



*Update Report # 47*

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The CHAIN Retrospective:  
1994-2002

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David Abramson  
Peter Messeri  
Angela Aidala  
Nina Sanger

Columbia University  
Mailman School of Public Health  
In collaboration with Medical and Health  
Research Association of New York,  
the NYC Department of Health and Mental  
Hygiene, and the NY  
Health & Human Services  
HIV Planning Council

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

## **ACKNOWLEDGMENTS**

A Technical Review Team (TRT) provides oversight for the CHAIN Project. In addition to Peter Messeri, PhD, David Abramson, and Angela Aidala, PhD, of Columbia University's Mailman School of Public Health, TRT members include Mary Ann Chiasson, DrPH, MHRA (chair); Susan Forlenza, MD MPH, NYCDOHMH; Kevin Garrett, HIV Planning Council; JoAnn Hilger, NYCDOHMH; Julie Lehane, PhD, Westchester County DOH; Jennifer Nelson, MHRA; and Tom Sentell, PWA Advisory Group.

We are particularly grateful to the 968 participants in the original NYC CHAIN Project -- unnamed but highly valued -- who shared their time and their experiences with us. We take their trust in us seriously, and hope that our project has served to amplify the voice of the HIV-positive community in New York City.

This CHAIN Retrospective is dedicated to the memory of **Leslie Sadler**, one of our senior interviewers, who died of AIDS in October 2001. Leslie was a compassionate and professional interviewer and advocate, and all who knew her were touched by her heart and soul. Leslie conducted over 400 interviews in CHAIN's first 3 years. As such, she became the first "face" of CHAIN, from 1994 through 1997. People responded to her because she was honest and open, and she was committed to improving the lives of people living with HIV and AIDS. For that, and for all that she taught us, we remain forever grateful.

This research was supported by grant number H89 HA 0015-11 from the US Health Resources and Services Administration (HRSA), HIV/AIDS Bureau with the supported of the HIV Health and Human Services Planning Council, through the New York City Department of Health and Mental Hygiene and the Medical and Health Research Association of New York City, Inc. Its contents are solely the responsibility of the researchers and do not necessarily represent the official views of the U.S. Health Resources and Services Administration, the City of New York, or the Medical and Health Research Association of New York.

## **Introduction – Looking Back Over Eight Years**

This CHAIN Report departs from the conventional report produced by the study team at Columbia University’s Mailman School of Public Health. With this report we have chosen to look back over the lifetime of the CHAIN Study, from its origins in 1994 through the eighth round of interviews in 2002. Each year the CHAIN team has produced a series of reports for the New York HIV Planning Council and its Work Groups, responding to the questions, interests, and priorities of the members of the Council, Work Groups, and liaisons with the Mayor’s Office of AIDS Policy Coordination. These reports have examined trends in health services utilization, particular models of care, unmet health and social service needs, and various outcomes among the CHAIN cohort – a representative group of HIV-positive adults in New York City – but they are “of the moment.” By definition, these reports are focused on the critical issues of the day facing policymakers, providers, and consumers. There is rarely an opportunity for a longer perspective. This report is designed, instead, as a documentary piece: highlighting some of our most consistent findings, and describing the research enterprise that we have developed.

In consultation with the CHAIN Technical Review Team, whose membership includes representatives from the Medical and Health Research Association of New York City, the Planning Council, the New York City Department of Health and Mental Hygiene, the Council’s PWA Advisory Group, and the Mayor’s Office of AIDS Policy Coordination, we have chosen this moment to look at the bigger picture. In the summer of 2002 we embarked on the recruitment of a new CHAIN cohort, an additional 700 individuals whose collective voice will help inform the decisions of the Council and the Work Groups going forward. The original CHAIN cohort was recruited in 1994 and 1995, and a refresher cohort was added in 1998. These individuals represented HIV-positive adults in the city who first became aware of their HIV status or received an AIDS diagnosis between 1980 and 1997. As the epidemic has shifted and the city’s service system has grown it has become increasingly important to add the voices of individuals more recently diagnosed with HIV or new to the system of care. With the recruitment of this new CHAIN cohort, we want to consider the lessons we have learned from the original and refresher cohorts.

