


Using Focus Groups to Elicit Consumer Priorities

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Ryan White HIV/AIDS Program Grantee Meeting

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 Dr. Irvine – project design & reporting; Dr. Santella – implementation & reporting; Dr. Fryer – facilitation, data analysis, reporting




Purpose

- To ensure that Ryan White Part A service priority recommendations are in line with consumer needs
- To gather data on the full range of service types (as categorized by HRSA) fundable under Ryan White Part A
- To explicitly gather opinion data, from individuals generally familiar with the RW services landscape and client populations




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Why Focus Groups?


- Relatively easy to assemble, inexpensive and flexible
- Appropriate when the goal is to learn from the perspectives of participants
- Good for groups with different literacy levels
- Open recording allows participants to confirm their contributions
- Provide rich data through direct interaction between moderator and participants
- Spontaneous, participants not required to answer every question; able to build on one another's responses



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Design of Focus Groups


- Review of 2006 Consumer Advisory Board Survey
 - Design
 - Instrument
 - Results
 - Limitations
- 2008 Focus Group Discussion Guide
 - Development by NYC DOHMH
 - Review by Planning Council
 - Consumer Committee and PWA Advisory Group
 - DOHMH Institutional Review Board (IRB) Review
 - Deemed out of IRB purview



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Design of Focus Groups (cont'd)


- Planning (the who)
 - Facilitator – consultant with experience in qualitative, HIV program, and community-based participatory research
 - Participants – largely consumer advisors to or committee members of the local Planning Council



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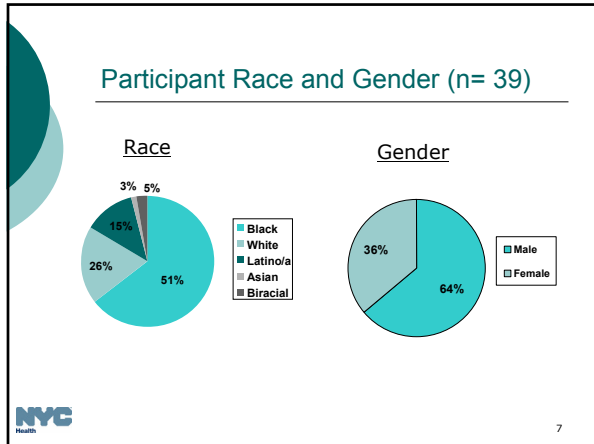
Focus Group Logistics

- Dates: April 10, 11, 24, 25
- Location: Cicitelli Associates (MN)
- Participant Residences: All 5 boros
- Quantity: 5 (N=39)
 - Adults only (4)
 - Mixed men and women (2)
 - Women only (1)
 - Men only (1)*
 - Youth only (1)
- Incentives: \$30 Metrocard and Meal



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* One woman attended "Men's Only" group accidentally and was allowed to participate




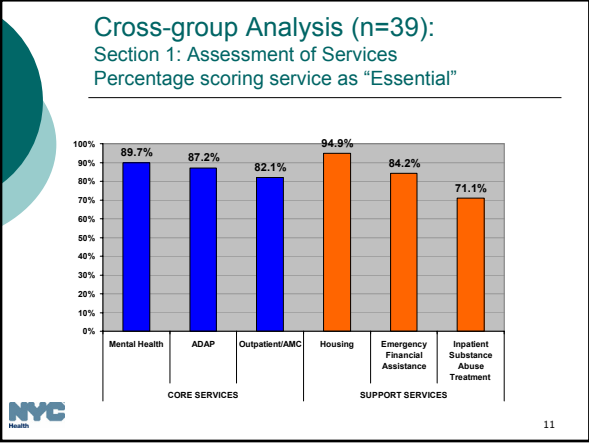
- ### Data Analysis
- Data Sources
 - Audio tapes
 - Transcripts
 - Note-taker observations
 - Analysis process
 - Data review and synthesis
 - Qualitative data coding by question, and searching for specific terms, with attention to areas of agreement and disagreement (majority & outliers)
 - Quantitative data compilation and frequencies
 - Interpreting data – feedback from others on the project team and present during the groups
- NYC Health 8

