls and decisionmaking, and on the Federal level if support can be given for that, then obviously for the people who are the consumers and providers of service have more say in the programs being designed, that they will be able to set the priorities that are reflective of the current epidemic, and that way they can mirror that epidemic and on the Federal level support can be given to obviously funding, but also to maintaining and in strengthening that community participation.

Mr. TOWNS. Thank you very much.

Let me just go back to you, yes, Doctor?

Dr. GUTIERREZ. Can I also respond to that? I think that the heart of the matter is the absence of health insurance for every person in the country. I think that you begin to blur some of the lines of who has and who has not, if everyone can have health care. And that means that at the Federal level there has to be an impetus to assure that every citizen in this country has it.

We also have learned from the epidemic a very important lesson, and that is that the medical model with respect to care for people in not enough, that the community-based support services is fundamental and sometimes far more effective in providing that continuity of care, those linkages, those referrals that often medical institutions fail in.

And so the partnership that has been established and in a sense the empowerment of community-based organizations to provide very creative programming in the area of social services, legal services, housing, and substance abuse treatment has been a lesson for the medical community. As you know, health care services is viewed very narrowly as medical care. That is not enough. And if AIDS has taught us anything, it is that without community-based services, it does not work.

And I do not believe having worked—having trained at Harlem Hospital during the epidemic and having practiced there for 7 years in a community health center, I will tell you that our problem was not access. We were in the neighborhood, the doors were open and we treated people respectfully; but the single problem was ability to pay, because the consciousness about people caring for themselves was there and I think it is bad when we continue to promote this notion that somehow poor people are not smart enough to know that it is important to care for themselves.

Mr. TOWNS. Thank you very, very much. We really need to get that message across, because when you look at what is happening in terms of even our funding, that is a problem, because the money is not going where the problems really are. Yes, thank you.

Mr. SHAYS. Thank you, everybody, for your testimony. We appreciate your being here.

Our third panel is Miss Delphine Mendez de Leon, vice president, Institutional Advancement of Brooklyn and Caledonian Hospitals; and Dr. Monica Sweeney, medical director, Bedford Stuyvesant Family Health Center. Our third witness is Ms. Helen Reyes, executive director, Musica Against Drugs; and our fourth is Miss Leona Fairweather, Caribbean Women's Health Association.

Our four witnesses, if they are here, if they would stay standing because we are going to swear you in.

What I am going to do is combine this panel with the fourth panel and that would be very nice for us because then we could spend a little bit more time.

Our fourth panel is—and I am going to blow this, I got into a dispute with my aide on whether it is Klylar or Caylar—Cylar, it is a combination between the two, both of us were wrong. That is the way it should be, we can compromise, we are both wrong. Lucie McKinney, also accompanied by Julie Sandorf. Lucie McKinney is the Stewart B. McKinney Foundation and Mr. Cylar is the Brooklyn Housing Works executive director. And then Mr. Joey Pressley, board member, LAMBDA, Independent Democrats.

Mr. TOWNS. I would also like to ask to join this committee is Senator Velmanette Montgomery, to also join this committee.

Mr. SHAYS. I would be delighted to have the Senator.

It is nice to have you here, and for the record, would you say your name again?

Ms. MONTGOMERY. Velmanette Montgomery.

Mr. SHAYS. And you are the Senator from what district?

Ms. MONTGOMERY. From the 18th Senate District in Brooklyn.

Mr. TOWNS. We are in her district right now.

Mr. SHAYS. Do you keep a good watch on us?

Ms. MONTGOMERY. Yes.

Mr. SHAYS. OK, well then you are allowed to stay.

Would you all raise your right hand please? Do you solemnly swear that the testimony you will give before this committee will be the truth, the whole truth, and nothing but the truth?

[Witnesses sworn.]

OK, everyone has answered in the affirmative.

Does our transcriber have all of the names that are here? If you could spell your name?

Ms. MONTGOMERY. V–E–L–M–A–N–E–T–T–E, Montgomery.

Mr. SHAYS. Now let me just tell you our need. We need to get the 2 o'clock flight——

Mr. TOWNS. Chairman is being direct, is he not?

Mr. SHAYS. Only because we have—our session starts at 4 today, a little earlier than we thought it would. And we are going to hear your testimony, we are going to take 5 minutes. I might show a little preference to Mrs. McKinney, but you would understand; not much though. And then we will—I would like a nice dialog among us. So this is nice, to have the two panels combined. I think what we will do is we will just start right down this way, OK? And so Ms. de Leon?

Ms. MENDEZ DE LEON. Mendez de Leon.

Mr. SHAYS. Mendez de Leon, nice to have you here.

Again, I am going to remind you——

Ms. MENDEZ DE LEON. Speak up.

Mr. SHAYS [continuing]. There is no—you have to yell out, you have to speak loudly.

Mr. TOWNS. Those people in the back, if you want to come forward, please do so if you cannot hear. Why don't you take this opportunity and just come up closer so you can hear. Sometimes these voices drop and—last chance.

Mr. SHAYS. Thank you.

STATEMENTS OF DELPHINE MENDEZ DE LEON, THE BROOKLYN AND CALEDONIAN HOSPITALS INSTITUTIONAL ADVANCEMENT; ACCOMPANIED BY DR. MONICA SWEENEY, MEDICAL DIRECTOR, BEDFORD STUYVESANT FAMILY HEALTH CENTER; KEITH CYLAR, COEXECUTIVE DIRECTOR, BROOKLYN HOUSE WORKS; LUCIE B. McKINNEY, CHAIRMAN, THE STEWART B. McKINNEY FOUNDATION; JOEY PRESSLEY, BOARD MEMBER, LAMBDA INDEPENDENT DEMOCRATS; VELMANETTE MONTGOMERY, NEW YORK STATE SENATOR FROM BROOKLYN; AND JULIE SANDORF, EXECUTIVE DIRECTOR, THE CORPORATION FOR SUPPORTIVE HOUSING

Ms. MENDEZ DE LEON. Thank you. Good afternoon.

My name is Delphine Mendez de Leon and I am the vice president for Institutional Development and Planning at the Brooklyn Hospital Center, a 701-bed multisite tertiary health care institution with facilities in northern and central Brooklyn.

Before I begin I would like to thank Congressman Towns for his support of the Ryan White CARE Act reauthorization bill which was voted out of the House last Thursday. It includes important pediatric care programs and HIV dental care programs.

Our service area includes some of the most medically underserved communities in the Nation and the residents of these communities are experiencing health crises of a magnitude usually associated with Third World countries. Of the more than 500,000 people living in our service area of Fort Greene, Bed-Stuy, Bushwick and Flatbush, more than half are eligible for Medicaid or are without health insurance. Infant mortality rates are more than twice the New York City average and more than three times the national rate. On average, there are 5 to 10 physicians for every 100,000 residents, and measle rates are more than three times the national average, due mostly to low child immunization rates. Due in part to AIDS, TB has also resurged with a fury and drug resistant strains are now common in New York City hospitals. More than half of those who contract these forms of TB will actually die.

The residents of these communities rely on hospitals like the Brooklyn Hospital Center as their primary source of health care in many instances. When programs or services are unavailable within the community, many residents lack the information resources to seek such services outside of the community.

Those who are HIV infected are even less able to fend for themselves in the complicated health care and social service environment of New York City, and it is therefore vital that the Department of Health and Human Services ensure that current funding for community-based HIV services be maintained and that the Department continue to examine new ways to assist health care institutions in providing adequate care to those who are infected with HIV.

The need for HIV services cuts across gender, ethnicity and age. In 1991 and 1992, there were more than 1,192 cases of adolescent and adult AIDS diagnosed in northern Brooklyn alone, and almost 1,600 in central Brooklyn. In 1993, 382 babies were reported HIV positive in both northern and central Brooklyn, and as of December 1993, there are almost 3,400 people living with AIDS in these communities, a rate of more than 337 cases per 100,000 people and an increase of almost 30 percent since 1989. At the Brooklyn Hospital Center, HIV related conditions accounted for almost 1,000 of our 31,000 discharges in 1993 and more than 5 percent of our total patient days.

While the majority of these cases stem from injecting drug abuse, many also represent young women who become infected from their partners, and children who are born infected or become infected through breast feeding. The mechanisms of transmission are preventable, even transmission from mother to child. But prevention requires concerted efforts on the part of government, social service agencies, health care institutions and providers, and individuals. Many prevention efforts already in place, such as substance abuse treatment centers, prenatal care programs, primary care centers that teach safe sex and responsible behavior, are jeopardized by the proposed Medicaid, Medicare and social service cuts.

Today, I have been asked to highlight for you the importance of continued funding for pediatric AIDS services and for dental services for HIV infected individuals. The Hospital Center's experience with providing dental care to HIV infected individuals and those at risk for infection demonstrates the need for rethinking of the funding and structure of Federal reimbursement for dental services.

In 1992, the Hospital Center received funding from the National Cancer Institute as part of a consortium of institutions located near large Hispanic populations. The grant enabled us to undertake an extensive telephone and community survey regarding diet and attitudes about health care and cancer. The results of this study indicate that the majority of Hispanics in northern and Central Brooklyn consume diets that are high in fat and sugar and low in fresh fruits and vegetables, a contributing factor in poor oral health.

Medicaid recipients and the uninsured as a group have poorer oral health than the insured. For those with HIV, poor oral health contributes to their decline and can hasten mortality. Like the population as a whole, many of the HIV infected individuals in our service area do not have a primary care physician, let alone a dentist or regular dental care.

AIDS patients as a group suffer from a higher incidence of oral disease. Many of the first symptoms of AIDS show up first in the mouth; thus, dentists are often the first to recognize the early stages of AIDS at an at-risk individual. For this reason, it is especially important that dental services for those at risk, rather than just for those who have already been diagnosed with HIV positive, be funded at levels that permit the provision of regular dental checkups for Medicaid recipients and for the uninsured.

AIDS patients suffer from some of the most debilitating and painful oral diseases, diseases that require ongoing care and regular visits to the dentist. As a result of the immune system breakdown, AIDS patients are more susceptible to oral herpes and rampant fungal diseases, as well as oral disease found only in patients who suffer from AIDS, including an extremely painful form of gum disease that frequently involves exposure of the bone.

Patients who are immunocompromised frequently complain of painful, aggravating mouth sores. Imagine a mouth full of canker sores that will not go away; as soon as one heals, another appears. The paint is incessant, making it extremely difficult to eat or speak.

The frequency of care required by patients with severe oral disease means that dental services must be easily accessible for AIDS patients. Currently, funding for outreach and direct care services is limited. Only one site in all of New York City, at Woodhull Hospital in Brooklyn, has received Federal funding to provide outreach and improve the accessibility of dental care for AIDS patients. More such funding is desperately needed to minimize the pain and suffering experienced by these individuals. For children with AIDS, the need is even more pronounced.

As you know, many of these children are orphans who rely on extended family members for care. Many of these caregivers are responsible for more than one child with AIDS. Thus, taking a weekly trip across the borough to wait all day in a clinic to receive dental care is not feasible or practical. If funding were available, hospitals like the Brooklyn Hospital Center would better be able to respond to this demand. For example, we could staff dental offices and medical vans that could go into different neighborhoods on designated days during the week to provide care following an appointment system.

Unfortunately, the present reimbursement arrangement does not make an allowance for extra costs such as this that would substantially improve the everyday life of children and adults infected with AIDS.

Mr. SHAYS. Could I ask you to summarize at this point?

Ms. MENDEZ DE LEON. Sure.

Mr. SHAYS. It is very important testimony. You will get a chance at the questions to respond. I would like to encourage the rest, even feel free to summarize your testimony. We will stay until about 1:15 or so, so we will have a good dialog among us.

Ms. MENDEZ DE LEON. OK. I wanted to just give you an illustration of a couple of cases. The Brooklyn Hospital Center has an average daily occupancy of 40 neonates——

Mr. SHAYS. You need to talk louder too, I am sorry.

Ms. MENDEZ DE LEON. We have the largest neonatal intensive care unit in Brooklyn. Approximately 170 of these babies will go on to be diagnosed with AIDS. The difference in the presentation and treatments of these children varies enormously. At the minimum, the NICU experience highlights the need for additional Ryan White moneys to provide for intensive counseling for at-risk pregnant women to encourage them to be tested so that they and their unborn children can best have a shot of healthy and prenatal lives.

We often see children after they have been diagnosed at about 3 years of age and these children unfortunately are not known to us before and their mothers may or may not have been diagnosed before they actually give birth. These individuals generally present themselves with severe neurologic problems, malnutrition, and a general failure to thrive. They are incapable of interacting with their environment and a lot of them at that point are living with individuals in a household who are also sick. Pediatricians do what they can at the Hospital Center.

As was mentioned the medical care model is not enough and what is urgently required is the coordination of services between providers as well as community organizations in order to provide for (a) the community outreach, (b) the prevention, (c) the education of these individuals, and finally, once these individuals in fact are identified as either at risk or actually coming down with the infection, they need to be put into what we call a continuum of care, so that once an individual enters into that continuum of care that individual is then followed, whether it be pre-hospitalization, during hospitalization or post hospitalization, so that patient is followed throughout the entire course of that illness.

[The prepared statement of Ms. Mendez de Leon follows:]

Subcommittee on Human Resources and Intergovernmental Relations

Hearing, July 17, 1995, Brooklyn Borough Hall

"AIDS in the 90's: Service Delivery to Emerging Populations"

Delphine Mendez de Leon, Vice President, Institutional Development & Planning
The Brooklyn Hospital Center

Good afternoon. My name is Delphine Mendez de Leon and I am the Vice President for Institutional Development & Planning at The Brooklyn Hospital Center, a 653-bed multi-site tertiary care healthcare institution with facilities in northern and central Brooklyn. Before I begin, I would like to thank Congressman Towns for his support of the Ryan White Care Act reauthorization bill (HR 1872) which was voted out of the House Commerce Committee last Thursday. It includes important pediatric care programs and the HIV dental care program.

Our service area includes some of the most medically underserved communities in the nation and the residents of these communities are experiencing health crises of a magnitude usually associated with Third World countries. Of the more than 500,000 people living in our service area of Fort Greene, Bedford-Stuyvesant, Bushwick and Flatbush more than half are eligible for Medicaid or are without health insurance. Infant mortality rates are more than twice the New York City average and more than three times the national rate. On average, there are only five to ten general or family physicians for every 100,000 residents. Measles rates are more than three times the national average, due mostly to the low child immunization rate. Due in part to AIDS, tuberculosis has resurged with a fury. Drug resistant strains are now common in New York City's hospitals. More than half of those who contract these forms of TB will die.

The residents of these communities rely on hospitals like The Brooklyn Hospital Center as their primary source of health care. When programs or services are unavailable within the community, many residents lack the information or resources to seek such services outside of the community. Those who are HIV infected are even less able to fend for themselves in the complicated health care and social service environment of New York City. It is therefore vital that the Department of Health and Human Services ensure that current funding for community-based HIV services be maintained and that the Department continue to examine new ways to assist healthcare institutions in providing adequate care to those infected with HIV.

The need for HIV services cuts across gender, ethnicity and age. In 1991 and 1992, there were more than 1,192 new cases of adolescent and adult AIDS diagnosed in northern Brooklyn and 1,575 in central Brooklyn. In 1993, 382 babies were reported HIV+ in both northern and central Brooklyn. As of December 1993, 3,391 people were living with AIDS in these communities, a rate of more than 337 cases per 100,000 people and an increase of almost 20% since 1989. At The Brooklyn Hospital Center, HIV related-conditions accounted for almost 1,000 of our 31,000 discharges in 1993 and more than 5% of our total patient days.

