



**New York City Ryan White CARE Act Title I  
Consumer Advisory Group Survey Report**

**April 2005**

**Prepared for the HIV Health and Human Services Planning Council of New York by the  
New York City Department of Health and Mental Hygiene  
Office of AIDS Policy Coordination  
and  
People Living with HIV/AIDS Advisory Group**

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**New York City Department of Health and Mental Hygiene**

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April 18, 2005

Dear Colleague,

Attached you will find the results of the recent survey conducted by the People Living with HIV/AIDS (PLWHA) Advisory Group of the HIV Health and Human Services Planning Council of New York. We conducted a survey of Title I Community Advisory Boards (CABs) from January 2005 to March 2005. This survey gave consumers an opportunity to set priorities and identify needs in the priority setting process for Ryan White Title I services.

We received 68 completed surveys, which is a 52% response rate. These responses will be used by the PLWHA Advisory Group to advocate for consumer needs in the planning for Ryan White FY 2006 Title I priorities. These recommendations identify the services and service gaps that are most important to consumers.

On behalf of the PLWHA Advisory Group, we want to extend our deepest thanks to those agencies that made the effort to collaborate with the consumers on their advisory boards to complete this survey in an expedited manner. We appreciate their commitment to consumer empowerment and to listening to the voices of consumers. We intend to conduct this survey on an annual basis for future planning cycles. We hope that all Ryan White Title I providers will see the value in this initiative and collaborate on future efforts to identify the needs of consumers.

We urge you to copy and distribute this report and to discuss the results with the consumers and others involved with HIV/AIDS. We feel that it is important for consumers to know that they have a voice in planning for HIV services and that the Planning Council will have documentation, through this survey, of the needs of people living with HIV/AIDS. The survey results are also available on the web at [www.nyhiv.org](http://www.nyhiv.org).

If you have any questions about the survey, please contact Stephen Bailous at the New York City Department of Health and Mental Hygiene Office of AIDS Policy Coordination at 212-442-3929 or via e-mail at [sbailous@health.nyc.gov](mailto:sbailous@health.nyc.gov).

Sincerely,

Steve Hemraj  
Co-Chairs, PLWHA Advisory Group  
Enclosure

Felicia Carroll

## The Advisory Group Survey

### **Background**

In preparation for developing FY 2006 funding priority recommendations for Ryan White CARE Act Title I services, the New York HIV Health and Human Services Planning Council's People Living with HIV/AIDS (PLWHA) Advisory Group conducted a survey of Title I Community Advisory Boards (CABs) from January 2005 to March 2005 (See Appendix D). Agency leadership were asked to survey their Community Advisory Board members to rank the top five Title I services that promotes access to and maintenance in HIV-related primary care, and to prioritize the top five service gaps experienced by PLWHA. One hundred thirty-two agencies received the survey and a packet to guide them in its completion (See Appendix A). In addition, members of the Advisory Group and PLWHA Initiative staff from the Office of AIDS Policy Coordination conducted follow-up calls to encourage agencies to complete the survey and to offer technical assistance (See Appendix E).

### **Summary of Results**

A total of 68 completed surveys were returned to the Office of AIDS Policy Coordination. Of the Title I agencies surveyed, PLWHA representation averaged 64% of the membership of the community advisory board. The breakdown of respondents by borough (location of provider) is Manhattan with 40, Brooklyn with 15, Queens with 7, Bronx with 6, and Staten Island with 2.

Section 1 of the survey presented a list of Title I service categories and asked respondents to rank the top five Title I service that help consumers access and maintain HIV-related primary medical care (See Appendix C). In Section 2 of the survey, participants were asked to identify the top five gaps in HIV-related services that they currently experience and describe why they think they are important needs. Finally in Section 3, a question was asked concerning overall satisfaction with the quality of the Title I services they receive. Each community advisory board came to a consensus on their response and submitted one completed survey.

Quantitative and qualitative analyses were conducted on the first two sections of the survey. The overall results were tabulated based on frequency of response. The tables below reflect the quantitative results of sections 1 and 2. Categories or areas of service are noted on the right side of the tables, and its accompanying ranking on the left side. This is followed by a qualitative analysis of Section 2 that summarizes the themes most commonly identified by the survey respondents.

