



# COMMUNITY FORUM REPORT

## Winter-Spring 2005



April 2005

New York City Department of Health and Mental Hygiene  
Office of AIDS Policy Coordination  
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*HIV Health and Human Services Planning Council  
of New York*

April 15, 2005

Dear Friends and Colleagues:

On behalf of the HIV Health and Human Services Planning Council of New York, we are pleased to submit to you the final report on the Winter-Spring 2005 Community Forums. These meetings, sponsored by the HIV Health and Human Services Planning Council of New York, focused on identifying the needs of individuals infected with and affected by HIV/AIDS, and gaps in services in communities throughout the city. Summary information from these meetings was produced by the Department of Health and Mental Hygiene's Office of AIDS Policy Coordination, and is being made available to the Planning Council's committees. The Planning Council and its committees will use this report to help determine Title I program goals and priorities during their planning for FY 2006.

First and foremost, we would like to thank the community members who came out to participate in these meetings. Your comments represent, as always, an invaluable contribution. We also want to express our thanks to the HIV CARE Network Coordinators, who helped us organize the forums and who mobilized their communities to participate. In addition, we would like to express our gratitude to those members of the Planning Council who took time to participate in these important meetings to listen to the voices of the community. Finally, we would like to thank the staff of the Office for AIDS Policy Coordination for their hard work in support of the Planning Council.

We look forward to continuing this important dialogue with the community in the future. If you have any questions about the information contained in this report or would like information about upcoming events, please feel free to call the Planning Council office at 212-788-2752, or visit our website at [www.nyhiv.org](http://www.nyhiv.org).

Sincerely,

Bill Stackhouse, Ph.D.  
Acting Governmental Co-chair

Patrick McGovern  
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**HIV Health and Human Service Planning Council of New York  
Community Forum Report  
Winter-Spring 2005**

**Table of Contents**

Introduction	4
<b>Background</b>	
<b>Process</b>	
<b>Summary of Findings</b>	
Findings	
Queens	6
Bronx	8
Staten Island	10
Brooklyn	14
Manhattan	16
Spanish-language Forum	18
Conclusion/Contact Information	20



# **INTRODUCTION**

## **BACKGROUND**

This document is the final report from a series of six community forums, sponsored by the HIV Health and Human Services Planning Council of New York (and one co-sponsored by the NYS DOH AIDS Institute), held from February 17 to April 8, 2005. The purpose of these forums was to allow the Planning Council to gather testimony from individuals infected with and affected by HIV/AIDS, providers of services to people living with HIV/AIDS, community members and advocates regarding the unique service needs of their communities. For this reason, this report represents an important tool for the Council to use in its strategic planning and priority-setting processes, as well as for others who are interested in HIV services in New York City.

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act is the federal government's largest investment dedicated specifically to treatment, care and services for PLWHA. Title I of the CARE Act is money for urban areas hard hit by the HIV epidemic. In 2005, the New York Title I Eligible Metropolitan Area (EMA), which consists of the five boroughs of New York City, plus Westchester, Rockland and Putnam Counties, received \$117.9 million in Title I funds.

The CARE Act mandates that Title I EMAs undertake a community planning process to decide how to best use the funds locally. The Planning Council, whose members are appointed by the Mayor through an open nominations process, sets priorities and allocations for the use of Title I funds. In order to accomplish this task, the Planning Council considers a wide range of data on the needs of PLWHA in the EMA. One of the most important sources of information is direct input from the community on needs for HIV-related services, particularly through annual community forums.

The testimony summarized in this report will be used in the 2005 priority setting and resource allocation process, which will set priorities for Title I services in Fiscal Year 2006 (March 1, 2006-February 28, 2007).

## **PROCESS**

Six forums – one in each borough of New York City, plus a Citywide forum in Spanish – were held from February 17 to April 8, 2005. Forum dates and locations were coordinated with all HIV CARE Network coordinators in the City. Notice of the forum was sent to the Planning Council's extensive mailing list and was posted on their website. Flyers were also distributed at all meetings of the HIV Planning Council and its committees, including the PLWHA Advisory Group. In addition, all Title II CARE Network Coordinators and the New York State Department of Health AIDS Institute sent flyers to their extensive constituencies.

Attendance per forum ranged from 40 to 75. Members of the Planning Council participated as panelists and moderated the meeting, with the support of Planning Council staff. At the beginning of each meeting, participants signed up to provide public testimony. Opening remarks laid out the purpose and goals of the forums and gave an overview of Title I and the HIV Planning Council. This was followed by a brief presentation on borough-specific HIV and AIDS epidemiological data (the full presentations are available on the Planning Council website – [www.nyhiv.org](http://www.nyhiv.org)).

Both oral and written testimony was received during these forums, and oral testimony was taped, in addition to staff taking notes. All written testimony that was more than one typed page is attached to this report, as well as summarized in the findings from each borough's forum.

## SUMMARY OF FINDINGS FROM THE COMMUNITY FORUMS

The six community forums held in February-April 2005 elicited testimony from consumers, providers and community members on needs for HIV services. Some topics were mentioned more frequently, some only by one or two people. Perhaps the strongest theme from the testimony at the forums was the general need to increase the availability of – and access to – HIV/AIDS services, and to expand programs. Many of the speakers also spoke of gaps in particular service areas for specific neighborhoods and boroughs. These comments are detailed in the borough-by-borough reports that follow this executive summary. Below is a list of the most commonly addressed topics across all the boroughs (list is alphabetical):

- Access to primary medical care
- Family support services
- Food and nutrition
- Housing
- Legal services
- Linguistically appropriate services
- Mental health services
- No cuts in funding
- Substance use services
- Services for immigrants
- Treatment education

In addition, many speakers provided testimony on a variety of non-Title I HIV issues. The most commonly raised non-Title I topic was HIV prevention and education for youth.