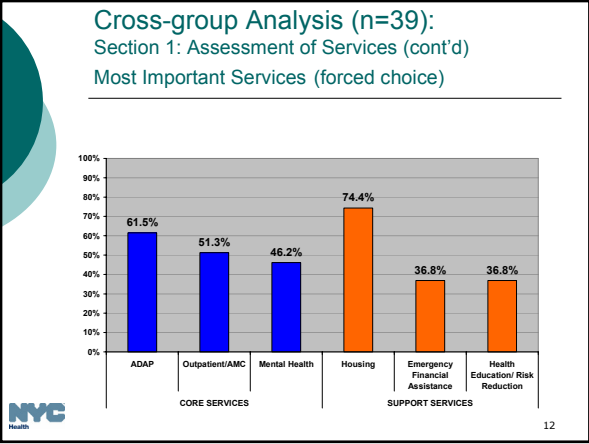
- ### Results
- The following slides reflect data from the four sections of the focus group guide:
 - Assessment of HRSA core & support services
 - Identification of gaps in HRSA core & support services
 - Overall satisfaction with HRSA core & support services
 - Geography & special populations
- NYC Health 9

Section 1: Assessment of Services

- Participant Tasks:
 - Prioritize both core and support services by assigning a number (1-3) to each core and support service
 - Select the *three most important* core and support services
- Individual Questions Asked:
 - How important/useful is this service for PLWHA to access and remain primary care?
 - Which services have the most lasting effect on HIV-related care and health outcomes?








Cross-group Analysis (n=39):
Section 1: Assessment of Services (cont'd)

Services with the most lasting effect on HIV-related health outcomes

Core Services	Support Services
Medical Case Management	Health Education/Risk Reduction
Mental Health	Housing
Outpatient/Ambulatory Medical Care	Linguistic Services
	Medical Transportation
	Outreach Services
	Psychological Support Services
	Rehabilitation Services
	Treatment Adherence Counseling



Key Quotes:
Section 1: Assessment of Services

Please tell me how important or useful the service category is for PLWHA to access primary care.

Another important intervention with ADAP has been over the years for many of us who have worked our whole lives before we got sick...we can't maintain Medicaid, and ADAP worked it out where they pay the spend down every month that we maintain Medicaid. And even today after everything that's been changed with Medicare...they continue to help pay the spend down.


Adult Male, Men's FG

Because housing is the foundation that holds everything together. If you don't have proper housing...if you're homeless and you can't cook for yourself, then you can't maintain your health. You might have to keep your meds in the refrigerator. So I think it's...very essential. It's like the nucleus of everything.

Adult Female, Women's FG

Housing is healthcare.


Adult Male, Men's FG



Section 2: Gaps in Services

o Individual Question Asked:

- How well do services meet the needs of PLWHA? Why?
- Which services do you think are currently under-delivered in NYC (which ones are least available or accessible), relative to client need for those services? Why?



Cross-group Analysis (n=39):
Section 2: Identification of Gaps in Services

Services currently under-delivered in NYC
 (least available or accessible)

Core Services	Support Services
Health Insurance Premium & Cost Sharing Assistance	Child Care Services
Medical Nutrition	Health Education/Risk Reduction
Mental Health	Linguistic Services
Oral Health	

NYC Health

Key Quotes:
Section 2: Identification of Gaps in Services

Which services do you think are currently under-delivered (least available or accessible) in New York City?

A lot of agencies have cut their child care services... but they have to realize that when that mother comes, maybe she has to have somebody watch her kid, because it's hard to interview a parent when the child is running up and down or the child cannot be sitting there for a period of time when...you have to do an assessment or a service find, et cetera.