**Section 1 Results: The top Ryan White Title I services that promote access to and maintenance in HIV-related primary care**

The table below shows the top ranked Title I service categories that promote access to and maintenance in HIV-related primary care.

*Recommendation Results (N=68)*

<b>Ranking</b>	<b>Category</b>
# 1	ADAP
# 2	Housing
# 3	Case Management
# 4	Mental Health
# 5	Food & Nutrition

**Section 2 Results: The top current gaps in HIV-related services**

The table below shows the top ranked current gaps in HIV-related services. Below the table are the most commonly identified themes related to the ranked categories.

*Recommendation Results (N=68)*

<b>Ranking</b>	<b>Category</b>
# 1	Housing
# 2	Mental Health
# 3	Supportive Counseling
# 4	Transportation
# 5	Client Advocacy

**Ranking # 1:**

- “We feel that if a person is stabilized with adequate housing, it makes it easier to get them to access medical care.”
- “This is important to stop the ‘revolving’ door effect.”
- “Existing housing units are in very poor conditions.”
- “PLWHA will end up in the street and consequently will find it extremely difficult, if not impossible to maintain their connection to services.”

### **Ranking # 2:**

- “Mental Health services are needed for us to obtain a better understanding of ourselves and our illness; too many people living with HIV and are MICA clients not getting care.”
- “There is a critical need for mental health services that are culturally appropriate.”
- “We are interested in services that offer a variety of treatment modalities to help people deal with stress.”
- “Mental health services are especially important for HIV clients because we would like to be treated as a total person.”

### **Ranking # 3:**

- “Emotional health is just as important as medical health.”
- “This service would provide us with the opportunity to speak amongst peers in a nonjudgmental environment.”
- “There is a need for a Men's Group to give each other support, especially a separate group for "Men Having Sex with Men" (either Gay or on the Down Low), so that they would have a comfortable environment to express their feelings.”
- “Family members and friends need more information on HIV/AIDS and case management services because the home that the client lives in may be unstable and therefore it’s harder for the client to stay on track.”

### **Ranking # 4:**

- “If the patient does not feel well and has no money to pay for transportation, he may not keep his appointments.”
- “This service would help patients get to treatment and support service providers when they are too weak for public transportation.”
- “There is very little transportation available, particularly for non-medical related appointments. Sometime people cannot get to food pantries or to appointments to see apartments, etc.”
- “This [service] should be expanded for HIV/AIDS participants to travel to facilities for health and social services, which would improve the quality of life-via escorts, car service, van pick-ups and etc.”

### **Ranking # 5:**

- “Job training and access to entitlements for the legal and undocumented immigrants was suggested as a way to keep all HIV people in the US engaged.”
- “Non-English speaking communities have greater difficulty accessing services, especially services located in the Bronx.”

- “People need assistance in dealing with landlords and entitlement issues.”
- “PLWH have multiple legal needs and occasionally need legal services on an emergency basis; helpful to have legal service that could address issues during a crisis to supplement other services that often have a wait list.”

### **Section 3 Results: Satisfaction with Title I services**

Forty-three percent of survey respondents were satisfied with the quality of the Title I services they receive. Twenty-three percent reported being very satisfied, 23% reported being somewhat satisfied, 10% reported being unsatisfied and the remaining 1% reported being very unsatisfied.

### **Conclusion**

The PLWHA Advisory Group is sharing the results of this survey with the HIV Planning Council, the Priority Setting and Resource Allocation Committee and other committees for use in the FY 2006 priority setting process. Additionally, the Planning Council and its committees will use this survey as an important part of the consumer-driven data that will inform their decisions concerning priorities and funding for FY 2006 Title I services. This report will also be posted on the Planning Council’s website, [www.nyhiv.org](http://www.nyhiv.org).

For more information, please contact Stephen Bailous at the NYC DOHMH Office of AIDS Policy Coordination, 40 Worth Street, Room 1519, New York, NY 10013, tel. 212-788-2752, or via e-mail at [sbailous@health.nyc.gov](mailto:sbailous@health.nyc.gov).

