



Report 2004-1

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Service Gaps and  
Utilization in the  
Continuum of Care in  
New York City

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**C.H.A.I.N. REPORT**

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## Introduction

In earlier CHAIN reports and articles drawing upon data from the New York City cohort it was evident that ancillary services had a profound and statistically significant effect upon increasing individual's entry in to medical care and retention in medical care (see Messeri, Abramson et al, 2002; Abramson, Sanger et al 2001)<sup>1</sup>. Case management, mental health services, drug treatment, and housing services were all positively associated with facilitating individuals' engagement with the medical care system. Conversely, unmet needs and service gaps among these key categories were negatively associated with entry and retention in medical care.

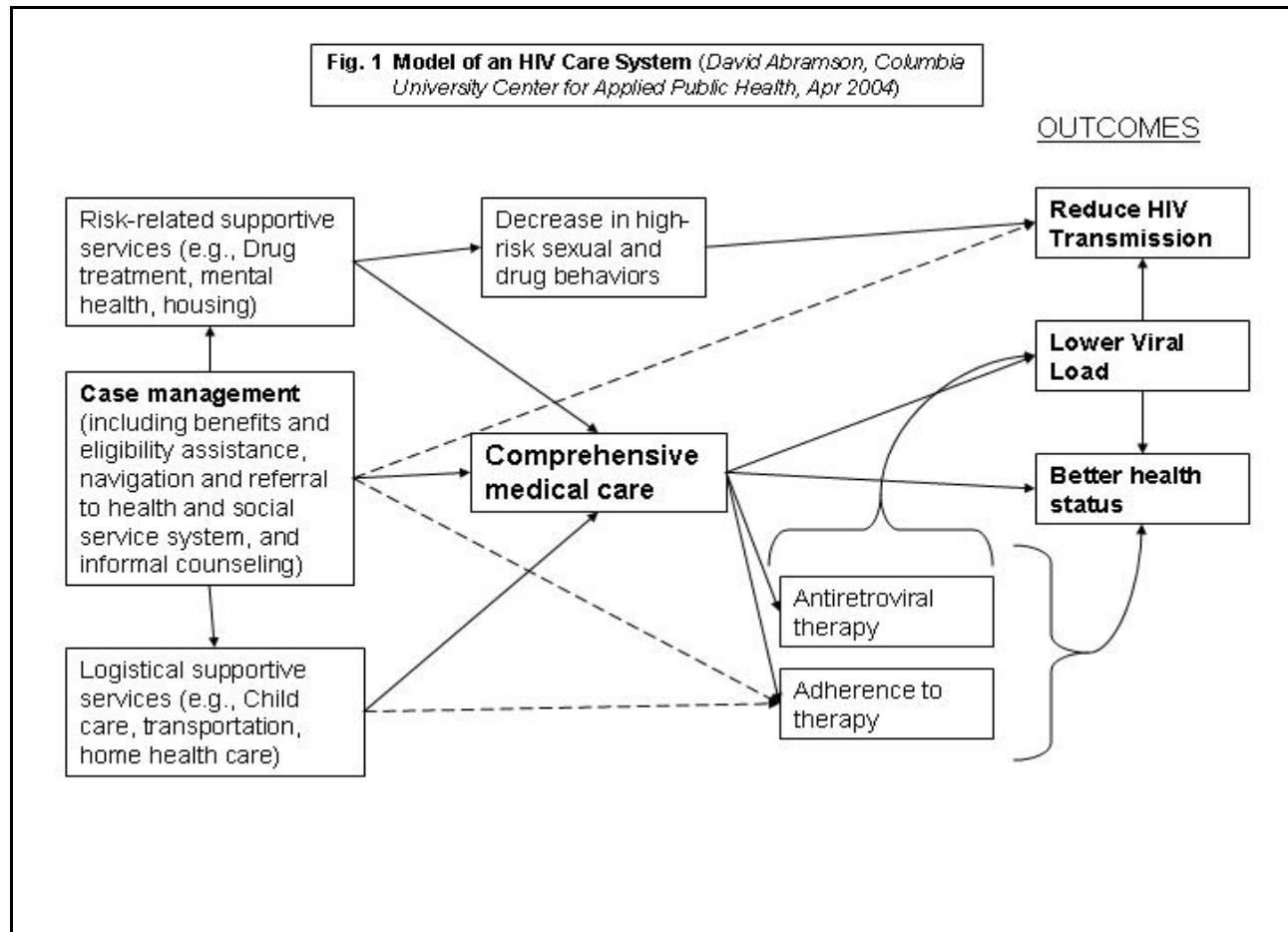
This report is an effort to provide a comprehensive look at service gaps and utilization within the continuum of care for respondents in the newly recruited NYC CHAIN cohort. Underlying the notion of service gaps is that of a system of care. Figure 1, on the following page, illustrates an "ideal" model of an HIV care system, one that encompasses both health and social services within in a continuum of care. The premise of such an HIV care system is that all the components within a system contribute – either directly or indirectly – to desired outcomes. This particular model HIV care system considers three desired end-points: (1) Better physical health for HIV-positive individuals, (2) lower or undetectable viral loads, and (3) a reduction in HIV transmission from HIV-positive individuals to others. Each component of the system has a role to play in achieving these outcomes. Central to the model is comprehensive medical care, which we have adopted from a World Health Organization definition as medical care that includes appropriate diagnosis and treatment of medical conditions; preventive care and well visits; and easy access to a medical provider for routine information and advice, as well as that needed in the case of urgent medical issues. Such comprehensive medical care plays an essential role in facilitating appropriate therapy and disease management. Ideally, comprehensive medical care should result in maintaining or enhancing a patient's immune status (evidenced by stable or increasing t-cell counts and by a patient's sense of better health status), and by decreasing a patient's HIV viral load, which should delay disease progression and also lead to decreased transmission of HIV to others.