The borough-by-borough summaries that follow provide a snapshot of some of the needs that people living with HIV/AIDS, service providers, caregivers and community members brought to the attention of the HIV Planning Council for consideration in planning for Ryan White Title I services.



# PUBLIC TESTIMONY

## **I. Queens Community Forum**

February 17, 2005, Queens Borough Hall

Attendance: Approx. 60

*Speaker #1 (PLWH, male, white)* There is a lack of programs for seniors. As epidemiological data shows, the average age at the time of an AIDS diagnosis is rising. Also, seniors are subject to diseases of aging (e.g., heart disease), but doctors do not ask about HIV. Also, seniors are at risk, but there are no prevention messages targeted to seniors.

*Speaker #2 (provider, male, white)* A) The number of clients at Queens HIV service organizations is growing and people need a wider range of services, but funding remains at the same levels. Queens does not receive a proportionate share of HIV funding. B) Newly opened or planned syringe exchange programs in Queens will offer comprehensive services to active substance users. These programs save lives and prevent further spread of HIV, but there is not adequate funding to operate them. C) Queens is the most ethnically diverse borough in the City with large immigrant populations, which poses challenges for service delivery. Changes in federal benefits programs will mean loss of services for many immigrants. Legal advocates are needed to help resolve these issues and gain access to services. D) There is a crisis in Queens due to a severe lack of affordable housing. PLWHA cite housing issues as their most pressing problem, as it exacerbates the difficulties of accessing and maintaining care. E) The number of new cases among women in Queens is growing, but existing funding does not reflect this change. F) There is a growing need for specialized legal services, particularly for times of crisis (e.g., incarceration, eviction). G) There is an increase in adolescent cases. More targeted prevention efforts are needed. Adolescent programs in Queens have had reductions in funding, harming these programs. Prevention efforts in general need to be increased to fight complacency that leads to high-risk behavior. H) Treatment education models need to be developed to improve adherence to therapy. There are no publicly funded treatment education/adherence programs in Queens. I) PLWHA who wish to return to work need vocational training and counseling. [See appendix for full written testimony]

*Speaker #3 (PLWH, male, African-American)* We need more harm reduction services. As a former crack user, I can attest to the need for more counselors; too many people are trying to access these services at the same time.

*Speaker #4 (PLWH, male, white)* AIDS Center of Queens County (ACQC) is doing a good job, bringing people of all kinds together in a diverse borough.

*Speaker #5 (provider, female, white)* Queens has had the highest populations growth of any county in New York State and is the most ethnically diverse. Due to fears of deportation by undocumented immigrants, the number of HIV-positive people is likely under-reported. Legal services are the lynchpin for this population, as they hold all of the other services together. We see clients in homes and hospitals and help them negotiate bureaucracies and obtain benefits and health care. We provide many services beyond those reported to our funders, and the most significant work is helping clients obtain medically appropriate housing. Stable housing is associated with accessing and maintaining care and services, improved health outcomes, and reduced transmission, and is a top priority. Legal assistance is the key to housing and avoiding homelessness. [See appendix for full written testimony]

*Speaker #6 (provider, female, white)* Queens is underserved by agencies with expertise in HIV services, and few have comprehensive legal services. Geographic layout of the borough is a barrier, with clients having to travel long distances to appointments. This makes off-site intake programs necessary, such as Queens Legal Services in Far Rockaway. We meet the client where they live. Legal services increase access to medically appropriate housing, which promotes improved health status and access to benefits. With funding

reductions, legal programs have been reduced, lowering access to services. Further reductions would be devastating to PLWHA in Queens. [See appendix for full written testimony]

*Speaker #7 (PLWH, female, African-American)* I moved to NYC to get better services than my were available in my home state in the south. I'm homeless and having trouble getting housing. We need more resources and funding.

*Speaker #8 (PLWH, male, Latino)* Given the new, virulent strain of HIV, we need more prevention services, especially targeted to youth.

*Speaker #9 (PLWH, Female, African-American)* If it weren't for harm reduction services and ACQC services like supportive counseling, I would not be here today, but in jail or worse. Harm reduction has kept me healthy. People need help, not budget cuts.

*Speaker #10 (PLWH, Female, African-American)* I get all my services at ACQC, which has been a wonderful agency. ACQC helped me re-enter into society after being homeless crack addict. They helped me help myself with housing assistance, group and individual therapy. Hope that all services will continue to be funded and available.

*Speaker #11 (provider, male, Latino)* Agencies often have no budget line for evaluation (e.g., a data collection person), and there is not enough for administrative costs, which are forced upon us by government funders' requirements. If you require us to collect data, help us pay for it.

*Speaker #12 (PLWH and provider, female, African-American)* The Planning Council is open to everyone, but many service providers only come when a particular service is in jeopardy. They should be there during the entire planning process through participation in committees.

*Speaker #13 (provider, female, Latina)* As a Title I-funded case manager, I know that undocumented immigrants and AOD users need many services. We need more funds for housing and legal services, which help families who need assistance. Title I is one of few funding sources for these services.

