



Executive Summary

**2009 Consumer Focus Groups
to Inform the Planning of Ryan White Part A Services**

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A. Overview

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was enacted in 1990 to support state, local, municipal, and private organizations to implement programs for HIV/AIDS-related testing, care, treatment, and supportive services. Ryan White [administered by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), HIV/AIDS Bureau] is a federal program is intended to fill the gaps left by individual insurance coverage and other sources of funding for HIV-related health care. Ryan White Part A grants provide emergency assistance to the eligible metropolitan areas (EMAs) and transitional grant areas (TGAs) hit most heavily by the epidemic. Part A funding to New York City (NYC) provides a safety net for the over 100,000 New Yorkers currently living with HIV/AIDS.

With the 2006 reauthorization of Ryan White as the HIV/AIDS Treatment Modernization Act (HATMA), greater emphasis was placed on core medical services and comprehensive service planning. The New York City Department of Health and Mental Hygiene (NYC DOHMH, the designated administrative body for Part A services in NYC) and its partner in Ryan White Part A planning, the HIV Health and Human Services Planning Council of New York (Planning Council), have been charged with “determin[ing] the needs of populations living with HIV disease and the capacity of the service system to meet those needs, through focus groups, surveys, or other methods” (Ryan White Part A Planning Council Primer, 2008).

The focus groups described here were undertaken to provide the Planning Council and the NYC DOHMH with consumer input to help inform the planning of Ryan White Part A services. The focus group data collection instruments were designed to elicit consumers’ perspectives on the quality and importance of different types of Part A-fundable services and their fit with local needs, and specifically to address the Planning Council’s Priority Setting and Resource Allocation criteria related to “consumer priority,” “access to and/or maintenance in care,” and “specific gaps/emerging needs” (e.g., in certain affected populations or communities).

B. Methodology

In 2009, the NYC DOHMH used a mixed-methods but primarily qualitative approach to solicit consumer input on the relative importance of and satisfaction with different core and non-core (support) services fundable under Ryan White Part A. To carry out this evaluation activity, the NYC DOHMH selected as consultants two sociologists with several years each of public health and HIV research experience. In late March and early April 2009, the consultants conducted 12 two-hour focus groups, representing 125 HIV-related service consumers from 38 different agencies. The focus groups were conducted in all five boroughs and included both mixed groups and groups broken out to reflect particular affected populations (women, men, transgender persons, older adults, young adults, and those whose primary language is Spanish). All focus group discussions were audio recorded and transcribed verbatim.

Key themes addressed in the focus groups included: participants' assessment of Part A services as relevant to HIV primary care utilization and consumer needs; satisfaction with the quality of Part A services; geographic differences; special populations; other (non-HIV related) health concerns; and participation in service improvements and planning. A detailed coding system was developed to capture material related to the topic areas outlined in the semi-structured discussion guide and emerging themes based upon consumer perspectives. This system was documented in a comprehensive codebook including code labels and definitions, emerging categories (sub-codes) within codes, and sample quotations; the codebook was followed by those analyzing the focus group data to ensure consistent coding. ATLAS.ti 5.0, qualitative data analysis software, was used to organize the coding of the focus group data.

In addition to engaging in the focus group interview sessions, all participants completed a brief quantitative survey collecting demographic information and measures of satisfaction with and prioritization of different Ryan White fundable core and support services. The quantitative data from this pen-and-paper survey were entered and analyzed (using SPSS Version 16.0) by a third consultant, contracted to assist the NYC DOHMH on special projects in the HIV Care, Treatment & Housing Program's Research & Evaluation Unit.

