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# Tri-County CHAIN

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*Report 2005-5*

## Service Gaps Update – A 3-Wave Analysis

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Hygiene, the Westchester Department of  
Health, and the NY Health & Human Services  
HIV Planning Council

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

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We are particularly grateful to all the participants in the Tri-County CHAIN Project who share their time and their experiences with us. We take their trust in us seriously, and hope that our project serves to amplify the voice of the HIV-positive community in Putnam, Rockland, and Westchester counties.

**Tri-County CHAIN Project**

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## Introduction

### Service Gaps

Table 2 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.

**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

Service	NEED	SERVICE GAP
<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 Waves 1, 2 & 3 (Tri-County CHAIN)**

Service	Tri-County Wave 1 (2001-2002)				Tri-County Wave 2 (2003)				Tri-County Wave 3 (2004-5)			
	NEED		SERVICE GAP		NEED		SERVICE GAP		NEED		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	Number with Need	Proportion of Full Cohort (n=315) 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=254) with Need	Among those with Need, the Number with a Service Gap	Proportion of those with Need Experiencing Service Gap
<b>HEALTH</b>												
<i>Comprehensive medical care</i>	398	<b>100%</b>	115	<b>29%</b>	315	<b>100%</b>	89	<b>28%</b>	254	<b>100%</b>	78	<b>31%</b>
<i>Patient/ Provider communication</i>	398	<b>100%</b>	186	<b>47%</b>	315	<b>100%</b>	167	<b>53%</b>	254	<b>100%</b>	-	-
<i>Treatment adherence</i>	275	<b>69%</b>	38	<b>14%</b>	238	<b>76%</b>	34	<b>14%</b>	202	<b>80%</b>	32	<b>16%</b>
<i>Antiretroviral therapy</i>	65	<b>16%</b>	15	<b>23%</b>	52	<b>17%</b>	8	<b>15%</b>	45	<b>18%</b>	7	<b>16%</b>
<b>CASE MANAGEMENT</b>												
<i>CM: Comprehensive care model</i>	307	<b>77%</b>	137	<b>45%</b>	269	<b>85%</b>	120	<b>45%</b>	214	<b>84%</b>	106	<b>50%</b>
<i>CM: Counseling model</i>	180	<b>45%</b>	72	<b>40%</b>	163	<b>52%</b>	76	<b>47%</b>	137	<b>54%</b>	66	<b>48%</b>
<b>HOUSING</b>												
<i>Financial Housing Services</i>	135	<b>34%</b>	74	<b>55%</b>	105	<b>33%</b>	56	<b>53%</b>	74	<b>29%</b>	14	<b>19%</b>
<i>Permanent Housing Services</i>	70	<b>18%</b>	27	<b>39%</b>	71	<b>23%</b>	41	<b>58%</b>	44	<b>17%</b>	19	<b>43%</b>

Service	Tri-County Wave 1 (2001-2002)				Tri-County Wave 2 (2003)				Tri-County Wave 3 (2004-5)			
	NEED		SERVICE GAP		NEED		SERVICE GAP		NEED		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	Number with Need	Proportion of Full Cohort (n=315) 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=254) with Need	Among those with Need, the Number with a Service Gap	Proportion of those with Need Experiencing Service Gap
<b>MENTAL HEALTH</b>												
<i>Professional Mental Health</i>	131	<b>33%</b>	74	<b>55%</b>	114	<b>36%</b>	77	<b>68%</b>	106	<b>42%</b>	82	<b>77%</b>
<i>Supportive Mental Health</i>	70	<b>18%</b>	45	<b>64%</b>	60	<b>19%</b>	36	<b>60%</b>	58	<b>23%</b>	27	<b>47%</b>
<b>ALCOHOL OR DRUGS</b>												
<i>AOD</i>	252	<b>63%</b>	190	<b>76%</b>	183	<b>58%</b>	132	<b>72%</b>	126	<b>50%</b>	92	<b>73%</b>
<b>TRANSPORTATION</b>												
<i>Transportation Services</i>	128	<b>32%</b>	85	<b>67%</b>	139	<b>44%</b>	115	<b>83%</b>	90	<b>35%</b>	60	<b>67%</b>

