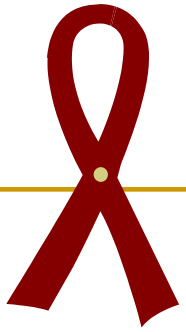

Citizens Advice Bureau (CAB)

Positive Living Program

Needs and Resources Study

By David Rubel and Beth Rosenthal
October 2006

Citizens Advice Bureau (CAB) Positive Living Program

Needs and Resources Study

Main Findings

1. ***Mismatch between location of services and cases****:* There is a significant Bronx geographic mismatch between the distribution of government funded services and PLWHA's cases. Most Ryan White Title One funded providers are concentrated in the South Bronx while most PLWHA's live outside the South Bronx. The geographic center for the Bronx would be (highest concentration PLWHA within a half mile radius) would be around 175th Street and Third Avenue. This mismatch exists for both preventive and direct services (case management, medical, harm reduction, nutrition, support groups).

2. ***A similar mismatch can be found with the geographic distribution of existing Harm Reduction programs in the Bronx.*** The IDU population is spread out over much of the Bronx. However, according to the New York City Ryan White Title I Services Comprehensive AIDS Resource Emergency (CARE) Service Directory (August 2002-July 2005 update), Harm Reduction programs are concentrated in the very southern part of the Bronx, in the Mott Haven, Morrisania and Highbridge neighborhoods. The Service Directory does not include Harm Reduction programs in the Fordham Bronx Park and Pelham Throgs Neck areas, although 32% of the total IDU risk factor HIV/AIDS population, (or 1,838 people) live in these two areas.

3. ***Focus Group Findings:*** the four focus groups offer a rich and detailed source of unfiltered consumer input about programming issues for both existing programs and new ones. There were issues that had similar responses in all four focus groups and there were issues and suggestions that were found only in the individual focus group. The focus groups provide good working information on a range of service delivery issues identified by CAB including: anonymity, incentives, co-location of services, evening and weekend hours, staff-client relations, publicity, is 1130 Grand Concourse a PLWHA consumer friendly site.

4. ***Harm Reduction Best Practices:*** Section Four of the Report is devoted to Harm Reduction. Nine separate findings regarding Harm Reduction are fully described in Section Four.

5. ***Settlement House niche:*** The CAB settlement house multi-service network of programs offers a unique model of service delivery that other Bronx based PLWHA's organizations do not provide. Almost all other Bronx PLWHA's organizations are single issue driven; they only operate programs for PLWHA. None of the other Bronx Settlement houses run Ryan White funded programs. CAB can build on its in house expertise and resources for enhancing existing or developing new programs for the following three groups of HIV clients: 50 years and older, families and people who want to transition to employment.

6. ***HIV 50 and older programming:*** Due to the success of the new drug treatments, PLWHA's are living longer and dealing with various issues of the aging process. In the Bronx, 31% of the current male HIV/AIDS group and 21% of the current female population are 50 years or older. 41% of all new male HIV cases occurred in the age group 40 or older. 34% of all new female HIV cases occurred in the age group 40 or older. To meet this rapidly growing trend, HIV 50 and older programming must be developed in the Bronx. According to our research, there aren't any weekly programs specifically set up for the HIV 50 and older group in the Bronx. There are programs that are being set up or currently operating in other boroughs and in cities across the country. Focus group participants identified various types of help that could be developed into a weekly program by CAB.

7. ***Transition to work programming:*** At least 30% of the focus group respondents showed serious interest in trying to get part or full time employment. According to our research, there aren't any *transition to work* programs operating in the Bronx specifically designed for the PLWHA's population. In Manhattan, the transition to work programs are oriented to professionals living with HIV or AIDS. However, Housing Works does operate a program for low skill and homeless people with AIDS (to work in their Thrift and Book stores). Harlem United for AIDS Vocational Education Program operates a transition to work program in Harlem (and recruits in the Bronx).

8. ***Reduce the Stigma of AIDS in the Bronx:*** Focus Group participants strongly voiced their concern that the stigma of having AIDS must be reduced in the Bronx. Some said that this was the most difficult part about being HIV positive. African Americans appear to feel the

most isolated. Family members do not understand how AIDS is transmitted. Stigma and ignorance about how AIDS is transmitted could be a big factor in low rates of testing.

9. ***No typical client:*** The Bronx PLWHA population does not have a typical client or even two typical clients. There are large groupings for five distinct populations (IDU, MSM, African Americans, Hispanics, age groups needing prevention and age groups needing treatment). Different approaches are needed to meet the various main groups that comprise Bronx PLWHA's population. This finding is especially relevant to prevention activities. While some groups are showing an increase in new cases (youth, women), prevention activities should still be targeted to all vulnerable age, ethnic and gender groups.

10. ***CAB-URS Data:*** When the Bronx wide PLWHA data are compared with CAB-URS data, the CAB-URS data shows that significant numbers of clients come from outlying Bronx neighborhoods.

11. ***Targeting the Bronx African American community:*** the CAB Bronx demographic report, as well as numerous citywide and national studies, have documented the trend in the growing numbers of African American new cases of HIV. So far, there have only been a few collaborations between Bronx African American churches and Ryan White funded providers- there is much more that can and needs to be done here. This is an area of intervention where CAB would be welcomed and would fit in with all of the Positive Living programs.

12. ***Unknown cases:*** Unknown cases make % of all risk groups. Informal questioning shows that most "Unknown" cases are men who have sex with men. Focus group with MSM, respondents said that unknown was MSM.

13. ***Testing is a big problem in the Bronx:*** An estimated 5,000 people are HIV positive and haven't been tested. New and creative strategies must be tried in the Bronx. Focus group participants offered excellent suggestions on rapid testing strategies.

Research methodology: CAB and the consultants met twice to discuss the reasons why the CAB had decided to conduct a needs and resources study of its Positive Living program. CAB furnished the consultants with background material on the Positive Living program including program reports, past studies and grant application narrative descriptions. The consultants identified four areas of information gathering and research:

1) Documentation and analysis of New York City Department of Health AIDS surveillance Data for both cumulative total and current trends (2001-2004)

2) interviews with CAB Positive Living staff and Bronx, Citywide AIDS programs resource people

3) focus groups with the following four population groups: HIV 50 and older, Men who have sex with men, drug users and women.

4) intensive review and discussion of international, national and regional Harm Reduction best practices, training providers and model curricula.

At each step of the investigative process, CAB staff worked closely with the consultants on identifying questions and refining the scope of the inquiry.

How the report should be used: the report data collection, analysis and findings should influence the thinking of the CAB Positive Living Program. It was designed from the inception to have useful and meaningful recommendations that can be implemented today. Another equally important use of the report is with long term planning. It can be a strong gauge on how the PL program has changed. With each passing year, the report will offer a written scorecard and helpful reminder of changes that have been made or can still be made.

Study Sections:

1. **Main Findings**

2. **Bronx Borough Wide/Neighborhood Documentation and Analysis of Pertinent HIV/AIDS Data Indicators (full version)** (let me know if you rather have the abridged version here)

3. **Discussion and Analysis of Report Findings (based on the information gathered from the summary of the demographic and cases data, staff/community interviews and focus groups)**

4. **Harm Reduction, Analysis, Best Practices and Recommendations**

5. **Action Strategy Recommendations**

Appendices:

1. **Interview Questionnaires**

2. **Full Copy of Focus Group Questions and Responses:**

- Men who have sex with men
- 50 years of older
- Drug users
- Women

3. **Harm Reduction Best Practices**

- Training resources and curriculum
- Directory of citywide and regional resources

Section 2. Bronx Borough Wide/Neighborhood Documentation and Analysis of Pertinent HIV/AIDS Data Indicators

By David Rubel

Definitions. PLWHA data can be broken up into two overall groups:

- **Current**: is the ***total*** number of PLWHA based on the 20 year cumulative number. Within the Current group are two sub groups: HIV and AIDS. This number does not include deaths.
- **Recent:** 2001-2004. Beginning in 2001, Dept. of Health began keeping more detailed data on the HIV/AIDS population. Within the recent group are two subgroups: people who tested positive for HIV for the first time; and concurrent diagnoses meaning people who tested for both HIV and AIDS for the first time.

2-A. Bronx PLWHA Cases by Neighborhood and Risk Factor

Current total of Bronx PLWHA by neighborhood and risk factor (as of 12/31/2004)

Bronx Neighborhood Area	MSM	Injection Drug History	Heterosexual	Perinatal	Other	Unknown	Total	%
Kingsbridge Riverdale	122	116	82	14	0	138	472	2
North East Bronx	195	293	327	53	6	527	1401	7
Hunts Point Mott Haven	292	918	555	113	21	849	2748	14
Pelham Throgs Neck	429	866	668	126	20	952	3061	15
Fordham Bronx Park	552	972	776	115	13	1220	3648	18
Crotona Tremont	444	1308	822	157	26	1346	4103	20
Highbridge Morrisania	524	1270	974	161	21	1442	4392	22
Total	2558	5743	4204	739	107	6474	19827	

source: New York City Dept. of Health and Mental Hygiene Surveillance Statistics 2004

1) overall borough wide geographic distribution: There are significant numbers of PLWHA in five out of seven Bronx neighborhoods. What is surprising is that Pelham Throgs Neck, though a much

larger area, has a slightly larger PLWHA than Mott Haven. The chart shows that the south central Bronx area has the highest concentration of the PLWHA (up to Fordham Road). If a CAB wanted to locate an office with the highest concentration PLWHA within a half mile radius, the address would be around 175 St and Third Avenue (not necessarily that intersection). The very south Bronx Mott Haven neighborhood 336 Grand Concourse site is a far distance for 80% of the Bronx HIV/AIDS population. This distribution is true for the main risk groups. According to the New York City Department of Health and Mental Hygiene Ryan White service delivery map, most providers are concentrated in the southern most part of the Bronx (see attached map).

2) **IDU is the largest risk factor**: in the five neighborhoods with a large PLWHA population, IDU risk factor is the most identified. Heterosexual transmission is the second in all five. (The MSM focus group voted almost unanimously that the unknown factor is mostly MSM).

3) **Little difference between neighborhoods:** All five neighborhoods with a large PLWHA population show a comparable pattern for risk transmission. In terms of risk transmission, it is better to think of the South and Central Bronx as one large area instead of as five separate neighborhoods.

2-A-2. Recent Years 2001 to 2004 New Cases of HIV/AIDS by Risk Factors

Bronx Neighborhood Area	MSM	Injection Drug History	Heterosexual	Perinatal	Other	Unknown	Total	%
Kingsbridge Riverdale	14	7	13	0	0	30	64	1.5
North East Bronx	43	23	82	0	0	168	316	7.5
Pelham Throgs Neck	134	74	126	0	0	267	601	14.4
Hunts Point Mott Haven	86	134	134	0	0	258	612	14.6
Fordham Bronx Park	128	81	181	0	0	370	760	18.2
Crotona Tremont	119	149	181	0	0	404	853	20.4
Highbridge Morrisania	131	143	222	0	0	468	964	23.1
Total	655	611	584			1965	4170	99.7

source: New York City Dept. of Health and Mental Hygiene Surveillance Statistics 2004

2-A-3. Comparison of Current and Recent Years 2001-2004 by Neighborhood for Total PLWHA Population

Bronx Neighborhood Area	Percent Breakdown Current	Percent Breakdown 2001-2004	Significant Change
Kingsbridge Riverdale	2	1.5	*No*
North East Bronx	7	7.5	*No*
Hunts Point Mott Haven	14	14.6	*No*
Pelham Throgs Neck	15	14.4	*No*
Fordham Bronx Park	18	18.2	*No*
Crotona Tremont	20	20.4	*No*
Highbridge Morrisania	22	23.1	*No*
Total	98	99.7	

4) analysis: The trend in new cases chart shows that there has been no significant change in the geographic distribution of cases by neighborhood within the past four years. **Because the *unknown* factor is such a large number, this factor warrants further investigation. Until the *unknown* is further broken down, the risk factors indicator is not very meaningful.** (The MSM focus group voted almost unanimously that the unknown factor is mostly MSM).

2-A-4. Borough wide analysis of trend in risk factors.

	MSM	Injection Drug History	Heterosexual	Perinatal	Other	Unknown
2001-2004 Bronx	15%	14%	22%	-	-	46%
Current Bronx	13%	29%	21%	3.75	.5%	32.6%

The risk factors have seen little change except for *IDH* and *unknown*. The IDU proportion for the Bronx has dropped by more than half. Despite this important drop in IDU, it is still by far the largest group within the PLWHA population.

Citywide perspective: Are there significant differences in transmission risk factor by borough and other borough differences (is there a Bronx story?). Citywide, the most significant increase in risk factor has been with MSM. "The percentage of all new HIV diagnoses that were among MSM increased from about a quarter to a third between 2001 and 2004, and the proportion of MSM among all males increased from 42% to 52%." (NYC Commission Report 2005).

2-A-5. Comparison of NYC with Bronx Current HIV/AIDS Cases

	MSM	Injection Drug History	Heterosexual	Perinatal	Other	Unknown
Percent of Bronx	13%	29%	21%	3.75	.5%	32.6%
Percent of New York City	28%	23.4%	18.5%	2.6%	.6%	27.1%

When the Bronx is compared with citywide data, the MSM is significantly different. **As is the case with the other risk factor comparisons, until "unknown" is further broken down, this information is incomplete.**

2-B. Bronx HIV/AIDS Cases by Age and Gender.

2-B-1 Bronx PLWHA Cases by Gender

	Cumulative	%		2001-2004	%
Males	12,272	59.5		2556	58.2
Females	8,355	40.5		1834	41.7

Overall, there is no evidence of a significant change in new PLWHA cases by gender. However, as the data will show below, there has been a significant change in age groups for both males and females.

2-B-2 Bronx PLWHA by Gender and Age

Age Group	PLWHA 12/31/2004 Current		New Concurrent Cases 2001-2004		New HIV (without AIDS) Cases 2001-2004	
	Male	Female	Male	Female	Male	Female
0-12	171	186			27	21
13-19	210	209			58	65
20-29	723	702	60	58	410	321
30-39	2,529	2223	210	126	617	508
40-49	4,857	3253	239	105	510	385
50-59	2,904	1374	103	59	198	127
60+	878	408	50	8	65	22

2-B-3. Bronx PLWHA by Gender and Age *Percentage Breakdown*

New HIV/AIDS Cases 2001-2004						Current PLWHA			
	Males	**%**	**Females**	**%**		**Male**	**%**	**Female**	**%**
0-12	27	1	21	1.1		171	1.4	186	2.2
13-19	58	2	65	3.6		210	1.7	209	2.5
20-29	470	18	379	21		723	6	702	8.4
30-39	827	32	634	35		2,529	20	2223	26.6
40-49	749	29	490	27		4,857	39	3253	39
50-59	301	12	186	10		2,904	23.6	1374	16
60+	115	4.5	30	1.6		878	7	408	5
Total	2547		1805			12272		8355	

2-B-4 Total PLWHA Cases, Risk Transmission by Gender as 12/31/2004

	MSM		IDU		Heterosexual		Unknown	
	#	%			#	%	#	%
Males	2646	100	4128	69	1543	35	3537	52
Females			1842	31	2788	65	3280	48
total			5970		4331		6817	

Bronx wide analysis:

1) Bronx has the highest proportion of young females with HIV/AIDS (of the five boroughs).