While the majority of these cases stem from injecting drug use, many also represent young women who become infected from their partners and children who are born infected or become infected through breastfeeding. The mechanisms of transmission are preventable, even transmission from mother to child, but prevention requires concerted efforts on the parts of government, social service agencies, healthcare institutions and providers and individuals. Many prevention efforts already in place, such as substance abuse treatment centers, prenatal care programs and primary care centers that teach safe sex and responsible behavior, are jeopardized by proposed Medicaid, Medicare and social service cuts.

Today, I have been asked to highlight for you the importance of continued funding for pediatric AIDS services and for dental services for HIV infected individuals. The Hospital Center's experience with providing dental care to HIV infected individuals and those at risk for infection demonstrates the need for a rethinking of the funding and structure of federal reimbursement for dental services.

In 1992, the Hospital Center received funding from the National Cancer Institute as part of a consortium of institutions located near large Hispanic populations. The grant enabled us to undertake an extensive telephone and community survey regarding diet and attitudes about health care and cancer. The results of this study indicate that the majority of Hispanics in northern and central Brooklyn consume diets that are high in fat and sugar and low in fresh fruits and vegetables, a contributing factor in poor oral health. Medicaid recipients and the uninsured as a group have poorer oral health that the insured. For those with HIV, poor oral health contributes to their decline and can hasten mortality. Like the population as a whole, many of the HIV infected individuals in our service area do not have a primary care physician, let alone a dentist or regular dental care.

AIDS patients, as a group suffer a higher incidence of oral disease. Many of the first symptoms of AIDS show up first in the mouth; thus, dentists are often the first to recognize the early stages of AIDS in an at-risk individual. For this reason, it is especially important that dental services for those at risk, rather than just for those who have already been diagnosed as HIV+, be funded at levels that permit the provision of regular dental check-ups for Medicaid recipients and for the uninsured.

AIDS patients suffer from some of the most debilitating and painful oral diseases, diseases that require ongoing care and regular visits to the dentist. As a result of the immune system breakdown, AIDS patients are more susceptible to oral herpes and rampant fungal diseases, as well as oral disease found only in patients who suffer from AIDS, including an extremely painful form of gum disease that frequently involves exposure of the bone. Patients who are immunocompromised frequently complain of painful, aggravating mouth sores. Imagine a mouth full of canker sores that will not go away - as soon as one heals, another appears; the pain is incessant, making it extremely difficult to eat or speak.

The frequency of care required by patients with severe oral disease means that dental services must be easily accessible for AIDS patients. Currently, funding for outreach and direct care services is limited. Only one site in all of New York City, at Woodhull Hospital in Brooklyn, has received federal funding to provide outreach and improve the accessibility of dental care for AIDS patients. More such funding is desperately needed to minimize the pain and suffering experienced by these patients. For children with AIDS, the need is even more pronounced. As you know, many of these children are orphans who rely on extended family members for care. Many of these caregivers are responsible for more than one child with AIDS. Thus, taking a weekly trip across the borough to wait all day in a clinic to receive dental care is not feasible or practical. If funding were available, hospitals like The Brooklyn Hospital Center could better respond to this demand. For example, we could staff dental offices in medical vans that could go into different neighborhoods on designated days during the week to provide care following an appointment system. Unfortunately, the present reimbursement arrangement does not make an allowance for extra costs such as this that would substantially improve the everyday life of children and adults infected with HIV.

We can look forward to a future where prompt, high-quality dental services are available conveniently and at a low-cost for all people with AIDS. But the current reality is far, far away from that future ideal. Except for extreme trauma such as a broken jaw, dental services are not currently reimbursed under Medicare and Medicaid coverage of dental services for adults is optional, not required of the states. In many states, only emergency dental care is covered. This lack of sufficient reimbursement is particularly profound for those dental clinics providing care for a significant number of AIDS patients. Dental clinics that become known as referral centers for AIDS patients risk serious fiscal problems, because the patients they serve have complicated treatment needs, requiring more resources than other dental patients. At The Brooklyn Hospital Center, we are able to make up in part for the difference between the costs and reimbursement of caring for children and adults with AIDS through a combination of federal and state grants, private funding and the goodwill of our staff dentists and oral and maxillofacial surgeons. But each year, it becomes more difficult to continue to provide the same level of care. Each year, the number of HIV infected individuals increases in our service area. Each year, opportunities for government and private grants shrink. And each year the number of patients referred to us by institutions that are not equipped to deal with the complexity of oral disease in AIDS patients increases. That is why the federal AIDS dental care reimbursement program is critical. It partially offsets unreimbursed care institutions such as The Brooklyn Hospital Center provide to HIV patients. Through this program, more than 26,000 patients in New York were treated in 1993 and 1994. In the first four years of the program, 36 New York institutions have received a combined $6.5 million as a result of this program.

Beyond dental care, children and babies with AIDS will suffer needlessly over the next several years as a result of cutbacks in many social programs. At a time when breakthroughs are being made on many levels in the care of AIDS stricken children and the prevention of transmission from mother to child, these cutbacks jeopardize the advances that have already been made and threaten to make life even worse for children with AIDS.

Central Brooklyn has one of the highest proportions of tested newborns with HIV serostatus in the United States and a rate of heterosexual transmission almost twice that of the rest of New York City. Nearly 60% of Brooklyn's female cases are in Central Brooklyn. At the same time, the rates for other sexually transmitted diseases such as gonorrhea and syphilis are among the highest. In 1993, in northern Brooklyn 106 of the very small number of newborns who were tested, tested positive for HIV. 276 tested positive in central Brooklyn. And, funding for prenatal care and education programs are threatened by proposed budget cuts on every level. Each of these factors points to a population that continues to be one of the highest at risk for future cases of mother-to-child transmission of HIV.

In light of the ACTG 076 trial, which found that prenatal administration of AZT substantially reduces the rate of transmission from mothers to infants and in light of other studies that indicate that many infants are born uninfected only to become infected through breast milk, a concerted effort is required on all levels of government to provide education, testing, counseling and care to pregnant and breastfeeding women. While many states are wrestling with the decision whether to institute mandatory testing for newborns, in the interim much can be done to minimize transmission from mother to child.

Funding for counseling and testing services for pregnant and breastfeeding women are essential. Current prenatal education programs must be expanded to include substantial counseling and to encourage pregnant women to be tested. Those who test positive must be encouraged to take AZT. Yet, many pregnant women seen in our clinics and at our walk-in sites are both ineligible for Medicaid and uninsured. For this reason, HHS must take the lead in carving out reimbursement for the use of AZT by pregnant women and provide increased grant funding for outreach and education programs for pregnant women and women at risk.

It is always helpful to provide illustrations of cases in point which highlight the need to expand funding for pediatric and dental AIDS services.

The Brooklyn Hospital Center maintains an average daily occupancy of 40 neonates - infants born premature - in the largest Neonatal Intensive Care Unit in Brooklyn. Approximately 170 of these babies each year will go on to be diagnosed with AIDS. The difference in presentation and treatment of these children varies enormously and, in most cases, can be better controlled if the mother's high risk status is known at birth. At a minimum, the Hospital Center's NICU experience highlights the need for additional Ryan White monies to be provided for intensive counseling for at risk pregnant women to encourage them to be tested so that both they and their unborn children can have the best shot at healthy and longer lives.

In our obstetrical clinic, one of the busiest in New York City, 15-20 HIV+ women are receiving prenatal care at any given time. The care provided to HIV+ women is more intensive than that provided to other pregnant women with one visit to the clinic per week and 5 daily doses of AZT. Again, early testing and counseling can significantly improve the quality of life for the mother and significantly reduce the chance that she will transmit HIV to her unborn child.

In our pediatric clinic, 40 children diagnosed with HIV are currently receiving care. Recently, the three year old child of a women diagnosed after birth with HIV presented with infections, severe neurological problems, malnutrition and with general failure to thrive. The child was incapable of interacting with his environment and was living with a sick mother who had failed to comply with treatment that had been recommended for her. Luckily, pediatricians at the Hospital Center recognized the mother's status and realized that the child's symptoms were likely indicative of HIV infection. With intense social service intervention, the child was able to be treated and has begun to interact with others on a more normal level. However, without this recognition by the medical staff and without qualified social service intervention, the child would most likely have been returned to the same environment where his health and well-being would have been in jeopardy.

Clinical services for children with AIDS are just the beginning. Funding for social and other support services as well as quality of life improvements is essential as well to ensure the children living with AIDS can continue to thrive and grow.

We were asked to provide you with a snapshot of the need for dental and pediatric AIDS services in our community. While these areas are in dire need of continued and increased funding, there are many other services needed by those who are HIV infected or at-risk for infection. I hope that you will go away from today's hearing with a better understanding of just how great the need is and work to carve out AIDS services from other programs to ensure continued funding and program growth in the future. It is essential that the AIDS dental care program is reauthorized under the Ryan White Care Act, as is provided in HR 1872. AIDS is a devastating disease that cuts down those who often have the most living yet to do, children and men and women in the their 20s and 30s. We at The Brooklyn Hospital Center appreciate this opportunity to share our experience with the community and welcome any questions you may have. Thank you.

Mr. SHAYS. The question I am going to be asking the witnesses that I do not want an answer to now, but I am struck by the fact that we look at this emerging population and I am wondering if this emerging population is less likely to know that they have AIDS or are HIV positive. So I will be asking that question later.

Can we go to our next panelist? Thank you, sir.

Can you say your name again and I will try to——

Mr. CYLAR. My name is Keith Cylar.

Mr. SHAYS. Keith Cylar. OK, thank you.

Mr. CYLAR. Mr. Chair, Mr. Towns, and members of the subcommittee. I am Keith Cylar, coexecutive director of Housing Works.

Since opening our doors in 1991, Housing Works has provided advocacy, permanent housing and a wide array of supportive services to thousands of homeless men, women and children. Currently Housing Works is providing supportive services to over 700 men, women and children, and a host of supportive services——

Mr. SHAYS. Mr. Cylar, can I ask you to speak louder?

Mr. CYLAR. Sure.

Mr. SHAYS. I think the problem is that we are all trying to read a whole statement and the faster you read it the softer your voice becomes.

Mr. CYLAR. OK, well then let me abandon reading my statement.

Mr. SHAYS. Believe me, I think it would be better for you.

Mr. CYLAR. I wanted to do that anyway. I hate reading statements.

Mr. SHAYS. The statement will go in the record, and what you say, that you live with daily, fire away.

Mr. CYLAR. OK. I want to take a different tack. I think everybody has outlined the problem of the emerging populations in great detail. I think I want to talk about the barriers and some of the barriers for the emerging populations are the same barriers that existed for the initial populations, and that first barrier has to do with the stigma related to this disease. As a black gay man living with this disease, I can personally tell you about the stigma of AIDS and HIV, the stigma of homosexuality in this country. As Jesse Helms so eloquently put forward about funding for this program and some misstatements about the amount of money being funded, it is not a disproportionate amount of money being spent on this disease.

Aside from that, I think one of the barriers that we have in this country for providing services is the absolute lack of housing. You cannot expect people who are inadequately housed, who are living doubled-up, who are living on the streets or in the shelters in New York City or throughout this country to be able to receive the kinds of care and services that they need. We have an epidemic of malnutrition in this country. So between malnutrition, homelessness, AIDS, TB, and substance use, and the overall general stigma attached to those diseases, those epidemics, where people are perceived of as being less than, they are perceived of as being bad, they are perceived of as being unworthy of treatment and dollars, I think that is one of the largest barriers.

As a result of all of those things, people oftentimes receive inadequate care. They are marginalized out of the political system and thereby oftentimes do not receive adequate levels of funding. If you take a look at the recent attacks on HOPWA, the Housing Opportunity for People Living With Aids, which is part of HUD, right now it is being defunded again for the third time within this Congress. HOPWA's services are crucial for many homeless people.

Those dollars provide the only source of housing money for those individuals. Without those services, without housing, an individual cannot take advantage of the primary care that they may be provided through Ryan White, they cannot take care of dental care that would be provided through Ryan White. Prevention and education messages are lost on individuals when they have to strive to find a place to live. You cannot survive without those kinds of things.

When we also look at prevention and education, we get hung up very much on whether or not we can tell people to use a condom or not because it is going to promote homosexuality. I have a real problem with that, because people are dying from this disease because this disease is being sexually transmitted, and the thing that will prevent that is a condom. It does not matter whether or not it is heterosexual or homosexual sex, that is the bottom line. And somehow in this process we have gotten very much concerned about judging whether or not a particular act is good or bad and that has limited the funding, it has limited the research, it has limited the prevention message that we need to get out to people.

When I say these things, a lot of times people get upset and they say, "AIDS is an issue within the black community" and historically that has been the line that we took.

Mr. SHAYS. Who gets upset? I am sorry.

Mr. CYLAR. People in general.

Mr. SHAYS. About what?

Mr. CYLAR. About the fact that I talk about homosexuality, that I talk about the stigmas associated with drug use, and I talk about the stigmas associated with homelessness. But I believe those are the real barriers and the misimages, the lack of honesty about these issues oftentimes clouds how we allocate money, how the political process views these people, and reflects I think a lack of humanity, reflected in the budget process that is going on both in New York State and in New York City.

Oftentimes we balance our budgets on the backs of the poor, the marginalized, and those people are the homeless people, those are the substance users, and those are the emerging populations that you see.

So I think when we talk about this disease we need to, No. 1, be honest, we need to be nonjudgmental, nonmoralistic, and look at this disease as an epidemic that it is and begin to treat it with compassion and humanity. I will stop there.

[The prepared statement of Mr. Cylar follows:]

HOUSING WORKS
Demand Housing
for Homeless People
Living with AIDS & HIV

Written Testimony to the
Subcommittee on Human Resources and
Intergovernmental Relations
Submitted by Keith D. Cylar, Co-executive Director
Housing Works, Inc.

Introduction

Mr. Chair and distinguished Members of the Subcommittee on Resources and Intergovernmental Relations, I am pleased to provide you with testimony on behalf of Housing Works, the nation's largest provider of housing and supportive services for homeless people living with AIDS and HIV and the largest minority-controlled AIDS Service Organization in the country.

I am Keith Cylar, Co-executive Director of Housing Works. Since opening our doors in 1991, Housing Works has provided advocacy, permanent housing and a wide array of supportive services to thousands of homeless men women and children. Currently, Housing Works is providing supportive housing to over 700 men women and children, and a host of supportive services to over a thousand people who are still awaiting a housing placement.

About 90% of our clients are Black or Latino. One third of our clients are women, some 70% of whom have dependent children. Many of our clients struggle with mental health problems, chemical dependence and a host of other issues, including trauma from physical and sexual abuse, that make AIDS just one of many complex and often chronic problems. Beginning with housing, we offer our constituency the tools to reintegrate themselves into a caring community, through which they are able to reclaim once ravaged lives. We haven't found a secret cure for AIDS, but we have found the means to give people hope and the sense that they are partners in plotting their own future. As proof, I offer you the fact that some 15% of our full time staff first came through our doors as homeless people in need.

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Housing Works got its start in a time when government was just beginning to accept its responsibility to care for people living with AIDS and HIV. With now more than 40,000 homeless people infected with HIV in New York City alone, I can't say that we have ever had all the resources we needed. But, with aggressive advocacy and lots of creativity and innovation, we have been able to pull together a variety of funding streams that allow us to meet real human need and to demonstrate what could and should be done if we could ever generate the political will to bring the AIDS crisis to an end.

I wish I could say that our demonstrated success was going to result in a new commitment on the part of government to draw people with HIV into a network of care. Unfortunately, I fear that service delivery in the 90's will be increasing difficult as the far right increases its political domination and Congress moves to balance the federal budget by eliminating federal programs that meet human needs, and block grants the programs that remain, attaching moralistic restrictions that satisfy a particular value system not matter how repressive the effect.