A note about the format of this report: After the opening introductory sections, we have selected 13 areas to touch upon in this report. For each area we will provide a brief description and several major findings. This should provide readers with an overview of CHAIN research at a glance. For further details on each of these areas we direct the reader to the specific reports from which they were drawn. A full listing of all CHAIN reports is included in the Appendix.

## **CHAIN – A Research Enterprise**

The CHAIN study is not a single study, but rather a constellation of studies that include the primary adult cohort study (the centerpiece of most CHAIN reports, also referred to as the Client Study in earlier reports), as well as associated projects such as those looking at HIV-positive adolescents; the training needs and potential “burnout” among HIV providers; HIV+ individuals “unconnected” to care; seniors living with HIV; and particular housing needs,

services, and models for HIV+ individuals and families (see Figure 1). In addition to the work done on behalf of the Planning Council, CHAIN has worked with MHRA to conduct several studies under contract to the federal Health Resources and Services Administration (HRSA) HIV/AIDS

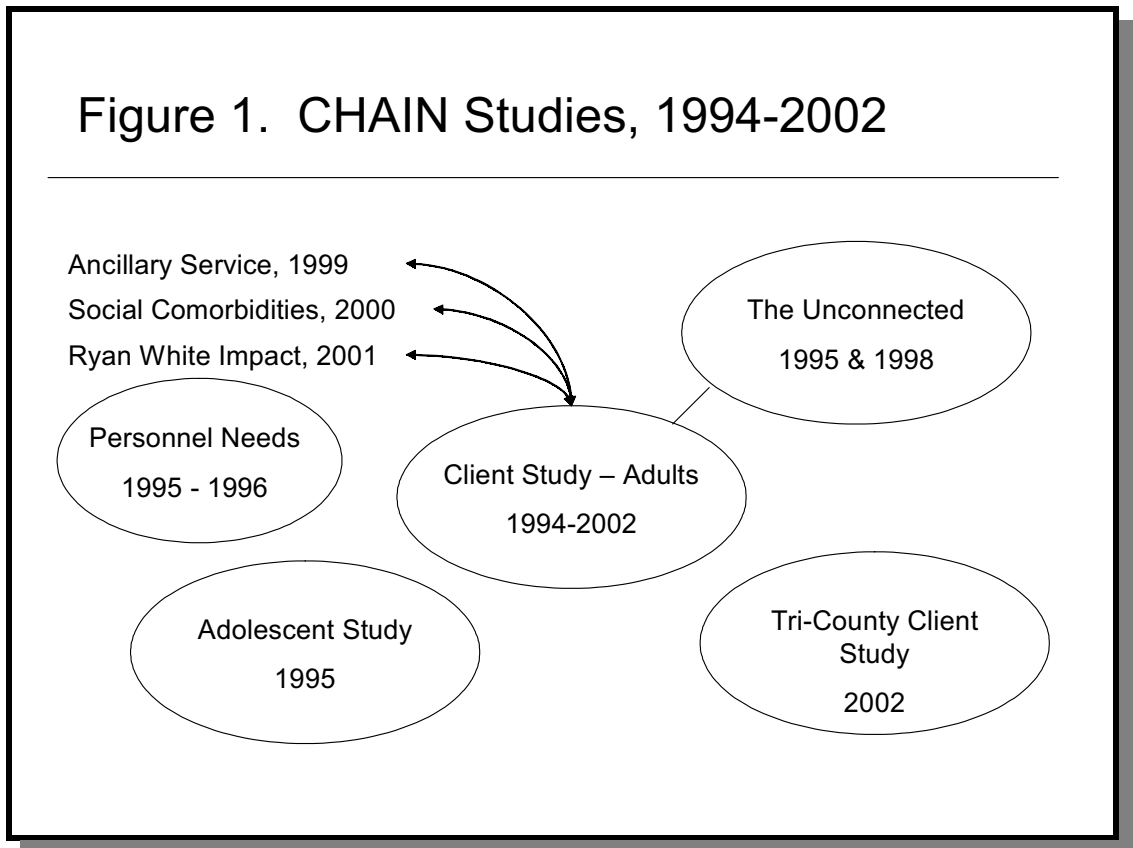
Bureau.