C. Focus Group Sample

Participants were purposively (non-randomly) selected based on age, gender, primary language, and borough of residence, to reflect the diversity of the populations living with HIV/AIDS in NYC. Participants were recruited through the use of flyers, distributed to Part A-funded HIV service providers in NYC, advertising the focus groups in English and Spanish. Clients were notified that participation required current experience with Ryan White Part A services. Those who called in to NYC DOHMH to respond to the advertisement (or word of mouth from providers or other clients) were put through a basic screening that covered the agency or agencies from which they were receiving Part A services, language preference, location preference, availability, and demographic eligibility as well as willingness to participate in any of the population-specific groups. One hundred and twenty-five (125) consumers participated. Participants were served lunch or dinner and received a \$4 MetroCard for transportation and a \$30 MetroCard for their time. Demographic and other descriptive data on the sample are provided in Table 1.

Table 1: Focus Group Participant Demographics

Age	Range	19 – 68 years
	Mean	47 years
Race	African American	59%
	White/Caucasian	6%
	Asian	3%
	Native American/Alaskan Native	2%
	Multi-racial	3%
	Other	22%
	Missing/Uninterpretable Data	5%
Ethnicity	Non-Hispanic/Latino	66%
	Hispanic/Latino	33%
	Missing/Uninterpretable Data	1%
Sex at Birth	Male	55%
	Female	42%
	Intersex*	2%
	Missing/Uninterpretable	1%
Current Gender Identity	Male	48%
	Female	40%
	Transgender (M-F)	6%
	Transgender (F-M)	2%
	Transsexual (any)	2%
	Missing/Uninterpretable Data	2%

HIV/AIDS Status	HIV-Positive, no AIDS diagnosis	56%
	Current AIDS diagnosis	38%
	HIV-negative**	6%
CAB Membership at a Part A-funded Agency	Member	53%
	Non-member	45%
	Missing/Uninterpretable	2%

* Intersex is a term to describe people who are born with reproductive anatomy that does not fit most common definitions of male and female; formerly known as hermaphrodite.

**Recruitment efforts were targeted to consumers living with HIV. A small number of HIV-negative consumers of Ryan White Part A services were allowed to participate because these consumers offered perspectives on special population needs.

D. Assessment of Services Survey

For the brief individual survey administered before each focus group interview session began, each participant was asked how important or useful each Ryan White fundable service is for the average person living with HIV in New York to (1) access HIV primary care and (2) remain in HIV primary care. The questions grouped services into core and supportive services and distinguished importance for access from importance for remaining in care. After rating each service category on a three-point scale of importance for a given outcome (access to care or remaining in care), participants were asked to select the *three most important* service categories for achieving that outcome. While consumers were asked to speak for the average person living with HIV in New York, they were also given the option to indicate they had no opinion about a particular service category or had an opinion, but based solely on personal experience.¹ In the final section of the survey, participants were asked to indicate their overall level of satisfaction (on a three-point scale) with each core and supportive service category they had utilized in New York, and then to select up to three service categories with which they had experienced the highest overall satisfaction.² Please see Table 2 for results of the consumer Assessment of Services Survey.

¹ Data on perceived importance of services (for access to and maintenance in care) in Table 2 reflect all non-missing, interpretable responses, including those from participants who indicated that their opinion was based solely on personal experience.

² The denominators for the percentages reporting the highest satisfaction rating can differ substantially for each service category, because respondents were asked to report satisfaction levels only for those services they had used in New York. Thus, for each service category, the denominator (for those reporting the highest possible level of satisfaction) excludes missing data, uninterpretable data, and “not applicable” (didn’t use this service) responses on that service category. In a presentation given previously to the PSRA Committee, the simply missing (vs. “not applicable”) responses had not yet been excluded from the denominators, which is why percentages reporting the highest satisfaction levels differ in this final summary report (corrected version).