Adult Female, FG2

...there was only one individual who ran a dental clinic for HIV positive individuals at a specific hospital I was attending. And once she retired, there was no specific dental and HIV clinic...it's really important to - and I guess there is no funding for it, to have specific - and this woman did it, I think, out of her own pocket, started a clinic specifically for HIV positive individuals.

Adult Female, Women's FG

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Section 3: Satisfaction with Services

o Individual Questions Asked:


- Which of the listed service categories provide the greatest client satisfaction rates in care? Why?
- Which service categories provide the lowest satisfaction rates in care? Why? What should change?

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Cross-group Analysis (n=39):
Section 3: Overall Satisfaction with Services

Services providing the greatest client satisfaction rates

Core Services	Support Services
ADAP	Non-Medical Case Management
Outpatient/Ambulatory Medical Care	Health Education/Risk Reduction (youth group)
Medical Nutrition (women's group)	Housing (youth group)




Key Quotes:
Section 3: Overall Satisfaction with Services

Which of the listed service categories provide the greatest client satisfaction rates in care? Why?

Here in New York there are two services that I think the City is delivering well. It's the outpatient and the ADAP. Everything else goes like she says, and it goes to funding, it goes to the size of the population here, it needs to be improved. And the reason I say...New York City is providing outpatient...that's because we have great doctors, we have specialists here, and we have a great ADAP program. And matter of fact, the State ADAP contribution is larger than Ryan White put together. This is why people flock to New York. So everything else here could use improvement, but those two, and again, you know, if you look at them, we've got the best hospitals here and then if you go and you hook up with a primary care attendant and he provides, puts you on a regimen and you can't afford it, there's means in this state to do it.


Adult Male, FG2



Cross-group Analysis (n=39):
Section 3: Overall Satisfaction with Services (cont'd)

Services providing the lowest client satisfaction rates

Support Services
Housing
Medical Transportation
Health Education/Risk Reduction
Food Bank/Home-delivered Meals
Linguistic Services
Child Care Services (women's group)



Key Quotes:
 Section 3: Overall Satisfaction with Services

Which service categories do you think provide the lowest satisfaction rates? What should change?

...I just want to say inadequate housing. While there's money being poured into housing, it's inadequate. And if we talk about places like HASA, that sends people to these single room occupancies, oh, my God, oh, my God, I just have to say. You've got to see these places...
 Adult Female, Women's FG

I am disabled and in a motorized scooter now for five years, and I will tell you first hand the ambulance service from the hospital and stress-a-ride [Access-a-Ride] are the most disgusting, gross unacceptable transportation. People are treated like sub-human. There's no respect. They yell at people. They're disrespectful. It's really disgusting.
 Adult Male, FG 2

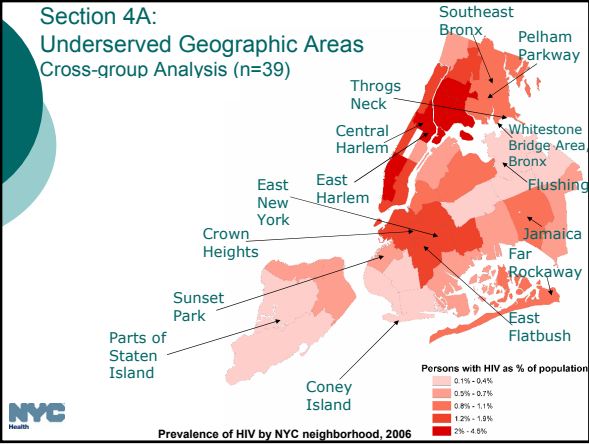
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Section 4: Geography & Populations

o Individual Questions Asked:

- Which specific PLWHA populations or geographic areas of NYC are currently under-represented with the available/funded services? Why?
- Which HIV-related services are those populations or geographic areas not receiving sufficient to meet need? Why?