The Urban AIDS Crisis

AIDS is a personal tragedy for individuals and a public health crisis for our nation. While AIDS has spread rapidly to every part of the U.S., it remains most devastating in New York City and other densely populated urban areas. New York City has an estimated 23,000 people living with AIDS and at least another 165,000 people who are living with HIV. These numbers exceed the entire populations of many American small towns and middle-sized cities. In addition, New York City has serious epidemics of chemical dependence, tuberculosis, and homelessness -- factors that stigmatize people living with HIV and AIDS and make it more difficult and expensive for them to obtain the services they need. Finally, AIDS has disproportionately affected New York City's minority communities, with 39% of all cumulative cases reported among Blacks and 30% among Hispanics, although Blacks and Hispanics make up just 25% and 24% respectively, of the total population.

Barriers To Service Delivery

There are a variety of barriers that have historically impacted on the delivery of HIV/AIDS services in general but with even greater impact within Black and Hispanic communities. The largest single barrier is the still pervasive attitude of prejudice toward people with AIDS, most recently evidenced in the statements by Senator Jesse Helms. Whether stated a virulently or not, there is still a generally sensibility that with the exception of babies and those unfortunate enough to have needed a blood transfusion, people with HIV somehow brought it on themselves. The truth is that according to the public health service says that when you combine all spending that is applied on research, prevention and treatment for AIDS/HIV approximately ^ billion dollars pales to the 36 billion spent on heart disease and 6.9 billion spent on cancer.

Sadly, that attitude is just as prevalent in our communities as it is in our larger society. Often this attitude translates into a complete denial of the impact of this disease in the African American and latino communities. In many Eastern cities, blacks and Latinos constitute a majority of the AIDS cases . In New York City, where AIDS is the number one killer of women between the ages of twenty -five and thirty -four, black women , with their Latina sisters , account for 84% of the adult female AIDS cases. In every risk category used, black people are disproportionately represented. Thus, even among gay and bisexual men and intravenous drug users, blacks are more likely to be infected than their white counterparts .This statistics are not new but have been true since 1989, yet it has not been until 1995 that communities of color have begun to recognize the significance of this disease. On average Black and Latino persons with AIDS are sicker at time of diagnosis than white people with AIDS and die nearly five times faster. Despite this, many of our community leaders disavow any responsibility for an organized community response.

Please do not underestimate the barriers caused by the stigma associated with HIV/AIDS. AIDS is indeed one of many historical burdens that weigh down communities of color. But that is an excuse that wears thin very quickly. The reaction of communities of color has not been only to the medical aspect of the disease AIDS, but to the related issues of homosexuality and drug use. These issues have to addressed if we are to develop service delivery systems that are effective with in our communities.

Because so many traditional organizations in urban communities of color for so long refused to address the crisis of AIDS, new organizations like Housing Works have been forced into existence. With little more than sheer determination, we have had to build whole new infrastructures from scratch. We have done these even while competing for money and support with our "white" counterparts who have historical received the majority of the funds designated for AIDS. As funding flattens, the competition for scarce public and private dollars will only increase. Without solid infrastructure and community support, we will be increasingly overburdened with demands that we cannot possibly meet. As a consequence, those who must turn to us for aide will in many instances be left unserved or underserved.

The demographics of AIDS in urban areas represent personal circumstances that are themselves barriers to effective service delivery. Homelessness itself is a critical barrier to effective AIDS services. For years, Government funded studies completely ignored epidemiology among homeless people for the simple reason that everyone new that the only way to deliver effective services would be to provide housing, an exceedingly expensive proposition. Even today, having been the largest single beneficiary of the Housing Opportunities Act for People With AIDS, New York City refuses to provide supportive housing to anyone with HIV who lacks an AIDS diagnosis. Expensive as housing is, one cannot imagine a more short sighted position. Not only do homeless people with HIV get ill more quickly,requiring the intensive medical interventions leading to a disproportionately using the most expensive of medical services, but, without access to the basic necessities for subsistence, they are forced to engage in high risk behaviors as a matter of survival. Thus, we have guaranteed that even if a cure is found tomorrow, the AIDS epidemic will continue to spread. Our demand for housing for all people with AIDS and HIV makes sense not just as a matter of compassion or because one subscribes to the universal declaration of human rights. It makes sense as a matter of basic public health. But then it would have made sense ten years ago to make prevention efforts among homeless people a major priority and we still haven't learned that less here in New York or in other urban areas.

As with homelessness, chemical dependence, and, equally important, our attitude toward substance users and chemical dependence, are a major barrier that interferes with service delivery among people living with AIDS and HIV. As we often say it, "dead addicts don't recover." Yet, far too many service programs and funding sources require that people be drug free before they can receive services. Well, if you have no access to care and no hope for the future, if your live remains filled with chaos and misery, how can you ever find the courage to even aspire to a different kind of life? The lack of nonjudgmental programs for people who are chemically dependent is an absolute barrier to services. The most obvious example of the way prejudice has interfered with both social science and common sense is the continued opposition to and lack of funding for needle exchange programs. But that isn't the end of it by any means. It's just one step toward serving people who use intervenous drugs. We must also recognize the impact of crack/cocaine use in the spread of HIV infection and fund the development of harm reduction programs that serve that population as well.

As a very proud Black gay man who is living with HIV, I must also point out the barriers created by the prejudices surrounding men of color who have sex with men. In the larger society, the stereotypes are clear. The AIDS population is gay white men and minority drug addicts. As if that were not bad enough, in our own communities, gay men of color are completely invisible. Yet Black gay men comprise between 10% and 20% of the men infected with HIV in New York City. Denial of our existence guarantees that we will continue to go underserved. In the face of social stigma, many gay men of color will continue to remain closeted, at risk of infection and at risk of infecting others.

Women Issues

Overwhelmingly, women infected with HIV are Black and Latina. Predominantly, they are from urban areas. The lack of basic health care services in communities where these women live only exacerbates the difficulties women with AIDS and HIV face in obtaining services. In many instances, low income urban woman are single parents with little of the social infrastructure they need to keep their families intact and to take care of themselves. Adding insult to injury, in the current political debate, women with AIDS and HIV are discussed and considered more for their reproductive capacity than for the value of their own lives. Thus the hottest single topic related to women with AIDS is not how to treat their HIV-specific needs, but the mandatory testing of pregnant women and of new borns with HIV. Irrespective of the tentative results of clinical trial 176, only under the most superficial analysis can coercive testing be described as in the best welfare of mother or child. In fact, this policy decision can only have a negative impact on women and Black and Latina women in particular. If our real goal is to protect the new born infant, then we should focus on developing meaningful services for women with AIDS in general and pregnant women specifically . Perhaps this is to simple for government to understand, but our experience at the grassroots clearly indicates that if women are offer adequate prenatal care and counselling regarding the potential risks of HIV, they will fully utilize the resources available to enhance their own health and to prevent the infection of their offspring. Tying service dollars to coercive measures will only force the construction of one more barrier to service.

The Ryan White Care Act, the Housing Opportunities for People With AIDS, along with federal appropriations to the Centers for Disease Control, are major sources of funding for AIDS specific services. These programs suffer from there individual programmatic flaws but also suffer from a lack of coordination and integration . HOWPA funding can be utilized to provide housing but can not be used to provide many of the essential services required to stabilize and keep a person housed. Little coordination has taken place to integrate HIV and TB services despite a clear correlation of risk. Prevention funding is completely segregated from service funding as if the target were two wholly different groups of people. The need for prevention measures integrated with case management services, housing programs, primary medical care, and transitional shelter cannot be too greatly underscored.

I cannot conclude my remarks without very frankly addressing the debate that is taking place right now in Washington D.C. with regard to the allocation of Federal dollars and the requirements that are often imposed. To be sure, many states and localities object to the imposition of mandates. We too see them as a two edged sword. But for communities of color, there is a reality that is all too often overlooked in the larger discussion. Our experience has generally been that the federal government has been far more sensitive to our needs than have, in many instances, local and state governments. This is a major element of the stake as the debate on the Ryan White Care reauthorization draws to a conclusion in the next few weeks. That is why we have so aggressively attacked the plan for a single appropriation between Titles I and II. A single appropriation would eliminate the role of Congress in targeting funds specific to the urban areas hardest hit by this epidemic . Given the realties of the economic conditions in urban areas heavily impacted by

HIV, it is unlikely that the financial commitment necessary to provide services to communities of color will continue without a strong federal mandate. On a much larger scale, we fear exactly the same impact as congress considers block granting Medicaid and takes up so-called "welfare reform.

I have raised only briefly many vital issues today. I can only hope that you share our sense of urgency and our passion regarding these matters. The reality is that for all too many of us, what is at stake is our very lives. Thank you.

Mr. SHAYS. Well, your statement was very appreciated. Was there anything that you said that was in your statement or you covered it pretty well, did you not?

Mr. CYLAR. There are some things that are not in my statement.

Mr. SHAYS. That will be inserted into the record.

Mr. CYLAR. Thank you.

Mr. SHAYS. We are going to come back with some questions took, as well.

Lucie—Mrs. McKinney.

Mrs. MCKINNEY. Mr. Chairman, before you put on the green light, I have two things to say. One, my testimony was fourteen minutes long and I have cut it to seven, and I hope that is OK; and second, to me this is a hallmark day. I think it will be the first time somebody has not asked me to talk softer.

Mr. SHAYS. This is true.

Mrs. MCKINNEY. This is true.

Mr. SHAYS. So you are basically saying do not turn this on until 2 minutes have gone by, is that what you are saying?

Mrs. MCKINNEY. At least.

Mr. SHAYS. Without objection, wait 2 minutes. No, you can start at green.

Mrs. MCKINNEY. The subject of this hearing, the Ryan White CARE Act, is of the utmost importance to me and for the 18 nonprofit organizations in Connecticut, who to a large extent rely on our government's promise to commit the necessary resources to care for persons with AIDS.

Ryan White and AIDS prevention programs are pivotal components to any successes we may achieve in our ongoing war against HIV disease, but it has been my experience that you cannot successfully alter the spread of this disease without first providing safe havens for people to be cared for. HOPWA is that vital link which makes Ryan White and HIV prevention dollars a vehicle for successfully combating the ever-burgeoning numbers of persons with HIV/AIDS who are at risk of homelessness or in fact already homeless.

To impose substantial cuts on Ryan White and HOPWA or even threaten them with elimination is nothing less than foolhardy, and would virtually cripple a marriage of program dollars which at the very least meet the basic needs of persons with AIDS in a cost effective, compassionate setting.

The Connecticut AIDS Residence Coalition plays an important role in the lives of persons with AIDS in Connecticut. Eighteen residential programs have been created where none existed before; coalitions have been formed between service providers to manage these dollars so that matching funds could be obtained. These programs will not continue without the ongoing commitment of funds for both Ryan White and HOPWA.

Let me also add here that the needle exchange program in New Haven, the first in the country, was highly successful, greatly reducing HIV transmission in the intravenous drug population.

Mr. SHAYS. You said in New Haven?

Mrs. MCKINNEY. This is in New Haven.

HOPWA and Ryan White programs are worth saving and funding. The return is enormous on what I consider a small investment in comparison. I am compelled to say as well, if you as individuals have concerns about the necessary funds to meet a national emergency, AIDS strikes me as one such example that has yet to receive the necessary funds to meet the challenge of this global pandemic.

Today's hearing is timely, given the current debate in Washington over budget concerns, with many opposing representatives jockeying to find appropriate solutions to this Nation's financial woes. Presently, citizens and politicians alike around this Nation are asking whether we can afford to provide services, housing, and medical care for persons with special needs; or should we?

Well, I am here to tell you, how can we afford not to? What will be the cost if we do nothing? If our housing programs were to end tomorrow, we could be forced to return to options that were available 15 years ago—the streets, the shelters, or the hospitals. In Connecticut, the average cost of utilizing a hospital bed is about $1,000 a day; while supportive housing costs combined with case management averages about $40 a day. Hundreds of millions of dollars would have to be spent by taxpayers in my State alone if the only options were hospitals and nursing homes.

We as service providers began to rely on your consistent pattern of commitment to the needs of persons with AIDS. Organizations like mine began to believe that Washington and State/local governments finally realize they had to join with us in a long-term commitment to help people with AIDS. How naive we were, given the current attitude of some of your fellow members. Specifically Senator Helms, who would have us believe that people with AIDS are undeserving of our care. That programs such as Ryan White and HOPWA should be cut and these moneys be made available for heart and cancer research. Mr. Chairman, Mr. Towns, I know of no other disease we currently face today that produces such rancor, bigotry and continued prejudice.

Senator Helms sullies the office he presently holds by this kind of behavior. He shames the Senate and this Nation in word and deed, and if it were in my power, Mr. Chairman, the Senator and Representatives like him would be asked to resign.

Mr. SHAYS. I might say that he also shames the Republican Party as well.

Mrs. MCKINNEY. Yes, he certainly does.

I submit to you, Mr. Chairman, a Nation is measured by how well it takes care of the least fortunate amongst us. Those of you who sit on important committees such as this need to remember that the seat you hold and those you represent go beyond the borders of your own districts. The decisions you will make affect thousands of men, women and children across this Nation.

We look to you to continue your partnership with us so the people with AIDS can continue to be served with compassion, love, and equality; the same equality you would expect to receive if you were in their position. My husband served nine terms in Congress and without a doubt demonstrated to his district, Nation and peers what compassion, fairness and concern for our neighbors in time of need was all about. If he were here, he would most assuredly support the reauthorization of the Ryan White CARE Act.

Furthermore, what is presently happening in ethnic and minority communities is that they are increasingly harmed by HIV disease.

Poverty, isolation and unequal access to health education and care as well as the current epidemic of drug use in some segments of these communities place many ethnic and minority individuals at increased risk. Public health campaigns on HIV disease have been slow to reach these communities and only recently have culturally appropriate initiatives been instituted in earnest.

Too often our medical, legal, social service and educational systems assume that all families with HIV disease need similar types of services and that all will make similar decisions regarding the care of children left orphaned. But culture plays a large part in how one views family, community, and the future. Unfortunately our current institutional systems often lack the flexibility to permit decisionmaking on cultural and social values that differ from the American norm.

I recently met a wonderful woman who lives in Bridgeport—two wonderful women who live in Bridgeport, both of whom are widows, who because of the loss of their children to AIDS are now raising a second family, their grandchildren. I ask you, who is going to help them if you cut back or eliminate Ryan White? They depend on that help.

In closing, I would like to read you a letter from a family who now has a home, thanks to HOPWA and Ryan White. This is a letter sent to Gary and I.

> Dear Lucie and Gary. I think of you often so I am writing to let you know how very grateful I am. All that I have and all that I am becoming was made possible by your foundation. You have given me a safe place to raise my children and that is so important to me. Ever since we have been in the house, I have grown so much. I get to send my son off on the bus each morning and be there for him when he gets home. I am enjoying watching my daughter play in a safe home, wondering where we would be if it were not for you. I am enjoying cooking and cleaning and washing my family's clothes. I enjoy walking out to get my mail. I enjoy drinking my coffee at night and reflecting on my day almost past. I enjoy calling my son in for the night, explaining to him that the day is almost over and that he needs to get ready for bed. You may think this is trivial, but these are the things that make me feel like a human being, a part of society. This home has given my family consistency. My son, who is in the fourth grade, no longer asks Mom, where am I going to go to school next year? He now talks about going to Fairfield High School and all the sports he wants to play there. These are the things that make my life so fulfilled. Stop by anytime. You will see that your house is my home where I am raising my children. To that I owe you everything. God bless you and your people, and all the hard work that you do. And thank you for our new life.

Thank you very much.