These studies have included work on the relationship between ancillary services and entry and retention in medical care, the prevalence of social comorbidities, and the impact of the Ryan White CARE Act on individual health outcomes. In addition, the Tri-County CHAIN Study began in

Westchester, Rockland, and Putnam counties in the fall of 2001, with a planned recruitment of 400 HIV+ adults by the fall of 2002. Finally, a new project exploring the issues faced by people who delayed entry in to medical care after their initial HIV diagnosis was initiated in the summer of 2002.

All of the studies conducted by CHAIN have a common theme – *appraising the system of care in New York City and its surrounding counties from the perspective of people living with HIV and AIDS.*

With the support of the Planning Council which, since 1994, has been willing to invest in the research infrastructure necessary to establish these studies, CHAIN has evolved into one of the most established HIV cohort studies in the country, and it is among the most comprehensive client-based HIV studies launched by any metropolitan area in the US. The products and process of the CHAIN research enterprise reflect the Planning Council's investment. Over an eight year period, CHAIN has:



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- Developed a questionnaire that collects as many as 850 distinct items during the course of a two-hour interview with each respondent;
  - Trained and deployed 94 interviewers, some of whom were themselves HIV+ or were former drug users. Every interviewer completed a seven to ten day training class and successfully passed an evaluation involving a mock interview and three probationary field interviews;
  - Coordinated client recruitment efforts with over 50 health and social service agencies, including agencies involved in street outreach, needle exchange programs, and soup kitchens who assisted us with finding individuals unconnected to the care system;
  - Conducted 4,159 interviews with the 968 respondents in the CHAIN cohort;
  - Assembled an in-house staff of project coordinators, programmers, analysts, data editors, and other support staff who have built and maintained the complex system necessary to move data from “pen-and-paper” questionnaire books, to bubble-coded sheets scanned in to a computer system, to an archiving system for all electronic data, to analytic data sets, and finally to finished analytical reports. This process has involved mastering and customizing computer programs using optical character recognition software, hierarchical database applications, statistical programming, as well as word-processing, geographic mapping, and presentation software;
  - Provided the necessary administrative and supervisory personnel to support the field and in-house research operation;
  - Refined a “follow-up” system involving mailed correspondence, phone calls, home visits, and neighborhood sweeps to locate and maintain respondents in the study;
  - Built multiple datasets used for analyses as well as those supporting the ongoing research work. These datasets include the individual-level client dataset, with responses from each interview; an agency database with over 2,800 sites of health and social services in New York City and the surrounding counties; a medications database with over 650 medications and vitamins; and qualitative datasets with open-ended responses from clients at various interview waves. In addition, there are datasets which assist research staff in assigning and following-up on client interviews (as classified material this dataset is restricted to key field supervisors) as well as datasets tracking the flow of data from the point an interview has been completed through various stages of data entry, quality review, and final creation of an analytical dataset. Throughout the entire process, individual respondents are identified by a unique number, with no personally-identifying characteristics;
  - Adhered to the principles of sound research practices and Institutional Review Board protocols by strictly maintaining client confidentiality, assuring that all identifiable data

have been maintained separately from the survey data, under lock and key accessible only to selected senior staff or on a rigorous “need-to-know” basis in order to carry out essential client-related activities.