Table 2: Consumer Assessment of Ryan White Part A Core & Support Services*

Question Set	Percentage of respondents indicating they speak only from personal experience		Services most often rated at highest level (highest importance or highest satisfaction)		Top three services** (from forced-choice questions)	
	Core Services	Support Services	Core Services	Support Services	Core Services	Support Services
Access to HIV Primary Care	25.9%	20.7%	(1) Mental Health Services (82.6%) (2) Oral Health Care (82.5%) (3) Early Intervention Services (82.3%) (4) Outpatient Substance Abuse Services (80.0%) (5) ADAP (79.8%)	(1) Housing Services (88.4%) (2) Health Education/ Risk Reduction (75.7%) (3) Emergency Financial Assistance (75.0%) (4) Legal Services (73.5%) (5) Outreach Services (72.7%)	(1) Medical Nutrition Therapy (26.1%) (2) Mental Health Services (23.9%) (3) Early Intervention Services (22.1%) (4) ADAP (22.0%) (5) Outpatient/ Ambulatory Health Care (20.0%)	(1) Housing Services (47.1%) (2) Emergency Financial Assistance (23.6%) (3) Outreach Services (19.0%) (4) Legal Services (17.5%) (5) Health Education/Risk Reduction (15.9%)
Remaining in HIV Primary Care	21.7%	17.8%	(1) ADAP (89.5%) (2) Outpatient/ Ambulatory Health Care (82.5%) (3) Mental Health Services (80.9%) (4) AIDS Pharmaceutical Assistance (80.7%) (5) Oral Health Care (79.6%)	(1) Housing Services (87.1%) (2) Emergency Financial Assistance (74.8%) (3) Psychosocial Support Services (73.9%) (4) Legal Services (72.2%) (5) Health Education/Risk Reduction (71.4%)	(1) ADAP (28.9%) (2) Mental Health Services (25.2%) (3) Outpatient/ Ambulatory Health Care (22.8%) (4) Outpatient Substance Abuse Services (17.1%) (5) Health Insurance Premium and Cost Sharing Assistance (15.6%)	(1) Housing Services (41.7%) (2) Non-Medical Case Management (16.5%) (3) Emergency Financial Assistance (16.3%) (4) Psychosocial Support Services (13.4%) (5) Medical Transportation Services (12.7%)
Satisfaction with Services			(1) AIDS Pharmaceutical Assistance (70.9%) (2) Outpatient Ambulatory Health Care (69.9%) (3) ADAP (69.4%) (4) Medical Case Management (69.0%) (5) Early Intervention Services (68.2%)	(1) Emergency Financial Assistance (67.9%) (2) Treatment Adherence Counseling (67.5%) (3) Psychosocial Support Services; Rehabilitation Services (62.5%, tied for 3 rd) (4) Health Education/Risk Reduction; Legal Services (62.2%, tied for 4 th) (5) Linguistics Services (61.4%)	(1) Outpatient Ambulatory Health Care (32.3%) (2) AIDS Pharmaceutical Assistance (27.8%) (3) Health Insurance Premium and Cost Sharing Assistance (22.4%) (4) ADAP (20.8%) (5) Mental Health Services (16.0%)	(1) Housing Services (24.8%) (2) Food Bank/Home Delivered Meals (19.8%) (3) Emergency Financial Assistance (19.7%) (4) Treatment Adherence (18.6%) (5) Non-Medical Case Management (16.3%)

* Table 2 shows service categories that appeared in the five most frequently reported at the highest importance or satisfaction level.

** Percentages shown here are lower because each survey could count toward a *maximum* of three service categories on each of the forced-choice questions. The comparatively high percentages on the simple importance or satisfaction rating questions reflect respondents' freedom on those questions to give the highest rating to as many service categories as desired.

E. Highlights of Focus Group Discussions

1) Access to and Maintenance in HIV Primary Care

Three major domains of factors emerged as perceived influences on access to and maintenance in HIV-related primary care: Consumer-Centered Factors, Systemic Factors and Specific Services & Elements of Service Delivery.

a) *Consumer-Centered Factors*

i) “Becoming a Patient.” Participants discussed the process of “*becoming a patient.*”

- For some, becoming an HIV patient required acknowledging their diagnosis. The time required by this process could delay entry into care.
- The process of becoming a patient could involve learning and understanding HIV-related health issues; becoming aware of available services; and learning to navigate the system and self-advocate for services.
- After “*coming to terms*” with their diagnosis, many participants said they were able to “*take control*” of their health, including maintaining consistent HIV care.

ii) Addressing the “Whole Person.” Participants expressed wanting providers to acknowledge the “*whole person*” behind the client.