[The prepared statement of Mrs. McKinney follows:]

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Lucie McKinney, Chairman

Subcommittee on Human Resources and
Intergovernmental Relations
"AID's in the 90's: Service Delivery to Emerging Populations"
Statement of Lucie C. McKinney
July 17, 1995

The Stewart B. McKinney Foundation, Inc. is a tax exempt organization.

. The subject of this hearing, the Ryan White Care Act, is of the utmost importance to me and to the 18 nonprofit organizations in Connecticut who depend on the kindness, the generosity of others; and to a large extent rely on our governments promise to commit the necessary resources to care for persons with AIDS.

Ryan White and AIDS prevention programs are pivotal components to any successes we may achieve in our ongoing war against HIV disease,but it has been my experience that you cannot successfully alter the spread of this disease without first providing safe havens for people to be cared for. Housing Opportunities for Persons with AIDS (HOPWA) is that vital link which makes Ryan White and HIV prevention dollars a vehicle for successfully combating the ever burgeoning numbers of persons with HIV/AIDS who are at risk of homelessness or in fact homeless:

To impose substantial cuts on Ryan White and HOPWA or even threaten them with elimination is nothing less than foolhardy, and would virtually cripple a marriage of program dollars which at the very least meet the basic needs of persons with AIDS in a cost effective, compassionate setting.

The Connecticut AIDS Residence Coalition, of which my organization is a founding member plays an important role in the lives of persons with AIDS in Connecticut. Homes have been created where none existed before; coalitions have formed between service providers to manage these dollars so that matching funds could be obtained. This has been possible because of Ryan White and HOPWA.

HOPWA and Ryan White are programs worth saving and funding. They are success stories in the historical context of this epidemic. The return is enormous on what I consider a small investment in comparison. I'm compelled to say as well, if you as individuals have concerns about having the necessary funds to meet a national emergency, AIDS strikes me as one such example that has yet to receive the necessary funds to meet the challenge of this global pandemic.

Today's hearing is timely, given the current debate in Washington over budget concerns, with many opposing representatives jockeying to find appropriate solutions to this nations financial woes. Presently, citizens and politicians alike around this nation are asking whether we can afford to provide services, housing, and medical care for persons with special needs; or should we?

Kara:

The reason I have to disguise myself is I'm concerned that my child, who does not have AIDS, won't be allowed to have friends at school or visit her house, I'm afraid she'll be called names or teased. I have to hide my face because I have a terminal illness that everybody's afraid of, and my child would pay for it. She is paying for it. She's in pain. She lives it. She breathes it. She goes to bed with it every night.

Some nights we talk about it. Some nights she says, "Mommy, you'll be the Nana of my children, won't you?" And I say, "I hope so." And the next night she says, "Why can't the doctors make you better?" And the next night she says, "You won't be there will you?" And the next night she'll say, "Who'll take care me?"

Dear God,

You knew I loved my mother and how much we were happy and that she had AIDS and her suffering, but why did you have to let her die? She was part of my life. Now I feel bad because she is no longer here to love me anymore. You took her away from me and I will never forgive you. She was my mother, but you took he r from me. She probably doesn't even know me because she is having a great time in heaven. I feel bad.

P.S. I will forgive you because I love you and you did that for a reason so she can be happy and I also forgive you because you are my father.

Love you Mom and God
Love Onivea

Dear Lucie and Gary

I think of you often so I am writing to let you know how very grateful I am .All that I have and all that I am becoming was made possible by your foundation. You have given me a SAFE place to raise my children and that is so important to me. Ever since we have been in the house, I have grown so much. I get to send my son off on the bus each morning and be there for him when he gets home. I'm enjoying watching my daughter play in a safe home, wondering where would we be if it weren't for your foundation. I'm enjoying cooking and cleaning (really!) and washing my family's clothes. I enjoy walking out to get my mail. I enjoy drinking my coffee at night and reflecting on my day almost past. I enjoy calling my son in for the night, explaining to him that the day is almost over and that he needs to get ready for bed. You may think this is trivial, but these are the things that make me feel like a human being, a part of society. This home has given my family consistency. My son no longer asks, "Mom where am I going to going to school next year?" He now talks about going to Fairfield high school and all the sports he wants to play there. These are the things that make my life so fulfilled. Stop by any time. You will see that your house is my home where I am raising my children. To that I owe you everything. God bless you and your people and all the hard work that you do. And thank you for our new life.

Love Jeannie and the children

I'm here to tell you ladies and gentlemen, how can we afford not to? What will the cost be if we do nothing? I remind you that presently HOPWA funds provide dollars for approximately 50,000 people with AIDS nationally. In Connecticut. we have a total of 5,816 cases of AIDS which translates into 54 AIDS cases per 100,000 population, ranking our state 11th among all states. Approximately 20,000 people are infected with HIV disease in Connecticut.. A significant number of people living with HIV/AIDS are in need of Supportive Housing. As of December 1994, 1,122 people requested supportive housing, but only 125 could be assisted because of lack of space or inappropriate supportive services.

If our housing programs were to end tomorrow, we would be forced to return to options that were available 15 years ago- the streets, shelters or hospitals. In Connecticut, and I suspect around the country, the average cost of utilizing hospitals beds is about $1,000 to $1,100 a day, while supportive housing costs combined with case management averages about $40 to $75 a day. Hundreds of millions of dollars would have to be spent by taxpayers in my state alone if the only options were hospitals and nursing homes.

We as service providers began to rely on your consistent pattern of commitment to the needs of persons with AIDS. Organizations like mine began to believe that

Washington and state/local governments finally realized they had to join with us in a long-term commitment to help people with AIDS. How naive we were given the current attitude of some of your fellow members.

For one brief moment Mr. Chairman I wish to step back in time. Oh about 8 years or so. While the silence around this nation became deafening, AIDS seemed destined to periodic discussion only upon the death of some celebrity and then once again became a faded memory. At the same time, quietly, with determination across this nation people from diverse backgrounds and life experiences came together with one clearly defined goal; to develop services and housing for people with AIDS. They drew their strength of conviction from the death of those they loved, and developed a showcase of case management services, housing, education, and preventive services. We owe an enormous debt of gratitude to the Gay community for their tireless efforts on behalf of Persons with AIDS and most of all establishing for all of us models of supportive services to adapt for our own communities. I raise this issue with you today because some individuals in positions of leadership, namely Senator Helms, would have us believe that people with AIDS are undeserving of our care. That programs such as Ryan White and HOPWA should be cut and these moneys be made available to Heart and Cancer Research. Mr. Chairman, I know of no other disease we currently face today that produces such rancor, bigotry, and continued prejudice.

Senator Helms sullies the office he presently holds by this kind of behavior. He shames the Senate and this nation in word and deed. Mr. Chairman, if it were in my power , the Senator and Representatives like him would be asked to resign.

This is certainly no time to pit one disease against another. The argument that AIDS receives a disproportionate amount of dollars compared to Cancer or Heart is without merit, and I oppose such a position. Comments by Senator Helms and a few of our elected officials have been cruel, bigoted, and unnecessarily mean spirited. Why are you so silent when one of your own says something so contemptable?

I submit to you Mr. Chairman a nation is measured by how well it takes care of the least fortunate amongst us. Those of you who sit on important committees such as this need to remember that the seat you hold and those you represent go beyond the borders of your own districts. The decisions you will make affect thousands of men, women and children across this nation.

We look to you to continue your partnership with us so the people with AIDS can continue to be served with compassion, love, and equality; the same equality you would expect to receive if you were in their position. My husband served nine terms in congress and without a doubt demonstrated to his district nation and peers what compassion, fairness, and concern for our neighbors in time of need was all about. If he were here he would most assuredly support the re-authorization of the Ryan White Care Act.

In the state of Connecticut, HOPWA has proven to be a highly successful program. Of the eighteen AIDS residence programs currently operating in the state, seventeen use federal HOPWA dollars for supportive services and rental assistance. All of the HOPWA money coming into the state currently is allocated. In addition, Connecticut has been the recipient of HOPWA awards for Special Projects of National Significance in 1994 and 1995. In short, the HOPWA program has served as a critical piece of the federal-state-private sector partnership to provide quality services and safe, supportive housing to people living with AIDS/HIV in our state. These residential programs could not have happened nor will they continue without the on-going commitment of funds for both Ryan White and HOPWA.

"What is presently happening in ethnic and minority communities is increasingly harmed by HIV disease. Poverty, isolation, and unequal access to health education and care, as well as the current epidemic of drug use in some segments of these communities, place many ethnic and minority individuals at increased risk. Public health campaigns on HIV disease have been slow to reach these communities, and only recently have culturally appropriate initiatives been instituted in earnest." In Ct we've successfully begun to bring together the African American and Hispanic communities where HIV disease is alarmingly on the rise and have created a partnership that is culturally sensitive to their respective needs: creating models of prevention, education, and healthcare, that respect their traditions yet are collectively innovative in dealing with and treating HIV/AIDS.

"Too often our medical, legal, social service, and educational systems assume that all families with HIV disease need similar types of services and that all will make similar decisions regarding the care of children left orphaned. But culture plays a large part in how one views family, community, and the future. Unfortunately, our current institutional systems often lack the flexibility to permit decision making based on cultural and social values that differ from the "American norm.""

In closing, Mr. Chairman I must bring to your attention one last concern of: mine that could have a detrimental effect on all our successes.

In your efforts to contain costs, various committee members are currently discussing a managed care approach to slow the growth of Medicare and Medicaid. It has come to my attention that private H.M.O.'s across this country have been denying benefits for emergency services. Not only, has this created additional obstacles for the poor, many of whom have AIDS, but it has frustrated the efforts of emergency room physicians. This type of cost shifting has placed an unwelcome financial burden on patients and hospitals. Ultimately, the decision to hospitalize someone should rest solely with the physicians- not an insurance company or a government agency trying to contain costs.

Mr. Chairman; There must be a better way to care for our neediest citizens- Today I challenge you to come up with the solution. Thank you for allowing me the time to speak to all of you in regard to thiis critical issue.

CIRCLE OF CARE

THE STEWART B. MCKINNEY FOUNDATION

Resource List

1. Presidents Commission On AIDS
   Chairman Admiral Watkins

2. Presidents Commission On AIDS
   Chairwomen Dr. June Osborn

3. The Forgotten Children of the AIDS Epidemic
   Edited by Shelley, Janice Gruendel, and Warren Andiman
   Yale University Press 1995

4. CT. AIDS Residence Coalition Standards of Care 1994

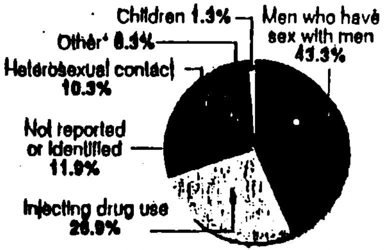
5. Department of Social Services (CT) Department of Health and Human
   Services, AIDS Division

CIRCLE OF CARE
THE STEWART B. McKINNEY FOUNDATION

UPDATE

Exposure to AIDS

Percentage of people in the United States who contracted AIDS in 1994 by type of exposure.



Total number of cases: 80,691

* Men who have sex with men and inject drugs; hemophiliacs; and recipients of blood transfusions or tissue.

Caring for People With H.I.V.

Cumulative grants awarded through the Ryan White Comprehensive AIDS Resource Emergency Act in the fiscal years 1991 through June 30, 1995. Pending grants yet to be awarded in fiscal 1995, spending will total more than $2 billion.

Alabama	$ 10,287,618	Nebraska	$ 1,031,716
Alaska	1,061,047	Nevada	4,732,261
Arizona	14,504,584	New Hampshire	717,850
Arkansas	4,801,404	New Jersey	96,982,765
California	400,708,580	New Mexico	3,715,398
Colorado	14,991,377	New York	468,074,914
Connecticut	16,291,613	North Carolina	10,832,007
Delaware	1,655,026	North Dakota	419,872
Dist. of Columbia	60,128,380	Ohio	12,858,964
Florida	178,419,854	Oklahoma	4,261,127
Georgia	53,108,595	Oregon	8,963,018
Hawaii	2,113,003	Pennsylvania	54,569,625
Idaho	568,982	Puerto Rico	78,612,601
Illinois	65,195,984	Rhode Island	3,191,069
Indiana	8,968,824	South Carolina	7,209,356
Iowa	1,895,351	South Dakota	500,000
Kansas	2,298,574	Tennessee	5,770,766
Kentucky	2,458,912	Texas	123,014,323
Louisiana	21,953,379	Utah	2,813,523
Maine	810,055	Vermont	748,940
Maryland	33,002,650	Virginia	9,067,739
Massachusetts	49,057,307	Washington	23,870,876
Michigan	22,158,670	West Virginia	774,743
Minnesota	3,958,743	Wisconsin	4,627,555
Mississippi	3,890,029	Wyoming	444,037
Missouri	28,703,492	Guam	16,937
Montana	456,197	Virgin Islands	170,167

Sources: Department of Health and Human Services; Centers for Disease Control and Prevention

Connecticut

Acquired Immunodeficiency Syndrome (AIDS)
HIV-AIDS Reporting System
Surveillance Report - 07/03/95

	Adult/Adolescent		Pediatric		Total	
Disease Category	Cases (%)	Deaths (%)	Cases (%)	Deaths (%)	Cases (%)	Deaths (%)
PCP	2265 (35)	1569 (69)	40 (29)	26 (65)	2305 (35)	1595 (69)
Other Disease w/o PCP	2155 (33)	1304 (61)	96 (71)	46 (48)	2251 (34)	1350 (60)
KS Alone	115 (2)	78 (68)	0 (0)	0 (.)	115 (2)	78 (68)
No Diseases Listed	1930 (30)	270 (14)	0 (0)	0 (.)	1930 (29)	270 (14)
Total	6465 (100)	3221 (50)	136 (100)	72 (53)	6601 (100)	3293 (50)

Age	Cases (%)
Under 5	115 (2)
5-12	21 (0)
13-19	21 (0)
20-29	1058 (16)
30-39	3108 (47)
40-49	1634 (25)
Over 49	644 (10)
Unknown	0 (0)
Total	6601 (100)

3.