*Speaker #14 (provider, female, African-American)* The current Title I RFP eliminates community-based treatment education, a service that gets people into care. The RFP will only target people already in care. Group-based peer education is very effective.



## **II. Bronx Community Forum**

March 28, 2005, Montefiore Medical Center

Attendance: Approx. 75

*Speaker #1 (PLWH, male, African-American)* We need Bronx AIDS Services (BAS) legal services and pantry. I was broke and they helped me with food to stay healthy.

*Speaker #2 (PLWH, female, African-American)* BAS legal and nutritional services sustain life. They have supported me, empowered me and taught me proper nutrition. We also need more medically appropriate housing. Also, I am disappointed that more Planning Council members are not present here.

*Speaker #3 (PLWH, female, African-American)* I am upset that legal services are threatened. Legal services helped me as a single parent threatened with eviction and with permanency planning for my five year-old son. More Council members should attend these forums.

*Speaker #4 (affected partner, male, white)* When I lost my wife to AIDS, I had no visitation rights with my children, and BAS legal services helped me. Cuts in legal services hurt all PLWHA and threaten the community.

*Speaker #5 (PLWH, female, Latina)* BAS nutrition services helped me to take my medications. Their legal services helped me and my child receive housing and deal with a domestic violence situation. Many women need domestic violence-related help.

*Speaker #6 (PLWH, female, African-American)* When my daughter died, BAS was a great help. They helped me with health care, food and nutrition and public assistance.

*Speaker #7 (PLWH, male, Latino)* We need better housing and more nutritional services.

*Speaker #8 (PLWH, female, Latina)* Legal services helped me with my children and foster children and should not be cut.

*Speaker #9 (PLWH, male, African-American)* People are still dying and many are suffering from the toxicities of HIV medications. Many will lose access to medical care because of changes in Medicare and Medicaid. We need to bring people into care who do not know their HIV status.

*Speaker #10 (PLWH, female, Latina)* Many people are turned away from legal services programs because of lack of capacity. They risk losing housing and custody of their children.

*Speaker #11 (PLWH, male, African-American)* We need the Planning Council to partner with us in advocacy in Albany and Washington on issues such as CARE Act reauthorization.

*Speaker #12 (PLWH, female, African-American)* PLWHA need to get involved in advocacy and the planning process.

*Speaker #13 (PLWH, female, African-American)* People in the HIV community need to know about the Council. Also, the across-the-board cut is not fair. Some programs should be held harmless (e.g., food/nutrition, legal). Also, make attendance at these forums mandatory for Council members.

*Speaker #14 (PLWH, male, Latino)* I am concerned about cuts in funding.

*Speaker #15 (PLWH, male, white)* We need to address funding concerns to the people in Washington. We need lobbyists for housing and other issues for New York.

*Speaker #16 (provider, male, Latino)* Exponents, Inc. has used Title I funds to reach hundreds of PLWHA – all of whom are substance users, most people of color, many homeless and formerly incarcerated. Low threshold programs are gateways to other services. Cuts mean turning people away. Cut underutilized programs and increase funding for CBOs to evaluate programs for effectiveness. [See appendix for complete written testimony]

*Speaker #17 (PLWH, female, African-American)* Our faith-based initiative addresses domestic violence and hunger – silent issues facing PLWHA. Legal and food programs are vital to address these issues.

*Speaker #18 (provider, female, Latina)* I have seen the positive impact of BAS nutrition programs on clients' health and quality of life. We have 50-70 persons on our waiting list and need more funds to serve them.

*Speaker #19 (PLWH, female, black/Caribbean-American)* Consumer advocacy in Washington is effective. Also, funds should go to faith-based organizations, which can access people who need services. More funds are needed for affordable housing, and the current Title I transportation program is inadequate.

*Speaker #20 (provider, male, white)* Lack of rental assistance, which stabilizes lives, is a major barrier to care. Also, legal services for immigrants are needed.

*Speaker #21 (provider, male, Latino)* Housing is a right and helps people get into recovery and get care. We need to come together to fight for reauthorization and to preserve services.

*Speaker #22 (PLWH, male, Latino)* All services are essential and should not be cut.

*Speaker #23 (provider, male, African-American)* Programs helped me deal with grief and access care.

*Speaker #24 (PLWH, male, Latino)* I moved from Puerto Rico four years ago to get essential services. I am worried that cuts in funding will imperil that care. Legal, pantry and nutrition services help me stay healthy. [Translated from Spanish]

*Speaker #25 (PLWH, male, African-American)* Harm reduction programs saved me and got me into care.

*Speaker #26 (provider, female, white)* There is an epidemic in the Bronx imposed by City policies that concentrate homeless services here. This affects the surrounding community. Also, the NYC Commission on HIV/AIDS has no Bronx representative. I suggest the following: keep support services in local communities; have a coherent policy on family services (e.g., foster care – get a New York State waiver from the federal government to pay for placing orphaned children).

*Speaker #27 (provider, male, African-American)* Schools are not providing effective HIV prevention.

*Speaker #28 (provider, male, African-American)* It is hard to place PLWHA in wheelchairs in appropriate housing. We need accessible housing for them.

*Speaker #29 (PLWH, male, African-American)* Cutting programs that target children is not fair. Housing and legal services help children and families.