Much like medical care, case management also plays a central role. Comprehensive case management has been shown to assist individuals in engaging with medical care and maintaining continuity, either directly or through risk-reducing supportive services (such as drug treatment or mental health services) or through logistical supportive services (such as transportation or child care). Service gaps – wherever they exist – are the "unwanted detours" in such an HIV care system, the very places where the system does not operate optimally.

In thinking about the ways that the components of such an ideal HIV care system work, consider that a comprehensive case manager might determine a client's need for risk-related services, such as professional mental health counseling or drug treatment, facilitate the referral

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<sup>1</sup> See D Abramson, N Sanger, P Messeri, MA Chiasson, "Assessing the Impact of the Ryan White CARE Act on Health Outcomes in New York City," report to the Health Resources & Services Administration, Nov 2001, and P Messeri, D Abramson, A Aidala, F Lee, G Lee, "The Impact of Ancillary HIV Services on Engagement in Medical Care in New York City," *AIDS Care*, 14(Suppl):S15-S30, August 2002.



and access to such a service, and also assure that the client has high-quality comprehensive medical care. The risk-related supportive services should help the client decrease or manage his or her high-risk behaviors. A comprehensive medical care provider should assess a client’s need for appropriate HIV treatment and antiretroviral therapy, and assist the client in adherence strategies or refer the client to someone who can help. With appropriate treatment and sufficient adherence, the client should feel better and have an enhanced immune system and an improved virologic status. The combination of decreased high-risk behaviors and a suppressed HIV viral load should also lead to a lower probability of the virus being further transmitted to others. This represents an ideal pathway through the system. Although the reality of people’s lives will often diverge from such an ideal, the system should exist to maximize the best possible outcomes for individuals and whole populations.

*Structure of this Report*

There are two primary sections within this report – Service Gaps and Service Utilization. The service gaps section focuses on twelve sentinel measures across six major service categories (health, case management, housing, mental health, alcohol or drug treatment, and transportation), covering tables 2 through 10. The service utilization section (tables 11 through 14) examines service use patterns for individuals and subgroups in the CHAIN cohort.

For most of these analyses, data were drawn from the baseline NYC CHAIN cohort II survey. A number of previous CHAIN reports have described the sampling strategy, study protocols, and cohort characteristics (see the Data & Methods section at the end for a brief description). The 622 respondents were drawn in 2002 - 2004 as a representative sample of HIV-positive adults in the system of care in NYC. These individuals represent the first 622 of 684 in the newly recruited NYC CHAIN cohort II. In addition, selected comparisons were made between the Tri-County cohort and the second NYC CHAIN cohort.

Several important caveats are in order for any reader. One should use great caution in interpreting any numbers or percentages in which the denominator (that is the size of the subgroup) is smaller than 50 people. In such instances, percentages will vary greatly, not be comparable or equivalent to groups greater than 50, and generally be very unstable.

Finally, where possible we have indicated statistically significant differences with the use of asterisks. Our convention is that a single asterisk is significant at the .05 level, two asterisks at the .01 level, and three asterisks at the .001 level.

### **Service Gaps**

Table 1 illustrates how needs and service gaps have been defined for 12 sentinel measures. These measures were selected and refined after a series of public presentations in both New York City and Tri-County as well as the convening of a Tri-County provider advisory group and consultation with the Westchester Department of Health and with the CHAIN Technical Review Team. They are not intended to cover every service funded within an HIV system of care, but rather to represent guideposts for assessing the system. These measures were also limited by the data collected in the CHAIN survey, which although it includes over 900 variables is still dependent upon a respondent's self-report. As such, a service gap may not measure directly whether the client received a particular service, but rather whether the client *perceived* receiving a specific service. This still provides powerful evidence. If a client believes that he or she has not received any case management (and cannot even identify anyone who has attempted to help them), one could argue that even if a case manager has provided services for a client it has likely had little impact.

CHAIN data may be used to measure "subjectively expressed" and "objectively assessed" needs. To illustrate, if a client reports that she needs or has sought out housing services, that is subjectively expressed by the client herself. If, on the other hand, a client reports that she has been unstably housed in the past 6 months – perhaps doubled-up on a friend's couch – that would be regarded as an objectively assessed need. If either is present, the client is regarded as having a need for housing services. A service gap would exist if the client reported that she had not received any housing services in the prior six months or she isn't living in specialized AIDS housing (which could be construed as a potential "solution" to her housing problems). For some health services, such as comprehensive medical care and patient/provider communication, it has been assumed that all HIV-positive adults have a presumptive need for that service.