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Cross-group Analysis (n=39):
 Section 4A (cont'd) : Services Under-delivered in Geographic Areas Highlighted

Core Services	Support Services
Early Intervention Services	Health Education/Risk Reduction
	Linguistic Services
	Outreach Services

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Cross-group Analysis (n=39):
 Section 4B: Underserved Populations

All populations mentioned:

- Undocumented or illegal immigrants
- Transgender population
- "Throw Away" youth
- Persons 55-70 years
- Young Mothers
- Women who have sex with women

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Health

Key Quotes:
 Section 4: Geography and Special Populations –


Which specific PLWHA populations or geographic areas of NYC do you think are currently under-represented with available/funded services?

...in the HIV community..... I love my gay boys, but it's just they're getting too much..... they need to share it with us [WSW].
 Young Woman, Young Adult FG

I would say the South Bronx. For the following reasons, you know, it has a high concentration of low income individuals. Number two, it's a high incidence of HIV and substance abuse. They have limited access, you know, to health education as it relates to HIV and harm reduction. And the last reason is they have poor access to quality care. To follow up what [he] was saying, I'm from Hunts Point, I had to cross the bridge, I had to come to East Harlem to get quality care.
 Adult Male, FG2


Coney Island. For the past couple of years, they've been under-represented, especially with the CARE networks, they do not cover Coney Island.
 Adult Male, FG2

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Applications of Focus Group Results

- NYCDOHMH reviewed draft report with Consumer Committee and AG (including participants), then with all PC members
- Priority-Setting/Resource Allocation Committee used findings to supplement other consumer data in priority setting process
- Planning Council to incorporate in development of the 2009-2012 Comprehensive Strategic Plan




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Conclusions

- It is important that consumers' voices be heard and their needs be incorporated into the Ryan White planning process
- Some of the most valued services were also those identified as lacking in quality or availability
- Providers, planners, and policy makers should be cognizant of perceived disadvantages for consumers in the paradigm shift in HIV care
 - Participants felt their needs had become second priority
- Integration of services is key to access and comprehensive care
 - "One stop shopping" should be widely available ²⁹





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Conclusions (cont'd, by section)


- Assessment of Services
 - Participants consistently selected the following services as most important, in the ranking and forced-choice exercises:
 - Mental Health, ADAP, and Outpatient/Ambulatory Care (Core)
 - Housing services, Emergency Financial Assistance (Support)
- Identification of Gaps in Service
 - Participants identified gaps in oral health care delivery, and noted few dentists specialize in working with HIV-positive populations
- Overall Satisfaction with Services
 - Consumers are most satisfied with ADAP and OMC
 - Housing is indicated as a service with poor consumer satisfaction
 - Medical Transportation is also consistently reported as a service with poor consumer satisfaction
- Geography and Special Populations
 - Some NYC geographic areas with high prevalence of HIV are perceived to be lacking in HIV/AIDS-related services
 - Stigmatized populations (transgender, undocumented/illegal, etc.) are in need of services






Limitations

- Findings may not represent the views of larger segments of the PLWHA population in NYC
- Focus group data have the potential to be skewed by particular group dynamics – though skilled facilitation can manage this
- Analysis of findings requires comparing narratives and expressions that are not easily categorized (subjective element of coding)
- Time constraints on the Planning Council's priority-setting process limited the number of groups that could be convened, the options for sampling, and the procedures for analysis of rich textual data





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Strengths and Recommendations


- Focus groups can be used efficiently to gather the opinions of HIV service consumers with a range of perspectives
- Focus group results can be rapidly and usefully applied for priority-setting, as part of the community planning process
- Focus groups can/should be supplemented with surveys and other data sources
- Future delivery and administration of services must continue to take into account consumer perspectives, as voiced by consumers themselves





Beyond the 2008 Focus Groups

- 2009 plans: more focus groups!
 - Spanish translation
 - Non-Planning Council-aligned participants
 - Additional topics/domains
- Re-evaluating Consumer Advisory Board Survey as additional vehicle for consumer input on priorities
- Using Return-to-Care Survey data with sample of 50 clients formerly out of care





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