### **Cohort Characteristics – Who is in the Study and Whom do they Represent?**

The objective of any good population study is to accurately represent the people belonging to a population of interest. Since it is often impossible to interview every member of a population, researchers and scientists assemble representative groups. For example, Nielsen Media Research, the company responsible for the “Nielsen ratings” that report the viewing habits of television-watching Americans, has assembled a national sample of 5,000 randomly selected households across the country. In each of these 5,000 households the company has placed a small recording device on each television set in the household. This Nielsen “meter” records every program that is watched. Data collected from these 5,000 households are then used to represent the viewing habits of 102 million American households, according to Nielsen, and often determine which television shows are renewed and which are canceled.

In the five boroughs of New York City there are approximately 60,000 - 75,000 HIV-positive people receiving agency-based health and/or social services (that is, not from a private medical practitioner).<sup>1</sup> The CHAIN cohort of 968 individuals – a baseline cohort of 700 individuals recruited in 1994-1995 and a refresher cohort of 268 individuals recruited in 1998 – “represent” the HIV-positive adult population in agency-based care, much the way that the Nielsen households represent all American households with television sets.

Generally speaking, the CHAIN cohort mirrors the epidemiology of AIDS in New York City. As illustrated in Table 1, the proportions of men and women, as characterized by their race and ethnicity, are relatively similar when compared to the cumulative AIDS cases reported between 1995 - 2000.

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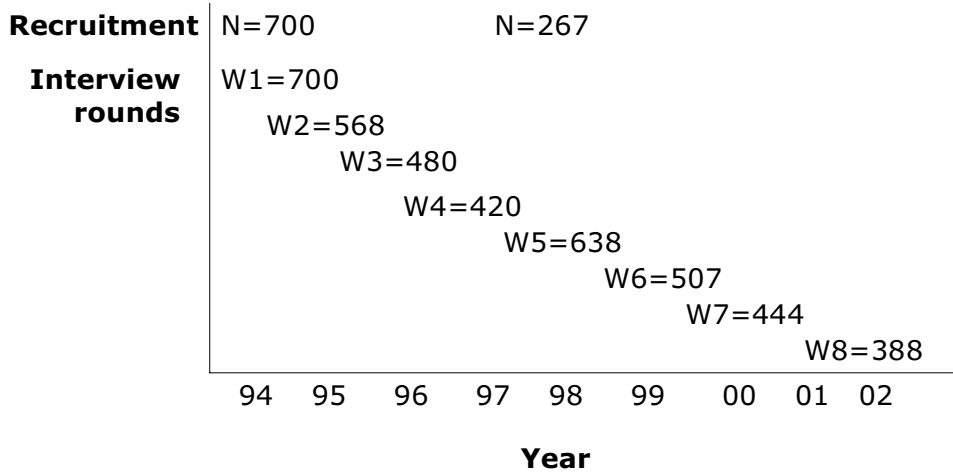
<sup>1</sup> This estimate is based on an unduplicated count of Medicaid recipients in FY1999, 47,834, reported in the FY2001 Title I Grant Application from the New York EMA. According to NYS hospital discharge data, the payor status for HIV-related conditions is two-thirds Medicaid and one-third other payors. Extrapolating from the hospital data to the Medicaid claims data  $((47,834 * 3) / 2)$ , one can estimate that there are approximately 71,751 people in care. Given the differences over time and the imprecision inherent in such an extrapolation, we have settled upon a wide range in order to illustrate the point.

**Table 1. Comparison of Epidemiological Data with CHAIN Data**

	Cumulative AIDS Cases, NYC†	CHAIN
	1995-2000	1995-2000
n	40,760	968
<b>MALE</b>	29,046	579
<i>Non-Hispanic White</i>	21%	21%
<i>Non-Hispanic Black</i>	43%	48%
<i>Hispanic</i>	34%	30%
<i>Other</i>	2%	1%
<b>FEMALE</b>	11,714	389
<i>Non-Hispanic White</i>	9%	6%
<i>Non-Hispanic Black</i>	57%	63%
<i>Hispanic</i>	33%	31%
<i>Other</i>	1%	<1%

† NYC DOH HIV/ AIDS Surveillance Program, "AIDS Surveillance Update, 4<sup>th</sup> Quarter 2000"