### Key Findings

- In order to establish a service gap, we first identify the people with a specific need, and then look to see how many with that need are not receiving the corresponding service. That proportion, of “not receiving service” divided by all those with a need, represents the service gap. In first looking at need, the areas of greatest need are comprehensive medical care (100% of respondents have a need for comprehensive medical care), patient/provider communication (100%), comprehensive case management (75%), treatment adherence (71%), and alcohol and drug treatment (71%) (see Table 2).
- Among people with a specific need, those areas with the greatest proportion of people not reporting a corresponding service are transportation services (77%), alcohol or drug treatment (70%), and professional mental health (63%) (see Table 2). However, one can estimate an “absolute” measure of service gap ranking by multiplying the service gap proportion by the proportion with need. For example, looking at alcohol or drug treatment, 71% of the cohort has a need for AOD treatment, and 70% of those individuals report a service gap, in that they did not report receiving AOD treatment. In order to understand how many people this represents in the entire cohort, one would multiply  $.71 \times .70 = .50$ . This means that half of the cohort has a service gap for AOD treatment. ***The result represents the proportion of the entire cohort who are experiencing a particular service gap.*** Using this method, the ***top five service gaps*** for the cohort are:
  1. alcohol or drug treatment (50% of the entire cohort)
  2. patient/provider communication (38%)
  3. comprehensive case management (30%)
  4. comprehensive medical care (24%)
  5. professional mental health (23%).
- In comparing the NYC and Tri-County cohorts (Table 2) many of the needs are remarkably similar. There are significantly larger service gaps in NYC for professional mental health than in Tri-County, whereas in the surrounding suburban counties there are greater service gaps in financial and permanent housing services.
- Tables 3 and 4 focus specifically on case management service gaps, since case management provides an integrative function among the ancillary services, and is hypothesized to be central to any HIV care system. In looking at subgroup differences, the only statistically significant difference exists among women, who are more likely than men to experience a service gap. Although not statistically significant, it is noteworthy that 49% of the 116 respondents in the Bronx with a need have a service gap, which is higher than in other boroughs. Table 4 illustrates the central role played by comprehensive case management. Comprehensive case management is often considered the linchpin to linking individuals to the necessary services to access to maintain them in care. As illustrated in Table 4, individuals who have a comprehensive case management gap also have significant service gaps in comprehensive medical care, supportive mental health, financial and permanent housing, and transportation. This suggests that if the comprehensive case management service gap is addressed, some of these other service gaps might also diminish.

- Table 5 illustrates which subgroups are significantly more likely to report specific needs or service gaps. Women express a greater need than men for transportation services, and experience greater service gaps than men in treatment adherence services and comprehensive case management. On the other hand, men indicate a greater service gap than women in professional mental health services. Since there is no single subgroup which appears to be more disadvantaged than another, across the board, it suggests that needs and service gaps may arise for other reasons than simply membership in a particular subgroup. Tables 6 through 10 represent the findings from a series of regression analyses which considered how many factors related to particular service gaps – gender, race/ethnicity, household income, high school education, age, children in the household, unstable housing, drug use, mental health, T-cell counts, opportunistic infections, insurance coverage, and delay seeking HIV medical care post-diagnosis. Among the key findings are:
  - Individuals with very low mental health scores are more likely to experience comprehensive medical care service gaps and financial housing gaps;
  - Individuals with less than a high school education or with annual household incomes below \$10,000 are more likely to experience medical communication and financial housing service gaps;
  - Younger individuals (20-34 years old) are more likely to experience permanent housing service gaps;
  - Women are more likely than men to experience treatment adherence and comprehensive case management service gaps, whereas all other things being equal men are more likely than women to experience professional mental health service gaps.

### **Service Utilization**

As illustrated in the notes to Table 11, service utilization data refer to client-reported services in the 6-month period preceding the interview, and are reported for the baseline interview (n=622). Several service categories, such as hospice or outreach activities, were excluded because CHAIN data cannot adequately capture them. The utilization data are not contingent upon self-reported need. In other words, an individual may report mental health services even if there are no subjective or objective expressions of need for mental health services. Subgroup comparisons are provided by gender, race/ethnicity, HIV risk, age group, and borough. As noted above, in some instances the absolute number of individuals in a group may be too small to reliably note proportional differences (particularly vulnerable are groups with fewer than 50 individuals).

*Key Findings*

- Overall, as illustrated in Table 11, the three highest areas of service utilization are primary medical care (97%), case management (72%), and dental care (71%). Mental health services (57%) housing (31%), and substance abuse services (24%) are used moderately. Food, home health care, legal services, and transportation services are reported by relatively few people in the cohort (2-7% of the cohort).
- There are only two statistically significant subgroup differences in service utilization: white respondents are more likely than either black or Latino respondents to report using substance use services, and middle-aged respondents (35-49 years old) were more likely than younger or older individuals to report using mental health services.

**Table 1. Measuring Needs & Service Gaps – Definitions**

<b>Service</b>	<b>NEED</b>	<b>SERVICE GAP</b>
<b>HEALTH</b>		
Comprehensive medical care	Positive HIV serostatus	Primary HIV medical provider does not provide ALL of the following: (1) Routine check-ups, well visits, vaccinations, (2) Source of health advice, (3) 24-hour access for medical emergencies
Patient/Provider communication	Positive HIV serostatus	Patient doesn't know t-cell or viral load, OR says current doctor "could do a better job explaining my treatment options to me"
Treatment adherence	On antiretroviral medications	Among non-adherent, not receiving treatment adherence services
Antiretroviral therapy	T-cell less than 200	Not on antiretroviral combination therapy
<b>CASE MANAGEMENT</b>		
CM: Comprehensive care model	(1) Current drug user OR (2) very low mental health score OR (3) recent episode of unstable housing OR (4) experienced a barrier to medical or social service because didn't know where to go, couldn't get child care, couldn't get transportation, or couldn't afford care or (5) says there's not enough money in the household for rent, utilities, food, or clothing	Among those with a need, no CM developed a care plan, assisted in getting or referring client to social services, or helped fill out forms for benefits or entitlements in past 6 months
CM: Counseling model	(1) Scored very low on mental health score OR (2) current drug user OR (3) practiced unsafe sex in past 6 months	Among those with a need, no CM counseled client regarding personal life, drug or alcohol problems, practicing safer sex, or periodically checked up on client in past 6 months
<b>HOUSING</b>		
Financial Housing Services	(1) Fairly often or very often not enough \$\$\$ for rent, OR (2) reported that s/he needed help with eviction, paying rent, or maintaining rental subsidy	No housing service received, OR client not living in specialized AIDS housing
Permanent Housing Services	(1) At least one episode of unstable housing or doubled-up in past 6 months, OR (2) reported that s/he needed help related to homelessness, critical need to move, physical access issues, poor housing quality, or dangerous neighborhood	No housing service received, OR client not living in specialized AIDS housing