Among young adults, ages 13 to 29, males and females are now equal for total number of PLWHA's. For the period of 2001-2004, in the age group of 13 to 30 years, the breakdown of males to females was Female: 45% to male: 55%. At what age did a person become HIV infected also needs to considered. Maybe half of the people in the 30-39 age group became infected prior to turning 30. *Here the Bronx is following citywide pattern regarding an increase in young women becoming HIV Positive.*

2) Within *both* young male and young female populations, *there has been a very significant increase in HIV cases*. For the age group13 to 29 years**:**

Females: 2001-2004 group was 24.6% vs. 11% for the current group.
Males: 2001-2004 group was 20% vs. 7.6% for the current group.

For young PLWHA group, ages 13 to 29 years, outreach efforts should be directed with equal resources to both males and females.

3) For both males and females, largest number of new cases is in the 30 to 39 years group. At least half this number actually contracted HIV when they were still in their 20's.

4) HIV prevention must still be targeted to older age groups as well as younger ones. 31% of the current male HIV/AIDS group are 50 or older. 21% of all current female HIV/AIDS groups are 50 or older. While there has been a significant increase in young people getting HIV/AIDS, older people must still be targeted for prevention. 41% of all new HIV cases in males occurred in the age group 40 or older. 34% of all new HIV cases in females occurred in the age group 40 or older.

5) Despite increase in young people with HIV/AIDS, disease management services must remain targeted to all age groups 21 and older; especially the 40 and older group. Most people (70% for males and 60% for females) who need HIV/AIDS services are over 40 years of age. The typical HIV/AIDS client who needs services will be over 40.

6) Growth in elderly population: Over the next 10 years, the HIV/AIDS 60 years and over population should increase significantly. This group will need an intensive network of support services. People will be managing both AIDS and other mainstream diseases such as heart and diabetes.

7) risk factor and gender: there are very strong differences with risk factors and gender. Men are much more likely to be IDU than women (69% to 31%). For heterosexual sex transmission factor, women are much more likely to be affected (65 % to 35%).

8) families caring for a member with HIV/AIDS: February issue of Archives of Pediatrics & Adolescent Medicine, a journal of the American Medical Association. Of adults receiving care for human immunodeficiency virus (HIV) in the U.S., 28 percent have children younger than 18 years old.

9) Targeting Prevention. Perception vs. reality: Despite a flurry of conferences and workshops on a "crisis occurring with young adults and HIV", HIV is actually occurring in older people at much higher rates than in younger people. In 2004, 24% of all new cases were in the 13 to 29 age group, and 71% were in the 30 to 59 age group. 3.7% was in 60 and over.

2-C. Bronx HIV/AID Cases by Race and Ethnicity:

2-C-1. Comparison of Bronx HIV/AID Cases by Race and Ethnicity

	2004 HIV New Cases	% of total	2001-2004 HIV Cases	% of Total	Concurrent AIDS Diagnoses 2001-2004	% of Total	Current PLWHA	% of total
Black Males	278	31	1279	29	370	37	5047	24
Black Females	200	22	1060	24	224	22	4133	20
Hispanic Males	241	27	1132	26	264	26	6361	31
Hispanic Females	139	16	708	16	147	14.6	3793	18
White Males	17		118	3	-	-	726	3.5
White Female	10		42	1	-	-	360	1.7
Asian					-	-	69	
Other					-		128	
Total	885		4339		1005		20617	

source: New York City Dept. of Health and Mental Hygiene Surveillance Statistics HIV Epidemiology Program. 2001, 2002, 2003 and 2004.

2-C-2 Comparison of Total Bronx Population with HIV/AIDS Cases by Race, Ethnicity

Ethnic Race Group	Bronx Total Population	2001-2004 HIV/AIDS Cases	Current PLWHA
Blacks	**30.7**	**54%**	**44**
Hispanic	**43.5**	**42%**	**49**
Whites	**22.6**	**3.6%**	**5**
Asians	**2.6**		**.3**
Other	**.7**		**.6**

2-C-3 Comparison of Total Bronx Population for HIV/AIDS Cases by Race, Ethnicity and Gender

	2001-2004 New HIV/AIDS Cases	2001-2004 Concurrent Diagnoses AIDS Cases	Current Total HIV/AIDS
Black Males	**29%**	**37%**	**24%**
Black Females	**24%**	**22%**	**20%**
Hispanic Males	**26%**	**26%**	**31%**
Hispanic Females	**16%**	**14.6%**	**18%**
Total	**95.00%**	**99%**	**93.00%**

Analysis:

1. Black proportion of the total HIV/AIDS recent cases, 2001-2004, is nearly double their proportion of the total Bronx population. Blacks make up 30% of the total population for the Bronx; Blacks make up 54% of 2001-2004 HIV cases for the Bronx**.**

2. There has been a very significant recent increase in the number of Blacks becoming HIV positive. Reflecting a national and citywide phenomenon, Blacks are now contracting HIV in much higher numbers than other groups. ***Both*** black males and females have very disproportionately high rates of ***new*** HIV cases.

3. While the total borough wide proportion of Hispanics contracting HIV has dropped, it is still close to half of all new Bronx cases (42% of the total).

***4. Females, both Black and Hispanic, are more likely to get tested than males*.** However, all four groups showed significant representation of the concurrent AIDS diagnoses. All four groups need outreach around the importance of getting tested.

2-D. Managing HIV and AIDS. Undiagnosed HIV and AIDS Cases

12/31/04 Clinical Status

	New HIV Case Concurrent AIDS Diagnoses	%	AIDS	%	HIV (non-AIDS	%	Total
Bronx	266	25	12770	62	7857	38	20627
Manhattan	219	21	18515	63	10973	37	29488
Queens	188	18	8604	67	4174	33	12778
Brooklyn	309	26	15293	66	7873	34	23166
SI	22	2					
Total	1004						

- **HIV management efforts to delay the onset of AIDS**: according to the data, the progression of HIV to AIDS is similar in the Bronx to the other boroughs.

- **How many people had concurrent diagnoses?** 23% of all new Bronx HIV cases between 2001-2004 had a concurrent AIDS diagnoses. In 2004, it was 29%.

- **Bronx estimate of undiagnosed HIV positive population**: There are an estimated 20,000 people with undiagnosed HIV in New York City. If we accept concurrent AIDS diagnoses factor as a basis for interpreting the number of undiagnosed HIV cases, then the Bronx has an estimated 5,000 people are HIV positive and have not been tested. How many years do people have the disease before they get tested? Undiagnosed HIV is dangerous for two reasons: Can result in the spread of the disease; without treatment, it can lead to rapid progression from HIV to AIDS. CBO service providers can make a big difference here. Are there new strategies that can make a difference?

- How long are people infected before getting tested? Which groups?

- **HIV and AIDS populations:** Number of people living with AIDS (Are they in greater need of services than the HIV population?)

- opportunistic illnesses and how they can be controlled to stop the progression of HIV to AIDS

2-E . CAB URS DATA and ANALYSIS

Zip Code	#
10452	79
10456	67
10453	41
10457	41
10467	28
10472	28
10468	25
10458	22
10451	21
10460	15
10454	12
10462	12
10473	12
10459	10
10455	9
10466	7
10469	6
10032	5
10033	5
10463	5
11207	4
10035	3
10031	2
10039	2

10474	2
10011	1
10023	1
10026	1
10030	1
10037	1
10038	1
10040	1
10044	1
10058	1
10461	1
10465	1
10470	1
10705	1
11203	1
11205	1
11212	1
11216	1
11237	1
Total	481

CAB-URS Data Key Findings:

- According to the URS data, CAB's Positive Living clients access services in closest proximity to their home address. ***228 clients or 47% came from the 4 zip codes (10453, 10457, 10452 and 10456) closest to the 1130 Grand Concourse office.***

- ***36 PL clients or 7.4% came from outside the Bronx.*** The desire for anonymity (choosing a provider far from where one lives) does not appear to be a big factor in client selection of services.

- The CAB PL program is reaching PLWHA in the central and east Bronx neighborhoods; PLWHA living outside the South Bronx are a large part of CAB's client base. ***While 42% of the total Bronx PLWHA cases live in Fordham, Pelham-Throgs Neck, Riverdale-Kingsbridge and Northeast Bronx UHF neighborhood areas, 163 or 34% of CAB PL clients live in these neighborhoods.***

- CAB doesn't draw many clients from the southern half of the South Bronx (Mott Haven, Hunts Point, Morrisania). ***Only 54 PL clients or 11% came from these five zipcodes (10454, 10474, 10455, 10451 and 10459) in the South Bronx.*** Most likely due to the concentration of service providers in the south Bronx, and competition for clients, CAB does not draw a large number from this area.

2-F. Citywide Comparisons

New Cases and Current Distribution- *Citywide Comparison*

	General Population %	New HIV Cases 2004		Current	
		Number	%	Number	%
Bronx		898	24.6	20628	22
Manhattan		961	26	29,493	31
Brooklyn		990	27	23,345	25
Queens		547	15	12778	13
Staten Island		73	2	1706	2

Gender Distribution-*Citywide Comparison*

	Males 2004		Females 2004		Males Current		Females Current	
	#	%	#	%	#	%	#	%
Bronx	542	60	356	40	12272	62	8355	38
Manhattan	757	79	204	21	23580	80	5908	20
Brooklyn	619	62	371	38	14410	62	8756	38
Queens	388	71	159	29	8875	70	3903	30
Staten Island	45		28		1057		648	

Teens and Young Adults-*Citywide Comparison*

Borough	Males Ages 13 to 29 2004		Females Ages 13 to 29 2004		Males Ages 13 to 29 Current		Females Ages to 13 to 29 Current	
	#	%	#	%	#	%	#	%
Bronx	139	66	74	34	933	50	911	50
Manhattan	184	81	42	19	1060	70	453	30
Brooklyn	151	64	86	36	1080	54	918	46
Queens	103	75	34	25	612	61	387	39
Staten Island								

1) For young people, ages 13 to 39, the Bronx has the highest proportion of current number of females with HIV/AIDS. ***For all young PLWHA's in the Bronx, the gender distribution is now 50%-50%.***

2) Comparison with nationwide trend: The Bronx has significant differences from the total NYC and nationwide PLWHA population. The Center for Disease Control (CDC) estimates that half of new

HIV infections in the United States occur in people under age 25. In the Bronx, this group is an estimated 27% of the total new cases.

2-G. New York City Policy Connection:

In October of 2005, New York City Commission on AIDS published a 51 page report on the progress of City funded efforts, recent epidemiological trends and policy recommendations. Below I have excerpted from the report where the greatest gains have been made and where the greatest problems are today:

Where the greatest gains have been made

- *Annual AIDS deaths among New Yorkers have decreased 75% since the peak in 1994.*
- *Maternal to fetal transmission of HIV in NYC has been nearly eliminated, decreasing from 320 cases of perinatal HIV transmission in 1990 to 5 such cases in 2003.*[16]
  - *HIV seroprevalence among IDUs has declined from an estimated 50% in the 1980s and early 1990s to about 13% today, and the number of people diagnosed annually with AIDS from injection drug use has fallen by 89%, from 6,626 in 1993 to 760 in 2003.*
- *Hospitalizations for AIDS-related causes in NYC declined by more than two thirds between 1995 and 2002.*[21]

Where the greatest problems are today:

- *Prevent risk-taking behavior among people who are HIV-negative as well as among those who know they are HIV-positive.Promptly diagnose HIV infection*
- *Link people newly diagnosed with HIV to care.*
- *Optimally treat and care for all of the more than 100,000 New Yorkers living with HIV/AIDS.*

Section 3. Discussion and Analysis of Study Findings

How the CAB Positive Living Program can use the research information for programmatic change.

1. ***Significant Bronx geographic mismatch between distribution of services and PLWHA's cases. Most Ryan White Title 1 funded providers are concentrated in the South Bronx while 42% of PLWHA's live outside the South Bronx. The geographic center for the Bronx would be (highest concentration PLWHA within a half mile radius) would be around 175th Street and Third Avenue. This mismatch exists for both preventive and direct services (case management, medical, harm reduction, nutrition, support groups).***

This finding was discussed in Section 2. Regarding matches between CAB and other providers:

- The Northeast Bronx has 1,400 PLWHA cases and only one Ryan White funded provider (a contract for client advocacy with Gay Men's Health Crisis).
- Pelham Throgs Neck has 3,061 PLWHA cases and doesn't have a single case management provider.

CAB should conduct a two prong outreach strategy to these areas: 1) mailings to all CBO's, elected officials, community boards that serve these two neighborhood areas (together they cover almost half of the Bronx). Since there are so few Ryan White funded services, these groups should be very receptive to disseminating CAB literature and using CAB as a source for referring their clients; 2) to the few Ryan White funded programs that complement the Positive Living Program range of services.

2. ***A similar mismatch exists between the need for Harm Reduction programs and the geographic distribution of existing Harm Reduction programs in the Bronx. The IDU population is spread out over much of the Bronx. However, according to the New York City Ryan White Title I Services Comprehensive AIDS Resource Emergency (CARE) Service Directory (August 2002-July 2005 update), Harm Reduction programs are concentrated in the very southern part of the Bronx, in the Mott Haven, Morrisania and Highbridge neighborhoods. The Service Directory does not include Harm Reduction programs in the Fordham Bronx Park and Pelham Throgs Neck areas, although 32% of the total IDU risk factor HIV/AIDS population, (or 1,838 people) live in these two areas.***

CAB should start conducting outreach at health clinics and CBO human services providers in East Bronx-Throgs Neck and Fordham, Bronx Park. Most of these groups would probably welcome a good source of referral for their AIDS clients and let CAB leave brochures in their offices. CAB's Ryan White Year 16 RFP application described outreach to these neighbor-hoods as part of the

harm reduction piece. A similar situation exists regarding Ryan White funded prevention programs (however, CAB is only funded to conduct prevention to people who already have contracted HIV; CAB does not have a contract to conduct prevention with high risk groups).

NYC RYAN WHITE TITLE I SERVICE 2005 DIRECTORY:

Kingsbridge/Riverdale		Northeast Bronx		Pelham/Throgs Neck	
Provider	**Service**	**Provider**	**Service**	**Provider**	**Service**
Partnership Homeless Services Corporation	Access to care and early intervention	Gay Men's Health Crisis, Inc./United Bronx Parents	Client Advocacy	Albert Einstein College of Medicine of Yeshiva University	Outpatient medical care
				HHC Jacobi Medical Center 1400 Pelham Parkway South	Mental health services and outpatient medical care
				Institute for Urban Family Health, Inc.	Maintenance in care (keeping PLWHA healthy by sticking to their medication regimen)
				Legal Aid Society .	Legal services
				RFCUNY/Bronx Community College/Health Force: Women & Men Against AIDS 522 Southern Boulevard	Custody planning
				Visiting Nurse Service of New York 974 Morris Park Avenue	Treatment education

In the above chart, all of these groups are potential partners for the CAB Positive Living program (both Harm Reduction and Case Management) regarding client referrals. None of them provide harm reduction or case management services.

3. When the Bronx wide PLWHA data is compared with CAB-URS data, the CAB-URS data shows that significant numbers of clients come from outlying Bronx neighborhoods.

- According to the URS data, close to half of CAB's Positive Living clients access services in closest proximity to their home address. ***228 clients or 47% came from the 4 zip codes (10453, 10457, 10452 and 10456) closest to the 1130 Grand Concourse office.***

- ***36 PL clients or 7.4% came from outside the Bronx.*** The desire for anonymity (choosing a provider far from where one lives) does not appear to be a big factor in client selection of services.