*Speaker #30 (community member, male, African-American)* We need to restore funding to programs. Also, ask CBOs to help get their clients to Washington for advocacy.

### **III. Staten Island Community Forum**

March 31, 2005, NY Public Library St. George Branch

Attendance: Approx. 40

*Speaker #1 (provider, male, Latino)* Prison releasees need discharge planning and follow-up services to ensure access to medical care, social services, and particularly harm reduction services. Increase funding in this area to meet these needs. [See appendix for written testimony]

*Speaker #2 (PLWH, male, African-American)* Preserve and enhance food pantry services. Food and nutrition programs keep me healthy and allow me to take my medications.

*Speaker #3 (PLWH, female, African-American)* The Staten Island (SI) community developed a mobile outreach unit through community efforts to promote access to care and education. This has also helped to promote an educated consumer population.

*Speaker #4 (PLWH, female, African-American)* I am living with AIDS for 10 years and have a large family, including grandchildren, that is facing many issues, particularly housing. Without appropriate housing, the health of my family is imperiled. The stress we have experienced over changes in our housing situation have negatively impacted our health.

*Speaker #5 (provider, female, white)* A recent Journal of AIDS Care article, as well as other studies, shows that ancillary services, particularly food and nutrition services, promote access to and maintenance in care. The changing face of the epidemic means that we have to re-examine the differentiation between primary medical and secondary care. Food is needed for medications, to manage opportunistic infections, and to deal with chronic infection.

*Speaker #6 (PLWH, male, white)* I am living with HIV since the 1980s, and the service safety net provides me with essential services, particularly food pantry and nutritional services. Also, mental health and supportive counseling has been instrumental for me, particularly in introducing complimentary therapies to support the healing of mind body and spirit. [See appendix for written testimony]

*Speaker #7 (provider, female, white)* We need more community-based treatment education and adherence services, especially since doctors are not providing them. Also, there is a growing population of immigrants on SI, many of them undocumented. They need mental health and primary care providers who speak their language in order to increase accessibility.

*Speaker #8 (provider, female, white)* We need more access to sterile syringes, given the high level of infection from injection drug use on SI (at over 45%, the highest percentage of any county in New York State). We need a comprehensive approach to access to free sterile syringes, coupled with support services. We need to increase outreach, educate the community on the efficacy of syringe exchange programs, increase the number of disposal sites, recruit more pharmacies to the ESAP program, and advocate to limit legal barriers to syringe exchange. [See appendix for written testimony]

*Speaker #9 (PLWH, male, white)* I have a problem with spend down issues, and have not been able to get complete dental and medication coverage. I have children and can't pay for all their expenses.

*Speaker #10 (provider/PLWH, male, African-American)* There is a need for early intervention services to get HIV-positive people into care. SI has highest death rate from AIDS of all five boroughs, and has more HIV/AIDS cases than 20 states. We know that there are a significant number of people on SI with HIV who are undiagnosed. There are people who have moved to SI and were getting care in another borough but have dropped out of care due to logistical problems. [See appendix for written testimony]

*Speaker #11 (PLWH, female, African-American)* As PLWHA, we worry about CD4 counts, viral load, eating right, housing, etc. Hearing about potential cuts to programs causes stress. St. Elizabeth Ann's adult day care program is the only one of its kind on SI and helps me to live with HIV and supports my health and quality of life.

*Speaker #12 (provider, female, Latino)* Speaking on behalf of male client who was unable to attend and is wheelchair bound: I have looked for appropriate housing for 2 years without success. I need housing that I can leave without assistance, particularly if there is an emergency.

*Speaker #13 (provider, female, white)* I want to acknowledge the new Title I grant for mental health services that has enabled us to offer psychiatric services in Spanish for the first time to fill an important gap in services. There are still major service gaps on SI. 1) Housing: SI is the only borough without congregate HIV housing, supportive SROs, or HIV family housing. 2) Clean syringes: SI is the only borough with no syringe exchange program. 3) Transportation: SI has no subway and insufficient bus routes, which are a barrier to care. 4) Food: The NY Times recently found that SI is the borough with the highest unmet need for food services. There is an acute shortage of programs here to feed the hungry. Also, SI's HIV pantry program is about to lose \$100,000 in HOPWA funding. [See appendix for written testimony]

*Speaker #14 (PLWH, female, African-American)* We need more programs for children of HIV-infected parents to help them deal with family issues. The Project Hospitality gives me and my family support, educates us on HIV-related issues, and helps my kids to cope with having an HIV-positive parent.

*Speaker #15 (provider, female, African-American)* We need broad outreach to all populations on SI to bring people who are undiagnosed into care.

*Speaker #16 (provider, female, white)* The permanency planning program of the Seaman's Society serves about 80 parents, children and caregivers on SI. We help with foster care arrangements and provider supportive services. Funding for this program is threatened and we may no longer be able to provide this needed service.