## Appendix A. The Advisory Group Survey Packet

### HIV HEALTH AND HUMAN SERVICES PLANNING COUNCIL OF NEW YORK PLWHA Advisory Group

January 10, 2005

Dear Ryan White Title I Service Provider:

Thank you for participating in the Ryan White Title I planning process. Enclosed please find The Advisory Group Survey (TAGS) along with materials that will support your organization's completion and expedited return of the TAGS survey.

#### Background and Purpose of the Survey

To ensure that future Ryan White Title I funding priority recommendations are in line with consumer and organization needs, the New York HIV Planning Council PWA/HIV Advisory Group is conducting a citywide survey of consumers through your organization's Consumer Advisory Board. As PWA/HIV needs are the root of a program's development, completing this survey gives consumers and agencies another vehicle to have their voices heard in the Title I planning process.

#### Survey and Packet Contents

The enclosed packet includes 1) a blank survey, and 2) a return survey envelope. If you are missing any enclosure please contact Steve Bailous at 212.442.3929 immediately.

The survey has three sections: 1) Recommendations on Title I services; 2) Overall satisfaction with Title I services; and 3) Identification of service gaps. To keep things simple, the PWA Advisory Group created the survey to be broad enough to capture needed planning information and simple enough to allow Consumer Advisory Boards to complete the form in the most efficient way. Please work with your Consumer Advisory Board and complete **ONE** survey to reflect the identified needs of the group as a whole.

#### Returning Your Survey

The deadline for returning the survey is Friday, March 11, 2005. This deadline is a "hard deadline" as the Planning Council's PLWHA Advisory Group needs ample time to meet and develop their final recommendations for next year's planning process.

**You can return your survey via fax or mail. The return fax number is 212.788.9360.** This number is also located on the survey. After faxing your completed survey, please mail the original with the return envelope.

#### Survey Technical Assistance Support and Contacts

Steve Bailous of the Office of AIDS Policy Coordination is the primary contact for this survey. Steve is available via telephone at 212.422.3929 should you have any questions about the survey content.

Thank you for completing this important survey. We look forward to advocating for your consumer and agency needs.

Sincerely,

Steve Hemraj  
Co-Chairs, PLWHA Advisory Group to the New York HIV Planning Council

Felicia Carroll

## Appendix B. The Advisory Group Survey HIV Care Services Letter

# HIV?CARE

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## NEW YORK CITY HIV CARE SERVICES PROGRAM

January 7, 2005

Dear Ryan White Title I Contractor:

Enclosed you will find a survey developed by the HIV Planning Council's PLWHA Advisory Group. The purpose of the survey is to get input from our contractors' Community Advisory Boards (CAB) to ensure that the 2006-2007 planning process is responsive to service needs articulated by people living with HIV/AIDS in New York City.

Please bring this survey to your CAB and complete it with the input of the group. Should you not have a regularly scheduled CAB meeting prior to the March 11 due date, I ask you to schedule a special meeting or use another mechanism to get their input. Since the beginning of the epidemic, the voices of people living with HIV/AIDS have been a vital factor in developing the service infrastructure that we have today. The PLWHA Advisory Group needs your help in making sure that those voices are represented in this year's planning process.

Sincerely,



Bettina Carroll  
Deputy Director/Programs  
HIV Care Services /MHRA  
(212) 343-8200  
e-mail address: bcarroll@hivcs.org

## Appendix C. The Advisory Group Survey Service Category Description

### **Service Category: Access to Care and Early Intervention**

The objective of this service is to identify those who are at high risk for HIV, help them assess their needs and service barriers, and facilitate their transition to HIV counseling and testing, HIV primary care, case management and other supportive services. Services provided include: assessments, health education, referrals for care and testing, treatment education, supportive individual and group counseling, and transitional case management. Programs may utilize professional and/or peer models of service delivery, and should target high-risk populations in such settings as low threshold harm reduction settings, sexually-transmitted disease clinics, homeless shelters and service sites, mental health service sites, HIV counseling and testing sites, emergency care centers and street-based settings.

### **Service Category: ADAP (AIDS Drug Assistance Program)**

ADAP provides HIV medications to uninsured and underinsured HIV infected individuals.

### **Service Category: Adult Day Treatment**

The purpose of this service is to provide a structured setting for HIV-infected adults to receive the daily care and the skills and motivation to better manage their own health care and lives. Funding was available to support four models of Adult Day Treatment programs.