<b>Service</b>	<b>NEED</b>	<b>SERVICE GAP</b>
<b>MENTAL HEALTH</b>		
Professional Mental Health	Scored very low on a mental health score (Mental component summary (MCS) $\leq$ 37.0)	Respondent did not report receipt of professional MH service (psychiatrist, psychologist, therapist, therapeutic social worker) in prior 6 months
Supportive Mental Health	Scored above 37.0 on mental health score AND (1) reported a need for help with emotional or psychological problems OR (2) felt counseling regarding sexuality and sexual issues was considerably or extremely important OR (3) strongly disagreed that "most of the time I am in firm control of my feelings and behavior"	Respondent did not report receipt of supportive MH service (support groups, clergy, case managers, peer workers) in prior 6 months
<b>ALCOHOL OR DRUGS (AOD)</b>		
AOD	(1) Current drug or heavy alcohol user OR (2) client said that treatment or further treatment is "considerably" or "extremely" important	No reported therapeutic or self-help AOD treatment in prior 6 months
<b>TRANSPORTATION</b>		
Transportation Services	(1) Delayed or didn't get med or soc svce because couldn't get transportation, OR (2) reported that s/he needed help or assistance with transportation in prior 6 months	No reported transportation service in prior 6 months

**Table 2. Measuring Needs & Service Gaps – Comparing NYC & Tri-County**

	NYC				Tri-County			
Service	NEED		SERVICE GAP		NEED		SERVICE GAP	
<i>[Note: see Table 1 for definitions of service]</i>	Number with Need	Proportion of Full Cohort (n=622) with Need	Among those with Need, the Number with a Service Gap	Proportion of those with Need Experiencing Service Gap	Number with need	Proportion of Full Cohort (n=398) with Need	Among those with Need, the Number with a Service Gap	Proportion of those with Need Experiencing Service Gap
<b>HEALTH</b>								
Comprehensive medical care	622	100%	148	24%	398	100%	115	29%
Patient/ Provider communication	622	100%	235	38%	398	100%	186	47%
Treatment adherence	440	71%	82	19%	275	69%	38	14%
Antiretroviral therapy	127	20%	35	28%	65	16%	15	23%
<b>CASE MANAGEMENT</b>								
CM: Social work model	466	75%	186	40%	307	77%	137	45%
CM: Counseling model	348	56%	134	39%	180	45%	72	40%
<b>HOUSING</b>								
Financial Housing Services	156	25%	50	32%	135	34%	74	55%
Permanent Housing Services	126	20%	37	29%	70	18%	27	39%
<b>MENTAL HEALTH</b>								
Professional Mental Health	233	37%	147	63%	131	33%	74	55%
Supportive Mental Health	85	14%	29	34%	70	18%	45	64%
<b>ALCOHOL OR DRUGS</b>								
AOD	440	71%	309	70%	252	63%	190	76%
<b>TRANSPORTATION</b>								
Transportation Services	132	21%	101	77%	128	32%	85	67%

\* p < .05

\*\* p < .01

\*\*\* p < .001

**Table 3. Sub-group differences in Case Management Service Gaps (row percentages)**

	Comprehensive Care CM		Counseling CM	
(Denominator of those with Comp Care CM Need / Counseling CM Need)	Among those with Need, the Proportion WITH a Service Gap	Among those with Need, the Proportion WITHOUT a Service Gap	Among those with Need, the Proportion WITH a Service Gap	Among those with Need, the Proportion WITHOUT a Service Gap
<b>Gender</b>				
<i>Women (n=186/132)</i>	46%	54%	42%	58%
<i>Men (n=275/213)</i>	36%*	64%	37%	63%
<b>Race/Ethnicity</b>				
<i>White (n=31/24)†</i>	42%	58%	42%	58%
<i>Black (n=244/181)</i>	42%	58%	39%	61%
<i>Latino (n=184/138)</i>	38%	62%	39%	62%
<b>Age</b>				
<i>20-34 year olds (n=47/32)†</i>	36%	64%	31%	69%
<i>35-49 year olds (n=291/229)</i>	40%	60%	39%	61%
<i>50+ year olds (n=128/87)</i>	41%	59%	39%	61%
<b>Borough</b>				
<i>Bronx (n=116/90)</i>	49%	51%	40%	60%
<i>Brooklyn (n=129/104)</i>	40%	60%	40%	60%
<i>Manhattan (n=99/61)</i>	36%	64%	39%	61%
<i>Queens (n=64/53)</i>	31%	69%	36%	64%
<i>Staten Island (n=22/16)†</i>	32%	68%	19%	81%
<b>HIV Risk</b>				
<i>MSM (n=80/64)</i>	30%	70%	39%	61%
<i>Prob Drug Use (n= 194/145)</i>	42%	58%	42%	58%
<i>MSM + PDU (n=38/35)†</i>	42%	58%	29%	71%
<i>Heterosexual (n=154/104)</i>	42%	58%	37%	63%
<i>Men of Color Sex w/Men (n=48/37)†</i>	35%	65%	32%	68%

\* p &lt; .05

\*\* p &lt; .01

\*\*\* p &lt; .001

Note: To illustrate, among 186 women with a need for comprehensive care CM, 46% reported a service gap. Among 132 women with a need for counseling CM, 42% reported a service gap. The only statistically significant difference occurs between men and women for Comp Care CM service gaps.