- Participants felt that health care and social service delivery were impaired by providers’ lack of understanding of consumers’ lives and identities.
- They stressed that care could be improved by greater attention to providing culturally competent care (taking into account and respecting the client’s age, gender identity, race/ethnicity, and sexual orientation) and communicating in a manner appropriate to a client’s level of understanding.
- Participants drew a connection between having the needs of the “*whole person*” addressed and being more engaged in care, having higher levels of satisfaction with services, and maintaining continuity of care.

b) *Systemic Factors*

i) Eligibility Criteria. Participants perceived eligibility for some services as being based on poor health, co-morbidity and/or risky behaviors (e.g. drug use), thus creating an incentive for poor health.

- Some participants described the frustration of services being discontinued once health indicators improved or employment increased to full-time.

ii) Information on Services. Participants described difficulties getting information on available services.

- Many reported turning to peers and support groups as alternative information sources.
- Some described case managers as information gatekeepers, who did not disclose all available services.

iii) Health Coverage. Instability in insurance coverage was described as creating a stressful environment and dissuading consumers from accessing or maintaining care, due to:

- concern that some services would not be covered by health plans;
- loss of insurance (e.g. changing employer, non-renewal of Medicaid);
- changes of medical plans or coverage within plans.

c) *Specific Services & Elements of Service Delivery*

- i) Housing Services. Housing was described as essential for accessing and maintaining HIV care. Regarding currently available housing services, participants discussed:
 - difficulty meeting the eligibility requirements for housing;
 - uncertainty about how to access housing services;
 - poor quality of housing available (especially SROs).
- ii) Case Management. Participants varied in their feelings towards case management services. Some praised case managers for adequately addressing consumer needs. Others were critical about whether/how much case managers assessed and met their needs. The following are services some participants reporting wanting but not receiving from their case managers:
 - linkages with other services;
 - assistance with treatment adherence;
 - help with navigating health insurance plans or Ryan White services;
 - information on services available.
- iii) Substance Abuse Services. For many participants, drug use had at some point emerged as an impediment to their health.
 - Substance abuse services were described as facilitating consumers' ability to access and remain in HIV-related primary care.
 - These services were perceived as both useful and readily available.
- iv) ADAP. Many participants described ADAP as essential for maintenance in care.
 - ADAP was described as easier and faster to obtain than other services (even in emergency situations) and as facilitating continual access to HIV medication.
 - Participants recalled times when they had relied on ADAP, due to the absence or loss of other insurance coverage.
- v) Other Factors Facilitating Care. Consumers described these service delivery factors as having a positive effect in their care:
 - quick turnaround for receipt of services;
 - pharmacists helping to schedule prescription refills;
 - transportation to and from appointments;
 - providers being responsive to consumers' needs;
 - a one-stop shopping model of care (though some consumers highlighted the need for non-HIV-specific multi-service agencies, so that clients would not feel publicly labeled as HIV-positive by virtue of their appearance at the agency).

2. Geography

- a) *Participants perceived agencies in Manhattan as typically providing the highest-quality services, while most other boroughs provided acceptable care.*
 - i) Participants weighed the decision to obtain care close to home or in other neighborhoods where they perceived services to be better and more readily available, or where they expected more privacy.
 - ii) Participants described varying enforcement of eligibility criteria by service location.
- b) *Staten Island focus group members overwhelmingly reported unsatisfactory care. Care was perceived as substandard for the following reasons:*
 - i) lower provider competency;
 - ii) stigma/discrimination from individual providers and agencies;
 - iii) no designated AIDS center;
 - iv) limited time with medical providers;
 - v) few prevention services.