### **Service Category: Air Bridge Project**

Programs are funded to identify people living with HIV/AIDS who migrate between New York and Puerto Rico and provide coordinated and continuous medical, case management and social services to these individuals.

### **Service Category: Assessment Teams in Emergency Care Centers and Harm Reduction Service Centers**

The initiative funds assessment teams in two settings: hospital-based emergency department and harm reduction service center, targeting either drug users or youth. The initiative aims to reach out to two groups of patients - those who are HIV infected and not engaged in care and those with risk factors - and link them to comprehensive care, counseling and testing.

Both programs provide assessment of patients' connections to appropriate HIV testing and care through collaboration with the center's staff, as well as connections to other services, such as transitional care coordination; crisis intervention and supportive counseling; health education; treatment education; orientation to HIV service system; and escort to services.

### **Summary of Service Category: Buddy Services**

This initiative provides people living with HIV/AIDS who need assistance with activities of daily living with home and field-based support services delivered by volunteers and unpaid interns to supplement the care provided by professional caregivers.

### **Service Category: Case Management**

This initiative provides low and/or high-intensity case management services to people living with HIV/AIDS to facilitate access to clinical care and concrete services. Case management services may be provided under a high intensity model to those not eligible for COBRA or under a low-intensity model, either as a stand-alone program or co-located with other services.

**Service Category: Client Advocacy (Legal Services)**

This initiative provides direct client advocacy and advocacy training either through an independent legal provider or by staff advocates in community-based settings. Client advocacy may be provided in the areas of family law, housing law, immigration law, permanency planning, and benefits programs. Program services include: assisting people living with HIV/AIDS (in particular, those who are not U.S. citizens and those who are incarcerated or recently released from prison) in accessing and maintaining all benefits for which they are eligible; offering Alternative Dispute Resolution (ADR), particularly mediation, for housing disputes; training of HIV/AIDS service providers as advocates; training of people living with HIV/AIDS to advocate for themselves.

**Service Category: Custody Planning and Family Support**

This initiative provides services for families that are planning for the long-term care of children whose parents are HIV-infected. Services include both permanency planning and transitional support for parents, children and new caregivers. Programs address the comprehensive needs of families, including access to financial, legal, mental health, and supportive services, either directly or through formal linkages with other service providers

**Service Category: Drop-In and Referral Center for HIV+ Releasees from Correctional Facilities (Riker's Island Project)**

This initiative provides a 24-hour drop-in transitional center for newly released HIV-infected inmates with linkages to comprehensive health, mental health, housing, AOD and other support services. The Center must be located in the Queens Plaza area of Long Island City, Queens, as close as possible to the Rikers Island releasee drop-off point, operating 24 hours a day for five days per week. Services must include screening and assessment of immediate and urgent service needs; development of an immediate transitional plan to connect the client to necessary services; crisis intervention and supportive counseling; referral to and assistance in accessing community-based services to a myriad of safety-net services; transportation assistance and escort to referral sites; and follow-up after referral.

**Service Category: Food and Nutrition**

This initiative provides home delivered meals, congregate meals and pantry bags, or any combination of these, along with nutritional assessment and counseling and access to other services through co-location of services or linkages with other HIV/AIDS service providers.

**Service Category: Harm Reduction and Other Services for Active and Relapsing Alcohol and Other Drug Users**

This initiative provides low-threshold and easily accessible harm reduction, recovery readiness, and relapse prevention services to HIV-infected individuals who are actively using drugs, relapsing or in recovery.

Services focus on the risks of re-infection with HIV and other infections associated with active substance use and ways of identifying and coping with triggers for alcohol and drug use. Services should be integrated with other services for people with HIV, and service models may include: community based AOD services, integrated primary care, mental health, social services, or housing programs.

**Service Category: Hepatitis C Screening and Treatment**

This initiative supports the development and provision of Hepatitis C screening and treatment services in existing HIV medical care settings to improve the medical management of co-infected individuals. Program services are either integrated into established hospital-based or community-based

ambulatory HIV care settings that serve a large number of co-infected individuals. Services include laboratory tests to screen for the presence of HCV and a wide range of supportive and educational activities.

