



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

May 2004

**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 the Persons Living with HIV/AIDS Advisory Group**

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PLWA/HIV ADVISORY GROUP

May 14, 2004

Dear Colleague,

Attached you will find the results of the recent survey conducted by the PLWA/HIV Advisory Group of the HIV Health and Human Services Planning Council of New York. In March and April, we surveyed Ryan White Title I consumer advisory boards regarding their needs for HIV services. 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 72 responses, double the return rate of previous years. These responses will be used by the PLWA/HIV Advisory Group to advocate for consumer needs in the planning for Ryan White FY 2005 Title I priorities. These recommendations identify the services and service gaps that are most important to consumers.

On behalf of the PLWA 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.

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, (e-mail: sbailous@health.nyc.gov).

Sincerely,

Rafael Abadia
Co-Chairs, PLWA/HIV Advisory Group
Enclosure

Dorothy Walker

The Advisory Group Survey

Background

In preparation for developing FY 2005 funding priority recommendations for Ryan White CARE Act Title I services, the New York HIV Health and Human Services Planning Council's PWA/HIV Advisory Group conducted a survey of Title I community advisory boards from March 2004 to April 2004 (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 people living with HIV/AIDS (PLWHA). One hundred thirty-four agencies received the survey and a packet to guide them in its completion (See Appendix A). In addition, members of the Advisory Group and PLWH 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 72 completed surveys were received from 62 organizations, double the return rate of previous years. Of the Title I agencies surveyed, PLWHA represented 56% of the membership of the community advisory board. The breakdown of respondents by borough (location of provider) is: Manhattan with 41, Bronx with 11, Brooklyn with 5, Queens with 3 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 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=72)

Ranking	Category
# 1	Case Management
# 2	Access to Care and Early Intervention
# 3	ADAP
# 4	Food/Nutrition
# 5	Transportation
# 6	Housing

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=72)

Ranking	Category
# 1	Housing
# 2	Legal Services
# 3	Food/Nutrition
# 4	Home Care and Supportive Services
# 5	Transportation

Ranking # 1: Housing

- “HIV + consumers continue to report extreme dissatisfaction with obtaining affordable and quality housing accessible to public transportation. All of our consumers reported housing as a systemic problem”.
- “The group identified this [housing] as the most pressing service need. Transitional housing only lasts 28 days, and then the person has to move. This could go on indefinitely and it creates stress for the PLWA. More funding is needed to either identify permanent housing or to expand the definition of transitional housing to exceed 28 days”.

- “Consumers recounted negative experiences with the emergency shelter system and HASA. They felt there were inordinate delays in processing and placement. They also expressed that there was not enough affordable housing available, and that there was not an effective mechanism in place to get the word out on housing options and availability”.
- “Appropriate, stable housing for families is a basic need in which all other services build on”.
- “Improved housing services”.
- “Persons who do not meet HASA criteria do not have a means of housing support to assist them in payments at the levels HASA will pay. The only income of regular Public Assistance allows for is \$215 for shelter allowance”.
- “Quality of housing after poor and not in desirable areas”.
- “Housing is important because it stabilizes the consumer and allows access to other service. Adequate housing is important for health”.

Ranking # 2: Legal Services

- “Legal Services imparts important information on how vocational training education and employment affect benefits. It also works as an advocate when there's a problem accessing services”.
- “This [legal] service will assist PWA/HIV with discrimination issues”.
- “PLWA's are not eligible for certain benefits struggle to understand the system from a legal standpoint”.
- “Clients need legal advocacy relating to benefits”.

Ranking # 3: Food/Nutrition

- “PWA/HIV have to not only be educated on the medication that they are taking but prepare meals should be what foods are now more beneficiary to their health. Those that are not able to prepare meals should be able to receive a well-balanced and nutritious meal that will look in conjunction with their medication”.
- “Not enough funds available to CBO's for pantries for those in need”.

Ranking # 4: Home Care and Supportive Services

- “The families of PWA/HIV require and can benefit from these services to better care for their infected family members, as well as to gain support for themselves in various areas, i.e., mental, physical and emotional”.
- “Clients who are very sick or disabled need house keeping assistance”.

Ranking # 5: Transportation

- “It's hard enough to get around and they don't give you car fare. You can lose documents and then you are on your own. You have to get to walk with your health no good.”
- “Need more [transportation] services”.
- “We need free flexible transportation to pantry programs & non-medical appointments (court dates, school conferences) that do not require 3 weeks in advance”.
- “Increased [transportation] services, more reliability”.

Section 3 Results: Satisfaction with Title I services

Ninety percent (90%) of survey respondents were satisfied with the quality of the Title I services they receive. Forty-five percent (45%) reported being very satisfied, 45% reported being satisfied and the remaining 10% reported being somewhat satisfied.

Conclusion

The PWA/HIV Advisory Group is sharing the results of this survey with the HIV Planning Council and its Planning and Evaluation Committee and workgroups for use in the FY 2005 priority setting process. The Planning Council and its committees and workgroups will use this survey as an important part of the consumer-driven data that will influence their decisions concerning priorities and funding for FY 2005 Title I services. This report will also be posted on the Planning Council's website, 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, sbailous@health.nyc.gov.

Appendix A. The Advisory Group Survey Packet
HIV HEALTH AND HUMAN SERVICES PLANNING COUNCIL OF NEW YORK
PLWA/HIV Advisory Group

March 1, 2004

Dear Ryan White Title I Service Provider:

Thank you for participating in the Ryan White Title I planning process. Enclosed please find (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 city-wide 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 Board 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, April 9, 2004. This deadline is a "hard deadline" as the Planning Council's PWA/HIV 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,

Rafael Abadia

Co-Chairs, PWA Advisory Group to the New York HIV Planning Council

Dorothy Walker

Appendix B. The Advisory Group Survey HIV Care Services Letter

HIV?CARE

NEW YORK CITY HIV CARE SERVICES PROGRAM

Dear Ryan White Title I Contractor:

Enclosed you will find a survey developed by the HIV Planning Council's PWA Advisory Group. The purpose of the survey is to get input from our contractors' Community Advisory Boards (CAB) to ensure that the 2005-2006 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. If you do not have a regularly scheduled CAB meeting prior to the April 2 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 has been an important part of developing the service infrastructure that we have today. The PWA Advisory Group needs your help in making sure that those voices are represented in this year's planning process.

Sincerely,



Judith A. Verdino
Director

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 and 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 (PWA), 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
PLWA/HIV 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 city-wide 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) Overall satisfaction with Title I services; and 3) Identification of unmet needs. Please consult your Consumer Advisory Board and complete **ONE** survey to reflect the identified needs of your PLWAs of the group as a whole.

The deadline for returning the survey is Friday, April 9, 2004. 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 consumer and agency needs.

OPTIONAL:

Agency Name: _____

Contact Person for Consumer Advisory Board (CAB): _____

Phone #: _____ E-mail: _____

What percentage of your CAB (Consumer Advisory Board) do PLWAs 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)	

Custody Planning and Family Support	
Drop-in Center for HIV+ Prison Releasees (Riker's Island Transitional Services Project)	
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	
Oral Health (Dental Care)	
Outpatient Medical Care in Hospitals/Clinics	
Outstationed Medical Care Teams in Non-Medical Setting (i.e., SROs, CBOs, needle exchange sites, mobile vans)	
PWA Leadership Training Institute	
Transportation 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, April 9, 2004
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

Hi _____ this is _____ 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 _____. 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 April 9th deadline doesn't give you much time to do this. We have this quick turnaround because we need to receive your completed survey by April 9th. 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 9th? Thank you for your support of this important PWA initiative.