- The CAB PL program is reaching PLWHA in the central and east Bronx neighborhoods; PLWHA living outside the South Bronx are a large part of CAB's client base. ***While 42% of the total Bronx PLWHA cases live in Fordham, Pelham-Throgs Neck, Riverdale-Kingsbridge and Northeast Bronx UHF neighborhood areas, 163 or 34% of CAB PL clients live in these neighborhoods.***

- CAB doesn't draw many clients from the southern half of the South Bronx (Mott Haven, Hunts Point, Morrisania). ***Only 54 PL clients or 11% came from these five zipcodes (10454, 10474, 10455, 10451 and 10459) in the South Bronx.*** Most likely due to the concentration of service providers in the south Bronx, and competition for clients, CAB does not draw a large number from this area.

4. ***Harm reduction program intervention models and best practices. (CAB is already working with the HRTI on best practices). Is there a harm reduction model that CAB should be looking at? Should CAB try more of a drop in model? Here are some harm reduction programs suggestions:***

A comprehensive and detailed discussion of these issue can be found in Section Four.

5. ***The CAB settlement house multi-service network of programs offers a unique model of service delivery that other Bronx based HIV providers can't? Almost all other Bronx HIV providers are single issue driven; they only operate programs for PLWHA. CAB can build on its in house expertise and resources for enhancing existing or developing new programs for HIV 50 years and older, families and workforce development.***

The consultants were asked to identify ways that CAB can build on its strengths as a settlement house that offers a wide range of family enrichment and preservation programs. The other Bronx HIV/AIDS service providers are all either single issue for HIV (one or more HIV related services) or HIV, IDU and health care. At the same time, CAB is only settlement house (or multi-service agency) in the Bronx with Ryan White funded programs. This fact places CAB in a very strategic and important position for HIV programming in the Bronx. CAB has a long history of offering a wide range of family services. It is a multi-service agency. This is its niche. The three areas that have the greatest potential for internal agency collaboration are:

- **HIV age 50 and older**
- **Vocational rehab and Transition to work**.
- **Family programming**

As it has done with its case management program, CAB should use its expertise in workforce development and senior services to respond to these two large gaps in AIDS programming in the Bronx. CAB is the only Bronx organization that has the expertise for internal agency collaboration. The consultants have undertaken some preliminary research for both workforce development and HIV 50 and older new programming. For more discussion, see findings five and six.

Domestic violence: The Bronx has the highest rate of domestic violence of the five boroughs. There is also strong that domestic violence is a factor in the increase of AIDS among women. This is one area that might be too much of a drain on CAB resources. Since it already runs numerous family programs, it does seem a good fit for CAB to offer HIV+ victims of domestic violence a safe place for family activities. SA, JH and BK all thought it was important to pursue this. However, BK questioned whether CAB has the resources to undertake this type of programming. BK suggested that we talk with Ann Paul, the Bronx coordinator for domestic violence services.

6. *Due to the success of the new drug treatments, PLWHA's are living longer and dealing with various issues of the aging process. In the Bronx, 31% of the current male HIV/AIDS group and 21% of the current female population are 50 years or older. 41% of all new male HIV cases occurred in the age group 40 or older. 34% of all new female HIV cases occurred in the age group 40 or older.****According to our research, there aren't any weekly programs specifically set up for the HIV 50 and older group in the Bronx. There are programs that are being set up or currently operating in other boroughs and in cities across the country.***

This is one program area where CAB can do some groundbreaking work in the Bronx. From an internet search, it is an issue that is just starting to get noticed by the main senior citizen organizations and government agencies.

- DFTA
- NYCHA
- NYC Council of Senior Centers
- UNH
- SAGE (has a Bronx group)
- Various NYC AIDS websites

The National Association of HIV over 50 has been around for 10 years and holds annual conferences. www.hivoverfifty.org/index.html It has an active New York City chapter that is run out of the Brookdale Center on Aging. Contact person is: Kathleen Nokes, RN, 212-481-7594.

The HIV 50 years and older have the following identified needs: As a start, CAB can try running a once week lunch and information program. The following areas of information should be

provided through guest speakers and in house expertise: nutrition, diabetes, cardiovascular, depression and social isolation. Depending upon interest and available funding, this could be expanded.

Focus Group Results: on July 28th, a focus group was conducted for the HIV 50 and older group. The findings from the focus group offer a starting point for developing new programming. All of the findings are listed in number 15 (focus groups) below. There was a consensus that this group strongly wants a program specifically designed for it. The most strongly preferred program pieces included a nutritious meal, access to information on health, medication management and aging issues (coping with AIDS, depression and another life threatening disease such cardiovascular, diabetes or cancer) and support groups (the respondents offered a long list of concerns). Offering a discrete location and venue will be a challenge.

Funding: Foundations are already starting to give out grants for this need group. 1) In 2006, New York Foundation gave the JAMAICA SERVICE PROGRAM FOR OLDER ADULTS $42,500 for an HIV/AIDS educational awareness and prevention program designed specifically for older adults. 2) Gay Men's Health Crisis (GMHC) has been awarded a $500,000 grant from the MAC AIDS Fund to develop an initiative that will meet the needs of people over the age of 50.

7. *At least 30% of the focus group respondents showed serious interest in trying to get part or full time employment.* ***According to our research, there aren't any vocational rehab and transition to work programs operating in the Bronx. In Manhattan, the transition to work programs are oriented to middle class professionals living with HIV or AIDS. There are a few programs oriented to low income and homeless people with AIDS. There is a large gap here; CAB has the in house expertise to respond. There are a series of programmatic steps that can be undertaken.***

Transition to Work is an issue that consumers have shown significant interest in. This is one area where CAB has the in house experience that other AIDS providers lack. At least 30% of focus group respondents expressed serious interest about getting part or full time employment (the drug user group had the least interest). This is an area that is slowly gaining the attention of policy makers and advocates. A review of recent NYC community forums and focus groups with PLWHA's shows that helping people to earn supplemental income or renter the workforce wasn't even one of the questions asked.

- **Bronx HIV Care Network Needs Assessment January 2006.** Never asked in any of the questions. Came up in one response.

- **East Harlem Needs Assessment May 1, 2002 page 48**. of the 10 different needs identified and % of participants responded, training and employment was not listed as one of the needs. While workforce wasn't even part of the questions, it does come up as a participant response. AIDS services are provided by mostly by government health agencies. The prism is confined to health related issues. Training has been overlooked. Also, advocates are fearful of any programs that might make work a mandatory requirement.
- *HIV Health and Human Services Planning Council of New York;* Community Forum Report Winter Spring 2005. Never mentioned during any of the Borough wide open forums.

If a transition to work program is going to be implemented, there are also some significant issues and concerns that should be addressed ;including:

- The Bronx is filled with community workforce development programs, adult education and two year colleges. Do PLWHA need a designated training program or just case management? Are there any advantages to running a training program specifically for PLWHA?
- ***Ryan White Title 1 and Title II*** does not directly fund programs that encourage people to enter the workforce. In contrast to all other Bronx HIV service providers, CAB is the only one that has its own separate workforce development division.
- Case management: any transition to work program is half case management and half workforce development. According to GMHC, one of the biggest hurdles with transition to work is helping clients overcome their fear of losing their benefits. The Social Security Administration and Medicaid rules governing transition to work are fairly complicated. This is an area of expertise that could help give CAB another borough wide niche.

"Transition to work" . NYC AIDS organizations that have set up work reentry programs:

- Gay Mens Health Crisis: for professionals and middle class occupations
- Housing Works: through its bookstore and thrift shops, it provides jobs and training for homeless people with AIDS.

- Harlem United For AIDS Vocational Education Program:

Below is an example of a transition to work program based in Harlem.

The Harlem United for AIDS Vocational Education Program with operating funds from DOH (New York Department of Health AIDS Institute) provides services for clients living in Manhattan and the Bronx. The

program provides an array of services designed to assist clients to pursue their educational/vocational goals that ultimately may lead to full time or part time employment.

The Vocational/Educational Program is designed to help clients of the Housing Division of Harlem United to re-enter the work force and inspire them by building skills that will make it possible to obtain and maintain independent living. Participation in this program will ultimately lead to remunerative employment and increase their quality of life. The Vocational/Educational Program aims to foster Harlem United's mission to provide barrier free access to care.

The Vocational/Educational Program services include:

- Weekly Support Groups
- Resume and Cover Letter Writing
- Filling Out Job Applications
- Job Interviews
- Medical Monitoring and Medication Adherence
- Life Skills Training
- Counseling Around Barriers to Medical Adherence
- Counseling Around Barriers to Vocational/Educational Training
- Referrals for G.E.D., ESL, Job Training
- Entitlements and Employability Counseling

Gay Men's Health Crisis has put together a lot of information related to transition to work including a seven page FAQ on why and how PLWHA can get engaged in transition to work programs. www.gmhc.org/health/treatment/ti/ti1803.html There are some excellent resources on transition to work on the web including. www.workingpositive.net/pages/1/index.htm

First Steps in Adult literacy and workforce development: for all PL clients and especially the IDU HIV population, CAB could pursue putting together a class for adult literacy skills (ABE, ESL, basic computer literacy or GED). **Through a partnership with the Consortium for Worker Education (CWE), free classroom instruction is now available:** The consultant has located a free professional instructor for either ESL, computer literacy, ABE or GED classes (through a partnership with the Consortium for Worker Education program). CWE can supply professional instructors and pay for their salary. **CAB staff interview notes:** BK noted that in prior situations, HR clients had a difficult time mixing in with the programs at 1130 Grand Concourse. HR programming (such as running job skills training classes) will most likely have to take place at 336 or another location. Scott thought that the classes should be run at the Living Room Drop in Center. Jessica thinks that around 30 PL clients may be interested. Finding a location is a problem. BK feels that classes have to be taught at a separate site for the HR clients. 336 Grand Concourse does not have enough room.

8. PREVENTION: While some groups are showing an increase in new cases (youth, women), prevention still requires targeting to all vulnerable age groups.

- CAB presently does not receive funding for prevention to non HIV Positive people. Prevention strategies have to be geared to HIV + high risk of transmission groups or seek funding for prevention to the new high risk populations (youth, heterosexual women, African Americans)

- Within the CAB network of services and programs, there are hundreds of people who might benefit from prevention education. Especially in the Living Room and other shelter programs. Scott wants to do rapid testing at the Living Room through a partnership with a testing provider.

- According to the 2004 Ryan White Funded Prevention Services Directory, a similar mismatch occurs regarding the geographic distribution of prevention services and cases. The prevention programs were concentrated in the South Bronx.

- Within the CAB network of services, there is a lot of potential for internal collaboration around prevention. CAB programs, in addition to the PL, serve high risk groups. More internal linkages need to be made between programs. AIDS Institute Model (?).

- Age 50 and older general population is misinformed about AIDS transmission. The National Association on HIV over 50 (www.hivoverfifty.org) is a nationwide network of researchers and community groups working with the older adult HIV+ population. Studies have already shown that prevention is a big need with older adults especially in the minority community. Many seniors are sexually active and not aware that they comprise a high risk group for contracting AIDS (especially African American Latino seniors). Seniors are not aware of how AIDS is transmitted. In a recent study conducted at Emory University in Atlanta, 514 women ages 50 and older were asked nine questions about their HIV risks. Only 13 percent said condoms were effective prevention; 63 percent inaccurately stated kissing is a mode of transmission; about half believed vasectomies provide protection; and, most surprising, 44 percent said abstinence was not at all or only somewhat effective in preventing HIV. The study was conducted in 2004. (www.aarp.org).

9. *Getting high risk groups tested remains a big challenge. New and creative strategies are needed to get young people tested.*

NYC Department of Health has made expanding the availability of rapid testing its big priority for 2006. In the Bronx alone, close to 5,000 people may by HIV positive and not know it. The longer someone is not aware that they are HIV+, the higher likelihood of worsening of condition and more expensive eventual care will be. Also, refusing to get tested is the biggest factor for causing new cases to spread.

CAB has stated that it doesn't want to become provider for rapid testing. Instead, CAB will offer its Living Room program as a site for rapid testing. Scott is looking into a partnership with Partnership for the Homeless or We Care About the Homeless for rapid testing at the Living Room. 1,200 homeless people use the living room. CAB may have to pay people to get tested. Half the population at the Living Room is using drugs or alcohol.

Suggestions from focus group participants: Focus group participants were very concerned with this issue. It is directly related to stigma about being HIV+ and ignorance about how HIV is transmitted. MSM group spoke of the importance of making it "cool" to be tested. Providers must get some HIP HOP celebrities (or other celebrities) to endorse getting tested. Rapid Testing vans should go to the street fairs and other community events. People who get tested should receive some gift (free baseball tickets) or other incentive.

10. *The Bronx borough wide HIV Planning Council does not have its own HIV/AIDS data collection, analysis and planning document? Does CAB want to take the lead here and share the data analysis with other Bronx CBO's?*

SA, JHS and BK all agreed that CAB should use the report to produce a research and analysis document that can be used by other Bronx service providers. The Bronx PLWHA Summary Demographic Report (eight pages) will be posted on CAB's website (based on NYC-DOH data). It will greatly help increase CAB's profile on the policy making level. Another suggestion is to put best practices on website (not just PL programs but all CAB programs). Bronx HIV Planning Council has a research needs document that is based on focus groups. Brooklyn HIV Planning Council has a 120 page needs assessment study. In an interview with Socrates Caba, he welcomed greater advocacy involvement by CAB in Bronx wide issues.

11. No typical client, different approaches are needed to meet the various main groups that comprise the Bronx PLWHA population.

During the short period of time that we have been working on this report, there have been various half and one day conferences and press releases issued by other organizations with misleading information about which group is the fastest growing or largest for PLWHA's in the Bronx or citywide. The data in Section I are very clear. HIV is a problem for all adult age groups, gender, race and ethnicity. While this fact would appear to make programming more difficult, the MSM focus group participants said that they didn't care about ethnicity and age in their support groups.

12. Shared focus group comments across all four groups and feedback on general assumptions

Combined Focus Group Findings

	Women	MSM	HIV 50 and Older	Drug Users
Stigma is a very big problem. For many the biggest daily problem	YES	YES	YES	YES
Family dynamic (closely related to stigma)	YES	YES	YES	YES
Incentives	Health People gives out metro cards	Very big issue. They all want $ or free things (including lunch served a the support group) to make ends meet	Serve healthy and good tasting food.	Bailey House gives out a rolling back pack; basketball tickets, money.
One stop shopping co-location	Doesn't seem to matter	16 prefer; 2 don't care		
Anonymity vs proximity	Don't care	11 want services outside where they live; 8 close by	Prefer anonymity	
Weekend hours		17 gave this high priority.		
Information	Health insurance, treatment medication, diet and nutrition,	13 want more treatment information; 16 want more advocacy related; 17 want more nutrition; 12 want		

		more government benefits		
Training and employment	Some interest, people are used to the security of govt. benefits. They will need a lot of support with this. Do not want to stand out by using VESID	Mixed responses. Most people don't want to risk losing their benefits or having a relapse and getting fired. There was also a lot misunderstanding about how benefits work. If training were offered, about 6 would take it seriously. Do not want to stand out by using VESID	Do not want to stand out by using VESID	Working is an illusive goal particularly those habituated to drug use and welfare and SSI dependence. It is not simply HIV that is limiting their employment options.
CAB 1130 GC and the Positive Living Program	Nobody knew about the PL program and only one person had been to CAB.	11 people said it didn't need to change. Already "gay friendly". Need to better publicize programs.	Only one person was aware of PLP.	
Rapid testing Challenges and Suggestions	Fear, ignorance, give people incentives	Have rapid testing van go to street fairs, reduce stigma of having AIDS, get celebrities involved, give out incentives,		
"Unknown Risk Factor"		17 out of 18 participants said that "unknown" was given by MSM. who did not want to disclose this.		
Homophobia (closely related to the stigma factor)		Very big problem. The stigma of having AIDS, not being able to tell family members. Big need for more public education. Too much ignorance about how AIDS is spread.		
Support group preferences	Support groups are very important, help with coping with depression	Weekly support groups are very important for coping. Race and age do not matter.	Want support group for their Age group. .race doesn't matter	
Housing		no		
Medication management	yes	no	Yes	yes
Clinics, doctors	Participants in all 4 groups bitterly complained about a lack of respect by medical clinic staff and doctors.			