**Table 3. Attrition Analysis - Are Those “Lost to Follow-up” Different from Those Who Stayed? (Tri-County CHAIN)**

Service	Interviewed in Wave 3				Not interviewed in Wave 3			
	NEED		SERVICE GAP		NEED		SERVICE GAP	
	Number with need in Wave 2	Proportion with Need in Wave 2	Among those with Need, the Number with a Service Gap in W2	Proportion of those with Need Experiencing Service Gap in W2	Number with Need in Wave 2	Proportion with Need in Wave 2	Among those with Need, the Number with a Service Gap in W2	Proportion of those with Need Experiencing Service Gap in W2
<b>HEALTH</b>								
<i>Comprehensive medical care</i>	248	<b>100%</b>	70	<b>28%</b>	67	<b>100%</b>	19	<b>28%</b>
<i>Patient/ Provider communication</i>	248	<b>100%</b>	63	<b>25%</b>	67	<b>100%</b>	20	<b>30%</b>
<i>Treatment adherence</i>	197	<b>79%</b>	28	<b>14%</b>	52	<b>78%</b>	9	<b>17%</b>
<i>Antiretroviral therapy</i>	35	<b>14%*</b>	1	<b>3%**</b>	17	<b>25%</b>	5	<b>29%</b>
<b>CASE MANAGEMENT</b>								
<i>CM: Comprehensive care model</i>	210	<b>85%</b>	95	<b>45%</b>	62	<b>93%</b>	27	<b>44%</b>
<i>CM: Counseling model</i>	136	<b>55%</b>	72	<b>53%†</b>	42	<b>63%</b>	16	<b>38%</b>
<b>HOUSING</b>								
<i>Financial Housing Services</i>	82	<b>33%</b>	47	<b>57%</b>	23	<b>34%</b>	9	<b>39%</b>
<i>Permanent Housing Services</i>	50	<b>20%</b>	31	<b>62%</b>	16	<b>24%</b>	9	<b>56%</b>
<b>MENTAL HEALTH</b>								
<i>Professional Mental Health</i>	99	<b>40%</b>	69	<b>70%</b>	26	<b>39%</b>	18	<b>69%</b>
<i>Supportive Mental Health</i>	43	<b>17%</b>	24	<b>56%†</b>	15	<b>22%</b>	12	<b>80%</b>
<b>ALCOHOL OR DRUGS</b>								
<i>AOD</i>	150	<b>60%</b>	111	<b>74%</b>	40	<b>60%</b>	26	<b>65%</b>
<b>TRANSPORTATION</b>								
<i>Transportation Services</i>	112	<b>45%</b>	93	<b>83%</b>	27	<b>40%</b>	22	<b>81%</b>

† p&lt;=.10

\* p&lt;=.05

\*\* p &lt;=.01

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

Significant differences between those who were interviewed in Wave 3 versus those who were lost to follow-up.

**Table 4. Number of Service Gaps across Waves** (row percentages)

	No Gap		Gap in 1 wave		Gaps in 2 waves		Gaps in 3 waves	
	n	%	n	%	n	%	n	%
<b>Health</b>								
<i>Comprehensive medical care</i>	107	43%	81	33%	44	18%	16	6%
<i>Patient/Provider communication</i>	23	9%	115	46%	88	35%	22	9%
<i>Treatment Adherence</i>	174	70%	65	26%	9	4%	0	0%
<i>Antiretroviral therapy</i>	228	92%	16	6%	4	2%	0	0%
<b>Case Management</b>								
<i>CM: Comprehensive care model</i>	82	33%	85	34%	58	23%	23	9%
<i>CM: Counseling model</i>	114	46%	97	39%	29	12%	8	3%
<b>Housing</b>								
<i>Financial Housing Services</i>	164	66%	68	27%	14	6%	2	<1%
<i>Permanent Housing Services</i>	189	76%	40	16%	16	6%	3	1%
<b>Mental Health</b>								
<i>Professional Mental Health</i>	97	39%	103	42%	40	16%	8	3%
<i>Supportive Mental Health</i>	185	75%	54	22%	8	3%	1	<1%
<b>Alcohol or Drugs (AOD)</b>								
<i>AOD</i>	69	28%	76	31%	60	24%	43	17%
<b>Transportation</b>								
<i>Transportation Services</i>	113	46%	79	32%	39	16%	17	7%

**Table 5. The Evolution of Service Gaps Among Respondents with Service Needs** (row

percentages)