*The following is a summary of handwritten testimony provided by clients and staff of Project Hospitality:*

- Supportive counseling has helped me control my life, taught me how to take medications correctly, talk to my doctor, and deal with depression.
- Supportive counseling has helped me a lot since I was diagnosed HIV-positive.
- I am concerned about cuts to programs that benefit the homeless and hungry.
- I access the food pantry, which helps me with my food budget so that I can maintain my health. Legal services have helped me with a living will and health care proxy.
- The pantry service has helped me to get well. I have also benefited from legal and supportive counseling services.
- The food and nutrition services have helped me have enough food each month and maintain a healthy diet, and taught me about food safety. Supportive counseling services have helped me to maintain my mental strength. I know that I am not alone and I have the support I need to function. Legal services have helped me learn my rights and helped with my will, health care proxy and power of attorney, as well as helped resolve housing problems.
- Project Hospitality (PH) helped me when I needed food. They had nutritious foods, like fresh vegetables and it is an excellent program.
- I live in PH scatter site housing, where I get many needed services. Also, I use their excellent food pantry program and their legal program helped with my will and health care proxy.
- Supportive counseling, legal and especially food and nutrition services have helped me a lot.
- PH got me housing and their staff has been very supportive and helpful, giving me hope to live.
- PH's transitional housing program has been wonderful, and the staff very supportive.

- Food and nutrition, legal advocacy and supportive counseling have played an important role in my life. They help me when I run out of food at the end of the month and helped me with my will and health care proxy. Without these services, I could become, once again, a homeless drug addict.
- PH's supportive counseling has always been there for me as a recovering addict. They helped me with housing, harm reduction, legal services, benefits, food and nutrition (to keep me strong and healthy) and case management.
- Food and nutrition services help to sustain me, supportive counseling helps me to make the right decisions to deal with challenges of daily life and legal services helps me with housing and discrimination issues.
- The food pantry helps me survive. The food is nutritional and helps me to live longer.
- The food pantry allows me to get enough to eat and to take my medications. My counselor helps me to deal with my diagnosis, and the treatment educator helps me deal with the side effects of meds.
- The food pantry and supportive counseling have helped me when I was down and out. Support groups give me valuable information to deal with the stresses of living with HIV.
- PH provides needed services to help with problems like housing and legal issues.
- The legal, food, housing and counseling services provided by PH are essential and contribute to the medical and mental health of PLWHA on SI.
- PH's food program increases opportunities for healthy eating for building healthier lives. Supportive counseling, housing and legal services are also essential.
- Legal advocacy, food and nutrition, housing and supportive counseling services link people to long-term community-based care and help achieve stability.
- Legal workers help clients who are unable to afford legal assistance needed due to disability or a life misfortune. Food programs also include educational trainings to help people adhere to a proper diet. Counseling includes intensive case management to help with housing and mental health issues and to connect people to medical care. Finally, affordable housing is extremely scarce.
- Cuts in programs will reduce quality of life for all PLWHA. Affordable housing is the greatest need.
- Cuts in programs will mean that people will not get essential services. It will affect families also.
- Many PLWHA have no access to housing due to mental health issues and limited income. PH programs help people cope, integrate them into the community and connect them to care.
- PLWHA are often fragile due to mental illness and substance use and are disenfranchised from the community. PH services prevent psychiatric decompensation, wrongful evictions, homelessness, and new HIV infections.
- Supportive counseling offers a low-threshold approach to helping people with serious mental illness stay on their medications and stay connected to care.
- Cutting legal services could mean more people in prisons where they would not have adequate care. Cutting counseling services would have a negative impact on the whole community.
- Many families depend on the food pantry program to supply them with healthy food. Cuts in this program will lead to hunger.
- I have been in pH scatter site housing since 1998 and I use their excellent food pantry. Their nutritionist has educated me about eating balanced meals.
- PH has gotten me housing and other assistance. They have given me the initiative to want to live.
- PH was there for me when I was on a limited budget and needed food. They provide healthy food like fresh fruits and vegetables, plus vital nutritional information.
- The food program has helped me to maintain a healthy diet and taught me about proper food safety. The legal program explained my rights in certain matters and helped with my will and health care proxy. The supportive counseling program gave me the support I needed to maintain my mental health.
- PH provides invaluable help with my food budget, allowing me to have enough to eat.
- I am a 50 year old African-American living with HIV for 11 years. PH has taught me how to take my medications and talk with my doctor. They have helped me to control my life and deal with my depression.

- I have received supportive services since the time of my diagnosis and I am concerned about cuts in funding. I rely on these services to help me cope with my HIV status. I see a case manager, a counselor and attend a substance use group to help me stay clean. I see my doctor at the clinic that is located at the harm reduction program. PH is the only place where I can get all of my services together.
- Supportive services have helped me acquire coping skills and become an advocate for PLWHA. Cuts to services will have a very negative impact on PLWHA in SI.
- Cuts to the food program will mean that I will not get enough to eat each month.
- Without PH services, my life would be in a shambles and my T-cell count would be extremely high. They have given me a will to live and help me keep my medical appointments and get enough to eat.
- The food program is essential to me – it gives me enough to eat and has taught me proper nutrition.
- Legal services helped me with my living will and health care proxy. Please keep funding in place to help newly diagnosed clients.
- Cutting legal, food and supportive counseling programs would interrupt my life terribly. I need to see the legal staff occasionally to update my papers. I can bring my son with me and they have peers to help out with him.



#### **IV. Brooklyn Community Forum**

April 7, 2005, Bed-Stuy Multi-Service Center

Attendance: Approx. 60

*Speaker #1 (PLWA, female, white)* I'm living with HIV for 20 years and I still need services. We need funding for clinics; there is not enough to help everyone who needs it.

*Speaker #2 (PLWH, female, African-American)* Legal services help with housing issues. Without a place to live, we can not focus on mental health, substance use and medical issues. We also need to educate youth to prevent them from becoming infected.