Focus Group Feedback on General Assumptions:

Location of Services

- People do not necessarily prefer services close to home. Services at a distance are preferred by some newly diagnosed people, particularly if they are hiding it; and also for drug users attempting to make a clean break from old bad habits. Having come to terms with HIV, and after disclosing it to everyone, and with greater age, services closer to home are preferable. The 50+ group also requested IN-HOME services and telephone assistance.

- Transportation is not a big impediment to service enrollment – Bronx PLWHs seem to travel willingly to Manhattan if the services meet their needs.

Is there any specific combination of services that you would most like to see co-located?

- Co-location of services is a good thing, but many PLWHs are connected to different sites, each of which provides something essential. Hubs include hospitals, supportive housing, drug treatment / rehab programs.

- Some people utilize the many services offered at Montefiore, but also enjoy coming to the agencies that provide their core support groups – e.g. Health People, Bailey House, Harlem United, Bronx AIDS Services -- and going to other groups elsewhere. It seems like a structure, a selection of communities, a change of scene and an opportunity to be in different locations and groups is preferred.
- Employment services and workforce preparation tied with HIV program participation would be a popular, and somewhat unique approach.

- Programs for personal empowerment / life change – e.g. self-esteem counseling, parenting classes

What kinds of information would you like to receive?

People were hungry for information, impelled to learn for themselves in order to find appropriate treatment when they mistrust doctors, and to educate their families and friends in order to sustain their fragile support. Each stage of HIV calls for distinct types of information. Workshops that provide timely information, and literature that can support PLWHA in educating themselves and others, would be helpful. Suggested topics include:

- Understanding HIV/AIDS and related illnesses
- Access to medical care and clinical trials
- Treatment Education – medication options, developments, and management
- Medication access and options
- Nutrition and food preparation
- Political action around HIV/AIDS, public speaking, advocacy skills
- Government insurance & benefits
- Different resources and benefits that are available – for education, training, self-sufficiency

- Knowledge about women's health, STDs and the connection between sex and HIV

- Understanding the links between incarceration and HIV transmission – and what to do about it.

- Understanding the links between drug use and HIV infection – + equipment for prevention and harm reduction

13. Individual findings from Drug Users focus group

The chief issues for drug users are: 1) self esteem / motivation; 2) self-control and discipline – e.g. in sticking to medication regimen and harm reduction strategies; 3) physical and mental complications of interactive drug/medicine effects; 4) lasting effects of trauma and habitual pain avoidance strategies.

- Difficulty expressing feelings and sharing, necessary if they are to find support from peers or benefit from therapy to address the pain that drove them to drugs
- Personal support/ coaching to stay drug free and take HIV meds
- Substance Abuse Treatment/ relapse and recovery services that address the complications of HIV medication interaction effects, and vice versa. There seems to be a disconnect in the distinct strategies and messages of drug treatment and HIV harm reduction services.
- Upon receiving an HIV diagnosis, drug users often relapse or intensify their drug intake and need intensive supportive interventions at that point.
- Criminalizing drugs, punitive interventions, the deprivation of dignity and freedom in prison contribute to further drug use and crime to support the drug habit. Rikers is a hotbed for HIV dissemination. Many drug users cycle through there.
- PLWHs who are drug users are the most vulnerable, most stigmatized and least self-sufficient sub-population. Drug treatment, prison, and medical care rarely address underlying mental health issues that contribute to substance abuse. These PLWHs could benefit from intensive therapy, but may also be resistant to it. Several substance abuse programs in the Bronx involve psychosocial therapies – need to explore how CAB can support mental health services for this population.

14. Individual findings from the Women's focus group

Major issues for women (separate from drug users) involve: 1) their roles as caregivers and parents, and the impact of their HIV status on the entire family / need for comprehensive family support ; 2) empowerment within heterosexual partner dynamics - particularly in confronting violence and betrayal.

- Children are traumatized by the illness of their parents. Their carefree childhood is shattered– as they become mom's caregiver, worried about mom's health and survival, burdened by the stigma of HIV. Many psychological problems result– children need counseling or family therapy.
- At school and in the extended family, children of parents with HIV/AIDS need to dispel misinformation, educate their peers, respond to taunts and rumors, defend their ill parents and retain their own pride. In order not to be frightened by scary things others say (e.g. your mom is going to die, you are contagious, we can't sit near you….) these children need to learn the facts, and also process how to assume a position of strength.

- Mothers often have their children with them while they receive service or participate in support groups. These children need activities or programs or on site childcare while waiting.

- Mothers are often the caregivers for their own aging parents. Their case management needs to supply resources for eldercare, elder abuse, etc.

- Parents with HIV/AIDS need help planning for childcare when they are too ill to handle it, and for ultimate support of their children should they die.

- Older children continue to stay with their parents, beyond the point of receiving financial support. HASA subsidies do not cover children over age 21 who are expected to move into their own apartments. COBRA can't help them unless they are HIV+. Their only (perceived) option for help with independent living is to enter a shelter.

- Many HIV+ women are surrounded by family and community violence. HIV prevention for women is integrally linked to the need for larger interventions for violence prevention and women's empowerment.

- Many heterosexual women contract HIV from their spouse or partner, and then face a variety of psychological and relationship challenges for which they need therapy or counseling or support groups. Anger, loss, betrayal, condemnation, unforgivable disregard are all part of the mix. For many, learning about their HIV status is the end of the relationship and the beginning of a new set of worries about meeting basic survival needs, learning to live with an undeserved "death sentence" and seeking new companionship and love.

15. Individual findings from the HIV 50 and older focus group.

HIV+ people over 50 share all the concerns of the other groups, depending upon their route to HIV. The distinct issues for this age group relate to : 1) the complications of HIV and other medical and psychological conditions that accompany aging; 2) social isolation. Many people in this 50+ group seemed ashamed and stigmatized (and depressed) by HIV. The stigma was still strong, and the pain quite palpable. More than half seemed uncomfortable speaking about it with old friends, family or neighbors, and many had faced rejection and humiliation. Their choice to keep their illness a secret results in strains or losses in old relationships, and a desire to associate more with other HIV+ people. 3) On the other hand, maturity leads to acceptance and transcendence. On the whole, this group tended to be the most positive about their HIV, finding grace in the learning and self-awareness that they gained from it (having processed the denial and anger and self-destructiveness of earlier stages). Specific needs identified (to add to others mentioned elsewhere, which were also issues for this group) include:

- Much of what people shared had to do with HIV, rather than aging. People spoke of HIV as the distinguishing feature of their lives – more important in their self-definition than any other physical or mental issues they faced. Seeking contact with other HIV+ people was their comfort zone.
- Many had multiple health issues that left them weakened.
- Medication management and unforeseen interactions among drugs for different conditions were major difficulties. Separate doctors for different conditions, plus a need for more HIV expertise, contribute to this problem. Information about medications and medication management for PLWHs is a need; educating doctors is another.
- Political advocacy for needed services and to restore funds, medical benefits, access to medications
- Home visitors – to provide company, comfort, tangible assistance – e.g. paying bills, getting groceries
- Hotline or warm line – to call if they need help or to talk to someone
- People over 50 to help others over 50. They don't want to talk to "a 25 year old with a degree."
- More places that people can call their own – community, familiar, similar age and HIV status.
- Help for family to plan for funeral and cover expenses
- Legal assistance – wills, estate planning, guardianship, medical directives, POAs.
- Exercise, nutrition, wellness programs have been helpful and would be welcome.

PROGRAMS, SERVICES, APPROACHES OR SETTINGS FOR HIV+ ADULTS OVER 50

- Provide literature
- Make home visits and educate families; improve family relationships and support for PLWHAs.
- Home visits, warm lines, contact and human support for PLWHAs
- Programs that strengthen PLWHAs worth, self-esteem
- Health insurance plans and options, Medicare part D
- Money management
- Movies, videos, theatre
- Retreats
- Family events
- Social and recreational activities
- Several in this group were still trying to be discrete about their illness, and would not want friends and neighbors to know they were going to an HIV program.

- A number of people indicated that they prefer to have choices, options, flexibility – by this age people know what they want and don't like to be told what to do.

16. Individual findings from the Men Who Have Sex with Men (MSM) Focus Group

MSM group perception and awareness of CAB's services: At the beginning of the study CAB staff expressed a concern that the MSM population doesn't consider the 1130 Grand Concourse building to be a gay friendly place**. "**The building is seen by the gay HIV population as too family oriented. This perception translates into low usage of CAB PL program and services"**.** At the MSM focus group, 10 participants said they familiar with CAB and had been inside the building. They said that the building was fine and did not need to change. At least two people said they use CAB for case management services.

- At least half of the participants would like to explore transitioning to work. Concerns over losing benefits, break in benefits, relapse, getting fired and stress were given as barriers to employment. 8 people would like training in computer skills.

- Stigma of having AIDS must be addressed through more public information campaigns. This will help both PWA's and encourage more testing. Participants said that the stigma of having AIDS, dealing with family members, was the most difficult part of daily life.

- Rapid testing needs to adopt community friendly strategies. Celebrities need to do advertising about "its hip" to get tested. Or incentives have to be given.

- Regarding the issue of testing and the very large number for the "unknown" group, 17 people said that unknown was "MSM". One person it was all three split evenly.

- When everyone was asked what was the most difficult part about having AIDS, no one mentioned housing or dealing with HASA. Many different responses were given including: depression, arrogant clinic staff and long waits, not being able to work and money, and medication management

- When asked about CAB and the 1130 Grand Concourse building, would they feel comfortable using the services there, 13 said they had no problem with the building. Many already had sought out services there or attended an activity. Several said it is already "very gay friendly".

- Participants will choose service providers based on incentives. The importance of incentives came up throughout the focus group.

- Will not use door to door van service because "people will know you have AIDS".
- 16 preferred co-location and one stop shopping
- 17 expressed strong interest in weekend programming
- 11 want services outside of their neighborhood, 7 want in their neighborhood
- African American church is homophobic.
- 17 said that the "unknown" factor in the DOH risk groups was MSM
- Teens must get tested. They need incentives to get tested. Go to City gyms. Get the mobile testing vans to have a "HIP HOP" style or approach. Give out condoms.
- STIGMA: there needs to be more billboard advertising about HIV and AIDS. People do not understand how infection works.

17. General Program Suggestions Across All Four Focus Groups

The suggestions listed below come unfiltered directly from the focus group participants (some of the suggestions may already be part of CAB PLP programming). In Section 5. Recommendations, these suggestions have been reformulated as new and meaningful programming options for CAB

- Across all groups, the need for supportive relationships, respect, acceptance and understanding was paramount. When such human connection is not available from family and friends, HIV programs provide an alternative community. The strength of this connection keeps people engaged in service.
- ***Support groups are the top choice of approach***. Support group composition: People do not need to be in separate support groups according to gender, race, culture, or parenthood. Being HIV+ is the biggest connector. Age is the second. Older PLWHs want to be with peers of their age; and presumably young people would have more to discuss with their age peers. MSMs prefer being with other gay people.
- Provide comprehensive structured programs that help people to create an alternative lifestyle and supportive relationships. To combat feelings of hopelessness and despair, overcome losses, and fight addiction, HIV services need to offer participants an environment of safety, respect, and inspiration.
- Several women described a plunge into despair, self-destruction, renewed and more vigorous drug use and dealing, upon hearing they were HIV+. Swift, sensitive support and information is needed at the time /place of diagnosis to avert further danger. Important to convey that diagnosis requires an intervention and doesn't mean death.

- Treatment Education – participants requested more help with understanding the effects of different drugs (legal and illegal substances) and medications (HIV and other meds). Especially for drug users and newly diagnosed – give sense of options and choices.

- Provide education about HIV to family members and community who need to be better informed about HIV/AIDS and how it is contracted. Public education, and targeted family education would be a welcome support. Their ignorance is not only a dangerous public health concern, but a source of tremendous pain for PLWHs. People who are ill need the support and understanding of those close to them, rather than shame and isolation.

  Public education should be provided directly or through partnerships with schools, after school programs, senior centers and services, hospitals and clinics, drug treatment facilities, corrections /probation programs.

  Offer HIV education for families:

  - Children of different ages, spouse, partner, former partners, parents and extended family relatives need help to understand and support the PLWHA.

  - Offer help with disclosure – provide anonymous calls to inform partners, averting the need for direct disclosure.

  - Home visits to reach intractable family members.

  - Community events offering food, theatre, films, videos, other incentives /giveaways to attract family members to receive information about HIV.

- ***Transition to work:*** There was a mix of responses here. While the majority will not seriously try to work, there is a significant number, as high as 30% of participants, who want help here. Connect people in HIV services to workforce preparation, GED, ESL, Adult Basic Education and other paths to employment. Clients must be assured that their government benefits won't be affected. Case Managers must be able to guide clients regarding what if any changes there will be with there government benefits.

- Positive spin – e.g. focus on health not disease; hope not self-hatred; achievement. Programs should treat participants as experts, playing to their strengths, and providing incremental reinforcement and rewards – programs can operate as clubs, courses with graduation, built in awards and incentives for incremental gains. People need to be helped to feel that they are improving, learning, stronger, valued. REMOVE elements that appear punitive, demeaning, patronizing, depressing.

- ***Client Incentives:*** clients want providers to offer incentives including food coupons, pharmacy discounts, toiletries, clothing, metrocards. (e.g. if people show up for x days, they get a metrocard.). Specifically, for the ISU group, many drug users only break their addiction through mandated substance abuse treatment. Harm reduction programs need to offer major incentives, if commitment is voluntary.

- ***The biggest incentive seems to be a chance to work.*** Tie program participation to employment -- employment can be related to HIV prevention and education: the learn one, do one, teach one model. PLWHs who have reached a point of acceptance of their own illness are often zealous

about getting the message out to others. Peer outreach and education is a win-win strategy for programs and certain HIV+ participants.

- Parents of young children need on-site childcare and supervised programming for their children. Children of parents with HIV should have specific supportive programming and peer group activities. Health People's youth mentoring programs are a good model for a much needed service that provides support and family integration for children whose parents have HIV/AIDS.

- Drug users want programs with longer hours and varied venues and activities. Their HIV services need to be better integrated with drug treatment and recovery programs. CAB can recruit more actively from drug treatment programs, and get to know their staff and approach in order to provide a meaningful alternative. Explore whether harm reduction can be an add-on or a next-step to drug treatment and drug substitution therapies.

