



C.H.A.I.N. REPORT

Tri-County CHAIN

Report 2002-6

Baseline Needs Assessment of the Tri-County Cohort

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Tri-County CHAIN Project

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Background

There has been a growing literature over the past fifteen years documenting the types of social and health care needs experienced by people living with HIV/AIDS and the ability of health and human service systems to meet those needs [Hines et al., 1997; London et al., 1997; Rife et al., 1991; Rosenheck et al., 1998]. Among the health care needs often considered are access to medical providers, access to medications, and appropriate levels of care and provider expertise; the most prominent non-medical needs are those related to housing, substance use and mental health services, nutritional services, and supportive “wraparound” services such as child care and transportation.

This report considers some of the needs expressed by respondents in specific issue areas, such as housing and drug treatment, and in other areas the need is inferred, as in mental health services for individuals scoring below 37.0 on the standardized Mental Component Summary score derived from the Medical Outcomes Study. Without speaking to the objective quality of medical care services, we also report on the expressed interest of respondents in having medical care services available closer to where they live.

Key Findings

- Although the total number of people who would prefer local medical care services is approximately one-quarter of those not receiving such local services, when it is considered among individuals who live in suburban Westchester and Putnam, or individuals in Rockland without access to a car, the issue becomes a more dominant one. In suburban Westchester and Putnam, between 35 - 39% would prefer local medical services. In Rockland, the disparity between individuals with or without a car is striking: whereas only 4% of those with a car would prefer local medical services, 57% of those without access to a car in Rockland would prefer local medical care services [see Table 1].
- Approximately one-quarter of the respondents expressed barriers in receiving medical care because of logistical issues, such as transportation, child care, or cost, and one-fifth of all respondents expressed barriers related to staff or provider attitudes, such as disrespect or insufficient concern for respondent’s privacy [see Table 2].
- There are generally high rates of satisfaction with medical care providers, and waiting times are generally reasonably short. Notwithstanding these high marks, approximately one-quarter of respondents are without comprehensive medical care that meets three basic criteria: that one’s medical provider be available for well-visits, health advice, and accessible 24 hours a day via phone, answering service, or beeper [see Table 3].
- As reported in the Health Status and Health Service Utilization report (2002-2), AIDS diagnosed respondents in Tri-County are less likely to be on HAART than are a comparable group of the NYC CHAIN cohort [see Table 4].

- In estimating the need for mental health services, we first looked at those individuals in the cohort who scored lowest on the national Mental Component Summary scale of the Medical Outcomes Study, which is utilized in the CHAIN questionnaire. Generally speaking, individuals who score 37 or below on this scale have associated clinical psychiatric symptomatology. One-third of the cohort (131/398) scored at or below this mental health cutpoint. Among these 131 individuals, 67 (51%) reported that they had not received professional or supportive mental health services in the past 6 months. This may suggest a lack of adequate mental health screening and referral mechanisms, stigma associated with mental health, or insufficient numbers of mental health providers in the area [see Table 5].
- There are 65 individuals in the cohort of 398 (16%) who report current substance use (cocaine, crack, heroin, or other illegal drugs, or alcohol abuse), and an additional 196 (49%) former drug users. Among these current and former drug users, a number have expressed an interest in beginning or continuing drug treatment. Among the current users, 45 of 65 (69%) expressed an interest in drug treatment, and among former drug users 126 of 196 (64%) expressed a similar interest in drug treatment (which includes support groups such as Alcoholics Anonymous or Narcotics Anonymous). When we looked at how many among these current and former drug users who expressed an interest in treatment are actually receiving any drug treatment, we found that 83% of the former drug users are not in treatment, and 69% of the current drug users are not in treatment, despite their reported interest in drug treatment [see Table 6].
- In order to estimate unstable housing, we ask respondents if they had spent even one night in the past 6 months in a situation in which they were homeless, on the street or in a shelter, in jail or prison, or temporarily doubled-up with friends or family. Among the 398 individuals in the cohort, 70 (18%) reported recent episodes of unstable housing. Also, we ask everyone if they have a need for housing services, which could include housing placement or remediation of ongoing housing issues such as rent assistance or maintenance. A total of 155 of 398 individuals (39%) indicated they had need for a housing service. As would be expected, a greater proportion of individuals who had been unstably housed, 43 of 70 (61%), expressed such a need [see Table 7].
- Lastly, we looked at which service areas are most commonly cited problems for respondents, and also explored the rates at which these problems were still unresolved. Excluding housing, the most-cited problems are financial issues (42%), food issues (30%), need for household items (20%), and transportation (19%). In looking at the areas in which the problems are still unresolved or unchanged, the most-cited areas are child care (88%), financial issues (81%), household items (73%), and job-related issues (70%) [see Table 8].