† Caution should be used in interpreting proportions with denominators under 50

**Table 4. Co-Occurring Service Gaps - NYC CHAIN Cohort II (2002-2003)**

Service	Comprehensive Care CM	
	Among those WITH a Comprehensive Care CM Service Gap (n=186), proportion who also have a ...	Among those WITHOUT a Comprehensive Care CM Service Gap (n=280), proportion who also have a ...
<i>Comprehensive medical care gap</i>	31%*	22%
<i>Patient/provider communication gap</i>	39%	41%
<i>Antiretroviral treatment gap</i>	32%	22%
<i>Treatment adherence gap</i>	26%	20%
<i>Professional mental health service gap</i>	65%	62%
<i>Supportive mental health service gap</i>	60%*	25%
<i>Financial housing service gap</i>	45%*	28%
<i>Permanent housing service gap</i>	42%*	22%
<i>AOD treatment gap</i>	72%	64%
<i>Transportation gap</i>	93%*	50%

\* p &lt; .05

\*\* p &lt; .01

\*\*\* p &lt; .001

**Table 5. Measuring Needs & Service Gaps – Subgroup Differences\***

Service	NEED	SERVICE GAP
	<b>Groups significantly more likely to experience a need</b>	<b>Groups significantly more likely to experience a service gap</b>
<b>HEALTH</b>		
Comprehensive medical care		– Blacks
Patient/Provider communication		– Problem drug user – MSM who were problem drug users
Treatment adherence	– Heterosexual HIV risk	– Women
Antiretroviral therapy		
<b>CASE MANAGEMENT</b>		
CM: Social work model	– Whites – Latinos	– Women
CM: Counseling model	– MSM who were problem drug users	
<b>HOUSING</b>		
Financial Housing Services		
Permanent Housing Services		
<b>MENTAL HEALTH</b>		
Professional Mental Health	– Whites – Latinos – Residents of Queens	– Men
Supportive Mental Health	– Residents of Bronx, Bklyn, Manhttn	
<b>ALCOHOL OR DRUGS</b>		
AOD		– Blacks – Latinos
<b>TRANSPORTATION</b>		
Transportation Services	– Women – Heterosexual HIV risk	

\* Note: These data represent statistical tests for subgroup differences by gender, race/ethnicity, HIV risk behavior, and borough. “Problem drug users” are defined as individuals who have used cocaine, crack, or heroin three or more times a week for a month or more, or who have ever injected drugs, or who meet the CAGE criteria for heavy drinking.

**Table 6. Medical Care Service Gaps Analysis**

Factor	Odds Ratio of Increased COMP MEDICAL CARE Service Gap	Odds Ratio of Increased MEDICAL COMMUN- ICATION Service Gap	Odds Ratio of Increased ARV TREATMT Service Gap	Odds Ratio of Increased TREAT ADHRNCE Service Gap
n	594	597	127	424
Male	0.80	1.06	1.05	<b>0.46**</b>
Female [ <i>reference group</i> ]	1.00	1.00	1.00	1.00
Black	1.58	1.37	1.35	1.68
Latino	0.79	1.05	1.05	1.08
White [ <i>reference group</i> ]	1.00	1.00	1.00	1.00
Household income under \$10,000	0.72	0.86	0.85	1.00
Less than HS Educ	1.06	<b>1.66**</b>	2.16	0.83
20-34 years old	1.86	0.68	0.32	1.01
35-49 years old	1.45	1.01	1.11	1.26
50+ years old [ <i>reference group</i> ]	1.00	1.00	1.00	1.00
Children under 18 in the household	0.87	<b>1.77*</b>	0.99	1.13
Unstable housing episode in past 6 months	1.11	<b>1.29**</b>	0.95	1.17
Never used drugs [ <i>reference group</i> ]	1.00	1.00	1.00	1.00
Former drug user	0.94	0.92	1.73	0.95
Current drug user	<b>1.83*</b>	1.03	2.39	<b>2.61**</b>
Very low mental health score (<37.0 mcs)	<b>1.96***</b>	1.42	0.96	1.21
500+ t-cell count [ <i>reference group</i> ]	1.00	1.00	--	1.00
200-499 t-cell count	1.12	0.96	--	0.89
<200 t-cell count	1.00	1.10	--	0.77
Recent opportunistic infection	0.74	0.86	1.39	1.07
Medicaid	0.59	0.74	0.50	2.01
ADAP-Plus	0.62	0.63	0.23	0.68
Delayed initial HIV medical care >3 months	0.92	<b>1.85**</b>	0.55	1.27

\* p &lt; .05

\*\* p &lt; .01

\*\*\* p &lt; .001

Note: In those groups with a “reference group,” such as male/female, one group is compared to the reference group. Men are .46 times as likely to report a treatment adherence service gap as are the reference group, women.