- Family programming is still a rarity, and remains a critical need. Programs like Felicia's at CAB need to be expanded and deepened beyond recreation. Need to begin family support groups / family group counseling to understand how to support PLWHAs, and to meet their changing needs as a family – e.g. alternatives for child care and support, custody and guardianship plans, legal services, community integration, cultivating new perspectives and frameworks for living with HIV in the family.

- While few people requested / stated the benefit of individual counseling or therapy, the need for personal reflection and counseling is evident. Since admission of this need or feelings of low self-esteem and depression are difficult and uncomfortable, it is not clear that PLWHs are "good candidates" for psychotherapy.

- HIV prevention and education services for people in and released from prisons - particularly Rikers - and their families – is important. CAB's work with families (in any of their programs) should be alert to the presence of returning prisoners / family members on parole or probation. Assistance in working with prison staff to sensitize and educate them. Counseling / education for inmates about HIV transmission, and ways to promote safe sex in prison and upon returning to the community. Programs inside the prison, and transitional programs can provide other types of assistance in relocating to the community (e.g. links to job training, housing, relapse and recovery programs) while imparting a health message.

- Housing: referrals to housing; eviction prevention; advocacy for repairs; more supportive housing, alternative low-income housing options. Pressure HASA to locate more suitable apartments, investigate the places they send people, and withhold funds until conditions are improved.

- Provide or link with Legal Services – wills, guardianship, POAs, health directives

- Help people to apply for life insurance or assist /coach them in how to acquire it

- Transportation between major types of services (e.g. from hospital to support group) would be helpful, metrocards would be a good start. (employers can obtain metrocards as employee benefits; if PLWHs are employed by CAB as peer educators, for example, this might be a way to provide a cash equivalent.)

- Counseling and empowerment for children with HIV+ parents; transitional help / referrals for older well children who are not yet independent but are cut off from DAS / HASA budget; intensive work on supporting self-esteem

- Caregiver respite and support – both for the PLWHA who is the caregiver for others, and for others caring for PLWHAs. One interesting program idea would be to link with home attendant training programs – e.g. Rick Surpin's, in the Bronx.

- Political Advocacy / organizing and voter education: Advocating for their own needs and benefits is important for PLWHs, and focus group participants rely upon social service agencies to get them organized and transport them into the advocacy arena. Validating their expertise and providing opportunities for them to be spokespersons and peer leaders is beneficial in many ways. At the same time, interviews with the HIV Planning Council and other Bronx providers noted that CAB is an influential player and hoped for more political involvement in support of a united Bronx effort to secure more funding and resources. And CAB is experiencing a loss of funding for buddy programs and recreation, etc – so stands to benefit directly from efforts to increase / restore funds; CAB is also well positioned to advocate on behalf of whole families and communities.

- Some spiritual dimension to the work. A connection to a higher power or vision, rather than religious dogma. Link to sensitive clergy who could visit at scheduled times might provide mutual access (recruitment for membership in religious institutions; client contact with caring clergy; agency connections to clergy who can make ongoing referrals…..) .

- Drug users: Participants hoped for staff to meet them where they are at; help them to be true to who they are, offer a hand to lift them up, make their day easier. Higher visions. Just offer encouragement, not judgment or requirements.

- Medical Management: help collecting and understanding medical records; locating comprehensive medical care, ideally with one primary provider over time. If relocating, assist with the transition to new medical care within more comprehensive services.

- **OUTREACH SUGGESTIONS / LOCATIONS**

For all groups

- Welfare office
- Hospitals (meet directly with patients while they are there)
- HASA; specific housing and supportive housing sites

Women

- health care providers – especially family medicine, gynecologists, OBGYN docs
- schools
- day care centers
- places of worship / faith communities
- flyers in local stores and agencies
- health fairs, health events

HIV-positive people over 50

- Fordham Road – shopping district

- Third Avenue - shopping district
- Subway
- Supermarkets
- Laundromats
- Veterans Administration

Drug Users

- Shooting galleries / street
- Needle exchange sites
- Halfway houses
- Rikers Island
- Drug treatment programs

18. How much flexibility does CAB have with its existing programs for responding to NAS recommendations?

- JSH, BK and SA: there is definitely flexibility to start new programs (by seeking new funding) or improve existing programs (modify contract objectives and deliverables).

- COBRA can grow by increasing caseload.

- BK: CAB needs to do more outreach. Most Ryan White referrals come from the HASA centers. CAB should be doing much more to promote and advertise its PL programs and services.

- 1,200 people use the Living Room. Can the CAB Living Room drop in center be used to recruit HR clients? What about a focus group?

19. Should partnerships with needle exchange programs be used for recruitment for the CAB harm reduction programs?

This is already happening with Bronx Lebanon Hospital and the Harm Reduction Educators. Is this helping with referrals to 336 Grand Concourse?

20. 2005-2006 internal agency operations: What new strategies are being employed by CAB? Based on the SEEDCO Report, DEBI Community Promise,meetings with the Harm Reduction Coalition and other recommendations for new service delivery strategies, what is the status of these efforts?

Seedco conducted a internal review of operations and proposed four recommendations in the spring of 2005. 1) Free transportation, 2) formalized orientation of new staff, 3) joint service plans 4)

using URS to track referrals (Seedco report only vaguely identified a problem without citing specific examples, internal referrals, of what wasn't working)

SA: does not think that internal referrals are a problem. Jessica: good programs are the best source of referrals. BK: acknowledges that internal communication could be improved. A lot of managers do not know about other programs.

Section 4. HARM REDUCTION

By Beth Rosenthal

FINDINGS – summary

Harm reduction approaches view injecting drug users (IDUs) within the larger context of their environment and the social networks and systems that impact them. Local and international harm reduction models emphasize drug user/PLWH direction of their own treatment plans and active involvement in the design of policies and programs. Contextual and structural variables such as poverty, violence and discrimination affect IDUs more acutely than other PLWHs, as contributing factors to their drug addiction and HIV infection. Harm reduction approaches aim to improve those conditions, while supporting individual empowerment. Harm reduction distinguishes harm at different levels - individual, community and societal - and of different types - health, social and economic. There are three types of harm reduction strategies:

- Harm reduction approaches with drug using clients: direct services (80%)
- Modify the environment to reduce drug-related harm (20%)
- Implement public policy changes

These findings support the recommendation that CAB's harm reduction program needs to provide a highly individualized package of resources for each participant, and also mobilize family, community-wide and larger systemic supports that can address the root causes of drug addiction and social alienation that contribute to the increase in HIV in the Bronx.

1. *Increased drug addiction produces a serious HIV risk for the Bronx.* In the Bronx, although HIV is the third highest cause of death, the rates of death from HIV decreased by -22.7% from 1990 – 1997. Over the same period, Bronx deaths due to drug dependency increased by 87.8%. [1] The prevalence of dangerous drug use indicates a growing risk for HIV infection, as IDUs tend to infect other drug users (by sharing injecting equipment) as well as their sexual partners and unborn children. Stemming the rise in drug addiction, as well as promoting treatment alternatives, are key harm reduction objectives.

2. *There is a disconnect between drug treatment and HIV harm reduction.* HIV medical care and ancillary services are often divorced from drug treatment interventions, sometimes offering conflicting advice or treatment. HIV practitioners and doctors are unprepared to deal with drug addicts; drug treatment programs are not attending to HIV issues. Interactive effects of ART medications and illegal or monitored substances such as methadone, are rarely considered. HIV-positive IDUs need comprehensive services that incorporate expertise from both fields to address their dual conditions; harm reduction programs may be the essential link between specialties. *This is a huge generalization. Is there supporting evidence. How does it relate to CAB? Isn't this something that the CAB Harm Reduction program already knows?*

[1] United Hospital Fund (uhfnyc.org/usr_doc/Bronx.pdf notes an increase of 90.8% for males, 66.6% for females age 18-64 .

3. *A drug treatment gap exists nationally and may affect Bronx HIV-positive IDUs.* Over three million Americans in need of drug treatment are not receiving services, largely because they are uninsured, or appropriate programs are unfunded or unavailable, leaving them at risk for increased danger from drugs and HIV transmission. Most Ryan White Title I and Title II services are planned without examining the substance abuse systems and services in their state and the funding mechanisms that support drug treatment. Separate laws and government structures for administration of HIV/AIDS services and substance abuse have produced bifurcated approaches to the common terrain of the HIV-positive IDU. Harm reduction programs work with IDUs at various points on the continuum between total chemical dependency and abstinence. Ensuring that harm reduction clients gain access to drug treatment, should they need it or be ready for it, should be imperative. A good grasp of the local drug treatment terrain is essential. *How does this relate to the work of CAB HR Program?*

4. *The complex issues confronting IDUs demand comprehensive services* that address the depths of their personal pain, and provide multiple supports for their recovery and restoration as contributing community members. Extensive, active linkages with community supports for these issues is critical. *How does this relate to the work of CAB HR Program? Are you trying to say that CAB doesn't practice this?*

5. *Community-level factors contributing to IDU HIV must be addressed.* Because people live in a social milieu, successful individual behavior change requires a parallel change in community conditions. Violence, crime, poverty, availability of drugs, moribund civic networks, disconnected service providers, and rejecting faith communities comprise a landscape that contributes to drug addiction and the spread of HIV through ignorance and lack of concern for other community members. Rebuilding the social fabric, instituting new civic structures, uniting service providers, holding government agencies such as police and child welfare accountable for supporting families, provides a more solid base for recovery. *This may be somewhat true, but it is way beyond the capacity and resources of CAB or any other HR provider. How is this information new or relevant?*

6. *The criminalization of drug addicts, and the current "war on drugs" contributes to increased HIV and other blood born illnesses, crime and family disruption*. Addicts assert that they are forced into criminal markets to buy poor-quality expensive substances. In prison, unsafe drug use and unprotected sex multiply HIV risk, while HIV prevention services are limited or nonexistent. HIV specialists and researchers stress the need to transform the frame to one that emphasizes a public health perspective and views addiction as a disease amenable to treatment. [2] Harm reduction programs can promote this position by advocating for different drug policies and increased treatment, and working more closely with prisoners to engage them in services, education and outreach. *How should the HR program try to "worki more closely with prisoners to engage them in services, education and outreach"*

[2] Haden, M. 2002. Illicit IV Drugs. A public health approach. Can J Public Health 93(6):431-4. OSI also has extensive information on this perspective.

7. *Policy and advocacy work are essential components of harm reduction.* From its inception, harm reduction strategies have focused on altering social conditions and structural factors that contribute to drug addiction and other dangers to public health. More than other types of HIV services, harm reduction demands interventions at the policy and legislative level that can produce broad systemic changes that tangible reduce harm – for example, mandating HIV testing, decriminalizing drugs, funding supportive housing and publicly funded drug treatment programs. Because drug users are often victimized by systemic abuse or neglect, harm reduction approaches incorporate learning about the system and engaging in advocacy as part of the healing and self-transformation process. *This is a nationwide systems change. It could take years to occur. It is far beyond the existing resources and capacity of CAB.*

8. *Organizing drug users and cultivating them as political advocates and peer educators are effective harm reduction interventions.* International public health initiatives have promoted and supported self-organization of drug users, and user groups have spontaneously emerged in over 30 countries to lobby for their health and human rights.[3] Public health activists and HIV specialists applaud the involvement of drug users in shaping programs and policies that effectively reach their peers. Shifting the view of HIV-positive IDUs from pariahs and service recipients to experts and leaders is consistent with harm reduction best practices. *Is this new? Are you saying that CAB HR staff view their clients as "pariahs". CAB HR program has already told us that they regularly talk with clients and try to shape programming based on client feedback. Is there something that they missed here?*

BACKGROUND INFORMATION SUPPORTING FINDINGS

Harm Reduction Definition and Practices: "Harm reduction is a set of practical strategies that reduce negative consequences of drug use, incorporating a spectrum of strategies from safer use, to managed use to abstinence. Harm reduction strategies meet drug users 'where they're at,' addressing conditions of use along with the use itself." (Harm Reduction Coalition) Harm reduction views individuals as responsible for their own choices, and as both agents and recipients of environmental influence. It is intended to empower the patient and consumer of health services. It affirms drugs users themselves as the primary agents of reducing the harms of their drug use, and seeks to empower users to share information and support each other in strategies which meet their actual conditions of use.

HRTC's Don McVinney discusses the value base of harm reduction as one of Compassionate Pragmatism versus Moral Idealism. It acknowledges that drug use is a reality, and people engage in unhealthy behavior and seeks to reduce the harm that results from that behavior. Most harm reduction programs have a hierarchy of goals, with the immediate focus on proactively engaging individuals,

[3] Efthimiou-Mordaunt. Op cit.

target groups, and communities to address their most pressing needs. Achieving the most immediate and realistic goals is usually viewed as first steps toward risk-free use, or, if appropriate, abstinence. [4]

Principles of harm reduction practice include[5]:[6]

- Understanding drug use as a complex, multi-faceted phenomenon that encompasses a continuum of behaviors from severe abuse to total abstinence, and acknowledging that some ways of using drugs are clearly safer than others.
- Recognizing that the realities of poverty, class, racism, social isolation, past trauma, sex-based discrimination and other social inequalities affect both people's vulnerability to and capacity for effectively dealing with drug-related harm.
- Providing services in a nonjudgmental manner, treating individuals with dignity regardless of their condition and behavior
- Bringing services to where people are at, increasing access, reducing impediments such as location and hours
- Any reduction in harm is a step in the right direction. Change is not necessarily linear.
- Quality of life and well being are criteria for measuring success.
- Policies are pragmatic, realistic, informed by and relevant to the individuals and communities.
- Treatment is nondirective and non-coercive, involving a collaboration and exchange of ideas between worker and client. Individuals are viewed as capable of taking a greater degree of control. Accomplishments are praised and validated. Worker prioritizes change and points toward realistic steps
- Ensuring that drug users and those with a history of drug use routinely have a real voice in the creation of programs and policies designed to serve them.

"Harm reduction approaches the participant as the expert of their story, respecting their solutions and pace. It involves the mediation of substance use through the provision of self-management strategies that are immediately effective in reducing personal and communal harm[7]

The above should only be one sentence and a footnote.

IDU HIV and Drug Addiction

IDU as significant risk factor for HIV: Worldwide, there are more than 132 million people who inject illegal drugs and in some regions more than 50 percent of them are infected with HIV. [8] Nationally,

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[4] Adapted from Hunt, N. 2003. "A review of the evidence-base for harm reduction approaches to drug use." Forward Thinking on Drugs. http://www.forward-thinking-on-drugs.org/ review2.html.

[5] compiled from Harm Reduction Coalition, Sheon, 2004 in http:///www.managingdesire.org; Brown, Luna et al.and other literature

[6] Brown, Nancy, Veronica Luna, M. Heliana Ramirez, Kenneth Vail, Clark Williams. 2005 Developing an effective intervention for IDU Women: A harm reduction approach to collaboration. AIDS Education and Prevention, 174(4) 317-333,. The Guilford Press.