*Speaker #3 (PLWA, female, African-American)* Legal services need to be preserved to serve the many new clients who need them for housing, to connect to them medical care, and to empower them. I'm blind from CMV, and legal advocates and medical advocates helped me to get my life together, get drug treatment and get into medical care.

*Speaker #4 (provider, male, white)* We need providers to go to Albany and DC to advocate for more resources for HIV services. We need to advocate with Republicans as well as Democrats.

*Speaker #5 (provider, female, African-American)* As a follow-up worker with HIV affected families, I see adolescent children of HIV-positive parents who become infected. We need to implement the HIV curriculum in schools and other community-based prevention to break the cycle of infection.

*Speaker #6 (PLWH, male, African-American)* It's important for consumers to become part of the planning process. We need to work with the Planning Council to advocate with legislators for more funding and resources, especially as people are developing drug resistance and dying.

*Speaker #7 (PLWH, male, African-American)* One of the main concerns in Brooklyn is our share of funding for HIV services. We have a hard time getting condoms and literature here. Providers don't come to our neighborhoods with new medical information – we have to seek them out.

*Speaker #8 (PLWA, female, African-American)* About half of peers I work with use legal advocacy services. It is the second highest service gap behind housing, is an essential service, and should not be cut.

*Speaker #9 (PLWH, male, African-American)* We need to educate the community and do targeted prevention. This can also bring people into care, but we need resources to do it. In addition to community forums, the Planning Council needs to come to community groups, etc. to see what's going on.

*Speaker #10 (PLWH, female, African-American)* My phone service was taken away, which is a hardship. Legal services programs did not have the resources to help me.

*Speaker #11 (PLWH, female, African-American)* We serve PLWHA in scatter site apartments, many of them over 50 years old, and we confront death on a regular basis. We need more funding for services. There is not enough to provide all the education and services needed in Brooklyn.

*Speaker #12 (Title II CARE Network Coordinator, female, African-American)* On behalf of 80 organizations and many individual members of the Bed-Stuy/Crown Heights HIV CARE Network, we have updated our local service delivery plan, based on new data, focus groups, etc. We found a need for: comprehensive one-stop services, affordable housing, services for PLWHA with co-occurring mental health and substance use issues, culturally competent services, an anti-discrimination campaign, training for parents to talk with children. With more rapid testing and more PLWHA identified, many are not acquainted with the care system. We need to educate them about early intervention and bring them into care through multiple modes of communications – peers, interactive, public information campaigns, etc. Providers need to support their

consumer advisory groups better, as they help enhance care through consumer input. Some Brooklyn organizations need TA to cope with various challenges (fiscal, managerial), so that they can provide services better. [See appendix for written testimony]

*Speaker #13 (PLWH, male, Latino)* We need to continue community-based treatment education. ACRIA, for example, has educated hundreds of consumers. The recent Title I RFP excludes community-based treatment education, which can be more effective than treatment education provided by a medical provider. These services help PLWHA gain knowledge they need and help them connect to medical care.

*Speaker #14 (community member, male, African-American)* My biggest concern is substance abuse in Brooklyn. Many users do not know what services are available. We need to fund more substance abuse services, particularly for people released from prison, who are often discharged with only the clothes on their backs and can quickly slip into substance abuse and homelessness.

*Speaker #15 (PLWH/peer educator, female, African-American)* Cuts to services will hurt PLWHA. Peer support is crucial to PLWHA survival. Providers need training on sensitivity and communicating with PLWHA.

*Speaker #16 (provider, female, white)* We need to resist the medicalization of the CARE act. Legal and other ancillary services are essential. HIV is not just a medical issue. Without social services, people will fall out of care and have more barriers to accessing care. Without CARE Act funding, there will not be HIV-specific legal services, which are already over-burdened – we already turn some people away (plus, NY State has already taken funding away from NYC). [See appendix for written testimony]

*Speaker #17 (PLWH, male, African-American)* I echo above comments. HIV is a holistic issue – PLWHA in shelters need housing, mental health and legal services. Without that, they can not get medical services.

*Speaker #18 (PLWA, female, African-American)* We need more assistance for women. At my church, many women are not willing to confront HIV. We need to get education to them.

*Speaker #19 (provider, female, white)* There is a need for more prevention. I see newly diagnosed people every month. Many think AIDS is a chronic, manageable disease, or that it is beneficial to be HIV-positive to get certain services. We need a public service campaign to combat this, particularly targeted to youth.



## **V. Manhattan Community Forum**

April 8, 2005, Union Settlement (East Harlem)

Attendance: Approx. 50

*Speaker #1 (PLWA, male, white)* I am a 64 year old living with AIDS for 11 years. We are seeing a rise in HIV over 50, especially in Harlem and upper Manhattan. Many ASOs have a clientele that is over 25% seniors, but they are not addressing this population. PLWHA over 50 also have diseases of aging, and doctors do not know how to treat them.

*Speaker #2 (PLWA, female, white)* Legal services helped me to access other services. Without them, it will be difficult to manage my life and be compliant with medications. Communities hardest hit by epidemic, particularly women, need legal services the most.

*Speaker #3 (PLWH, male, white)* The face of the epidemic has changed, with the newly infected mostly people of color. Funding should be targeted to areas where people are most affected.