	Adult/Adolescent	Pediatric	Total
Race/Ethnicity	Cases (%)	Cases (%)	Cases (%)
White, Not Hispanic	2461 (38)	13 (10)	2474 (37)
Black, Not Hispanic	2593 (40)	78 (57)	2671 (40)
Hispanic	1370 (21)	43 (32)	1413 (21)
Asian/Pacific Is.	10 (0)	1 (1)	11 (0)
Am. Indian/Alaskan	14 (0)	0 (0)	14 (0)
Unknown	17 (0)	1 (1)	18 (0)
Total	6465 (100)	136 (100)	6601 (100)

Patient Groups	Adult/Adolescent Transmission Modes**		
	Males (%)	Females (%)	Total (%)
Homosexual or bisexual Men	1782 (36)	0 (0)	1782 (28)
Intravenous (IV) drug User	2426 (48)	827 (57)	3253 (50)
Homo/Bi IV drug User	252 (5)	0 (0)	252 (4)
Coagulation disorder	37 (1)	2 (0)	39 (1)
Heterosexual contact	315 (6)	534 (37)	849 (13)
Transfusion with blood/products	29 (1)	32 (2)	61 (1)
Risk not reported/Other	171 (3)	57 (4)	228 (4)
Total	5012 (100)	1452 (100)	6464 (100)

	Pediatric Transmission Modes		
	Males (%)	Females (%)	Total (%)
Coagulation disorder	2 (3)	0 (0)	2 (1)
Parent at risk/has AIDS/HIV	68 (92)	62 (98)	130 (95)
Transfusion with blood/products	3 (4)	0 (0)	3 (2)
Risk not reported/Other	1 (1)	1 (2)	2 (1)
Total	74 (100)	63 (100)	137 (100)

**1 patients were diagnosed with AIDS as adults but have evidence of being HIV infected as children. They

National

Table 1. AIDS cases by state, reported in April 1995; cases and rates per 100,000 population, by state, reported May 1993 through April 1994, and May 1994 through April 1995; and cumulative totals, by state and age group, through April 1995

16th Adults 10th Pedi

	Apr. 1995	May 1993 - Apr. 1994		May 1994 - Apr. 1995		Cumulative totals		
State of residence	No.	No.	Rate	No.	Rate	Adults/ adolescents	Children < 13 years old	Total
Alabama	74	536	12.8	609	14.4	3,203	52	3,255
Alaska	9	75	12.5	83	13.7	292	4	296
Arizona	69	608	15.4	604	14.8	3,950	19	3,969
Arkansas	24	280	11.5	295	12.0	1,676	25	1,701
California	20	15,050	48.2	10,819	34.6	80,766 2	452 4	81,218
Colorado	54	896	25.1	723	19.8	4,810	26	4,836
Connecticut	253	1,413	43.1	1,109	33.9	6,125 — 16th	139 10	6,264
Delaware	18	262	37.5	323	45.7	1,303	11	1,314
District of Columbia	69	1,526	263.5	1,423	249.6	7,458	114	7,572
Florida	365	8,479	61.8	9,160	65.7	45,923 3	1,045 2	46,968
Georgia	181	2,107	30.5	2,376	33.7	12,899 8	133	13,032
Hawaii	24	342	29.3	242	20.5	1,629	13	1,642
Idaho	5	54	4.9	69	6.1	299	2	301
Illinois	155	2,457	21.0	3,223	27.4	14,945 6	168 8	15,113
Indiana	62	796	14.0	510	8.9	3,447	27	3,474
Iowa	13	97	3.4	142	5.0	783	8	791
Kansas	9	253	10.0	265	10.4	1,453	9	1,462
Kentucky	17	304	8.0	273	7.1	1,596	13	1,609
Louisiana	54	1,137	26.5	1,292	29.9	6,851 12	91	6,942
Maine	-	118	9.5	111	9.0	597	5	602
Maryland	33	2,226	44.9	3,234	64.6	11,311 9	223 6	11,534
Massachusetts	137	2,387	39.7	1,476	24.4	9,664	160 9	9,824
Michigan	152	1,189	12.6	1,117	11.8	6,584 14	74	6,658
Minnesota	29	434	9.6	406	8.9	2,447	16	2,463
Mississippi	38	406	15.4	431	16.1	2,100	35	2,135
Missouri	75	792	15.1	700	13.3	5,813	41	5,854
Montana	-	29	3.4	28	3.3	175	2	177
Nebraska	8	121	7.5	108	6.7	619	7	626
Nevada	11	462	33.4	423	29.0	2,307	18	2,325
New Hampshire	6	90	8.0	112	9.9	548	7	555
New Jersey	314	5,035	64.1	4,839	61.2	25,825 5	587 3	26,412
New Mexico	2	153	9.5	225	13.6	1,139	4	1,143
New York	916	17,897	98.6	13,234	72.8	85,274 1	1,677 1	86,951
North Carolina	64	1,379	19.8	1,041	14.7	5,650	80	5,730
North Dakota	-	18	2.8	12	1.9	60	-	60
Ohio	72	1,337	12.1	1,302	11.7	6,920 11	80	7,000
Oklahoma	17	393	12.2	278	8.5	2,250	17	2,267
Oregon	36	519	17.1	539	17.5	3,087	12	3,099
Pennsylvania	284	2,967	24.7	2,683	22.3	13,396 7	202 7	13,598
Rhode Island	33	337	33.7	274	27.5	1,278	15	1,293
South Carolina	52	1,171	32.3	1,038	28.3	4,689	58	4,747
South Dakota	6	18	2.5	18	2.5	89	4	93
Tennessee	86	899	17.6	896	17.3	4,140	34	4,174
Texas	738	6,373	35.4	5,206	28.3	32,102 4	264 5	32,366
Utah	15	140	7.5	153	8.0	1,057	20	1,077
Vermont	6	75	13.0	36	6.2	241	3	244
Virginia	81	1,335	20.6	1,198	18.3	6,640 13	121	6,761
Washington	61	1,653	31.4	1,031	19.3	6,319 15	22	6,341
West Virginia	10	75	4.1	115	6.3	523	6	529
Wisconsin	34	407	8.1	385	7.6	2,280	23	2,303
Wyoming	-	21	4.5	13	2.7	120	-	120
Subtotal	4,791	87,128	33.8	76,202	29.3	444,652	6,168	450,820
Guam	-	1	0.7	-	-	14	-	14
Pacific Islands, U.S.	-	-	-	-	-	2	-	2
Puerto Rico	218	2,731	75.7	2,477	68.1	14,304	315	14,619
Virgin Islands, U.S.	5	34	32.9	64	61.6	232	8	240
Total*	5,033	89,997	34.4	78,879	29.8	459,601	6,493	466,094

*Totals include 399 persons whose state of residence is unknown.

Mr. SHAYS. Lucie, that is a precious letter, precious letter. We could all take the joy of those simple things. Thank you for all the good work that you have done for so long. She is a real hero, if you do not know that.

Mr. Pressley.

Mr. PRESSLEY. Before you start the clock.

Mr. SHAYS. Before I start—OK, fair enough.

Mr. PRESSLEY. I have invited two of my colleagues here also to help field questions. One is Colin Robinson, who is the executive director of Gay Men of African Descent, and also Jeff Haskins, who is the executive director of People of Color in Crisis.

Mr. SHAYS. Well, it is nice to have you both here. All three of you.

Mr. PRESSLEY. Start the clock.

I would like to thank Chairman Christopher Shays, Congressman Edolphus Towns and the Subcommittee on Human Resources and Intergovernmental Relations of the Committee on Government Reform and Oversight for inviting me to speak today about emerging populations.

I am here today to testify on the behalf of Lambda Independent Group Democrats, a Brooklyn-based lesbian and gay political organization focused on articulating the concerns of lesbians and gays in the political arena.

As we move even further into the second decade of the HIV and AIDS epidemic, there is still no end in sight to the ravage and despair caused by this disease—a disease which has rapidly become the health crisis of this country. Statistics clearly depict that the number of people living with AIDS continues to escalate by leaps and bounds. The CDC reports that AIDS is now the leading cause of death for men and women between the ages of 25 to 44. Health authorities estimate that 350,000 citizens of New York State are HIV positive. As of March 1995, nearly 86,794 cases of AIDS were reported in New York State representing one out of every five reported cases of AIDS in the United States.

New York State leads the Nation in AIDS cases among women. Females comprise almost 20 percent of all adult AIDS cases here in New York State. From December 1993 to July 1994, there was a 17-percent increase in the number of AIDS cases amongst women in our State, and by the end of 1997 it is believed that the number of women with AIDS will double from 1992 statistics.

Of the 86,794 reported cumulative cases of AIDS in New York State at the end of March 1995, 75,633 or 87 percent occurred in New York City, and in fact New York City has more cumulative cases of AIDS than Los Angeles and San Francisco combined. As of March 31, 1995, the Borough of Brooklyn, the geographical base of Lambda Independent Democrats, had 18,355 cumulative cases of AIDS representing one-quarter of the city's total. Some of us know that if Brooklyn were to secede from New York City, then it would be the fourth largest city in the Nation; however, many may not know that if Brooklyn were counted as a city, then it would also rank fourth in the number of AIDS cases, behind New York, Los Angeles and San Francisco, as reported by the Brooklyn AIDS Task Force.

Our organization is extremely concerned about the development of an HIV and AIDS care prevention service network not only in Brooklyn but across our city, State and country as well—a network designed to provide a vigorous response to the havoc that AIDS has and will wreak on communities across this Nation. The Ryan White CARE Act and the Community Prevention Planning and Housing Opportunities for People with AIDS structures are steps in the right direction. Unfortunately, more work is needed. This network must support, undergird, expand and enrich many existing services, some of which were developed in the 1980's. Just as importantly, proactive responses must be created to stop the spread of HIV and AIDS in underserved communities before they become decimated by AIDS.

The development of proactive responses to stem the tide of the AIDS epidemic in underserved communities has been slow at best. This is clearly exemplified in the development of services for communities of color. During the early years of the first decade of the AIDS crisis, advocated forewarned government officials that comprehensive and culturally appropriate services needed to be developed reaching people of color communities. These visionaries saw that the AIDS cases would explode within communities of color if programs providing a full range of culturally competent and sensitive services, including prevention multilingual education services in languages other than English and Spanish were not developed. These forward thinking people saw the need to develop powerful community responses to HIV and AIDS in traditionally underserved and historically disadvantaged people of color communities.

Although HIV and AIDS programs have been developed targeting communities of color, many would argue that the government's response is a case of too little too late. Of the 75,633 cumulative cases reported in New York City as of March 1995, 53,730 or 71 percent were amongst people of color. As of May 31, 1995, blacks and Latinos made up 81 percent of all cases between the ages of 20 to 24 in New York City. While well over 90 percent of these cases occurred in black and Latino communities, Asian Pacific Islanders and Native people have experienced an increase in caseloads in their respective communities as well. During 1994 there was a 24-percent increase in New York City adult AIDS cases amongst people of color. Women of color make up almost 90 percent of all female AIDS cases. From December 1992 to March 1995, there was a 106——

Mr. SHAYS. Is that in New York City?

Mr. PRESSLEY. In New York City.

Mr. SHAYS. 90 percent?

Mr. PRESSLEY. 90 percent. From December 1992 to March 1995 there was a 106-percent increase in the number of AIDS cases amongst women of color. HIV and AIDS is not simply emerging in communities of color. The disease has emerged and has caused much pain and despair within communities of color. Black and Latino people have been especially ravaged by AIDS. More culturally competent and appropriate services are needed to stem the tide of the epidemic amongst people of color—services which will even better address the diversity of communities of color.

Another emerged group with Lambda Independent Democrats believes must be addressed is the extremely diverse group of gay men of color. This past week has been quite a trying one for me. Although I took the week off from work at the New York AIDS Coalition, I did not get much rest. My roommate, a black gay man, was and is at home quite ill. With spiking fevers, erratic bowel movements, AIDS related dementia, and a host of other challenges, it has been very tough for him. After coming home last week, my roommate's physical appearance is a shadow of what he was before entering the hospital 2 months ago. In some ways my roommate is lucky. Many black gay men are not as lucky.

Quite often we will hear from individuals that the AIDS epidemic has shifted in recent years from gay men to new population groups of racial minorities and women. I am here today to testify for Lambda that that while statistics may show that new infections are slowing amongst gay men as a whole, cases continue to explode amongst black and Latino men who have sex with men. In a recent CDC Morbidity and Mortality Weekly Report, it was reported that since June 1981 three MSA's, New York, Los Angeles and San Francisco, have reported 27 percent of all AIDS cases amongst men who have sex with men. During the 5-year surveillance period, rates of AIDS opportunistic infections increased 8 percent, 12 percent and 7 percent respectively in those cities. In all three MSA's the rate for white men decreased 20 percent, 16 percent and 3 percent respectively, and the rate for black men, for black men who have sex with men increased 49 percent, 48 percent and 53 percent in New York, Los Angeles and San Francisco.

In closing, we implore you to develop services that respond to the increasing caseloads that are exploding in communities of color and also taking a close look at the increased caseloads amongst men who have sex with men.

Lambda implores you to finance resources for these organizations and we also implore you that too often when we look at combating the AIDS crisis that what happens is we look at putting out the next fire. Maybe the vision should involve keeping new fires from getting started so that new populations will not emerge. When looking at AIDS in the 1990's, Lambda strongly urges you to keep in mind that long-range, innovative and courageous strategies must be developed serving all communities. Lambda encourages government officials to take leadership in making certain that reality-based HIV prevention strategies are introduced and supported throughout the Nation.

And finally, the ultimate goal is to find a cure. Funds must be continually channeled into research. Thank you for your time.

[The prepared statement of Mr. Pressley follows:]

TESTIMONY OF LAMBDA INDEPENDENT DEMOCRATS

July 17th 1995

I'd like to thank Chairman Christopher Shays, Congressman Edolphus Towns, and the Subcommittee on Human Resources and Intergovernmental Relations of the Committee on Government Reform and Oversight for inviting me to speak at this hearing regarding "AIDS in the '90s: Service Delivery to Emerging Populations."

My name is Joe Pressley and I am here today testifying on the behalf of Lambda Independent Democrats, which is a Brooklyn-based Lesbian and Gay political organization focused on articulating the concerns of Lesbians and Gays in the political arena. During election years, Lambda conducts candidate forums which we use to endorse individuals seeking publicly elected offices on all levels of government serving the borough of Brooklyn. Lambda is also bent on providing information through community meetings and its monthly newsletter to guarantee that its constituents have a heightened impact on the shaping of importance to us in the political arena.

As we move even further into the second decade of the HIV and AIDS epidemic, there is still no end in sight to the ravage and despair caused by this disease—a disease which has rapidly become the health crisis of this country. Statistics clearly depict that the number of People Living with AIDS continues to escalate by leaps and bounds. The Centers for Disease Control reports that AIDS is now the leading cause of death for men and women between the ages of 25-44. Health authorities estimate that 350,000 citizens of New York State are HIV positive. As of March 31, 1995 nearly

86,794 cases of AIDS were reported in New York State representing one out of every five reported cases of AIDS in the United States. New York State leads the nation in AIDS cases among women. Females comprise almost 20% of all adult AIDS cases here in New York State. From December 31, 1993 to July 31, 1994 there was a 17% increase in the number of AIDS cases amongst women in our state, and by the end of 1997, it is believed that the number of women with AIDS will double from 1992 statistics. Of the 86,794 reported cumulative cases of AIDS in New York State at the end of March 1995, 75,633 or 87% occurred in NYC, and, in fact, New York City has had more cumulative AIDS cases than Los Angeles and San Francisco combined, which rank 2nd and 3rd in cities most impacted by the epidemic. As of March 31, 1995, the Borough of Brooklyn, the geographical base of Lambda Independent Democrats, had 18,355 cumulative cases of AIDS representing nearly ¼ of the city's total. Many of us know that if Brooklyn were to secede from New York City, then it would be the 4th largest city in the nation; however, many may not know that if Brooklyn were counted as a city, then it would also rank fourth in the number of AIDS cases behind New York, Los Angeles and San Francisco.

Our organization is extremely concerned about the development of an HIV and AIDS care and prevention service network, not only in Brooklyn, but across our city, state and country as well — a network designed to provide a vigorous response to the havoc that AIDS has and will wreak on communities across this nation. The Ryan White CARE Act and Community Prevention Planning structures are steps in the right direction.

Unfortunately, more work is needed. This network must support, undergird, expand and enrichen many of the existing services — some of which were developed in the 1980s. Just as importantly, proactive responses must be created to stop the spread of HIV and AIDS in underserved communities before they become decimated by AIDS.

The development of proactive responses to stem the tide of the AIDS epidemic in underserved communities has been slow at best. This is clearly exemplified in the development of services for communities of Color. During the early years of the first decade of the AIDS crisis, advocates forewarned government officials that comprehensive and culturally appropriate services needed to be developed reaching People of Color communities. These visionaries saw that AIDS cases would explode within communities of Color if programs providing a full range of culturally competent and sensitive services including prevention multi-lingual education services in languages in addition to English and Spanish were not developed. These forward thinking people saw the need to develop powerful community responses to HIV/AIDS in traditionally underserved and historically disadvantaged People of Color communities.