[7] Majoor and Rivera, 2003.

nearly 26% of diagnosed AIDS cases were associated with injection drug use (IDU) in 2003, making injection drug use the second highest incidence of HIV exposure and transmission in the United States. In NYC, IDUs account for 23.4% of all PLWHs; NYC's IDU numbers are dropping since the City instituted needle exchange programs (December, 2004). Among Bronx PLWHs, injection drug users account for 14% of all new cases, and 29% of the cumulative total. As of 12/31/04, there were 5,743 IDUs in the Bronx – a larger number than other risk groups.
In the Bronx, HIV is the third highest cause of death (43.3/100,000) behind heart disease and malignant neoplasms. While Bronx HIV deaths are decreasing (-22.7%), Bronx deaths due to drug dependency are increasing. Drug dependency is the cause of death for 14.1/100,000, an overall increase of 87.8% from 1990 – 1997. [9] The prevalence of dangerous drug use indicates a growing risk for HIV infection, as IDUs tend to infect other drug users (by sharing injecting equipment) as well as their sexual partners and unborn children. Stemming the rise in drug addiction, as well as promoting treatment alternatives, are key harm reduction objectives.

Given the persistence of addiction, another important goal would be to reduce the harm associated with unsafe injection practices. The introduction of syringe exchange was followed by a 75% decrease in the number of HIV infections in NYC. [10] Other Bronx harm reduction programs offer needle/syringe exchange, an increasingly important component: CAB needs to update its approach to include this key resource. *No they don't.*

IDU as an HIV risk factor is actually decreasing each year.

Drug Policy: The criminalization of drug addicts

Predominant US policy fails to view addiction as a public health issue, treating it instead as a crime.

The ineffective "war on drugs" emphasizes crop eradication, interdiction and domestic law enforcement. The federal government spends approximately two-thirds of its drug intervention dollars on incarceration and prosecution and only about a third on drug education, prevention, research, and treatment combined. (Harm Reduction Educators) Drugs have become stronger, cheaper and more easily available; and more Americans are in prison for drug related convictions than ever . (OSI website) Since 1980, the number of adults incarcerated in state and federal prisons, local jails, and on probation or parole has more than tripled, with one-third of this expansion due to an increase in the number of drug law violators put behind bars (mostly women, African-Americans, and Latino/as).

A UN task force on HIV/AIDS charges repressive drug laws with catalyzing the HIV epidemic by imprisoning drug users in prisons or forced rehabilitation centers where IDU and sex continue, yet effective drug treatment, HIV prevention measures and HIV treatment are often unavailable. [11] Organized drug users view their criminalization as the cause of most of their health and social problems

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[8] Canadian HIV/AIDS Legal Network & Vancouver Area Network of Drug Users [VANDU] et al : 2006 . "Nothing About Us Without Us" Greater, Meaningful involvement of people who use illegal Drugs: A public health, ethical and human rights imperative.
[9] United Hospital Fund (uhfnyc.org/usr_doc/Bronx.pdf notes an increase of 90.8% for males, 66.6% for females age 18-64 .
[10] Soros Foundation – OSI. *Saving Lives by Reducing Harm: HIV Preventionand Treatment for Injecting Drug Users.* PDF file on website.

[11] UN Millennium Project Task Force 5 Working Group on HIV/AIDS, 2004 Interim report. UN Development Group, as quoted by OSI

– e.g. they are forced into criminal markets to buy poor-quality highly priced substances. [12] Drug addiction also has a devastating impact on communities, contributing significantly to incidents of property crime, child abuse and neglect, and emergency room visits, as well as increased HIV rates.

The need for harm reduction: In the absence of effective measures to reduce drug consumption and unsafe injection, HIV is spreading rapidly among IDUs. The risk of HIV infection associated with intravenous drug use has motivated many public health and drug abuse authorities to rethink their priorities in dealing with IV drug use, moving them toward harm reduction. Harm reduction programs help those unable or unwilling to abstain from drug use to make positive changes to protect their health and the health of others. As such, harm reduction is intrinsically linked to drug treatment options.

Other countries have more progressive drug policies – which suggest different approaches that might be embraced here. England, Denmark, Canada, Australia and Holland show greater tolerance toward drug use, and offer innovations beyond the now widespread needle exchange programs, such as subscription heroin, open regulated sales of marijuana, sanitary, monitored user rooms for safe injecting, and far more drug user involvement in setting policy and developing effective programs. The UN International Guidelines on HIV/AIDS and Human Rights,, among others, recommend drug user involvement in shaping policies and programs as an ethical and human rights imperative.

What does any of this have to do with 336 Grand Concourse? Unless you can show an actual connection to a new approach or activity for providing services, it is irrelevant to the study.

Drug Treatment Gap and Treatment Modalities:

Drug addiction is one of the most common diseases in the United States, and has many characteristics of a chronic illness – remissions and relapses, variable severity, and responsiveness to different types of interventions. It is estimated that over nine million Americans need drug treatment, making addiction more prevalent than coronary heart disease and stroke and as prevalent as cancer. (OSI)

While private treatment options are adequate, uninsured drug users need publicly funded treatment, which is relatively scarce. The U.S. Department of Health and Human Services estimates that there are over three million Americans in need of drug treatment who are not receiving services. (OSI website) *We assume that many CAB harm reduction clients may be victims of this treatment gap.* Increasing access to health insurance, engaging IDUs in drug treatment and supporting treatment alternatives can simultaneously address multiple social problems.

Types of Treatment: There are four general modalities of drug treatment. CAB staff should be aware of the resources available for drug treatment, ensuring that clients are engaged in the most appropriate model. These modalities include:

- Outpatient Drug-Free Programs provide individual, group and family counseling. Patients served are typically dependent on cocaine and/or alcohol. Programs employ a wide variety of counseling styles. Historically called "drug-free", many are now appropriately using medication combined with behavioral therapies to maximize therapeutic response. These medication-based therapies include psychiatric treatment and outpatient detoxification.

[12] Efthimiou-Mordaunt, Andira. _____. Junkies in the House of the Lord. Dissertation.

- Opioid Agonist Programs treat people dependent on heroin. They provide counseling and either methadone or Levo-Alpha Acetyl Methadol (LAAM), two medications which block the withdrawal, craving and euphoric effects of heroin. Carefully regulated by federal and state agencies, methadone and LAAM are initially administered under direct observation. A specialty area within outpatient treatment, this modality is beginning to integrate psychiatric and medical care and to broaden the range and intensity of behavioral therapies provided. Opiate substitution is the most effective form of treatment for opiate dependence and also prevents HIV among IDUs.

- Inpatient Rehabilitation Programs are designed for people dependent on alcohol or drugs. They may last several days to weeks and often use counseling techniques based on self-help programs. Medical and psychiatric screening may be available. Discharged patients are usually referred to outpatient programs and self-help groups.

- Therapeutic Communities are long term residential treatments for people who are unable to discontinue drug use through other treatments. Lasting six months or longer, they offer a highly structured program which uses behavior modification and assigns increasingly responsible tasks to resocialize residents.

Are you saying that CAB staff are not aware of this? Did you ask them when you conducted the staff interviews or before you decided to include this in the study?

Disconnect between HIV care and drug treatment:

Harm reduction programs work with people who are or have been users of diverse types of drugs -- cocaine, heroin, methamphetamine and club drugs. Staff should know the distinctions among these drugs, as well as their effects, strategies of use and appropriate treatment. Users may be anywhere on the continuum from active use to recovery, from abstainers to recreational users to severely and persistently chemically dependent. They may be at risk for various types of harms associated with different modes of administration; dose, mind set, and setting in which drugs are taken. Each of these dimensions should be mindfully incorporated in a harm reduction plan.

OSI states: " Since the beginning of the epidemic, there has been a distinct gap between HIV prevention and drug abuse treatment. The capacity to treat IDUs and the recognition of HIV transmission through substance abuse has not proportionately met the need for sustainable HIV prevention. Harm reduction and needle (syringe) exchange programs directly address this discrepancy and make this intervention in order to educate IDUs on HIV prevention and transmission. These programs, however, cannot stand alone in combating HIV/AIDS within IDU populations and require more extensive initiatives inclusive of substance abuse treatment."(OSI website)

Until recently, there has been little effort to link HIV services and medical care with substance abuse treatment. National surveys explored what types of services are specifically provided for HIV-positive

substance users through Ryan White Title II and Title I, within the context of the overall delivery system for substance abuse treatment services within states. [13]

- Only 18 states (92 provider agencies nationally) fund some form of substance abuse treatment through Title II funds, most commonly outpatient counseling. The most commonly described harm reduction services offered through Title II include pretreatment counseling, outreach and education, and prevention case management. Irrelevant.
- 88% of the Title I respondents reported funding some form of substance abuse treatment through Title I funds, most commonly outpatient counseling (75%); also residential treatment (35%) methadone maintenance 28%, acute detox 21%, inpatient treatment 14%, acupuncture detox (12%), other collateral, support services (19%). One quarter of the Title I grantees fund some form of harm reduction program through their Title I funds , largely pretreatment counseling , drop in counseling, outreach and education, case management, residential programs, and acupuncture detox.
- Top systemic barriers to care for HIV positive substance users, cited by both Title II and Title I providers were: lack of housing options, inadequate insurance coverage for substance abuse treatment, too few residential programs and detox beds. Programmatic barriers included failure to support women with children in programs, insufficient recovery readiness services, a need for more HIV training for substance abuse treatment providers, and a lack of outreach to bring people into care. Many noted that HIV positive substance abusers fall through the cracks.

These national surveys raised questions that CAB might explore. For example, does Medicaid reimburse for HIV care, prevention, support services in substance abuse treatment settings? Are HIV services collocated with substance abuse treatment? sources of funding do cover substance abuse treatment: Medicaid, other state funds, county funds, city funds, other CARE act, Medicare, private insurance, CSAT, VA) Are there Medicaid benefits for substance abusers? Are harm reduction services funded through housing sources, e.g. Shelter Plus Care? Best practice is that Title II funds provide wrap-around services for HIV-positive substance abusers. Most Title I and Title II providers nationally plan their programs without data about available substance abuse treatment slots or waiting lists or other funding streams to pay for detox or residential treatment.

This may or may not be relevant. It is hard to tell. Some of these questions are based on existing regulations and should have been further investigated before ending up in the study, it should be prepared as a list of questions for 336 GC staff. Anyway, much of it is systemic and beyond CAB resources.

[13] Ryan White CARE Act Title II Survey: Services for HIV-Positive Substance Users. Carol Tobias, Starr Wood, Mari-Lynn Drainoni. AIDS patient Care and STDs Volume 20, no 3, 2006., p. 205-212. and Ryan White CARE Act Title I Survey: Services for HIV-Positive Substance Users. Carol Tobias, Starr Wood, Mari-Lynn Drainoni. AIDS patient Care and STDs Volume 20, no 1, 2006., p. 58-67.

Complex issues of IDUs require comprehensive services :

Because PLWHA who are also drug users need primary health care, substance abuse treatment and support services, they require care delivery strategies that are comprehensive and innovative. There is a strong association between substance use and HIV disease, and data indicate that substance users are less likely to access outpatient HIV care, and less likely to receive ART than other people with HIV; they are known to experience more difficulty engaging in care.

Harm reduction services need to be embedded within an array of resources that address the multiple concerns affecting HIV-positive IDUs. Basic survival needs for housing, food, health and safety must be addressed before clients can successfully engage in higher level personal change – e.g. engaging in safe behavior. Extensive, active linkages with community supports for these issues is critical. Then harm reduction services such as counseling, case management and support groups need to be supplemented with closely coordinated or co-located ancillary services such as medical care, mental health resources, employment and training, housing, parenting, and family supports. Building in incremental rewards and incentives encourage clients to take charge of accessing the resources they need.

Are you writing a primer on Harm Reduction?

Community –level factors contributing to IDU HIV must be addressed:

Substance abuse stems from socioeconomic problems including poverty, violence, discrimination, peer pressure, and a lack of education on high-risk health practices.

The literature stresses the importance of addressing contextual variables and AIDS-related policies in order to bring about effective HIV risk reduction in general, and for IDUs in particular.[14] CDC's two-dimensional framework of structural factors (1998) defines one dimension as four barriers or facilitators: economic, policy, societal and organizational. The second dimension is the systems that implement and support each type of barrier or facilitator: government, service organizations, private business, workforce organizations, faith communities, justice system, media, educational system and healthcare system. Social and environmental consequences must be reconciled with the well-known medical effects of the epidemic.[15]

HIV/AIDS has been associated with urban environments, poverty, STDs, IDUs, and the limited participation of urban residents in the design and delivery of health services. Studies of AIDS in Harlem and the Bronx view the disease as a result of planned shrinkage, intentionally devastating people of color. They suggest that "urban desertification is related to the epidemiologic factors of sexual activity and IDU," and recommend community-level interventions such as restoration of services. [16]Economics, race, gender and societal attitudes confound HIV risk and prevention. Structural interventions such as increasing access to health insurance and health care, mandating drug treatment, promoting supportive

[14] Parker, RG., Easton and CH Klein . 2000. Structural barriers and facilitators in HIV prevention: A review of international research, AIDS (London, England) 14(supple 1): S22-S32.
[15] Akukwe, C. 2001.
[16] Wallace, R. 1990. Urban Desertification, public health and public order: "planned shrinkage", violent death, substance abuse and AIDS in the Bronx. Soc Sci Med 31 (7): 801-13. This work complements a 1990 study by McCord and Freeman [New England Journal of Medicine, 1990] on Harlem.

housing, can enhance prevention efforts: advocacy for such interventions is an appropriate component of a harm reduction program. [17]

Sexual behavior and associated risk are tied not simply to people's personal behavior and thought but to the likelihood of disease exposure in their ethnic group, the power and choices associated with power in that group and the alternative means available of meeting their overall sexual, romantic, economic and social goals. AIDS interventions must simultaneously address the individual, social and cultural spheres for meaningful change. A continuum of approaches targeting the structures and environments that influence individual behavior is needed.

Beyond the structural and community-level barriers to care, many HIV-positive IDUs are burdened with complex personal issues which complicate their treatment. For example, women who use drugs may be grappling with trauma – violence, rape, etc., male control and domination, economic hardship, and reproduction issues. Some people carry triple diagnoses of HIV, substance abuse and mental health disorders; depression is associated with addiction. The dual stigmatization of being addicts with HIV exacerbates their alienation and plummeting self esteem. Harm reduction interventions need to aggressively address these multiple layers.

The societal context is important. However, the task of the study is to make meaningful connections between societal forces and service delivery. If we can't figure out any specific service delivery connection, then it doesn'

Needle exchange section omitted: Since CAB has already said that they are not interested in needle exchange, it is not relevant to the study.

Education and Information: Because IDUs are so frequently falling through service gaps, many try to educate themselves about their conditions and choices. Supporting their quest for information, and involving them in the design of workshops, is a useful strategy. Focus group participants suggested various topics of interest (see Section Three of the Report). PLP staff suggestions for client retention (from meetings with the Harm Reduction Coalition and the AIDS Institute) included offering cooking classes, GED, smoking cessation, parenting, and poetry workshops [with Hostos Community College]. Additional training can cultivate leadership and train peers for outreach and other roles.

Organizing Drug Users and Cultivating them as Political Advocates

Marginalization and stigmatization are features of the HIV-positive IDUs experience; understanding the psychological impact of this treatment is necessary to get beyond its grip. While some drug users become paralyzed or self-destructive, others mobilize to address their collective needs.

"Whether policies hinder or facilitate primary HIV prevention is ultimately dependent on the acceptability of an intervention to those already infected and those at risk." Many authors stress the importance of actively involving people living with HIV in public health and policy leadership roles. [18]

[17] Lassarini, Z and R. Klitzman, 2002 .
[18] Peterman, T., K.M. Blankenship, D. Cohen et al. (2___) Developing social and environmental prevention interventions. Int. Conf AIDS. 13.