3. Special Populations

- a) *Transgender Persons*
 - i) Transgender group participants described barriers to care due to stigma, provider biases, and not being able to change documents to reflect preferred gender identity.
 - ii) These participants also expressed concern regarding interactions between hormone therapy and HIV medications (which may interfere with ARV adherence).
- b) *Adults Over Age 50*

Participants in the over-50 focus group expressed concerns about:

 - i) ignorance and misperceptions about HIV among older individuals;
 - ii) provider discomfort with discussing sexuality with older clients;
 - iii) co-morbidity of HIV with other illnesses;
 - iv) the long-term impact of taking HIV-related medications;
 - v) service restrictions on dental and vision care;
 - vi) limited availability of home health care.

4. Community Advisory Boards (CABs)

- a) *Non-Members of Community Advisory Boards*

Participants who were not members of Part A-funded agency CABs expressed:

 - i) being unaware of the existence of CABs; or
 - ii) their agencies not having CABs due to lack of consumer participation.
- b) *Members of Community Advisory Boards*

Perceived benefits of participating in Part A-funded agency CABs included:

 - i) having a place to voice concerns;
 - ii) finding out new information that may impact the lives of PLWHA;
 - iii) working to improve services;
 - iv) obtaining information to disseminate to other consumers.

Participants also voiced concerns about Part A-funded agency CABs, such as:

 - i) seeing their feedback censored from reports to protect agency reputations;
 - ii) having their concerns ignored or minimized;
 - iii) finding that their priorities were not taken into consideration in decision making;

- iv) experiencing the frustration of conflict in meetings (e.g., meetings focusing on minor vs. critical matters or leading to confrontation rather than cooperation);
- v) witnessing a lack of incentives for participants to take the group seriously;
- vi) seeing a lack of participation from providers;
- vii) seeing a lack of youth participation in CABs.

F. Summary

In short, accounts offered in the 12 NYC 2009 consumer focus groups described:

- ✓ different steps in “*becoming an HIV patient*;”
- ✓ the value of addressing the client as a “*whole person*;”
- ✓ a critical view of the eligibility criteria for certain services;
- ✓ limited information on available services;
- ✓ concerns about health insurance;
- ✓ mixed experiences with case management;
- ✓ the importance of housing, ADAP and substance abuse services;³
- ✓ the role of prompt service delivery, logistical supports and one-stop shopping in increasing access to care;
- ✓ the perceived inconsistency of services by borough;
- ✓ limited knowledge of and participation in CABs; and
- ✓ specific barriers experienced by populations addressed in the composition of these groups.

G. Recommendations

Suggestions from participants in the focus groups included:

- a) Provide guidance for the newly diagnosed.
 - i) Case management services could facilitate the process of acknowledging HIV status, as a first step toward accessing care.
 - ii) A guide could be developed to help consumers “*come to terms, navigate, and advocate*” for services.
- b) Disseminate information regarding available HIV services.
 - i) This could be accomplished by using case managers and service providers as hubs for referrals and information on available services.
 - ii) The aforementioned guide could help by including: explanations of common lab tests, definitions of HIV-related terms and a provider directory with detail on services.
- c) Clarify eligibility criteria for services.
 - i) Correct any misperceptions or actual provider practices that may function as disincentives for positive health behaviors.
- d) Aid consumers in navigating health coverage plans.
- e) Expand access to good-quality housing.
- f) Improve linkages with other services (e.g., thorough assessment of consumer needs, one case manager referring to multiple services, doctor’s office as hub for services).

³ ADAP and housing also figured heavily in the quantitative survey results, as the services most often selected among respondents’ top three most important core and supportive services for remaining in primary care, and (in the case of housing) as the one most often selected among respondents’ top three supportive services for accessing primary care. The quantitative results differed, however, in their emphasis on mental health services, as the category second most often selected among the top three most important core services for access to care and for remaining in care.

- g) Provide a one-stop shopping model of care.
- i) Caveat: There should still be the option to obtain HIV services at a multi-service agency that is not HIV-specific, so as not to be instantly identifiable as a PLWHA.
- h) Address needs in underserved areas like Staten Island.
- i) Provide culturally competent services tailored to the needs of special populations.
- j) Increase CAB awareness among consumers and strengthen the role of CABs in improving services.

H. Acknowledgments

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