	Total Number with Need	Persistent Gaps		Developing Gaps		Gaps Addressed		Needs Met		% Having Persistent/Developing Gaps
		n	%	n	%	n	%	n	%	
<b>Health</b>										
Comprehensive medical care	248	32	13%	45	18%	64	26%	107	43%	31%
Patient/Provider communication	248	76	31%	120	48%	29	12%	23	9%	79%
Treatment Adherence	217	3	1%	29	13%	34	16%	151	70%	15%
Antiretroviral therapy	65	3	5%	4	6%	9	14%	49	75%	11%
<b>Case Management</b>										
CM: Comprehensive care model	179	27	15%	45	25%	30	17%	77	43%	40%
CM: Counseling model	237	56	24%	56	24%	47	20%	78	33%	47%
<b>Housing</b>										
Financial Housing Services	114	12	11%	7	6%	22	19%	73	64%	17%
Permanent Housing Services	72	14	19%	8	11%	9	13%	41	57%	31%
<b>Mental Health</b>										
Professional Mental Health	150	43	29%	59	39%	14	9%	34	23%	68%
Supportive Mental Health	79	9	11%	20	25%	7	9%	43	54%	37%
<b>Alcohol or Drugs (AOD)</b>										
AOD	159	94	59%	21	13%	18	11%	26	16%	72%
<b>Transportation</b>										
Transportation Services	115	51	44%	20	17%	16	14%	28	24%	62%

## DATA & METHODOLOGY

### Background

The purpose of the Tri-County CHAIN Study is to assess the impact of the full continuum of services delivered to HIV positive persons living in Westchester, Rockland, and Putnam counties, 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 2001, the Planning and Evaluation Subcommittee of the New York HIV Health and Human Services Planning Council authorized the Westchester Department of Health (WDOH) and Medical and Health Research Association of New York City, Inc. (MHRA), to develop a longitudinal study of Tri-County residents living with HIV similar to the existing New York City longitudinal project. The Mailman School of Public Health at Columbia University was contracted by MHRA to conduct the survey and carry out analyses of survey data.

### Sample Design

One of the major goals of this study is to assemble a cohort that is broadly representative of all Tri-County 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 the Tri-County region providing HIV services to at least ten clients. Since there were only 32 agencies or sites of service identified during this procedure it was determined to sample clients from the entire universe of agencies rather than sampling from this list.

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 residents of Westchester, Rockland, or Putnam counties, at least 20 years of age, and HIV-positive for at least 6 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 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, at a minimum), who would be present for such a recruitment. The Tri-County CHAIN Field Director 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, WDOH and MHRA. Whenever possible, interview questions were taken from earlier surveys administered to persons living with HIV and were designed to match questions asked of participants in the New York City CHAIN study. 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 fifteen were conducted in Spanish and six in Creole.

## GLOSSARY OF TERMS

**AIDS Institute (AI) criteria for care**—AI criteria for appropriate medical care for HIV+ persons consists of: 1) required number of medical care visits (further contingent upon T-cell count and antiretroviral use); 2) self-reported complete physical and blood work; and 3) self-reported T-cell count.

**AOD**—Alcohol and other drugs.

**Barriers to care**—Barriers to care (lack of information) were established via questions such as: “Did you ever delay or not get assistance you thought you needed” because “you didn’t know or weren’t sure where to go” for medical or social services?

**Comprehensive medical care**—Respondents were considered to receive comprehensive medical care if they responded “yes” to the following three questions: Is your routine medical provider someone you can go to for (1) “routine check-ups,” (2) “information or advice about a health concern” and (3) “someone you could call up 24 hours a day in case of a medical emergency?”

**Cultural/language barriers to care**—Established via the following questions: “Did you ever delay or not get assistance you thought you needed” because the staff “. . . Do not speak your language? . . . Are not competent to deal with your problem? . . . Are often not polite, disrespectful or insensitive to your needs?” Are you not sure that they “. . . would understand your problems?” or are “not good at listening to your problems or needs?”

**Help with taking meds**—Established via responses to the question: “Has anyone suggested ways to help you take your medicine on time and in the right way?”

**Hetero**—HIV risk group for persons who risk exposure to the virus via heterosexual contact.

**MSM**—Men who have sex with men.

**Objective need for mental health services**—Established by a score of less than 37.0 on the Mental Health Component Summary score of the SF-36, developed by the MOS.

**PCS score**—Physical Component Summary score of the SF-36, developed by the MOS. Scores of 45 and above are considered “high.”

**PDU**—Problem drug users, who have used cocaine, crack or heroin three or more times a week for a month or more, or who have ever had a serious alcohol problem, or who have ever injected drugs.

**Professional mental health services**—Mental health services provided by a psychiatrist or psychologist.

**Supportive mental health services**—Mental health services such as counseling provided by a case manager, clergy, etc.

**Unstable housing**—Any episode of living in the street, a shelter, a single-room occupancy, or doubled up with a friend or relative in past 6 months.