Although HIV and AIDS programs have been developed tragetting communities of color, many would argue that the government's response is a case of "too little too late." Of the 75,633 cumulative cases reported in New York City as of March 31, 1995, 53,730 or 71% were amongst People of Color. As of May 31, 1995, Blacks and Latinos made up 81% of all AIDS cases between the ages of 20 to 24 in New York City. While well-over 90% of these cases occurred in the Black and Latino communities, the Asian, Pacific Islander and Native people have experienced an increase in caseloads in their respective communities and, similar to the Black and Latino communities, are greatly underserved. During 1994, there was a 24% increase in New York City adult AIDS cases amongst People of Color. Women of Color make up almost 90% of all adult female AIDS cases. From December 31, 1992 to March 31, 1995 there was a 106% increase in the number of AIDS cases amongst women of Color. HIV/AIDS is not simply emerging in communities of Color. The disease has emerged, and has caused much pain and despair within communities of Color. Black and Latino people have been especially ravaged by AIDS. More culturally competent and appropriate services are needed to stem the tide of the epidemic amongst People of Color — services which will even better address the diversity of communities of Color. Lambda also implores you to preserve and protect live-saving social service programs such as Medicaid, Medicare and public assistance, which are programs that many people living with AIDS (especially those of color) rely on for support.

Another "emerged" group which Lambda Independent Democrats believes must be addressed is the extremely diverse group of Gay men of Color. This past week has been quite a trying one for me. Although I took the week off from my job at the New York AIDS Coalition, I didn't get much rest. My roommate, a Black Gay man, was/is at home quite ill. With spiking fevers, erratic bowel movements, AIDS related dementia, increasing lesions, and a host of other personal challenges, this has not been a good week for him. After coming home last week, my roommate's physical appearance is a shadow of what he was before entering the hospital two months ago. A physically fit man, who spent constant hours in the gym, my roommate (my friend) has lost incredible amounts of weight, his skin has taken on an ashen look, and the disease has rendered his body weak.

In some ways my roommate is lucky. He has an extremely supportive family that cares a great deal about him and a roommate who is a source of information for him regarding HIV and AIDS issues. Unfortunately, many others aren't so lucky. Many Gay men because of rampant homophobia are left without adequate family support and access to adequate care.

Quite often we will hear from individuals that the AIDS epidemic has shifted in recent years from Gay men to "new population groups of racial minorities and women." I am here to testify for Lambda that while statistics may show that new infections are slowing amongst the Gay men as a whole, cases continue to explode amongst Black and Latino men who have sex with men. In a recent CDC "Morbidity and Mortality Weekly Report" it was reported that "since June 1981, three metropolitan statistic areas (MSAs) (New York, Los Angeles, and San Francisco) have reported 27% of all AIDS cases among MSMs (men who have sex with men). During the 5-year surveillance period, rates of AIDS-OI (opportunistic infections) increased 8%, 12%, and 7%, respectively, (mid-1994 rates: 44.4, 34.9, and 127.7, respectively). In all three MSAs, the rate for

White men decreased (20%, 16%, and 3%, respectively), and the rate for Black men increased (49%, 48%, and 53% in New York, Los Angeles and San Francisco respectively." Similarly, there has been marked growth in AIDS cases among Latino men who have sex with men.

Men of Color who have sex with men are increasingly making up a larger portion of people with AIDS throughout this borough, city, state and nation. As of January 1995, there were 57,838 total AIDS cases among men in New York City. Of these, 20,973 (36%) were among Black men. Almost half of the male cases were attributable to men-who-have-sex with men. In this category, there were 6,476 AIDS cases among Black men that were attributable to sex between men. Despite these statistics, overall funding patterns do not sufficiently address the need for HIV/AIDS services among Black Gay Men. In a recent paper prepared by Gay Men of African Descent (GMAD), a Black Gay organization based here in New York City, reference was made to a 1989 national survey of 1,000 Black men who have sex with men from large and medium-sized urban areas, which included 14% who lived in New York City. Gay Men of African Descent's paper stated, "Only 54% (of the 1,000 Black MSMs) reported always or nearly always practicing safer sex and 43% said they were likely to not worry about having unsafe sex once in a while. A majority said AIDS had impacted how they feel about themselves, most worried, and some had become afraid to have sex; a third rarely discussed AIDS with anyone, and only about half said they would be willing to share their AIDS diagnosis with their families or believed they would be supportive;

almost a quarter believed that a cure for AIDS is available but being withheld. Responses of men not affiliated with an organization consistently reflected less knowledge and riskier attitudes, beliefs and behaviors."

Lambda implores government bodies to find more financial resources for the development of community-based infrastructure to address the HIV/AIDS prevention and care needs of Gay men of Color. The Center for Disease Control reports shocking rates of increase in HIV infection among Black and Latino men. We know that much of the new infection is attributable to unsafe sex between men, whether these men identify as gay or not. With no preventive vaccination in sight, effective (and I might add courageous) prevention programs are the only way to stem the tide of new infections. Courageous because our prevention programs must begin to reflect reality — the reality is that people engage in a range of sexual activity and must be armed with information on how to engage safely. Such courageous programming would involve using schools to reach young people and to speak openly and honestly about sexuality. Nationally, Gay and Bisexual men comprised 82% of teenage AIDS cases (ages 13 to 19). In the 20 to 24 age group, Gay and Bisexual men make up 60% of the total number and with an incubation of usually about ten years we know that many of these individual were infected as teenagers. Life saving prevention services must be developed to reach these young men. To reach men who have sex with men (men who quite often choose not to identify as Gay or Bisexual), we must begin the task of getting all communities to be sensitive to the needs of this group. Many MSMs are not affiliated with community based services because many programs only address men who identify as Gay. One individual recently told me of a caseworker who told a self-identified Bisexual client that "it would difficult for her to render services because she simply had problems with the Bisexual lifestyle." As a result, MSMs are often not exposed to a great deal of information. Many, including those of color residing in this borough of Brooklyn and across the city, are often forced to travel outside of their communities to seek services sensitive to their needs.

Services must be developed to reach MSMs where they live, regardless of how they identify. Existing organizations, such as Brooklyn's People of Crisis and New York City's Gay Men of African Descent, which are organizations created by and expressly serving Black men who have sex with other men, must be strengthened to meet the needs of this rapidly increasing group. Similar organizations must be created and supported in other People of Color Communities. Furthermore, as needed resources are channeled into communities of Color, existing and new programs must be better armed to provide sensitive prevention and care services to men of Color who have sex with men so that people will not have to leave their communities to access services and receive information on how to prolong and save their lives and save the lives of their male and...yes... female partners as well.

The AIDS epidemic is not static and is not predictable (just ask those from the early years of the first decade who did not seriously consider that AIDS and HIV would explode in communities of Color). The groups that I have mentioned earlier are not emerging populations — they have emerged! Unfortunately, there are groups out there which we are simply ignoring. One such group are women who have sex with women. There is not much data on women to women transmission of HIV; however, we do know that agencies are noting that a growing number of their female clients indicate that they engage in sexual activity with other women. Similar to men, these women are forced to travel outside of their communities to receive services sensitive to their needs and concerns. As a result, projects must be developed providing information to women who engage in sexual activity with other women but may not consider themselves at risk for HIV.

Too often the response to combatting the AIDS crisis has been to move on and put out the next fire. Maybe the vision should involve keeping new fires from getting started. When looking at AIDS in the 90s, Lambda strongly urges you to keep in mind that long-range, innovative and courageous strategies must be developed serving all communities. Lambda encourages government officials to take leadership in making certain that reality-based HIV prevention strategies are introduced and supported throughout the nation. And finally, the ultimate goal is to find a cure. Funds must be continually channelled into research.

Information for the above was gathered from:

The Centers for Disease Control
Gay Men of African Descent
Gay Men's Health Crisis
The New York AIDS Coalition
The New York City and State Departments of Health
People of Color in Crisis

Mr. SHAYS. Thank you very much.

Senator, you need to move the mike to you, even though it does not pick up—do not even think that it projects your voice because it will not. I am told by Mr. Towns, that he has a driver, that if we are in the car at 1:30, in the car, we can make the 2 o'clock. We are going to try that at 20 after, so you could spend your 5 minutes—we could have a good dialog, and if we go to 25 after, we will run.

Ms. MONTGOMERY. Congressmen Shays and Towns, I thank you for being so gracious to allow me to join this panel.

Mr. SHAYS. It is a privilege to have you.

Ms. MONTGOMERY. Thank you. And I certainly understand how it is that Mrs. McKinney got 7 minutes and I have two. I understand giving due deference to your constituents, so Congressman Towns and I——

Mr. SHAYS. Not just any constituent, the constituent.

Ms. MONTGOMERY. The constituent. I certainly agree with that.

Let me say I am here specifically to talk about the whole issue of prevention as I see it and I understand that Congressman Towns has talked about where we will be with HIV/AIDS in the year 2000. So I want to speak to the issue of adolescent health care because it is my understanding from the experts in the field that an area where there is such an extreme explosion in new cases is among teens and young adults who probably contracted the disease as teens.

And while I certainly advocate abstinence, as I think we all do, we recognize that the fact of the matter is that teens do engage in what many of us would consider irresponsible behavior on many levels, one of them being premature sex, and therefore, the whole issue of prevention must be dealt with with adolescents in a very specific way.

The State of New York now has received a grant from the Robert Wood Johnson Foundation, which is a national foundation looking at ways of providing health services specifically to adolescents and children. And the purpose of this grant is to help the State develop a plan for funding school-based health clinics, comprehensive school-based health clinics, in a way that makes them permanent, a permanent part of our health delivery system.

The State of New York has been able to expand to some extent the school-based health services in the State, especially in New York City; but I must say that the initial thrust of that was through the Robert Wood Johnson Foundation initiative that they took some 5 years in the past where they funded school-based health centers in particular. What is needed and what is comprehensive as I see it.

In addition to the regular health care services, we need to have a firm system of sex and health education. That is the part that is very difficult vis-a-vis what was stated by Mr. Cylar I believe. The problem of talking about it, discussing it, and being comfortable dealing with that issue, especially with teens and preteens. And the question of family planning counseling, being part of a comprehensive adolescent health is crucial.

Those must remain as components of school-based health services, in addition to AIDS prevention services, including the distribution of condoms in schools. That is where children are, that is where large numbers of teens are, that is where they are every day, they have people there that they trust. If there is a health clinic at that school, those teens will take advantage of it. And in New York State, every single health clinic requires that there be parental consent for any young person to receive health services. So I advocate that this is an important aspect of any school-based health program.

In addition, we have tried to do, we have begun to initiate a little bit mental health services funded through the Department of Mental Health in the State, connecting a mental health component to school-based health so that there is crisis intervention services as well as long-term services to children and hopefully eventually to their families.

What have we done in the State? We have, as I have said, we have begun to look at school-based health as our primary system of delivering health care to young people in particular and we would like to continue to strengthen that. We have even in our Republican Senate, we have been able to get a 2-year extension on our school-based health funding in the budget process this year, so there is a lot of hope there.

We have been very reluctant to vote out a bill that I have sponsored for some years along with the Health Chair in the Assembly, a needle exchange bill, which we would certainly like to see done; but we have not been able to do that yet. We have been able to maintain the mental health funding, which is specifically targeting mental health services in schools, and we have been able to so to speak target some of our resources, the AIDS prevention resources, toward prevention education and training.

I would only ask that the Ryan White funding reflect the reality that prevention is the—at this point in time the only cure so to speak, and that we need to be able to continue to treat adolescents as a particular and special needs category of people that we have a possibility of turning around if we can work with them in the right way, if we can reach them early enough, and if we can provide them with information which they can use to protect their lives.

Let me just invite you, whenever you have another opportunity to come to Brooklyn, about three blocks from here the Jewish Board of Family Services has an excellent example of a day treatment, AIDS day treatment program which is very, very wonderful. It is in the district of Congressman Towns and myself and I think that it is where we really need to be going as one aspect of dealing with this issue. Thank you.

Mr. SHAYS. Let me just go through a series of very brief questions. Were you intending to testify as well?

Ms. SANDORF. Yes, sir.

Mr. SHAYS. I am sorry. OK, that was not made clear to me, I am sorry; so I welcome your testimony. I am going to be pretty strict on your time, so I am going to ask you to not read.

Ms. SANDORF. No, I am cutting this down about three-quarters.

Mr. SHAYS. OK, but feel inclined not to read, I think you will cover the big stuff.

Ms. SANDORF. Thank you, Mr. Chairman and Congressman Towns. My name is Julie Sandorf and I am the president of the Corporation for Supportive Housing.

Mr. SHAYS. Can you just refresh me? That is nationwide?

Ms. SANDORF. It is a national, nonprofit organization that has aggregated significant philanthropy to invest in supportive housing for folks who are homeless and have special needs, including individuals who are HIV infected and who have AIDS.

Mr. SHAYS. A little louder please?

Ms. SANDORF. Including individuals who are HIV infected and have AIDS.

What I would like to talk about today is the good news and the wise investment of both HOPWA, Ryan White, and McKinney moneys in community-based housing and support services. We read in the papers every day about budget slashing, which often feels very reckless in this incredible need to reduce the deficit. What I would like to talk about is how those three programs have been so incredibly cost-effective and why they should be maintained, because there is no cost-free alternative when we want to provide decent care and support to people with HIV and AIDS.

Mr. SHAYS. That is a nice expression, no cost-free alternative.

Ms. SANDORF. There is no cost-free alternative here.

I would like to talk a little bit about supportive housing. Supportive housing marries permanent housing with support services that enables an individual who is HIV infected or has AIDS to live independently with support and health in the community setting. Supportive housing is a grassroots movement started in the late 1980's by nonprofit organizations like Housing Works, Minority Task Force on AIDS in New York, STANDUP Harlem, Common Ground—many, there are about 400 AIDS related housing organizations community-based in the country—who identified housing and service needs of the population as their highest priority.

The goal of supportive housing for people with AIDS is to enable the tenant to live a stable, independent life and to the extent possible avoid costly hospitalizations and emergency treatment. Supportive housing is not only effective in terms of an individual's quality of life, but it is cost-effective. It stabilizes folks who then could access managed care services rather than emergency rooms and extended hospitalizations. On the average, supportive housing for people with AIDS costs about $27 to $44 a day, compared to $1,000 or $1,200 for acute care hospitalization.

I would like to go through a case study on a gentleman named Marty and his four housing options in New York City. Marty is diagnosed with AIDS, loses his job and his apartment. He takes up residency in a city shelter where his condition rapidly deteriorates. He is admitted to a hospital acute care bed and is diagnosed with tuberculosis.

Marty has four housing options in New York City. He has the street. Since Marty can no longer live in a shelter due to his AIDS diagnosis, he tries to survive on the street. This leads to rapid and severe deterioration of his health and will pose a risk to those whom he comes into contact with due to his TB diagnosis. Without access to primary health care, Marty is forced to use hospital acute care for all his health needs, which he can be expected to spend a minimum of 5 days per month in acute care bed. His housing cost is zero, his service and care cost is about $72,000 a year.

Commercial SRO's. Hospital puts Marty in touch with the city's Department of AIDS Services where he learns that he can get a single room occupancy apartment in a commercial SRO. Without access to services though, Marty will again be forced to use expensive community care when he becomes ill. Annual housing costs they are paying to a private landlord, $8,400 to $16,000 a year. Support service costs, $72,000 a year.

AIDS skilled nursing facility. Marty could be placed in a skilled nursing facility even though he does not require this level of care and can continue to live independently given proper——

Mr. SHAYS. You are relating to this, Keith?

Mr. CYLAR. Yes.

Ms. SANDORF [continuing]. Given sufficient——

Mr. SHAYS. I feel like I am in a Baptist Church, he is about to say Amen, he is nodding his head.