Table 1. Local Access to Medical Care

Question	Responses	Proportion of total (n=381)
Do you know of HIV medical care in your neighborhood or community?	<i>Yes, and I use it</i>	52%
	<i>Yes, but I don't use it</i>	16%
	<i>No</i>	29%
	<i>Don't know</i>	2%
Among those who don't use or don't know of HIV medical care in their neighborhood (n=182), would you prefer to get such services locally?	<i>Yes</i>	25%
	<i>No</i>	68%
	<i>Doesn't matter</i>	8%
Unmet need for local medical care services = would prefer local medical care but presently not available (45 / 182)		25%
Does preference for local medical care services differ by access to a car and geographical location? (Among those not presently using local medical care)	<i>Proportion of urban Westchester residents with access to a car who would prefer local medical care services (6/26)</i>	23%
	<i>Proportion of urban Westchester residents without access to a car who would prefer local medical care services (11/53)</i>	21%
	<i>Proportion of suburban Westchester and Putnam residents with access to a car who would prefer local medical care services (11/28)</i>	39%
	<i>Proportion of suburban Westchester and Putnam residents without access to a car who would prefer local medical care services (8/23)</i>	35%
	<i>Proportion of Rockland residents with access to a car who would prefer local medical care services (1/24)</i>	4%
	<i>Proportion of Rockland residents without access to a car who would prefer local medical care services (8/14)</i>	57%

* p < .05

**Table 2. Barriers to Medical Care:
Reasons that respondents delayed or didn't seek care**

Logistical Barriers		Provider/Staff Barriers	
<i>ANY LOGISTICAL BARRIERS</i>	23%	<i>ANY PROVIDER/STAFF BARRIERS</i>	20%
<i>Transportation</i>	12%	<i>Staff disrespectful</i>	9%
<i>Cost too much</i>	8%	<i>Staff didn't listen</i>	9%
<i>Unsure where to go for services</i>	5%	<i>Staff didn't understand the problem</i>	9%
<i>Need for child care</i>	3%	<i>Staff not competent</i>	7%
<i>Language barriers</i>	2%	<i>Didn't trust staff to safeguard privacy</i>	3%
		<i>Felt discriminated because of drug use</i>	3%
		<i>Felt discriminated because of sexual orientation</i>	2%

Table 3. Waiting time, Satisfaction, and Comprehensiveness of Medical Services

Characteristic ¹	WAVE 1	Geographical Area		
	Total Cohort	Urban Westchester	Suburban Westchester & Putnam	Rockland
n	398	213	112	73
Waiting time (n=380)				
<i>Less than 30 minutes</i>	72%	70%	83%	64%
<i>31-60 minutes</i>	19%	21%	12%	26%
<i>Over one hour</i>	8%	9%	6%	11%
Satisfaction with medical provider (n=398)				
<i>Satisfied</i>	88%	91%	83%	88%
<i>Dissatisfied</i>	12%	9%	17%	12%
Comprehensive medical care ¹ (n=398)				
<i>Not comprehensive care</i>	28%	25%	35%	28%
<i>Comprehensive care</i>	72%	75%	65%	72%

¹ Comprehensive medical care is based on the respondent reporting that his or her medical provider: (1) provides well-care visits, (2) is available to discuss health issues, (3) is available 24 hours a day, either directly or through a service or beeper

* Significant at $p < .05$

Table 4. Comparative Use of Highly Active Antiretroviral Therapy (HAART) Between Tri-County and New York City Respondents (2001-2002)

	Tri-County Cohort Diagnosed Prior to 1998 (n=307)	NYC Cohort Diagnosed Prior to 1998 (n=388)
<i>Number of respondents who have ever been diagnosed with AIDS</i>	209	320
<i>Proportion of respondents who have ever been diagnosed with AIDS who are currently on HAART</i>	43%*	50%

* Significant at $p < .1$ **Table 5. Use of Mental Health Services**

	Mental health score > 37.0 (average)		Mental health score <37.0 (poor)	
	n	%	n	%
<i>Did not receive mental health service</i>	179	67%	67	51%
<i>Received mental health service</i>	88	33%	64	49%
Unmet need for mental health services: 67 of 398 respondents had apparent need for mental health services but did not receive any professional or supportive mental health care			17%	

Table 6. Expressed Need for Alcohol or Drug Services

	Among former drug users, expressed a need for drug treatment (n=126)		Among current drug users, expressed a need for treatment (n=45)	
	n	%	n	%
<i>Not currently receiving any drug treatment</i>	105	83%	31	69%
<i>Currently receiving drug treatment</i>	21	17%	14	31%
Unmet need for drug treatment services: 136 of 398 respondents expressed a need for drug treatment services but were currently not receiving any drug treatment			34%	

Table 7. Need for Housing Services

	Stably housed respondents (n=328)		Unstably housed respondents (n=70) ¹	
	n	%	n	%
<i>Expressed a need for housing services</i>	112	34%	43	61%
Unmet need for housing services: 155 of 398 respondents expressed a need housing services				39%

¹ Any episode of unstable housing, such as a night in shelter or on street, in jail or prison, or temporarily doubled up with friends or family in past 6 months

Table 8. Progress Towards Resolving Problems

Problem area	# of respondents with this problem	% of total cohort (n=398)	# of respondents who reported no progress or problem has gotten worse	% whose problem has not been resolved or problem has gotten worse
Financial issues	166	42%	135	81%
Food	119	30%	54	45%
Household items	80	20%	58	73%
Transportation	77	19%	45	58%
Legal issues	53	13%	34	64%
Job-related issues	40	10%	28	70%
Home care	33	8%	18	55%
Child care	17	4%	15	88%

Note: Problems were identified by respondents in response to the question: Did you need help or assistance in this area in the last six months?"

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. Sixteen of the three hundred and ninety-eight interviews were conducted on an abbreviated survey (a "short form") that captures most of the variables used in analyses. We have tried to note the appropriate denominator in the tables when the item being reported was not a part of the abbreviated form. These short forms were primarily used when respondents were physically or mentally unable to complete the entire survey.