Self-organized drug user groups have emerged in many countries, practicing harm reduction and HIV prevention. These groups have distributed condoms and needles to injectors, trained police about drug culture, run day programs, safe injecting sites, and Hepatitis C groups, published newsletters and magazines with information on drug treatment and policies, and participated in advisory bodies setting drug treatment and HIV policies and practices. Public health experts recognize the essential role drug users play as peer educators, outreach workers and central voices in policy and program development.

Did you talk with 336 GC about this? Is this a new idea to them? Can you provide some examples (written description, websites) that CAB staff can look into?

RECOMMENDATIONS

Strengthen connections between the harm reduction program and drug treatment resources: Although some referral relationships exist between CAB and local drug treatment programs, there could be greater awareness of the drug treatment world, and alignment between the PLP and the other programs that harm reduction clients are utilizing. Harm reduction is on a continuum with more demanding forms of drug treatment. Linkage agreements with drug treatment programs, or perhaps co-located services, would sharpen this connection. *This is too vague. Give actual examples. List groups and reason why CAB should be working with them.*

Outreach and engagement: Outreach efforts can increase the number of people in treatment, engage underrepresented patient populations in care and attract patients at an earlier stage of addiction. CAB's outreach to date has the objective of bringing people in for services, but staff report difficulty in engaging new clients, and may need to devote more time, and change outreach locations and strategies in order to successfully connect with IDUs. Street outreach by recovering people or efforts to target prisoners prior to their release, are two viable options.

Individualized harm reduction interventions: Recognize that participants are in different stages of recovery or relapse, bring diverse issues and histories, and have individual priorities and capacities. They may use drugs for pleasure, to ease pain, to connect with others, and to self-medicate for psychic distress. Harm reduction approaches contend with those motivators, and attempt to help people to meet those needs with healthier, safer behavior. In keeping with the best harm reduction practices, participants should be the director of their own service plans. *How? Can you provide an example of how another Ryan White group is doing this? What are the results?*

Flexible, client-centered services: The harm reduction program can be designed as a drop in center, rather than a full day treatment program. It might operate more as a club with choices of activities or committees or support groups. Programs and training sessions as well as individualized service/treatment plans designed by the participants can be reinforced with different incentives leading incrementally to tangible steps toward "graduation" or job placement.

Are you saying that CAB should completely restructure the 336 program as a drop in center. That is a big recommendation. You have to provide reasons and show why there would be a better chance of success. Are there examples from other groups that prove this is a more successful model?

Integrate Harm Reduction with Comprehensive Services *(what does this mean)**:*** The package of services needed by IDUs includes drug treatment, HIV and general medical care, urine testing, counseling, access to medication, workforce preparation, vocational training and job placement *(these are not essentials services, they are optional)*, psychiatric care, family therapy and more.

- IDUs living with HIV face significant risk of death from causes including hepatitis C-related liver disease and overdose. CAB should collaborate with healthcare providers to ensure that clients are addressing these problems. *(is this something they are not presently doing?).*
- Health Resources and Services Administration (HRSA), through Ryan White CARE Act and in collaboration with the Substance Abuse and Mental Health Services Administration (SAMHSA) fund projects that link health care, substance abuse treatment and mental health services for PLWH. CAB may wish to pursuing this funding, as a joint effort with local hospitals and drug treatment programs. *How likely are they to get this funding? Did a NYC group get funding? What did they do with it? Can some of this be done with existing Ryan White funds?*

Interagency Service Integration: Good communication between agencies that interact with the same patients is an essential feature of quality care. If CAB is linked with other agencies for ancillary services, or developing plans for co-located services, ongoing case conferencing and other forms of service integration are important. *I thought CAB already had these linkages. Are you suggesting other ones? Which ones?*

- Enhanced service coordination within CAB: *PLWHs need housing, childcare, recreation, nutrtition, etc. and CAB already provides it……need better mechanisms for internal referral and resource utilization.*

Strengthen Support Groups: Focus group participants repeatedly mentioned the need to change "people, places and things" in order to fight their addiction and develop healthier alternatives. Many are newcomers to the Bronx, having intentionally left family and old habits behind, or moving from a residential drug treatment program or shelter, or living in an SRO. They are seeking community and structure. Ongoing support groups provide an alternative community which has been effective in engaging IDUs and maintaining them in harm reduction programs. Group members can help each other with treatment adherence and medication management, and provide support for making personal changes. Skilled staff leadership of support groups is essential, and trained peer leaders would be welcome.

Offer HIV Testing: The New York City Health Department estimates that over 90% of injection drug users (IDUs) linked to services (e.g. substance abuse treatment; syringe exchange programs) have been tested for HIV. However, barely 10% of IDUs not in such services have undergone HIV testing. Promising strategies to reach IDUs include models that recruit through social networks, and offering Hepatitis C testing alongside HIV testing. [19]Community based sites account for more than 50% (40,000 tests) of the HIV testing in NYC. The New York State Department of Health's 2005 Guidance for HIV

[19] HRC letter to CNYC Health Commissioner Dr. Thomas Frieden, 2/16/2006. on website.

Counseling & Testing has dramatically simplified and streamlined requirements for HIV testing. CAB may want to consider adding HIV testing, Hep C testing and possibly urine tests for IDUs.

Work with families and community supports: Behavior change occurs within the context of a social milieu. This begins with agency-based support groups, which create a safe space and new relationships. To successfully transform and reintegrate participants back in to the community, assistance in restoring or replacing their "outside" social networks is essential. IDUs, perhaps more than other PLWHs, have to overcome dysfunctional relationships and stigmatization. They need help to cultivate the acceptance, understanding and support of families and new friends. Counseling, support groups, social events, entertainment and classes are options for fortifying positive social networks. *This is very difficult for any CBO to undertake. Are there examples from other groups here? What about clergy partnerships?*

Expand the counseling repertoire: Given the complex mental health needs of the typical harm reduction client, CAB should either develop a mental health component, or link with a psychiatric service provider. Absent those connections, the staff should cultivate a broader range of counseling / therapeutic techniques in order to work more deeply with individual clients and groups.

- Three strategies include *cognitive-behavioral therapy; behavior therapy / dialectical behavior therapy*; and *psychodynamic therapy/ relational analysis*. (see North Central Bronx example in Best Practices)
- *Use Motivational Interviewing*: Incremental change in the direction of recovery has been supported by the use of "motivational interviewing", a technique coined by Miller and Rollnick, (www.motivationalinterview.com). Motivational Interviewing is defined as "a client-centered, directive method for enhancing intrinsic motivation to change by exploring and resolving ambivalence" (Miller and Rollnick, 2002). It is a way of talking with clients about changing aspects of their behavior in a way that minimizes resistance and increases the probability that some change will occur. It has been effective in facilitating behavior changes, including drug user's injecting practices and sexual behavior. Trainings on this technique are available through HRC (see appendix).

Is this new information for the CAB staff? Have other groups been successful with incorporating the motivational interviewing techniques into their client work?

Use Incentives / Behavior Modification: Drug users respond well to incentives or immediate pay-offs each time they receive services or take a step toward their treatment goals. Effective harm reduction programs utilize a variety of incentives: reimbursement for travel, metrocards, nutritious snacks, prepackaged meals, extra syringes, health and safety kits, stipends, education reimbursement, access to job training programs, and implementing a service fund to pay for the treatment of choice as requested by individual consumers. Several programs tie employment as peer educators or other vocations, to achievement of personal goals. Should the PLP develop a workforce preparation component, this enticing incentive will be readily available.

Interagency collaboration around system-wide service and funding issues: CAB could be more present and vocal in the **Bronx HIV Care Network**, which has committees that address substance abuse and case management, among others. Their collective advocacy efforts around funding and services are also important. As recently as 2002, CAB was involved with 14 other agencies in the *Bronx*

HIV Community Consortium, a joint advocacy and service effort that acted as a central referral network formed in 1996 and originally led by Bronx AIDS Services. [20] The referrals through this network might be helpful now.

Return the PLP to incorporate principles of Harm Reduction. (see background information above) Design the program so that it is tightly integrated and aligned with harm reduction principles and practices. Ensure that it is user-friendly, client-centered, and incorporates incentives toward growth and self-sufficiency within a supportive social milieu. Harm reduction distinguishes harm at different levels - individual, community and societal - and of different types - health, social and economic . There are three types of harm reduction strategies:

- Harm reduction approaches with drug using clients: Direct services
- Modify the environment to reduce drug-related harm
- Implement public policy changes

CAB's harm reduction work should aim for all three levels. It currently addresses only level #1. *Can you provide any examples where CBO's are successfully addressing the other two levels?*

Improve Community-level conditions: Harm reduction approaches are intended to create positive changes on the communal level. CAB has thus far focused on services to individuals, without attending to community-level conditions that contribute to continued drug use and HIV transmission. Community organizing interventions around violence prevention, improved access to low-income housing, youth leadership development, creating parenting supports, civic participation, strategies to reintegrate returning prisoners, activation of faith based support networks – would transform the environment into one that provides more structural supports for IDUs and all PLWHs. Perhaps other departments at CAB are cultivating such community supports – strengthening internal links would be helpful. *Can you provide any examples where CBO's are successfully organizing on a community wide basis and at the same time, can show how these activities are directly helping the HR clients? CAB needs to see real life examples.*

Organize Drug Users: Provide leadership development and organize the PLP consumer advisory board, ensuring that it represents drug users in the harm reduction program. Meaningfully involve clients in program decisions and plans. Develop ways to involve clients as peer educators and outreach workers, with stipends or other compensation. Cultivate CAB clients as spokespersons on the HIV/AIDS issues of importance to them; help them to participate in larger PLWHA groups.

Engage in Advocacy and Policy Work: Senior staff expressed awareness that the agency has not committed to doing advocacy around HIV/AIDS, but it is clear that CAB's expertise and standing in the Bronx would make them a key player. They could work with other CBOs in borough-wide and citywide groupings, connect with the city's Prevention Planning Group and HIV Planning Council, and the State Health Department's AIDS Institute. CAB can participate in citywide deliberations about HIV testing, care, and treatment options, contributing the expertise of staff and clients in shaping effective programs.

[20] original members were: BAS, CAB, Allied AIDS Services, Community Healthcare Network, Dominican Sisters Family Health Service, Highbridge-Woodycrest Center, Morris Heights Health Center, The Osborne Association, Project Return Foundation, Inc., Promesa, Services for the Underserved, United Bronx Parents, Urban Health Plan, Inc., and VIP Community Services.

Systems Change: Although this may be a stretch for the PLP, CAB should strive to place its harm reduction work within the larger context of systems and structural change. As a settlement house involved in most aspects of family and community life, CAB is uniquely situated to embrace this broad perspective. A respected community leader and advocate, CAB has the legitimacy and vision to help the Bronx understand the political and economic environment that fuels its AIDS epidemic, and develop collaborative means to transform that environment.

Staff Composition and Development: Throughout the literature, IDUs respond well to staff and board members who are HIV-positive with a history of substance abuse, reflective of the ethnic/racial composition of the population, who are trained and prepared to lead groups and act as role models. Staff preparation is needed to help them to engage hard core drug addicts, lead support groups discussing personal and sensitive topics, convey expertise on medications management and other technical information, work with complex and challenging individuals, and cultivate leaders and advocates. It is also important to have a political understanding of the causes of marginalization and its effects on clients and service providers. CAB staff suggested an interest in training on stage-based counseling for outreach workers, Safety Counts training from CDC, training on safe injection, different drugs and Hep.

This should be looked into. Have other groups found this to be helpful? How was it done? Is this a tie in with the practice of paid peer workers?

C. Training and support resources are included in a separate appendix to this report.

Section 5. Action Strategy Recommendations

1. **Respond to the documented geographic mismatch between the geographic distribution of services and clients:** CAB should conduct outreach to PLWHA's who live in outlying Bronx neighborhoods. Complementary service partnerships should be developed with the few Ryan White providers that have sites in these neighborhoods and/or establish referral relationships with other CBO's (with no direct PLWHA's programming) that operate in these neighborhoods.

2. **HIV+ 50 years and older.** Big gap in the Bronx. CAB has the expertise, capacity and client base to respond to this new and fast growing area of need. Foundations are already giving grants for this need group. In 2006 New York Foundation gave the JAMAICA SERVICE PROGRAM FOR OLDER ADULTS $42,500 for an HIV/AIDS educational awareness and prevention program designed specifically for older adults.

Gay Men's Health Crisis (GMHC) has been awarded a $500,000 grant from the MAC AIDS Fund to develop an initiative that will meet the needs of people over the age of 50.

3. **Building on the strength and niche of the Settlement House Model.** CAB already runs a wide range of programs for seniors, children and youth, families, and adults in need of workforce development. Most of these programs overlap with the Positive Living Program. Intra-agency collaboration could strengthen the PLP and help launch new programs and expand community building efforts.

4. **Transition to work programming:** CAB has the workforce development and case management in house expertise and resources to launch a *Transition to work program.* While the majority will not seriously try to work, there is a significant number, as high as 30% of participants, who want help here. These clients want help with workforce preparation or re-entry, GED, ESL, Adult Basic Education career track training and job placement. Clients must be assured that their government benefits won't be affected. Case Managers must be able to guide clients regarding what if any changes there will be with there government benefits. There are foundations and some government funding sources that may look favorably on this as a demonstration program.

5. **Harm reduction best practices:** Most important priority is moving Harm Reduction program to a better located site with more space for programming. *In Section Four of the Report are recommendations for Harm Reduction programming.*

6. **Bronx wide activities:** CAB should try to incorporate into its other family programming efforts to reduce the stigma of having AIDS as well as educating people about AIDS.

7. Bronx HIV-AIDS Public Policy. Post Section 2 of the Report on the CAB website. This information is presently not available. The Bronx PLWHA's demographic documentation and analysis is an important piece of information. Practitioners can benefit from it. It will also help increase the profile of CAB in the area of AIDS policy and advocacy.

8. **Client incentives.** Incentives have to be increased if CAB wants to see an increase in participation in PL other than case management. Another big source of incentive is offering opportunities for peer to peer education and support services. PLWHA's who

have reached a point of acceptance of their own illness are often zealous about getting the message out to others. Peer outreach and education is a win-win strategy for programs and certain HIV+ participants. Other incentives include food coupons, free lunches at support groups, pharmacy discounts, toiletries, clothing, metrocards. (e.g. if people show up for x days, they get a metrocard). Some groups spend a lot of time raising community funds and donations for incentives.

9. **Focus groups offer an unfiltered view into the every day lives of a diverse range of Bronx PLWHA's.** . The comments and suggestions covered a wide range of issues. Some were devoted to how providers can be more consumer friendly or sensitive; others were about needed changes in perception in the at large community. There were interesting suggestions and ideas for community wide programming and organizing efforts around how to change people's perceptions about AIDS**.**

10. **CAB-PLP staff conference workshop:** CAB PLP staff should review the focus group suggestions and comments and determine which ones are most helpful for making improvements to the PLP programs. (the full list begins on page). A useful exercise would be to take the comments and present hem in a workshop format at the next PLP half day internal staff conference.