Ms. SANDORF [continuing]. The annual cost of the AIDS skilled nursing facility, $127,000 to $182,000 a year.

The last option, supportive housing, which could be congregate supported housing, folks living in one house, supported efficiency apartments, in an SRO, or scattered site apartments where the services are provided either through case management at offsite—all of those options are good and viable depending on the need of the individual.

Marty chooses to move into the Times Square Hotel which is a supported single-room occupancy hotel that was renovated and has provided services to a range of tenants. Marty gets renal dialysis in the privacy of his own apartment. He maintains regular contact with an offsite clinic, minimizing hospital stays. He enrolls in computer training. He is reunited with his family, he sits on a tenant advisory committee, and the annual cost to the city, State and local government is about $21,000 a year.

I would like to give you another example——

Mr. SHAYS. Let me just say that we are not going to be able to get to another example. I am sorry, Julie.

Ms. SANDORF. OK.

[The prepared statement of Ms. Sandorf follows:]

SUPPORTIVE HOUSING:
A SOLUTION TO THE PROBLEM OF SERVICE DELIVERY TO THE HOMELESS POPULATION WITH AIDS

Testimony presented to the
U.S. Subcommittee on Human Resources and
Intergovernmental Relations

Presented by
Julie Sandorf, President
Corporation for Supportive Housing

At the Hearing on
"AIDS in the '90s: Services
Delivery to Emerging Populations"

July 17, 1995

I. The Problem

In recent years, New York City has become the epicenter of the inter-related epidemics of HIV/AIDS, substance abuse and tuberculosis (TB). According to the 1995 Interim HIV/AIDS Strategic Plan for the City of New York, close to 200,000 New Yorkers may be infected with HIV. According to the New York City Department of Health, there were 16,963 adults living with full blown AIDS at the end of 1993. The data on New York City's current HIV/AIDS population bears out a national trend: the population is shifting from gay white males to racial minorities and women. It is estimated that close to three-quarters of the people with AIDS in New York City are racial minorities: 42% are African American and 32% are Latino.

New York City's changing HIV/AIDS population is increasingly at risk of problems that compound conditions of poor health, including substance abuse (particularly intravenous drug use), mental illness and homelessness. Measuring the exact number of homeless people with AIDS is extremely difficult. However, it is estimated that 10-25% of the 50,000 homeless individuals in New York City are HIV-infected. On the streets and physically weakened by the ravages of substance abuse and poverty, this newly emerging population with AIDS is much more likely to succumb to illness at an early stage, and is much more vulnerable to contracting TB, particularly multiple drug-resistant forms of the disease.

One of the major causes of homelessness among people with AIDS is the episodic and unpredictable nature of the illness. Because people with AIDS occasionally become sick and are unable to work for stretches of time, they can easily lose their sources of income, their job, and ultimately their housing. Once they no longer have stable housing, they are often unable to maintain the nutrition, hygiene and medical treatment that is necessary for them to sustain good health. They then become trapped in a cycle of medical and psychological crises, necessitating costly emergency care. In order to avoid homelessness, studies show that more than half of all people with HIV and AIDS will need some form of housing assistance.

There are many barriers to effectively treating the homeless population with AIDS. Because homeless individuals with AIDS must concern themselves with basic safety and survival, they are not in a good position to access HIV-related services, and when they do, they often do not follow a steady treatment regiment. This is especially problematic in instances of TB-infection, when a lapse in treatment can cause the person to develop multiple drug-resistant TB.

There are no comprehensive, reliable data on the homeless population with HIV/AIDS and other special needs in New York City, however, it is believed that:

- Approximately 80% of the HIV homeless are male, and 20% are female. Two-thirds are either African American or Latino.

- About half are estimated to be Medicaid eligible, but many are not enrolled. Those who are not Medicaid eligible typically do not have health insurance.

- Many of the homeless HIV population cycle through the jail and prison systems, and many are ultimately discharged without access to decent housing, health or support systems.

There are considerable costs associated with homelessness among the HIV/AIDS population. According to recent studies:

- At any given time, approximately 30% of all people with HIV disease in acute care hospitals are there because no community-based residential program is available.

- The average cost of an AIDS acute care bed is $1085 per day.

II. The Solution

There is a solution to the problem. Over the past few years, supportive housing has emerged as a compelling answer to the crisis among homeless persons with AIDS. Supportive housing is a grassroots movement started in the late 1980s by non-profit organizations who identified the housing and service needs of homeless populations as a highest priority. Many of these groups are mission driven organizations who "backed into" housing development and management from mental health, substance abuse, and AIDS delivery fields out of frustration with their inability to serve their clients without providing access to appropriate housing.

The goal of supportive housing for people with AIDS is to enable the tenant to live a stable, independent life, and to the extent possible, to avoid costly hospitalizations and emergency treatment. This is a condition almost impossible to achieve in the absence of permanent, affordable housing that provides a level of supportive help at the right time. As a result, many people with AIDS who do not have permanent housing and service supports end up in a "revolving door" in and out of homelessness, from the streets, to shelters, to hospital emergency rooms, to treatment facilities, nursing homes, and back again -- all at significant cost to the individual, the government and the tax payer.

Supportive housing is not only effective, it is cost effective, both in the long and short run: it stabilizes a population which can then access managed care services rather than emergency rooms and extended hospitalizations. On average, supportive housing for people with AIDS costs $27-$44/day, compared to $1,000 to $1,200 for acute care hospitalization.

The following are examples of some success stories of supportive housing for people with AIDS.

A. Supported SROs

One type of supportive housing model for people with AIDS is the Supported Single Room Occupancy (SRO), which often provides on-site services, but helps tenants to maintain a level of normality by living with others who do not have AIDS.

The Times Square on West 43rd Street in Manhattan, for example, is a 652-unit facility with SRO and efficiency-style rooms for a mixed tenant population, including 50 persons with AIDS. Low-income working individuals are intentionally mixed with formerly homeless individuals with a history of chronic mental illness, homeless persons from the general shelter population, and people with AIDS in order to create an integrated and supportive residential community for a wide spectrum of individuals in need of low-cost housing. The overall aim is to provide a residential rather than institutional setting.

The Times Square's approach to serving the needs of people with AIDS is to provide support when needed, but to enable the individual to remain as independent as possible. Many of its services are preventative, early intervention strategies that are seen as part of a continuum of care. For instance, an on-site nurse is available in emergency situations, but is also skilled in fitness instruction, and is available at all times to help tenants to maintain their cardio-vascular fitness. An example of one of their most successful preventative interventions is the provision of Gatorade to tenants at risk of becoming dehydrated. Early on, staff at the Times Square noticed that one of the major problems facing their AIDS tenants was severe dehydration, which tended to rapidly become an emergency condition requiring costly hospitalization. The simple solution was to provide free Gatorade to any AIDS tenant who requested it. Since the program went into effect, none of the Times Square's tenants with AIDS have been hospitalized due simply to dehydration.

The Times Square staff also believe that a vital factor in helping people to remain healthy is the formation of an informal supportive community. To help people maintain their psychological well-being, it organizes numerous free on-site and off-site recreational activities that are available to all tenants of the SRO. It also offers opportunities for people to work light jobs in order to maintain their sense of purpose in life. To access off-site medical and social services, the Times Square offers a free van service.

B. Congregate Housing

Another type of supportive housing model for people with AIDS is congregate housing, where most if not all tenants are people with AIDS and there is an emphasis on creating a community within that population.

STANDUP Harlem is a grassroots community-based organization founded in December 1990 by Louis Jones, a formerly homeless person living in recovery and living with AIDS. Located in Central Harlem/Morningside Heights, STANDUP Harlem's mission and therapeutic philosophy is to provide empowerment and alternatives to active drug addiction and destructive behaviors, and to promote a sense of well being, healing and wholeness. The process begins with the people themselves. Organizationally, STANDUP is conscious of how disabling it is for persons living with AIDS and substance abusers to become dependent upon institutions. Consequently, people who come to STANDUP Harlem are never referred to as "clients," but rather as participants, guests or members. Many of STANDUP's staff members live in residence with guests, reinforcing a communal process which itself reflects the shared living and extended family values that are the fabric of African-American and Latino cultures.

Louis Jones, founder and director of STANDUP, is typical of the organization's members. A heroin user for more than 15 years, Jones had been cycling in and out of homelessness and jail and had become HIV-positive before he decided to "stand up" and face his disease in 1990. His disclosure of the much feared and often denied disease transformed him, and led him to devote his life to the task of creating a safe and accepting community for others who were homeless, HIV-positive and destitute. His idea was to reclaim a derelict crack house at 145 West 130th Street for use as a residence for homeless men and women. As Jones recalls, "We just welcomed people with what we had." People coming off the street "got a meal and a shower. They were welcome. They were home. It was O.K. to cry. It was O.K. to be angry. And then we saw that people weren't ashamed anymore of their HIV. People started to recover emotionally. Astounding things were happening."

Today, STANDUP Harlem provides a web of supports for an extended community of people of color facing the crisis of AIDS, alcohol and drug abuse and poverty. The program at West 130th Street provides stabilization for HIV positive persons, and often helps them to develop their own personal strategies for staying healthy, including meditation, acupuncture, herbal therapies and other alternative treatments. It provides peer support and counseling for substance abusers who are in recovery, and it provides Low Threshold Services to active drug users as well as addicts seeking recovery, providing alternatives to institutionalization. Some of its members have been able to come to STANDUP Harlem upon release from prison, as alternatives to continued incarceration.

C. Scattered Site Housing

Yet another supportive housing model for people with AIDS is scattered site housing. This type of housing is most appropriate for individuals who are capable of living relatively independently and do not need intensive support. The New York City Human Resources Administration's scattered site housing program allows non-profits throughout the city to rent apartments in private buildings and sublease them to people with AIDS. The program is widely viewed as a success, both by advocates and city officials. It has grown significantly, and currently allows 39 non-profits to contract with the city to manage and lease apartments for about 1,600 individual families at a cost of about $40 million in city, state and federal funds.

The Minority Task Force on AIDS (MTFA), which is a diverse non-profit organization that originated in Harlem to assist people of color affected by HIV/AIDS, runs a scattered site housing program. MTFA employs a client centered, community focused approach to provide education, outreach, advocacy, supportive housing and direct services. It seeks to improve and extend the quality of life for people with AIDS by encouraging self-determination.

MTFA premises its work on the understanding that AIDS is not necessarily a single crisis in an individual's life, but it is often one of many barriers to the health and well being of an individual. To reduce the negative consequences of AIDS, it is necessary to address the myriad of problems that New York's poorest, most vulnerable populations face, including the lack of access to health care, education and employment opportunities, and the prevalence of substance abuse, poor nutrition and inadequate housing.

MTFA's scattered site housing program for people with AIDS currently provides 60 apartment units for 45 single individuals and 15 families, along with case management and counseling services. MTFA's support services are designed to meet the needs of its diverse target population, which includes gay and bi-sexual men and women of color, IV drug users, and persons with prostitution and prison backgrounds. Because the organization believes that AIDS affects the well-being of whole communities, MTFA extends its services not only to those with the HIV virus and those at risk of infection, but also to loved ones, family members, friends, and neighbors. Its services include case management, substance abuse and mental health counseling, preventative TB counseling, recreational and support group activities, meals program, a transportation program, an after-school children's program, HIV prevention, outreach and education, and community education.

III. Conclusion

As evidenced by the examples cited above, there is a solution to the crisis of AIDS among the emerging homeless populations of racial minorities and women. Non-profit, community-based organizations are reaching out to these populations with a high level of compassion, will and resourcefulness. It is clear, however, that the problem will never be adequately addressed without the political will on the part of our society to apply the needed resources to the problem.

IV. Marty: A Case Study

Please see the attached.

V. The Corporation for Supportive Housing

The Corporation for Supportive Housing (CSH) is a national, non-profit intermediary organization whose mission is to expand the quantity and quality of service-supported permanent housing for individuals with special needs who are homeless and at risk of becoming homeless. CSH focuses on and serves individuals with special needs because they are the largest percentage of the homeless and at-risk population, and are the most visibly and persistently poor. CSH was created in 1991 by three of America's leading foundations: the Pew Charitable Trusts, the Robert Wood Johnson Foundation, and the Ford Foundation.

MARTY

Marty is diagnosed with AIDS and loses his job and his apartment.
He takes up residency in a city shelter, where his condition rapidly deteriorates. He is admitted to a hospital acute care bed and is diagnosed with tuberculosis.

MARTY HAS FOUR HOUSING OPTIONS:

STREET

Since Marty can no longer live in a shelter due to his AIDS diagnosis, he can try to survive on the street. This will inevitably lead to the rapid and severe deterioration of his health and will pose a risk to those with whom he comes into contact due to his TB diagnosis. Without access to primary health care, Marty will be forced to use the hospital acute care unit for all his health needs which will be considerable: he can be expected to spend a minimum of five days a month in an acute care bed.

Housing Cost: $0
Service/Care Cost
$72,000
($1,200/per day acute care)

Total Annual Cost
$72,000*

***plus possible costs of treating others he infects with TB**

COMMERCIAL S.R.O.

The hospital puts Marty in touch with the Department of AIDS Services, where he learns that he qualifies for a single-room occupancy apartment in a commercial SRO subsidized by D.A.S. Without access to services, however, Marty will be forced to use expensive emergency care whenever he becomes ill, just as he would if he lived on the streets — minimally five days a month.

Annual Housing Cost:
$8,400-$16,800
Service/Care Cost
$72,000
($1,200/per day acute care)

Total Annual Cost
$80,400-$88,800

AIDS SKILLED NURSING FACILITY

Marty can be placed in a skilled nursing facility, even though he does not require this level of care and can continue to live independently given sufficient support.

Annual Cost
$127,750-$182,500

SUPPORTIVE HOUSING:

Marty chooses to move to the Times Square where he receives support from on-site staff who help him:

- get renal dialysis in the privacy of his own apartment
- maintain regular contact with an off-site clinic, minimizing hospital stays
- enroll in computer training
- reunite with his family
- sit on the tenant advisory committee

Annual Cost:
$21,170-$25,500*

***actual cost at the Times Square**

Mr. SHAYS. It is 15 after—why don't we just—there are some questions that need to be asked.

Ms. SANDORF. OK, just in conclusion——

Mr. SHAYS. I apologize. I did not know you were on the witness list, it says you were accompanying Mrs. McKinney, it did not say you were to testify. I am sorry.

Ms. SANDORF. OK, just to conclude. The dollars that are spent on community-based supports with community-based organizations who are the front line providers are the critical dollars that are going the longest and are serving the best possible way. There is a network of community-based organizations that are giving you returns on your investments far more than what you are seeing in escalated Medicaid costs of not doing this.

Mr. SHAYS. So our challenge will be to how we present that to Congress, because I agree with it.

Ms. SANDORF. We have great backups, statistics and graphs and charts.

Mr. SHAYS. The key is to show that those costs are not long-term out in the future——

Ms. SANDORF. No.

Mr. SHAYS [continuing]. But that will occur right away, and I think your story is a good one to do that.

I am struck by a few things. First off, Mr. Pressley—and I need these answers fairly short. If I am right, you do not have to go elaborate.

Are you in a sense disagreeing with the opening presentation of Panel 1 or are you just qualifying it?

Mr. PRESSLEY. I am not sure—in terms of?

Mr. SHAYS. Well, they are basically talking about an emerging population and the feeling I get from you is hold it, this population has been here a long time.

Mr. PRESSLEY. I think—and I think people sort of mentioned this earlier—I think part of the problem is that when we start talking about these emerging populations it becomes almost a case of putting out fires, and what we tend to forget sometimes is that there are populations out there that will also need continued support and continued prevention support and care services as well. And I think what happens also, what really frightens me is the black gay man, to be quite honest with you, is that I look at this chart and I see homosexual men as part of the initial population, and then part of the testimony that I just gave to you is that cases are exploding amongst men of color, and I do not see that on any chart up here. And I am wondering what happens—do black gay men and men of color who have sex with men, do we get left out of the equation when you talk about new programs that need to be targeted for us.