**Figure 2. CHAIN Chronology**



**Table 2. Status of Respondents from Original Baseline Cohort**

	Wave 1	Wave 2	Wave 3	Wave 4	Wave 5	Wave 6	Wave 7	Wave 8
Dates (years)	94-95	95-96	96	96-97	97-98	99	00-01	01-02
Fielded from previous wave(s)		700	580	486	435	385	356	285
<b>Ineligible</b>								
<i>Died</i>		58	48	31	23	17	24	7
<i>Moved from NYC</i>		11	16	7	10	8	8	8
<b>Eligible</b>								
<i>Mentally or Physically Unable</i>		3	2	1	0	2	0	0
<i>Institutionally inaccessible</i>		7	5	2	3	7	1	1
<i>Refused</i>		15	6	4	5	8	12	2
<i>No contact / Lost to follow-up</i>		38	23	21	11	36	37	23
<b>INTERVIEWED</b>	<b>700</b>	<b>568</b>	<b>480</b>	<b>420</b>	<b>383</b>	<b>307</b>	<b>274</b>	<b>244</b>
<b>Contact rate (Intervwd/Eligible)</b>		<b>90%</b>	<b>93%</b>	<b>94%</b>	<b>95%</b>	<b>85%</b>	<b>85%</b>	<b>90%</b>

**Table 3. Status of Respondents from Refresher Cohort**

	Wave 1	Wave 2	Wave 3	Wave 4	Wave 5	Wave 6	Wave 7	Wave 8
Dates (years)					97-98	99	00-01	01-02
Fielded from previous wave(s)						268	254	184
<b>Ineligible</b>								
<i>Died</i>						2	14	7
<i>Moved from NYC</i>						2	6	1
<b>Eligible</b>								
<i>Mentally or Physically Unable</i>						0	1	0
<i>Institutionally inaccessible</i>						3	0	0
<i>Refused</i>						11	12	0
<i>No contact / Lost to follow-up</i>						49	51	32
<b>INTERVIEWED</b>					<b>268</b>	<b>201</b>	<b>170</b>	<b>144</b>
<b>Contact rate (Intervwd/Eligible)</b>						<b>76%</b>	<b>73%</b>	<b>82%</b>

Since the project's inception in 1994, the research team has conducted eight waves of interviews, allowing for an interval of approximately six to twelve months between interviews. At each successive wave of interviews a small number of study participants were lost to follow-up. The research team has used a number of resources and strategies to recontact or confirm the status of individuals lost to follow-up, and occasionally an individual who has been lost to follow-up in an earlier wave is recontacted and interviewed at a subsequent wave. On average, as illustrated in Tables 3 and 4, CHAIN has retained between 73%-95% of all eligible clients who were fielded at each subsequent interview wave. Figure 2 represents the chronology of CHAIN interviews by wave.

In the two-hour long interviews, conducted in a face-to-face setting by community-based trained interviewers, participants are asked about: (1) their encounters with the health care delivery system, (2) their need for services, (3) their access, utilization and satisfaction with health and social services, (4) key sociodemographic characteristics, (5) informal caregiving from friends, family and volunteers, and (6) their quality of life with respect to health status and psychological and social functioning. A number of items have been added over the years related to antiretroviral therapies, specific medical care services, viral load levels, and other topics of interest to policymakers, planners, providers, and clients on the Title I Planning Council.

## Issue Area:           **The Unconnected**

In two reports, Technical Report 9 and Briefing Paper 1 we explored the epidemiology and circumstances of HIV-positive adults unconnected to a system of regular medical care. We sought to understand who was unconnected and how they compared with individuals better integrated into the HIV care system; what were their needs for health and social services; what were the individual and organizational barriers they faced; and how the world of the unconnected had changed between 1995 and 1998. We defined someone as unconnected if they (a) had been aware of their HIV status for at least 3 months, (b) had no regular source of medical care for their HIV infection, and (c) reported no HIV case management services. We recruited these individuals into the study through an acquaintance sampling technique, in which we asked CHAIN respondents if they knew anyone unconnected to care; through targeted recruitment efforts at soup kitchens, homeless shelters, gay cruising spots, and needle exchanges; and by accompanying outreach workers who provided episodic medical and social services to the homeless, mentally ill, drug users, and sex workers. In 1995 we recruited 41 unconnected individuals, and in 1998 we recruited 24 unconnected individuals.