*Speaker #4 (PLWH, male, Asian/Pacific Islander)* The Leadership Training Institute (LTI) is a unique PLWHA-inspired initiative that helps people to advocate for both their own health care as well as for HIV issues broadly. LTI helps empower PLWHA to overcome barriers to self-empowerment, and helps them cope with treatment adherence, and to advocate for their own needs on planning bodies and advisory boards. Title I research funds should include money for developing curricula for LTI trainings.

*Speaker #5 (PLWH, female, African-American)* Legal services are a vital entity. It is devastating to PLWHA to not be able to obtain legal services when facing eviction and other legal challenges. Increase funding to meet the need, particularly of the newly diagnosed.

*Speaker #6 (PLWH, female, African-American)* Without legal services, I would be homeless now. They helped with housing problems and SSI and went to court with me to resolve legal issues.

*Speaker #7 (PLWH, female, African-American)* Stress is a killer for PLWHA. We need to live as healthy a life as possible. Legal services help relieve stress that arises over benefits and housing.

*Speaker #8 (provider, male, white)* 96% of clients at Exponents/ARRIVE live below poverty level, and many are in unstable housing, are dual diagnosed with hepatitis C, TB, and mental health issues, and all have substance use issues. They live in the neighborhoods with the highest rates of hospitalizations. That CARE Act programs are vital to substance users and to the overall health of the community can not be understated. Any cuts would be devastating. CARE Act services to substance users are a vital safety net that can not be replaced. Substance use services are critical, especially for prison releasees – it connects them to benefits and medical care and is a gateway to crucial life sustaining services, but are being cut. As we change drug laws and more people leave prison, we are setting them up for failure. In this context, low threshold/harm reduction programs fill the gap. Unlike many programs, we do not require abstinence for participation. This gives us an opportunity to implement a proven model (using peers, etc.) to meet people where they are at without judgment. This is a major advance in the approach to addiction. Thousands have completed our programs. No one is ever mandated or coerced to participate. This disproves the belief that drug users will not seek out programs on their own for treatment. Harm reduction programs should be the last programs cut.

*Speaker #9 (PLWH, male, Latino)* Undocumented immigrants have been told that they have to go to social security with a letter from a legal services representative, and they are being contacted by the immigration authorities. There is a fear is that HASA will make undocumented immigrants go to the immigration service (INS). Some PLWH living here might be deported to their home countries, where treatment is not available. The Planning Council should look into what is going on, and what is the position of City agencies. My partner is threatened with deportation, and he is my support as I live with AIDS and cancer, a very stressful position to be in. Also, we need language services for people who do not speak English to access services and have their voices heard at the Planning Council.

*Speaker #10 (provider, female, Latina)* We need to address all substance use, not just intravenous drugs. Alcohol and other drugs impact PLWHA. Also, it is difficult to get into senior settings to do education. Make sure that health educators are updated as soon as possible so we can get information to the community.

*Speaker #11 (PLWH, male, Latino)* HASA placed me in an inappropriate setting, and has not provided me with adequate services. The City needs to fully implement Local Law 49.

*Speaker #12 (PLWH, female, African-American)* Legal advocacy leads to better living for PLWHA. Almost all PLWHA need legal advocacy, especially women, to help with housing, benefits, immigration, and permanency planning. Legal services were ranked the second highest priority by the Social Services Workgroup, and are essential to obtaining and keeping appropriate housing.

*Speaker #13 (PLWH, male, Latino)* Latino men who have sex with men (MSM) in the Bronx are disproportionately affected by HIV/AIDS, and with particular barriers that keep people from getting targeted services, such as a silent epidemic of domestic violence in this population. Also, services are dispersed. We need one-stop, culturally sensitive services, including housing, legal services, home care and transportation. We need to fund an MSM-targeted initiative at a CBO in the Bronx.

*Speaker #14 (PLWH, male, Latino)* I was denied medication and health care when I was incarcerated. This is not fair.

*Speaker #15 (PLWH, female, African-American)* The Planning Council members need to attend these forums to hear the concerns of the community.

*Speaker #16 (PLWH/provider, male, Latino)* I am concerned with the merger of treatment education and treatment adherence. Some people are not in treatment yet but need more basic treatment education as a gateway. Also, we need to provide more funds for evaluation, especially as government funders are asking providers to prove the effectiveness of programs. Government benefit programs are a disincentive for a PLWH who wants to return to work. Across-the-board cuts are not appropriate. Instead, we should target under-utilized services for cuts. CARE Act funding is the lynchpin for harm reduction services, so we can not reduce that.

*Speaker #17 (provider, female, African-American)* We serve clients in SROs, but we do not have the kinds of mental health services that they need. We need services that allow providers to go into the community to meet people's needs, not just wait for clients to go to the hospital. Mental health services are needed to get people into medical care. This is also true of housing and legal services. Some clients in wheelchairs are placed in walk-up apartments, and use legal advocates to try and get appropriate housing.

*Speaker #18 (provider, male, African-American)* Food and nutrition programs need to be enhanced. This is an essential service, and there is an increasing demand for it. Lack of proper nutrition hurts PLWHA in many ways, including by exacerbating diabetes.



## **V. Citywide Spanish-language Community Forum**

April 4, 2005, Union Settlement (East Harlem)

Attendance: Approx. 50

All comments translated from Spanish by DOHMH staff.

*Speaker #1 (provider, female, Queens)* As a service provider, I see that Latinos/Hispanics are an underserved population, especially undocumented immigrants who have alcohol and drug related issues. They need rental assistance, legal services and psychotropic medications to deal with mental health issues. Providers are unable to meet the demand for services. It's very hard to work with a population that has so many needs, when there are not enough resources to meet the needs.