**Table 7. Case Management Service Gaps Analysis**

<b>Factor</b>	<b>Odds Ratio of Increased COMPREHENSIVE CM Service Gap</b>	<b>Odds Ratio of Increased COUNSELING CM Service Gap</b>
n	442	334
Male	<b>0.58*</b>	0.88
Female	1.00	1.00
Black	1.45	1.55
Latino	1.22	1.45
White	1.00	1.00
Household income under \$10,000	<b>0.22***</b>	<b>0.24***</b>
Less than HS Educ	1.03	0.99
20-34 years old	1.23	0.92
35-49 years old	1.22	1.21
50+ years old	1.00	1.00
Children under 18 in the household	<b>0.47*</b>	0.71
Unstable housing episode in past 6 months	0.82	0.94
Never used drugs	1.00	1.00
Former drug user	0.71	0.99
Current drug user	0.97	1.12
Very low mental health score (<37.0 mcs)	0.87	1.28
500+ t-cell count	1.00	1.00
200-499 t-cell count	0.98	0.63
<200 t-cell count	1.37	0.84
Recent opportunistic infection	0.90	0.80
Medicaid	0.42	0.68
ADAP-Plus	0.36	0.83
Delayed initial HIV medical care >3 months	0.68	0.72

\* p &lt; .05

\*\* p &lt; .01

\*\*\* p &lt; .001

**Table 8. Housing Service Gaps Analysis**

Factor	Odds Ratio of Increased FINANCIAL HOUSING Service Gap	Odds Ratio of Increased PERMANENT HOUSING Service Gap
n	152	122
Male	1.39	0.87
Female	1.00	1.00
Black	1.04	1.84
Latino	1.27	0.93
White	1.00	1.00
Household income under \$10,000	<b>3.05*</b>	0.55
Less than HS Educ	0.78	0.96
20-34 years old	0.60	<b>6.19*</b>
35-49 years old	0.78	1.20
50+ years old	1.00	1.00
Children under 18 in the household	0.56	0.70
Unstable housing episode in past 6 months	0.66	0.99
Never used drugs	1.00	1.00
Former drug user	1.66	1.63
Current drug user	1.32	1.68
Very low mental health score (<37.0 mcs)	<b>2.43*</b>	0.51
500+ t-cell count	1.00	1.00
200-499 t-cell count	0.43	0.80
<200 t-cell count	<b>0.33*</b>	0.89
Recent opportunistic infection	0.62	0.53
Medicaid	0.20	0.51
ADAP-Plus	0.44	1.12
Delayed initial HIV medical care >3 months	0.72	0.61

\* p &lt; .05

\*\* p &lt; .01

\*\*\* p &lt; .001

**Table 9. Mental Health Service Gaps Analysis**

Factor	Odds Ratio of Increased PROFESSIONAL MENTAL HEALTH Service Gap	Odds Ratio of Increased SUPPORTIVE MENTAL HEALTH Service Gap
n	226	82
Male	<b>2.56**</b>	1.67
Female	1.00	1.00
Black	0.92	0.56
Latino	0.83	0.41
White	1.00	1.00
Household income under \$10,000	0.63	2.24
Less than HS Educ	1.59	0.30
20-34 years old	1.55	2.83
35-49 years old	0.81	1.01
50+ years old	1.00	1.00
Children under 18 in the household	1.08	0.85
Unstable housing episode in past 6 months	<b>0.61**</b>	<b>0.42*</b>
Never used drugs	1.00	1.00
Former drug user	1.28	2.83
Current drug user	1.41	5.16
Very low mental health score (<37.0 mcs)	--	--
500+ t-cell count	1.00	1.00
200-499 t-cell count	1.75	0.93
<200 t-cell count	2.04	0.47
Recent opportunistic infection	0.89	0.64
Medicaid	<b>0.11**</b>	0.20
ADAP-Plus	0.24	0.86
Delayed initial HIV medical care >3 months	1.21	0.46

\* p &lt; .05

\*\* p &lt; .01

\*\*\* p &lt; .001

**Table 10. AOD & Transportation Service Gaps Analysis**

Factor	Odds Ratio of Increased AOD Service Gap	Odds Ratio of Increased TRANSPORTATION Service Gap
n	420	118
Male	1.28	0.80
Female	1.00	1.00
Black	<b>2.40*</b>	2.06
Latino	1.88	1.62
White	1.00	1.00
Household income under \$10,000	0.74	<b>0.08**</b>
Less than HS Educ	0.86	1.81
20-34 years old	1.04	9.50
35-49 years old	1.03	0.86
50+ years old	1.00	1.00
Children under 18 in the household	0.77	0.42
Unstable housing episode in past 6 months	<b>0.73**</b>	0.79
Never used drugs	1.00	1.00
Former drug user	<b>0.09***</b>	1.47
Current drug user	<b>0.07***</b>	3.17
Very low mental health score (<37.0 mcs)	0.96	0.96
500+ t-cell count	1.00	1.00
200-499 t-cell count	1.08	1.17
<200 t-cell count	0.93	0.57
Recent opportunistic infection	0.98	2.01
Medicaid	1.23	0.12
ADAP-Plus	0.60	0.42
Delayed initial HIV medical care >3 months	1.02	2.71

\* p &lt; .05

\*\* p &lt; .01

\*\*\* p &lt; .001

**Table 11. Service Utilization (NYC CHAIN data, 2002-2003)**

<b>Service</b>	<b># Who Received Service</b>	<b>% Baseline Cohort (n=622) who Received Service</b>
<i>Ambulatory Medical Care</i>	603	97%
<i>Case Management</i>	449	72%
<i>Dental Care</i>	440	71%
<i>Food Bank/Home delivered</i>	41	7%
<i>Home Health Care</i>	11	2%
<i>Housing Services (any)</i>	193	31%
<i>Legal Services</i>	37	6%
<i>Mental Health Services</i>	352	57%
<i>Substance Use Services</i>	149	24%
<i>Transportation Services</i>	39	6%

**Notes**

Amb med care = any reported HIV primary medical care.

Case management = any reported case management or case worker assistance.

Dental care = any reported dental service.

Home health care = refers to any reported assistance with activities of daily living.

Housing services (any) = refers to any placement or financial assistance services

Mental health services = refer to any professional (psychiatrist or therapist) or supportive (support group, peer)

Substance use services = refer to any therapeutic or self-help drug treatment.