**Service Category: Home Care and Supportive Services**

This initiative provides a comprehensive and coordinated array of home health care and support services for HIV-infected clients and support services for caregivers and affected family members. Integrated programs that incorporate a range of service elements are strongly encouraged, especially where the primary recipient's family members require assistance. Support services can be provided to caregivers and should include counseling, respite and child care during appointments, hospitalization, and assistance with household chores. Specialized services should be provided to postpartum women who have learned of their serostatus and to their child (as a result of mandatory testing of newborns).

**Service Category: Housing**

This initiative provides transitional housing and supportive services in targeted geographic areas for persons living HIV/AIDS. Services include case management (to assist clients in gaining access to health care, mental health care, substance abuse treatment services, financial entitlements, etc.), food and clothing assistance, and housing placement assistance.

**Service Category: Mental Health Services**

This initiative offers licensed outpatient mental health services as part of a comprehensive and integrated approach to meeting the needs of people living with HIV/AIDS. Services are offered by co-locating or out-stationing mental health services in settings such as primary care facilities, alcohol and other drug treatment programs, housing programs, social service agencies, or case management programs. In addition, freestanding mental health clinics provide access to such services through established linkages with other providers.

**Service Category: Oral Health (Dental Care)**

Programs are funded to establish oral health care (dental care) services that are integrated into HIV ambulatory medical care settings. This will improve patients' access to appropriate and continuous oral health care and to allow for service provision in a familiar setting. Services must be co-located in an HIV ambulatory medical care setting and integrated into the overall package of routine health care services provided by the HIV primary care team at the site.

**Service Category: Outpatient Medical Care in Hospitals/Clinics**

This initiative provides comprehensive outpatient medical care, including subspecialty care, to HIV-infected adults, adolescents and children. Programs should be designed to promote access to care, to enhance utilization of care, and to maintain individuals in quality medical care. Specialized services models may be implemented to meet the needs of specific populations such as women with children, adolescents, undocumented immigrants, and the homeless. Services may be provided in a hospital outpatient department, community-based clinic or may be co-located with other services, such as mental health services, alcohol and other drug use treatment, methadone treatment, or in housing settings, in order to remove barriers to care.

**Service Category:** Outstationed Medical Care Teams in non-medical settings (i.e., SROs, CBOs, needle exchange sites, mobile vans)

Programs are funded to provide health care services in non-medical settings, such as SROs, CBOs, needle exchange sites, and mobile vans that house a high density of documented HIV+ individuals in order to engage HIV+ persons not in care, are funded to provide on-site medical triage and HIV Primary Care, and to provide the support services necessary to assist individuals to receive the full continuum of care in more traditional health care settings.

Programs target East Harlem, the South Bronx, or any area of Brooklyn where the target population are clustered. Programs must have complete outpatient and inpatient medical services available at their facility or through formal linkage agreements.

**Service Category:** People Living With HIV/AIDS Leadership Training Institute (PWA/LTI)

People Living With HIV/AIDS Leadership Training Institute (PWA/LTI) is a statewide initiative that provides training, skills building, motivation and education to people living with HIV and AIDS (PWHA), to support the development of involved and effective HIV positive community leaders. Training topics include: community organizing, planning and decision making, advocacy and policy-making advice. Training is provided in a supportive, inclusive and interactive environment.

**Service Category:** Transportation Services

This initiative provides transportation services to HIV-infected individuals to ensure access to health care and/or psychosocial support services. Transportation may also be provided to escorts accompanying clients.

## Appendix D. The Advisory Group Survey

### HIV HEALTH AND HUMAN SERVICES PLANNING COUNCIL OF NEW YORK PLWHA Advisory Group

Thank you for participating in the Ryan White Title I planning process. To ensure that future Ryan White Title I funding priority recommendations are in line with consumer needs, the New York HIV Planning Council PWA/HIV Advisory Group is conducting a citywide survey of consumers through your organization's Consumer Advisory Board. As PWA/HIV needs are the root of a program's development, completing this survey gives consumers another vehicle to have their voices heard in the Title I planning process.

The survey has three sections: 1) Recommendations on Title I services; 2) Identification of Gaps in services; and 3) Overall satisfaction with Title I services. Please consult your Consumer Advisory Board and complete **ONE** survey to reflect the identified needs of your PLWHAs of the group as a whole.