### **Key Findings**

- The unconnected are not significantly different from the main agency-based cohort in terms of age, gender, or race/ethnicity. They do tend to be poorer, more unstably housed, more likely to be intravenous drug users, and at an earlier stage of the disease.
- “Unconnectedness” may be thought of as an issue of delaying care. As the disease progresses an individual is more likely to find stable forms of medical care and appropriate social services.
- The first unconnected cohort reported that HHC facilities were likely to be their initial HIV medical provider. The second group reported prisons and drug treatment programs as their first source of care, suggesting a more developed “institutional capture” among this population.
- In 1999 it appeared that there were fewer unconnected individuals than at earlier stages of the epidemic, however they seemed to be more difficult to reach and to engage. There were proportionally more “hard core” homeless, chemically addicted and seriously mentally ill among the unconnected in 1999. Their multiple, serious problems were poorly addressed by agencies who, as a result of funding, licensure, or mission, focused on single rather than multiple diagnoses.
- Based on our fieldwork and analyses of respondents’ periodic lack of regular medical care we have estimated that the number of unconnected individuals is equal to a range of 3.5% to 10% of the individuals in care (see the calculations in the appendix). If there are 75,000 people in care, then one could estimate between 2,625 - 7,500 unconnected individuals in New York City.

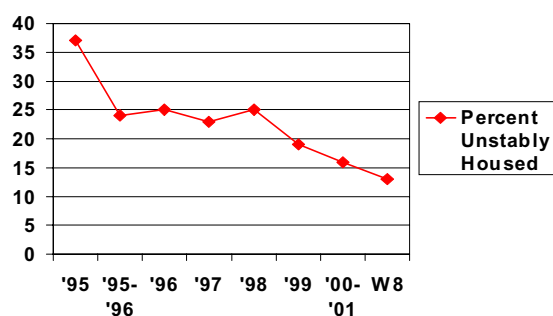
## Issue Area:            Housing

The issue of housing may represent the fullest evolution of CHAIN analyses. Beginning with Technical Report #10 we described the patterns of unstable housing, offered descriptions of the problems experienced with housing, and conducted a “gap analysis” of DAS eligibility and DAS assistance. In Update Reports 16, 27, and 32 we refined measures of instability, examined trends of continued need for housing after periods of homelessness, and explored the relationship of other services – such as mental health, case management, and drug treatment – with housing stability. In Update 30 and 41, we analyzed the relationship of housing services to receipt and retention in medical care and to clinical health outcomes and health status. For the purposes of our analyses, *unstable housing* is defined as an individual reporting that he or she has spent any night in the past 6 months homeless; sleeping on the street; in a shelter, SRO, or welfare hotel; in an abandoned building; in a public or private space not intended for sleeping; in jail, drug treatment, or a halfway house with no other permanent address; or temporarily doubled up with friends or family.

### Key Findings

- Although the level of unstable housing has declined since 1995, homelessness or unstable housing is persistently associated with barriers to medical care, lower rates of service utilization, and poor adherence to complex treatment regimens.
- Among unstably housed individuals who find stable housing, 40% are again unstably housed within two years. Among the formerly homeless, the average length of stable housing is only 25.5 months.
- Accessing agency-based housing services improves an unstably housed individual’s likelihood of gaining and maintaining permanent housing, particularly if the service continues after placement. Additionally, case management, mental health, and drug treatment are equally important in acquiring and maintaining stable housing.
- Receipt of housing service is positively associated with entry in to medical care, reported adequacy of medical care, and initiation of combination therapy.
- Individuals with a history of homelessness can be completely adherent to treatment regimens, including individuals who also struggle with mental illness and/or substance abuse, provided that supportive services (case management, mental health services, relapse prevention support groups, etc) are provided in addition to housing. Independent living situations, such as scatter site programs, that maintain contact with residents and facilitate service linkages appear to be as successful as congregate settings with onsite services in supporting good adherence.