11. New suggestions for locations for outreach.

For all groups

- Welfare office
- Hospitals (meet directly with patients while they are there)
- HASA; specific housing and supportive housing sites

Women

- health care providers – especially family medicine, gynecologists, OBGYN docs
- schools
- day care centers
- places of worship / faith communities
- flyers in local stores and agencies
- health fairs, health events

HIV-positive people over 50

- Fordham Road – shopping district
- Third Avenue - shopping district

- Subway
- Supermarkets
- Laundromats
- Veterans Administration

Drug Users

- Shooting galleries / street
- Needle exchange sites
- Halfway houses
- Rikers Island
- Drug treatment programs

12. **Foster stronger collaboration with churches especially the African American church**. Many of the issues and problems raised by focus group participants will take years to change. The most strategic collaboration to be made here is between CBO's and churches. Latino and African American focus group participants had different experiences with their churches. Over the past few years, an AIDS network of concerned clergy has been growing in the Bronx. A full time community organizer position devoted to working with local churches is very much needed. Also, people improve with some spiritual dimension to the work. A connection to a higher power or vision, rather than religious dogma. Link to sensitive clergy who could visit at scheduled times might provide mutual access (recruitment for membership in religious institutions; client contact with caring clergy; agency connections to clergy who can make ongoing referrals…..).

13. **Success with Rapid Testing will require creative strategies:** the best place to start might be with CAB's own youth programs. What kind of incentive do they need? What about their friends and more hard to reach youth? Would they get tested if there was a testing van at a street fair with well known Hip Hop performers.

14. **Market both CAB PLP and other CAB Programs**: many focus group participants were not aware of CAB's housing and eviction prevention programs or other CAB programs. CAB needs to continue to publicize both its PLP and related programs to Bronx residents.

Section 4. Appendices:

1. Copy of Questionnaire used for the Staff and Community Interviews

Interviews that were conducted for this study:

CAB STAFF:
*Scott Auwarter
*Bibi Karim
*Jessica Houk Smith
* Miriam Rabban
* Kara Schackett
* Tyler Griswold
* Felicia Thomas
* Keona Serrano
* Barbara Richardson
* Leslie Shaw
* Ellen Friedman, CAB adolescent program
* Sierra Hare, CAB proposal writer (formerly with PLP)

OTHERS:
* Chris Norwood, Health People
* Socrates Caba (Chairman, Bronx HIV Planning Council)
* Reverend Christine Jackson Bronx Faith & Medicine Health Access & Outreach Program, Albert Einstein College of Medicine
* Don McVinney, Harm Reduction Training Institute, National Training Director
* Marion Reidel, Consultant with HRTI, Columbia University School of SW

Very brief " best practices suggestions" talks with:
* Fran Barrett, CRE
* Matthew Lesieur, NY AIDS Coalition
* Donna Futterman, MD, Montefiore Adolescent Aids Progam
* Doris Russell, GMHC Women's Institute
* Reena John, HIV Women's Collaborative

2. Full Copy of Focus Group Question and Answers:

- Men who have sex with men
- 50 years of older
- Drug users
- Women

4. Harm Reduction Best Practices Research

- Training materials
- citywide resources
- curricula

BEST PRACTICES / MODEL HARM REDUCTION PROGRAMS

The Open Society Institute – Soros Foundation - supports a citywide effort in **Baltimore,** Maryland, to address the combined needs of HIV positive people with a history of substance abuse. Their effort is not a model for CAB, as it is on a different scale – it promotes systemic change (e.g. creating the infrastructure for citywide drug treatment on demand capacity; connecting Baltimore with NIDA for clinical trials), but their findings are instructive. They believe that "the integration of services targeting poverty-related barriers to self-sufficiency is an important approach in the treatment of drug addiction among marginalized populations."(OSI website) They have found that drug users seeking publicly funded treatment in Baltimore have a variety of social problems that impact their prognosis -- unemployment, limited education, few job skills, homelessness, and drug availability. Recognizing that drug treatment alone cannot improve their lives, OSI funds programs that integrate ancillary community-based services and resources. They support one-stop shopping or comprehensive case management models that connect IDUs with medical and psychiatric care, recovery housing, family therapy, and job training and placement. Effective programs tend to use incentives to encourage follow-up on referrals. OSI notes that "addressing these needs through targeted services increases the likelihood that marginalized, recovering drug dependent people will both reduce drug use and become productive and valued members of their families and communities."

How old is this study? What have they learned so far? How do they measure success?

The Lower East Side Harm Reduction Center, a pioneer in the harm reduction field, operates a comprehensive program for HIV-positive IDUs that includes a mobile health unit, syringe exchange, acupuncture, a Hepatitis project, holistic health, volunteer program, men's program, special women's programming, peer education, and mental health services. Their holistic services are accessible on demand, and they provide various ways for clients to participate.

Street outreach to active drug users engages typically disenfranchised people and coaxes them into contact with services. Weekly "walkabouts" by a small team distributing supplies, reach over 1600 contacts a year. A drop-in center is their base for ongoing agency activities. Their Vital Services Program provides crisis intervention, substance use counseling, case management and mental health services, involving a case manager and various specialists in addressing acute issues for new clients. Psychiatric social workers conduct individual assessment, treatment planning, referrals, and supportive counseling customized for PLWHs; a psychiatrist is on site weekly for psychotherapy, medication management, referrals, and other mental health services. This is an example of how one harm reduction program can address multiple client needs.

A drop in model is a big change (and we don't know if that is the answer. When the HR program was at a different location, it had high numbers) Did you interview them? What would they attribute to their high number of contacts. How do they measure program effectiveness?

St. Ann's Corner of Harm Reduction (SACHR) [21]

SACHR is located 312-314 Cypress Avenue, in the Bronx, and services clients who are mostly Latino (over 70%), and African-American, high-risk injection (or other) drug users and people who have unprotected sex. SACHR utilizes a one-stop shopping approach, offering multiple, holistic services through five components. Their model affirms relationships and helps participants to become "the creative directors of their own lives", developing the capacity to change from victim / reactor to self-directed agent. Clients work with addiction specialists, using *Motivational Interviewing* (Miller & Rollnick, 1991) and a *Stages of Change* model, following their own treatment plan. At each stage, comprehensive services are tailored to individual needs and resources, and participants learn alternative survival strategies.

Each intervention is a step in a continuum of improvement, following Maslow's hierarchy of needs.

1. Palliative Care – Initially clients are engaged by addressing their physiological / survival needs– providing food, shower, hot drinks, syringes, condoms, clothes, boots, sleeping bags, or an indoor space to stay. Meeting these needs provides a sense of safety and self-worth that lay the cornerstones for the changing of high-risk behaviors.

2. Stress reduction – This second level attempts to heal and renew the body, stir spiritual awareness, and help people to be more interactive. SACHR provides sanctuary space for centering and reflection, listening to music and body work to change stress levels, support relaxation and condition the urge for thrill-seeking. Having a safe space to be helps participants to shift to a different mode.

3. Provide wide range of information – This component addresses the mind, to increase awareness of ideas and options, and make the participant his/her own change agent.

4. Healing and empowerment - This component addresses Maslow's needs for belongingness, love, and esteem. Participants gain support to heal from past wounds and gather power for upcoming changes. Support groups and mental health services – crisis intervention, assessment of psychiatric disorders, regular counseling – produce greater self awareness. Interventions move from primarily individual to more relational. Social skills are taught as participants gain knowledge and implement new learning – steps toward changing high risk behaviors. (*Social learning theory)* Support groups provide an alternative to the world of dysfunctional drug use, help participants to form a new alternative community, be affirmed, and self-transform.

5. *Social Integration* – The agency supports participants in their journey back into society, as self-regulating individuals. Case management monitors the pace of change, helps clients to gain more independence, negotiate their environment, and gain support from their community social network.

New York Harm Reduction Educators (NYHRE) views harm reduction as an evolving set of practices and collective wisdom. Their program provides mobile outreach, needle exchange and harm reduction on the streets of the Bronx. NYHRE's program incorporates "harm reduction building blocks" or components that reflect a particular consciousness about working with active drug users and other marginalized people. These include:

[21] SACHR: An example of an integrated harm reduction drug treatment program.
By Bart Majoor and Joyce Rivera. December 17, 2003. Science Direct Journal of Substance Abuse Treatment.

Acknowledgment and Acceptance
Accessibility
Accommodation
Incremental Changes - Baby Steps
Behavior versus Consequences
Capable (drug users as)
Client-centered
Continuum (drug use as a)
Incremental Change
Choices
Coping mechanism (drug use as)
Culturally Appropriate and Sensitive
Drop-in
Drug user (versus drug abuser)
Environments
Goals
Incentives and Retention
Meeting Users Where They Are
Remaining Non-judgmental
Patience
Respect
User friendly

Each of these components can be described in detail. For example, being user friendly means being easy to understand, easy to use, comfortable and stress free. It means that:

- Service is on-demand
- Service is provided in a one-stop-shopping environment
- Directions are easy to follow, tasks are manageable, and people feel welcome.
- Treatment regimens are designed to be easy to follow.
- Procedures are not unnecessarily intrusive
- Rules and regulations are not coercive or punitive.
- Waiting and examining rooms are warm, friendly, and comfortable and waiting times are short.
- Forms consumers fill out are short and easy to complete.

Santa Clara County HIV/AIDS Prevention and Control Program[22]

This is an example of an interagency collaboration on engagement and education of female IDUs. In April 2000, the California State Office of AIDS funded the Santa Clara County HIV/AIDS Prevention and Control Program to offer a series of four prevention workshops in conjunction with sexually transmitted infection and HIV counseling and testing, to female IDUs or partners of IDUs. The goals were to teach women to recognize their own HIV risk, inform them about local health services, and encourage them to initiate and sustain drug-related and sexual practices to prevent HIV. Four agencies, evaluated by Palo Alto Medical Foundation Research Institute, collaborated on the intervention.

The design included four group sessions, providing education, referrals and on-site HIV and STI counseling and testing. The initial workshops were:

[22] Brown, Nancy, Veronica Luna, M. Heliana Ramirez, Kenneth Vail, Clark Williams. Developing an effective intervention for IDU Women: A harm reduction approach to collaboration. AIDS Edcuation and Prevention, 174(4) 317-333, 2005. The Guilford Press.

1. Infectious Diseases: HIV & Hepatitis. How people get infected with HIV, women and risk, risky behavior, hepatitis – avoiding it and/or living with it

2. Nutrition and Self Esteem: what is a well balanced diet, vein care, living with HIV or hep, thinking positive and feeling food about ourselves

3. Safer Injection Techniques And Local Resources: needle exchange, cleaning needles, finding and using local resources

4. STIs and Safer Sex: using male and female condoms, making safer sex fun, how STIs are transmitted, how to avoid STIs.

Recruitment strategies for workshops included outreach by staff and flyers distributed at places where IDUS congregate, including local methadone center, sober living environments, clinics, needle exchange sites, gay, lesbian and bisexual community center, homeless shelters, local women's jail.

Participants received incentives for being tested, for returning for test results, and for attending each workshop. Different agencies hosted each workshop, providing space for testing and babysitting, someone to greet women, babysitter, and a warm nutritious meal. Questionnaires assessed how each participant's life was impacted by IDU, how they heard about the workshop, the perceived benefits of participation, need for additional info, and suggested changes.

Participants continued to request additional workshops and seven were provided -- overdose prevention, women's sexual rights, domestic violence, substance abuse treatment, Hep B and C- communication, and abusive relationships. Sexual partners were invited to attend "the fifth workshops"; separate workshops also offered for bisexual, lesbian, and heterosexual couples. With each session, more women wanted to participate on a deeper level, as they felt ownership and empowerment. They received mentorship and outreach training, and then helped recruit participants for other workshops. The agencies also provided additional services suggested by the participants: a women-only needle exchange; clothes closet – free work clothes; food baskets, holiday gifts for families, toiletries, outreach and mentorship training, and a referral table at each workshop.

Advice: Word of mouth was the most successful outreach strategy.
Rapid HIV or STI testing should be available to ensure that women receive results.
Participants can be incorporated in the planning and evaluation of services and programs. Participants should be given support, training, and technical assistance required to function as peer educators.

North Bronx Healthcare Network Growth and Recovery Program[23]

This is an adult outpatient substance abuse program at North Central Bronx Hospital and Jacobi Medical Center. Unlike harm reduction, this program has abstinence as its goal; patients often have mandates for treatment from the legal system, child custody, and/or public assistance services. This

[23] Futterman, Roy, Maria Lorente and Susan Wilverman. North Bronx Healthcare Network. Beyond Harm Reduction:L A New model of substance abuse treatment further integrating psychological techniques. J of psychotherapy Integration. 2005, Vol. 15, no. 1, 3-18.

network utilizes promising psychological techniques that are effective in work with drug users engaged in relapse prevention. These focus on what happens in treatment in an attempt to make changes in patients' life outside of treatment. Three strategies include *cognitive-behavioral therapy* (Safran & Segal, 1990); *behavior therapy / dialectical behavior therapy*; and *psychodynamic therapy/ relational analysis*. The Network has attempted to integrate these practices in their substance abuse treatment model. They also include a vocational /job placement component, which can be instructive for CAB. Principles of their practice include:

1. Psychological and substance abuse treatment should be integrated and administered comprehensively.
2. Aggressive efforts at engagement and retention of patients for the long term is a priority.
3. Development of a sense of community, creates a treatment alliance to the program as a whole, is critical for difficult psychological and recovery work to be done.
4. Full integration of vocational rehab services and overall functional improvement maintain long-term sobriety.
5. Process orientation is crucial for treating prevalent characterological issues.
6. Support and ongoing training of a professional staff are necessary for clinical success.
7. Psychodynamic and cognitive-behavioral psychological techniques should be integrated in treatment.

Sessions highlight behaviors, process. Promote insight, behavior change, symptom relief. Theory and techniques of relapse prevention are also used. Patients are encouraged to discuss each relapse to discern triggers that led up to the relapse and plan ways to notice them. *Motivational interviewing techniques* are also employed to help patients explore their ambivalence about substance use.

This customized program includes:

- Comprehensive integrated services for substance abuse and psychiatric care (with medications)
- individual counseling
- vocational rehab
- recovery groups – 12 step, relapse prevention, psychodynamic therapy, men's women's community meetings,
- cognitive-behavioral skills training – e.g.. Anger management and stress reduction
- acupuncture.

Patients stay in the program from 6 months to 1 year and then enter aftercare, weekly or biweekly sessions with care coordinator, perhaps combined with aftercare group, individual therapy, visits with vocational counselor.

Psychodynamic Exposure Therapy: helps patients to discuss their emotions, rather than avoiding them. They are encouraged to cross-talk freely and engage each other, describe and feel their emotions, set the agenda, discuss what they miss about using drugs. Behaviors toward group leaders and therapists are highlighted and explored – patients are given feedback and comments on their behavior. Aggressive efforts are made to engage and retain patients in treatment. Treatment interfering behaviors are addressed directly, before they escalate into relapse.
Intertherapist cohesiveness and collegiality provide a positive model for patients. Patients feel a strong sense of community in the program, and program itself becomes a secure base. Patients develop a trusting treatment alliance that becomes a fundament for their tolerance of interventions that are harder to swallow.

Vocational Integration: Everything in the program is prevocational: attendance, tardiness, quality of participation are important for referral to vocational and educational services. Vocational assessment and prep work immediately. These goals are critical for maintenance of sobriety post-discharge.

Functional Improvement: Within the first 90 days of the Growth and Recovery Program, patients are able to have stretches of sobriety, or indicate a clear need for a different type of program. Patients learn various relapse prevention skills, CBT skills re: anger management, and more, and gain the capacity for direct communication and healthier relation to their own emotional life.

These examples of best practices could be a starting point for working with the 336 program. Did you get a chance to discuss any ot them with Miriam?