The deadline for returning the survey is Friday, March 11, 2005. Please return your survey via fax or mail. The return fax number is 212.788.9360. This number is also located on the survey. After faxing your completed survey, please mail the original with the return envelope.

Thank you for completing this important survey. We look forward to advocating for your

**OPTIONAL:**

Agency Name: \_\_\_\_\_

Contact Person for Consumer Advisory Board (CAB): \_\_\_\_\_

Phone #: \_\_\_\_\_ E-mail: \_\_\_\_\_

What percentage of your CAB (Consumer Advisory Board) do PLWHAs represent? \_\_\_\_\_

### SECTION I: RECOMMENDATIONS

For this section, please identify the top 5 Ryan White Title I services that help you access and stay in primary care. (Please see attached service descriptions). Please rank your recommendations "1" through "5", with #1 as your top priority.

Access To Care and Early Intervention	
AIDS Drug Assistance Program (ADAP)	
Adult Day Treatment	
Air Bridge Project	
Assessment Teams in Emergency Care Centers and Harm Reduction Service Centers	
Buddy Services	
Case Management	
Client Advocacy (Legal Services)	

Dental Care	
Drop-in Center for HIV+ Prison Releases (Riker's Island Transitional Services Project)	
Emergency Rental Assistance	
Food and Nutrition	
Harm Reduction, Other Services for Active and Relapsing Alcohol and Other Drug Users	
Hepatitis C Screening and Treatment	
Home Care and Support Services	
Housing	
Mental Health Services	
Outpatient Medical Care in Hospitals/Clinics	
Supportive Counseling	
Transportation Services	
Treatment Adherence	
Tuberculosis Services	

**SECTION II: CURRENT GAPS IN YOUR SERVICE**

**RYAN WHITE TITLE I PROGRAM SERVICES**

**What are the top 5 HIV-related services needed that you are not currently receiving?**

1. \_\_\_\_\_

Please briefly state why your group believes this is an important need.

2. \_\_\_\_\_

Please briefly state why your group believes this is an important need.

3. \_\_\_\_\_

Please briefly state why your group believes this is an important need.

4. \_\_\_\_\_

Please briefly state why your group believes this is an important need.

5. \_\_\_\_\_

Please briefly state why your group believes this is an important need.

**SECTION III: SATISFACTION WITH TITLE I SERVICES**

**Overall, how satisfied are you with the quality of the Title I services you receive?**

Very Satisfied     Satisfied     Somewhat Satisfied     Not Satisfied     Very Unsatisfied

**Please FAX completed survey by Friday March, 11, 2005  
to 212-788-9360, Attn: Steve Bailous and**

**USE THE ATTACHED ENVELOPE TO MAIL THIS FORM**

**THANK YOU!**

## Appendix E. The Advisory Group Survey Telephone Script

# TAGS SCRIPT

Hi \_\_\_\_\_ this is \_\_\_\_\_ I'm calling for the People Living with HIV/AIDS Advisory Group to the HIV Health and Human Services Planning Council. We are conducting a **Survey on HIV/AIDS Services** with Title I Consumer Advisory Boards. We sent a copy of the Survey to your agency to the attention of \_\_\_\_\_ in January and in February by e-mail. Have you received it?

**A. (YES)** Great. We are hoping that you will have a meeting with your CAB to fill out the Survey. We realize that the March 11 deadline doesn't give you much time to do this. We have this quick turnaround because we need to receive your completed survey by March 11th. to report our findings to the Planning Council before they set spending priorities. If you need someone to go thru the Survey with you or your CAB we can help.

Do you need help to complete the survey on time?

**If yes,** What can we do to help you? I'll make a special request for you and someone will get back to you soon to arrange the assistance you request. Thanks you for your support of this important PWA initiative.

**If no,** We will be looking forward to receiving your completed Survey. Can you fax it to me now? Thank you for your support of this important PWA Initiative.

**B. NO.** (If the Survey has not been received.) We must not have your contact information correct. Can you give me the correct mailing address? The e-mail address? Fax and phone numbers? Which is the best way for us to get the survey to you? I'll be glad to get a copy of the Survey to you as quickly as possible. Is there any thing we can do to help you complete the survey and return it before April 9<sup>th</sup>? Thank you for your support of this important PWA initiative.