**Table 12. Service Utilization by RACE/ETHNICITY & GENDER,**

Service	RACE/ETHNICITY			GENDER	
	White, non-Hispanic	Black, non-Hispanic	Hispanic	Male	Female
<i>TOTAL (n)</i>	37	345	231	366	249
<i>Ambulatory Medical Care</i>	100%	37%	96%	95%	99%
<i>Case Management</i>	76%	68%	77%	78%	64%
<i>Dental Care</i>	73%	72%	68%	71%	70%
<i>Food Bank/Home delivered</i>	14%	6%	6%	7%	6%
<i>Home Health Care</i>	0%	2%	2%	1%	3%
<i>Housing Services (any)</i>	32%	32%	29%	30%	33%
<i>Legal Services</i>	5%	6%	6%	4%	8%
<i>Mental Health Services</i>	57%	57%	58%	53%	61%
<i>Substance Use Services</i>	41%*	21%	26%	25%	22%
<i>Transportation Services</i>	16%	7%	4%	6%	7%

\* p < .05

\*\* p < .01

\*\*\* p < .001

**Table 13. Service Utilization by RISK & AGE GROUP**

Service	RISK				Age Group		
	MSM	PDU	MSM + PDU	Hetero	20-34	35-49	50+
<i>TOTAL (n)</i>	116	250	44	212	54	378	190
<i>Ambulatory Medical Care</i>	94%	98%	93%	99%	98%	67%	67%
<i>Case Management</i>	75%	72%	75%	70%	72%	71%	74%
<i>Dental Care</i>	72%	68%	66%	75%	67%	71%	72%
<i>Food Bank/Home delivered</i>	9%	5%	16%	5%	9%	7%	5%
<i>Home Health Care</i>	2%	1%	0%	3%	0%	2%	2%
<i>Housing Services (any)</i>	26%	32%	34%	32%	41%*	32%	26%
<i>Legal Services</i>	8%	4%	5%	8%	11%	5%	7%
<i>Mental Health Services</i>	53%	57%	50%	59%	41%	63%	48%
<i>Substance Use Services</i>	13%	40%	34%	9%	17%	27%	21%
<i>Transportation Services</i>	5%	5%	9%	8%	6%	7%	4%

**Table 14. Service Utilization by BOROUGH**

	Bronx	Brooklyn	Manhattan	Queens	Staten Isl
<i>TOTAL (n)</i>	151	170	139	85	31
<i>Ambulatory Medical Care</i>	94%	98%	99%	94%	100%
<i>Case Management</i>	68%	78%	66%	72%	90%
<i>Dental Care</i>	62%	75%	74%	68%	74%
<i>Food Bank/Home delivered</i>	6%	4%	9%	8%	3%
<i>Home Health Care</i>	3%	0%	3%	2%	0%
<i>Housing Services (any)</i>	30%	34%	30%	19%	32%
<i>Legal Services</i>	2%	8%	6%	11%	3%
<i>Mental Health Services</i>	56%	64%	50%	48%	58%
<i>Substance Use Services</i>	26%	28%	21%	14%	19%
<i>Transportation Services</i>	7%	6%	6%	5%	10%

\* p &lt; .05

\*\* p &lt; .01

\*\*\* p &lt; .001

## DATA & METHODOLOGY

### Background

The purpose of the NYC CHAIN Study is to assess the impact of the full continuum of services delivered to HIV positive persons living in New York City, and to identify unmet needs for services. The interviews for this study present quantitative profiles of respondents' needs for health and human services, their encounters with health care and social service organizations, their satisfaction with services, and their current health status. The people who participated in the baseline survey are being re-interviewed at approximately annual intervals.

In 1993, the Planning and Evaluation Subcommittee of the New York HIV Health and Human Services Planning Council authorized the Medical and Health Research Association of New York City, Inc. (MHRA) to develop a longitudinal study of NYC residents living with HIV. The School of Public Health at Columbia University was contracted by MHRA to conduct the survey and carry out analyses of survey data. The first representative cohort of 700 individuals, NYC CHAIN Cohort I, was recruited between 1994-1995, and interviewed over eight rounds, which varied from 6 months to 1 year intervals. A refresher cohort of 268 individuals was added to NYC CHAIN Cohort I in 1998. A second representative sample of 684 HIV-positive adults, NYC CHAIN Cohort II, was recruited between 2002-2004. This report represents an analysis of the first 622 respondents in the NYC CHAIN Cohort II. In addition, a third representative sample of 398 HIV-positive adults was recruited in Westchester, Rockland, and Putnam counties in 2001-2002.

### Sample Design

One of the major goals of this study is to assemble a cohort that is broadly representative of all residents living with HIV. The simplest strategy for achieving this goal, drawing a random household sample, is not feasible because persons with HIV are relatively rare in the population, and many are, for good reason, reluctant to disclose their HIV seropositive status. Therefore, to approximate the ideal sample, several sampling strategies were developed.

#### *Agency-based random recruitment*

The first strategy involved sampling clients and patients drawn from rosters of agencies providing medical and social services to persons living with HIV. To achieve a representative sample of clients, a two-step sampling procedure was followed. The first step involved identifying all health and social service agencies in New York City providing HIV services to at least twenty clients. Medical and social service agencies were independently randomly sampled within each borough and further sampled within Ryan White funded and non-Ryan White funded categories.

The second step involved recruiting a random sample of clients from each participating agency. Random selection of clients was intended to minimize the tendency of agencies to refer their most satisfied and/or easier to reach clients. Each agency that agreed to help recruit participants assembled a list containing anonymous identifiers for all persons living with HIV who had contact with the agency within a year of constructing the list, and also designated one of their

employees to act as a liaison/coordinator between the Columbia team and the sampled individuals. In order to be eligible for the study, individuals had to be NYC residents, at least 20 years of age, and HIV+ for at least six months. The Columbia team randomly drew between 15 and 25 identifiers from each agency list. The identifiers were returned to the agency coordinators, who made initial contact with the sampled clients to explain the purpose of the study and to determine if they were willing to participate. Only then did the agency coordinator send the names, addresses and telephone numbers of consenting clients to the Columbia field staff to schedule and conduct the interviews.