*Speaker #2 (PLWH, male)* I am very concerned about what the changes to Medicaid will mean to my community and me. I want you to help me fight the cutbacks.

*Speaker #3 (PLWH, male, Queens)* I came to the US from Chile two years ago fleeing persecution against HIV infected individuals. Here I was faced with other problems – discrimination due to my immigrant status and difficulty in navigating the system. People think that all that an HIV-positive person needs is medication covered by ADAP, but people need more than that. We need food and nutrition, housing, service providers that want to provide services, and to be treated with dignity. I lived in a shelter in Brooklyn where the housing director created conflicts amongst the residents. This should not be happening.

*Speaker #4 (PLWH, male, Brooklyn)* I am here to fight on behalf of Proyecto Familia.

*Speaker #5 (Provider, male, Brooklyn)* I am here to dispel the notion that the Planning Council had in terms of turnout and lack of need for this event. I know that people were against this and that is why we are here. I lead a congregation in Brooklyn, we need more information and education in Spanish, so that we can keep our community informed and educate ourselves.

*Speaker #6 (PLWH, female, Brooklyn)* I am a peer leader at Proyecto Familia. We need more educational programs in Spanish. If we are to live 20 years or more with the virus, then we need to be prepared individually and as a community.

*Speaker #7 (PLWH, male, Brooklyn)* People claim that services cannot be funded because of lack of funds, but PLWHA need better services and on-going education.

*Speaker #8 (Provider, female, Brooklyn)* We need educational trainings in Spanish. There are proposed cutbacks to legal services, this should not be. People with kids who are in the advanced stages of the disease need legal services. Legal services provide a voice for single mothers and their kids when they most need it.

*Speaker #9 (PLWH, male, Brooklyn)* PLWHA need medications that are not covered by ADAP. We need additional moneys to be added for rental assistance and we need more adherence and mental health support groups. I suffer from depression, and support groups have helped me stay on my medication and alleviate my depression.

*Speaker #10 (PLWH, female, Brooklyn)* We need more trainings in Spanish, and housing assistance.

*Speaker #11 (PLWH, male)* I am here on behalf of all those people that are HIV Positive and are also undocumented. They have many barriers to care, especially fear, and need assistance.

*Speaker #12 (PLWH, male, Bronx)* HASA needs to have more Spanish speaking case managers or interpreters. Case managers should not use other clients as interpreters; this is a break of confidentiality.

*Speaker #13 (PLWH/Provider, male, Manhattan)* Through the Air Bridge Program, I am able to help many people like myself. Just this week I picked someone up at the airport who had nowhere to go for assistance.

*Speaker #14 (provider, female, Brooklyn)* Spanish resources are scarce. At my agency, I am the only Spanish speaking staff member. That means that everything dealing with our community falls on me. On behalf of all the people that need services in Spanish, I ask that you allocate more resources to hire the personnel to handle the demand for services. If you are unable to increase funding for agencies to provide the services, then provide us with the means to connect clients to places that can provide them with services, such as carfare for referral to help bridge those gaps.

*Speaker #15 (PLWH, female)* I am part of the campaign “HIV Stops With Me”. There is a need for more methadone services. We need to realize that HIV and drugs go hand in hand. We need more community forums about the virus to improve ways of getting information to the community. The community needs to be informed of the many changes in HASA that affect people and their ability to manage the virus. Education is very important at all levels.

*Speaker #16 (PLWH, male, Bronx)* I have been having problems with the services that I am being provided at hospitals. Hospital workers treat people poorly. They make decisions on behalf of patients without their consent. I have had problems in at least two hospitals where I am no longer able to receive services. One closed my case management services, because they said that I complained too much. The other labeled me as dangerous and a trouble maker because I complained about the quality of the services. Also, there is not enough housing available. The apartments that are shown to PLWH are in substandard conditions. There are insufficient interpreter services, and clients are asked to interpret for other clients – a clear violation of confidentiality laws.

*Speaker #17 (PLWH, male, Manhattan)* I am currently housed on the 4<sup>th</sup> floor of an inadequate apartment building where there is no elevator. HASA is not doing its job- it thinks that it’s a prevention program. They are constantly trying to give me condoms when what I need is decent apartment. They are contributing to duplication of services by imposing condom education on me and billing Medicaid. Undocumented immigrants get better service than people born in the US.

*Speaker #18 (PLWH, male, Queens)* Undocumented PLWHA need services. I am here to represent those PLWH/A who are also undocumented, some of whom are afraid to come here and talk about their needs.



## Conclusion

This report will be distributed to the HIV Health and Human Services Planning Council and its committees (Needs Assessment, Integration of Care, Access to Care, Maintenance in Care, Consumers, PLWHA Advisory Group, Priority Setting & Resource Allocation) for their use in the planning for Title I-funded HIV services for FY 2006.

The committees will formulate recommendations for services based on numerous data sources, including the testimony presented at the community forums and summarized here. The Planning Council recognizes the ever-increasing need for services for the expanding number of people living with HIV/AIDS in New York City. The Planning Council will use the information in this report to enhance existing services and plan for additional services should funding become available.

**For more information on the HIV Planning Council or for additional copies of this report write or call:**

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*This report is dedicated to the memory of our dear colleague, friend and advocate, Cliff Mosley.*