Figure 3. Trends in Unstable Housing

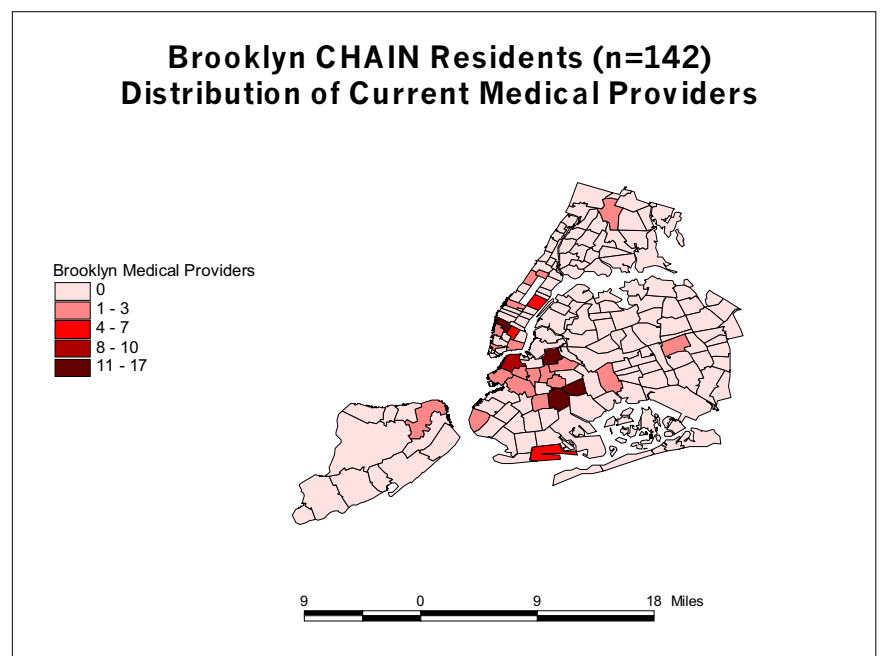


## Issue Area: Migration to Services

A common question posed to CHAIN has been, where do people go to access care? Do people tend to travel across borough lines as they seek care? Do they go beyond their neighborhood boundaries? And if they do “migrate to services,” what is the impetus for such travel. In Update 2 and 11 we examined migration at borough and neighborhood levels, and in Update 40 we presented city-wide maps of service utilization and migration. Initially we examined medical care, case management, and Alcohol or Drug (AOD) treatment services; in the mapping analysis we added supportive mental health services (such as support groups) and professional mental health services (psychiatrist or psychologist).

### Key Findings

- Slightly over one-quarter of respondents reported going outside their borough for medical care or case management, whereas 40% accessed drug treatment services outside their borough.
- At a neighborhood level, over 70% of respondents reporting traveling to another neighborhood for medical or case management services.
- As illustrated in the adjacent map, which shows the location of primary medical providers reported by CHAIN respondents who lived in Brooklyn, clients tended to travel to southern Manhattan and to Queens for their medical care in addition to the care they received mainly in central Brooklyn (similar maps are available for all the boroughs).
- Generally, individuals living in Manhattan and Staten Island tended to stay within their borough boundaries for most of their services. Bronx residents traveled primarily to northern Manhattan when they went outside their borough, and Brooklyn and Queens residents were the likeliest to travel across borough lines.
- The principal reason that people traveled outside their neighborhood or borough was that they were satisfied with the services they received. A small number of respondents mentioned privacy issues related to their desire to travel away from home for their medical and social services.