#### *Agency-based sequential enrollment*

In addition to the agency-based random recruitment we employed a sequential enrollment strategy, in which all clients present at a given site during a specific time period were invited to participate in the study. Such a strategy could only be used at sites with sufficient numbers of clients (nominally 10-20 clients, as a minimum), who would be present for such a recruitment. The CHAIN research team would coordinate recruitment with an agency coordinator from the participating agency. The agency would maintain a roster of all eligible clients present during the recruitment period so that a later analysis could be conducted to determine if CHAIN recruited most (or all) eligible clients present, and if those recruited were reasonably representative of all eligible clients present.

#### **Interview Schedule**

All interviews are conducted in person by trained interviewers. The major topics covered during the interviews include (1) initial encounter with the health care delivery system, (2) need for services, (3) access, utilization and satisfaction with health and social services, (4) sociodemographic characteristics of respondents, (5) informal caregiving from friends, family and volunteers, and (6) quality of life with respect to health status, psychological and social functioning. The interview schedule was developed based upon a listing of questions under each of these broader topics that was circulated to the Planning and Evaluation Subcommittee, the Work Groups, and the Technical Review Team chaired by MHRA. In particular, information on use of health and social services was obtained using questions developed for a federally funded study of AIDS service utilization. Health status was assessed using survey questions that have well established psychometric properties (such as the Medical Outcomes Survey scale, and indices measuring health locus of control, and self-efficacy) and which have been widely administered to HIV positive populations. The interview takes between two and three hours to complete, dependent upon issues relevant to each client's unique service needs. Most interviews were conducted in English, although a number were conducted in Spanish.

#### **Cohort representativeness**

Table A-1 illustrates the comparison of the newly recruited CHAIN cohort of 684 individuals with reported AIDS cases, more recently reported HIV non-AIDS cases, and with a duplicated count of Ryan White CARE Act-funded encounters. Whereas the original NYC cohort of 1994-1995 and the refresher cohort of 1998 tended to "look" more like AIDS epidemiology of New York City, the currently constituted cohort appears to be proportionally

different than the population of people living with AIDS. In particular, there are fewer white men and women in the new cohort than the AIDS epidemiology, and a greater proportion of black and Latino respondents in the new cohort. What is striking, however, is that the new cohort more closely mirrors the Ryan White encounter data. This suggests several possible explanations: (1) the epidemiology of HIV/AIDS is changing in New York City, such that more blacks and Latinos are becoming infected and entering the system of care, particularly when compared with people who have been living with the virus longer and who have progressed to an AIDS diagnosis; or (2) white individuals living with HIV/AIDS in NYC are less likely to seek care at the majority of health and social service agencies, as they did at earlier recruitment periods for CHAIN, and may be more selective in the services they need and attend; or (3) there are sampling issues in the CHAIN recruitment and enrollment of the new cohort such that white PLWHA do not have an equal probability of entering the cohort as do black and Latino PLWHAs. This last might include the possibility of a greater reluctance of white individuals to participate in the cohort study, or a greater reluctance to be approached by the agency coordinators who helped facilitate the recruitment process for CHAIN. Although we do not have definitive answers as to which of these possibilities most closely represents reality, we suspect that the first two explanations – a changing epidemiology, and selective use of services by white PLWHA – are the most likely causes.

**Table A-1. Sample Representativeness, New York AIDS Cases and CHAIN New Cohort**

	New York City Surviving AIDS Cases 12/31/01 <sup>1</sup>		NYC HIV Diagnosed, w/o AIDS, 2002 <sup>2</sup>		Ryan White Encounters, 3/2001 - 2/2002 <sup>3</sup>		CHAIN New Cohort 6/2002-6/2004	
	Female	Male	Female	Male	Female	Male	Female	Male <sup>4</sup>
<b>Total N</b>	<b>13,092</b> (27%)	<b>35,053</b> (73%)	<b>1,709</b> (36%)	<b>2,976</b> (64%)	<b>10,765</b> (39%)	<b>16,962</b> (61%)	<b>268</b> (39%)	<b>416</b> (61%)
<b>White</b>	12%	26%	6%	22%	9%	8%	6%	10%
<b>Black</b>	54%	40%	64%	45%	53%	53%	62%	47%
<b>Latino</b>	33%	33%	28%	31%	37%	37%	31%	41%
<b>Other</b>	<1%	1%	2%	2%	2%	2%	<1% (1)	2%

<sup>1</sup> Source: Semi Annual Report (June, 2002), Surveillance Update, including Persons Living with AIDS in New York City, HIV/AIDS Surveillance Program, Department of Health, the City of New York, p24

<sup>2</sup> Source: HIV Surveillance and Epidemiology Program Quarterly Report, April 2003, NYC Department of Health and Mental Hygiene, p. 3. Data are based on HIV+ cases reported to the NYC DOHMH HIV/AIDS registry who did not have a concurrent AIDS diagnosis. Providers are required to report all HIV+ cases after June 2000, and labs are required to report all detectable viral loads and all cases with CD4 counts below 500.

<sup>3</sup> Source: HIV CARE Services. Data represent a duplicated count of first time encounters with Ryan White CARE Services in FY11, March 2001 - February 2002.

<sup>4</sup> Seven transgender cases are included in male category.