Mr. SHAYS. So in one sense, I am getting the sense that it is important to know that it is emerging; but we have not dealt with the entire population adequately enough, so it is almost—I guess what I am saying is the challenge is so big and we are not dealing with the challenge significantly enough. They are talking about emerging populations when we have not even dealt with the primary population. It just says do more, but not necessarily change.

Mr. PRESSLEY. Exactly, exactly. And I think also, if I could just add to that——

Mr. SHAYS. You do not have to say exactly because I was fumbling around here. It was very gracious, you are a good man. Keith, excuse me. Your comment in the beginning—basically would you comment on just what I asked?

Mr. CYLAR. I would say that you are right and I would say that historically that gay men of color, substance users, have always been disproportionately impacted by this disease. Unfortunately, the attention has gone to white gay men and that communities of color have been consistently under-represented when it comes to targeting funds and targeting solutions.

Mr. SHAYS. Ms. Mendez de Leon, as you were speaking, I began to wonder, is this so-called emerging population as they asked in the beginning not as aware that they may have contracted the disease? Is this a population that just is kind of left in the dark a little about their own condition? Let me ask and also say this to you. I had not thought about—obviously I should have, but I had not though about the fact that nursing a child, a child born by a mother HIV positive, the child does not yet have the disease——

Ms. MENDEZ DE LEON. Correct.

Mr. SHAYS [continuing]. I make an assumption that most children born of HIV or positive mothers are likely to have the disease.

Ms. MENDEZ DE LEON. No, that is not correct.

Mr. SHAYS. Incorrect.

Ms. MENDEZ DE LEON. Incorrect.

Mr. SHAYS. Does anybody have a percent here? Fifty percent?

Ms. MENDEZ DE LEON. I think it is less than that, it is about a quarter is what I was going to say. About a quarter.

Mr. SHAYS. About 25. So the exact—the need to identify those children born of mothers who in fact have the disease, an extraordinary need to do that.

Mrs. MCKINNEY. No.

Mr. SHAYS. No?

Mrs. MCKINNEY. I disagree with what you all are doing down there to identify, to automatically test all the babies. And the reason—there are two reasons. One——

Mr. SHAYS. I did not get to that, but I was going to.

Mrs. MCKINNEY. Well, that is where you were. One, confidentiality is gone. I do not believe in mandatory testing anybody; but, look at it this way. The mother—by the time you test the baby, if the baby is HIV positive, there is not much you can do. But if the mother had found out that possibly she had HIV at the beginning of her pregnancy, it has been proven that AZT taken by a pregnant mother cuts that 25 percent of babies down to about 8 percent.

Mr. SHAYS. But it is also logical, is it not, Lucie, to suggest that the mother not breastfeed her child?

Mrs. MCKINNEY. Well of course. Well of course. But I am just saying to you, what is the point of identifying the babies? What are you trying to get at here? Do you see what I am trying to say?

Mr. SHAYS. Identifying the babies are identifying the mothers.

Mrs. MCKINNEY. If you are identifying the babies, you are automatically identifying the mothers. I think there should be much more of a push to not mandate but counsel the mothers. Say to the mothers, if you think you are at risk for HIV, if your lifestyle has been such, we suggest, and counsel her in taking an HIV test in order to better help her unborn baby.

Mr. CYLAR. Can I add to that?

Mr. SHAYS. Yes, and then I will——

Mr. CYLAR. It is not just counseling, but it is also providing services——

Mrs. MCKINNEY. Right.

Mr. CYLAR [continuing]. If the woman is homeless, if the woman does not have medical benefits, if she does not have entitlement, she is not going to take an HIV test.

Mr. SHAYS. Let me just say that we are in my colleague's district and I would like to give him time also. He is driving and he may decide to leave later than I want.

Mr. TOWNS. You be assured you will be on the 2 o'clock.

Mr. SHAYS. I just want to also say, Ms. Sandorf, that your testimony will be very helpful to us in how we articulate our presentation to the Congress.

Ms. SANDORF. I would be happy to be of assistance.

Mr. SHAYS. Thank you.

Mr. TOWNS. Again, let me thank all of you for your testimony and to say to you, Senator Montgomery, we really appreciate your involvement——

Mr. SHAYS. Thank you, Senator.

Mr. TOWNS [continuing]. In this area on the State level. And of course, how we can work together, stand ready to do so.

Also, let me just say to you too, Mrs. McKinney, I had the opportunity to serve with your husband for many, many years in the Congress, so I know of his great work and I am happy to see that many of the things that he talked about on the floor of the House, that you are now making certain that we keep them alive. So I would like to thank you for that.

Mrs. MCKINNEY. Thank you.

Mr. TOWNS. And all of you, for the work that you are doing. Of course, I know in terms of the work that Lambda is doing here for many, many years as well.

Let me sort of ask this very quickly, in terms of if you could modify one program or regulation which affects a Federal program that offers services to AIDS patients, what would that modification be, and then of course why?

Mr. SHAYS. Good question.

Mr. CYLAR. I think my first answer would be to——

Mr. SHAYS. A little louder, please?

Mr. CYLAR. My first answer is to eliminate the prohibition on needle exchange programs. I think we need to move away from—needle exchange and active drug users are probably one of the fastest growing population of people infected, either because of the men directly or because of the women that they have sex with secondarily. I think we need to remove that barrier and I think I would also investigate funding more harm reduction programs. My agency runs a needle exchange program that is the only needle exchange program that is part of a comprehensive social service agency. It can be done and it can stop the spread of this virus.

Mr. TOWNS. Anyone else?

Mrs. McKINNEY. Well, I am going to put my two cents in. I do not want to modify anything. In Connecticut alone we had 900 and some odd—922 persons who were homeless with HIV/AIDS who qualified for housing, and we could only house 128 or 129, I think that is the number, in the State. So we had to turn away close to 800 individuals who qualified, who were on the street, who were homeless, who qualified for one of the many housing programs in the State of Connecticut. You cannot cutback on HOPWA, you cannot cutback on Ryan White. I want an increase.

Mr. SHAYS. He was not suggesting a cutback.

Mrs. McKINNEY. I thought he said to modify meaning cutback on.

Mr. TOWNS. No, no, no. I did not mean——

Mrs. McKINNEY. I am sorry.

Mr. SHAYS. So you would increase it?

Mrs. McKINNEY. Oh, my, increase—I have been asking for that for years.

Mr. SHAYS. For the record, for the record.

Mrs. McKINNEY. Yes, I would definitely ask for an increase.

Mr. TOWNS. And let me agree with you, for the record.

Ms. SANDORF. I just want to add something to what Lucie said and this is going forward. There is a lot of discussion about block grants and folding all of these programs into giant block grants left to the discretion of States and localities. I think what Keith mentioned about stigma is a very, very real thing, and we have seen in localities across the country, thankfully not New York as much, where mayors of certain towns will say, I do not want housing for people with HIV in my city or my town, take your HOPWA and take your Ryan White and take it somewhere else. And unless there is earmarking of these funds specifically for these issues and these populations, it is not going to be spent on these folks.

You cannot just collapse everything in a block grant and expect the political pressures on the mayors and the council people, et cetera, in these towns to just be so compassionate, because it has not happened and it has been the Federal carrot and stick that has allowed these developments to occur around the country. You take that away, you are not going to see it and you are not going to see these people being served.

Mr. TOWNS. Well put. I am very concerned about block grants, block grants. I think that coupled with the fact that there is a cut, but at the same time in terms of the block grants, and I think that the reason we are not hearing a lot of outcry from the Governors and from the mayors is because they just want to get their hands on the money.

Ms. SANDORF. That is right. And they will not have to spend it on these populations.

Mr. TOWNS. Right.

Ms. SANDORF. And that is the danger.

AUDIENCE VOICE. I would argue along with the Senator——

Mr. TOWNS. Wait please—was he sworn in?

Mr. SHAYS. Well, he is with the——

AUDIENCE VOICE [continuing]. About the importance of HIV prevention and I think a decade of senseless prohibitions and the kinds of prevention programs that Federal dollars can support has crippled the Nation's response to HIV, and we certainly know that prevention is the most cost-saving intervention that we have.

Mr. SHAYS. You will need to give your name to the gentleman who is transcribing. You will be the first witness in the history of my committee that has spoken and has not been sworn in.

Mr. TOWNS. He was sworn in.

Mr. SHAYS. Oh, he was?

Mr. TOWNS. Yes, sir.

Ms. MONTGOMERY. We thank you for your leadership. This is extremely important, especially in New York State. Connecticut is a leader, your State is a leader, and to have a Republican saying unequivocally that this is really one of the issues that we all must pay attention to——

Mr. SHAYS. Thank you.

Ms. MONTGOMERY [continuing]. Be sensitive to in planning for is very important.

Mr. TOWNS. Let me just say to you my views and my feelings about this Member of Congress. I have said to him, being that we are the minority now and I cannot be chair of the committee being I cannot be, I cannot be, so therefore, I will accept the fact that I would select him to be it if I could. But the point of that being I cannot be it. Because his views on it and his leadership has been excellent on this particular issue.

Mr. SHAYS. I thank my colleague. I saw the ranking member and pleaded that he be the ranking member himself. It is mutual.

Mrs. MCKINNEY. Can I just say——

Mr. SHAYS. You want to get the end words?

Mrs. MCKINNEY [continuing]. Just 2 seconds?

Mr. SHAYS. Yes, ma'am.

Mrs. MCKINNEY. For the people in the room that did not see it, I just want you to know that Congressman Shays got up on the floor of the House and submitted a bill on HOPWA and he knew he was dead before he went in there because of what the higher-ups were doing to him. But——

Mr. SHAYS. We are still working on it, Lucie.

Mrs. MCKINNEY [continuing]. He stuck to his guns, and thank you very much.

Mr. SHAYS. Thank you very much. God bless.

[Whereupon, at 1:30 p.m., the subcommittee was adjourned.]

[Additional material submitted for the record follows:]

Testimony of Dr. Monica Sweeney, Medical Director of the Bedford Stuyvesant Family Health Center which service the residents of the Central Brooklyn/Bedford Stuyvesant Community.

I am Monica Sweeney, Assistant Professor of Medicine and Preventive Medicine at the SUNY Health Science Center at Brooklyn. I am also Chairperson of the Public Health Committee for the Medical Society County of Kings. As a Primary Care Physician, I appreciate the opportunity to comment on the problem of HIV and AIDS.

Although the assembled professionals are aware of most of the statistics on the incidence and prevalence of HIV and AIDS, I will just quote a few so that we all have a handy reference of the magnitude of the endemic in its 2nd decade.

* Central Brooklyn's Bedford Stuyvesant/Crown Heights neighborhood is one of the top three neighborhoods in the nation devastated by AIDS. With almost 3,800 cases by mid-1993, this neighborhood of 314,000 adults had a higher cumulative number of AIDS cases than the states of Alabama (1,452), Colorado (2,245) and Connecticut (2,500). Adult AIDS case rates in Brooklyn have more than quadrupled in the past five years and have tripled for children in the past four years. The North and Central parts of Brooklyn have been hardest hit with AIDS. Greenpoint, Downtown/Heights and East New York also display exceedingly high rates of AIDS.

* By October 1993, almost 400 of Brooklyn's children had been diagnosed with the disease. This number is now close to 500. Only one in five of those AIDS infected were white, and more than seven out of ten were Black or Hispanic. The overwhelming majority of AIDS cases **(62 percent were in some way related to IV drug use.**

* 51.9% of adult AIDS cases in New York City are African American.

* 86% of the women who have developed AIDS in New York State are from New York City. 53% of women with AIDS

- * 15% or nearly 10,000 reported AIDS cases in New York State are among young adults age 20 -29.
- * AIDS is the leading cause of death in Bedford Stuyvesant among adolescents and young adults age 15 - 44.
- * For NYC, from 1989 to mid-1993 the cumulative number of adult AIDS cases increased by 185.1 percent, to over 55,000. **<u>In Brooklyn, the increase was over 226 percent, up to almost 13,000 cases.</u>**

As noted from the previous statistics there is a great need to reach IVDU. One of the programs just instituted at Bedford Stuyvesant Family Health Center is a group of PEER counselors. Peer counselors are volunteer infected or affected by HIV. The PEER counselors are doing outreach to non-HIV community based organization (CBO), and businesses to leave literature and condoms in the establishment. Additionally, HIV talks are given at the same sites, referred to by our staff as HIV 101.

Another group of volunteers do outreach to teach harm reduction, and risk reduction, both to those whose HIV status is known and to those whose status is unknown.

Other services available in the Community:

- * Substance recovery group support.
- * Information sessions - e.g., permanency planning (planning for placement of children on the death of an HIV infected parent) & loving carefully - demonstration of safer sex techniques.
- * Case management.

Any effort to decrease the incidence of AIDS must include aggressive measures to provide more and better drug treatment services. As I write this statement, a couple presented to our Center - the man an IVDU has been waiting two (2) months to get into a drug treatment program.

* There is the need to establish a network so that neither a client nor social worker has to call all the programs in Brooklyn to make the appropriate placement for the clients. (A clearing house)

* There are no needle exchange programs in Bedford Stuyvesant. Since 62% of the AIDS cases is related to IVDU harm reduction around drug use is very important. There are only 7 harm reduction/needle exchange programs operating under approval from NYSDOH. 15,000/of an estimated 200,000 drug users are enrolled.

There is inadequate arrangements to provide confidential testing. As of June 1, 1994, the City no longer pays for the uninsured to receive confidential testing. As of July 1, 1995, the City no longer does any testing except the confirmatory test if the screening test is positive.

Although there are provisions for anonymous testing the purpose of testing is lost if the client doesn't return for the results.

Adolescents benefit from tailored repeated and personalized messages. Each time an adolescent enters the health care system for any reason the health care provider must seize the opportunity to make an assessment of the knowledge level, risk behavior of the patient, and counsel accordingly.

A Haitian woman 8 months pregnant, recently visited the Center seeking prenatal care. She was undocumented and uninsured. When asked why she hadn't come in for care sooner, she said she was afraid that she might have AIDS and would be sent back to Haiti. After allaying her fears regarding possible deportation, a referral was made to the high risk clinic at our back up hospital. This was done because our treatment protocol requires the assignment of "high risk" status when a patient presents in her last trimester of pregnancy. There is an urgent need for expanded culturally sensitive AIDS education.

In Central Brooklyn there is a great need for more Primary Care providers as well as outreach workers. The burn out factor, coupled with low pay and demanding working conditions impacts on the ability to recruit and retain qualified staff.

I frequently have to cancel AIDS case conferences for the staff and other scheduled continuing educational activities because of the need to provide medical care.

The approaches that we've used for the past decade to decrease the spread of AIDS haven't worked. I implore us to explore new ways to deal with the spread of AIDS. Public education should begin in the school, should be in churches, supermarkets, bars, theaters, video parlors, in short, any place where people tend to congregate, because public health education and prevention efforts are the only effective means of reducing HIV infections.

Funding is needed to expand existing services and to add new ones.

* Counseling and support for women around the issue of self-esteem.

* Intervention through therapy and counseling when adolescents engage in high risk behavior, before they become HIV positive.

* Using the media (especially TV) in new and expanded ways.

* Decriminalizing drug use.

* Looking at techniques that have worked to reduce other STD's and use them, e.g., partner notification, tracking contacts.

* Make HIV education, prevention strategies and treatment mainstream.

[Additional material submitted for the record can be found in subcommittee files.]

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