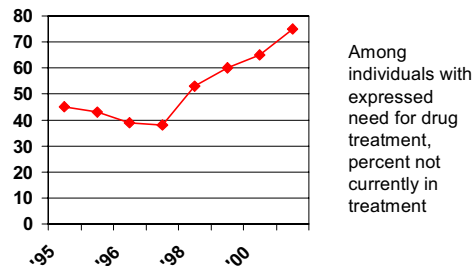
## Issue Area: Unmet Needs

In a number of CHAIN reports we examined expressions of need for various services, the subsequent receipt of services, and self-reported resolution of the expressed needs. Among the reports which featured these assessments of need and unmet need are Technical Reports 8 and 16, and Update Reports 3, 5, 6, 7, 8, 9, 16, 22, 24, 28, and 29. In the most direct measure of unmet needs, we asked respondents if they needed a particular service, such as housing, transportation, child care, job placement, etc., and then subsequently asked if they received any practical help from a professional or someone affiliated with an agency, and whether or not the problem was resolved or continued to persist. In several reports we explored “objective” expressions of need, such as unstable housing (presumed need for housing), low mental health scores (presumed need for mental health services), or current intensive drug or alcohol use (presumed need for drug treatment). Several reports looked at the “lagged” effect – in other words, does a report of case management in an earlier wave lead to the resolution of a specific problem (such as housing) in a subsequent wave?

### Key Findings

- Overall, the level of unmet need has diminished among the CHAIN cohort. Among the possible explanations are: (a) the care system has improved at resolving needs, (b) individuals have become more experienced at resolving their needs, (c) the need is no longer expressed, even though it persists, or (d) over time the people with the greatest unmet needs (such as the unstably housed) have been lost to follow-up. It is likely that all four of these explanations are at work in the diminishing trend line.

Figure 4. Drug Treatment Need Trends



- Some needs, such as the need for drug treatment illustrated above, have increasingly been unmet.
- Certain groups report the greatest proportion of unmet needs. Single women with children and men living alone are the likeliest groups to report unmet needs. The single women, in particular, are the likeliest to report needs for appropriate medical care, and also the likeliest to report lower rates of HAART and lower rates of adherence.

## Issue Area: Service Utilization

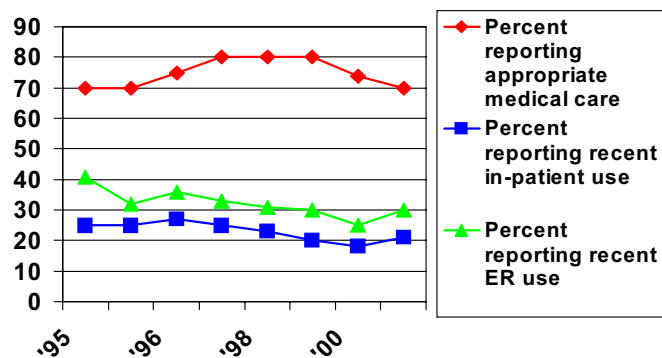
At each round of interviews we asked a series of questions about where people access medical and social services. Based on the name of the agency provided by a respondent, we assigned an agency code. Much like asking a representative group of subway riders in New York City what subway lines they ride over an eight year period, and then using the answers to examine subway ridership trends, we have done the same for the city's health and social service system. The CHAIN agency database encompasses over 3,000 providers, and CHAIN respondents have reported on over 24,000 service encounters. Based on these data we have developed reports that are group-specific, such as those on adolescents (Technical Report 8) and women (Update 28); service-specific, such as those on mental health service utilization (Technical 16, Update 9), dental services (Update 33), and complementary medicine (Update 27); and system-wide, such as those on pathways to medical and mental health services (Updates 36 and 40, respectively). Service utilization trends appear throughout other reports as well, since they often provide a picture of how and where people are using the city's HIV care system.

### Key Findings

- Given a cohort that has grown more experienced with the service system, it is not surprising that we have found relatively stable rates of service utilization. As the graphic to the right illustrates, there has been a very gentle decline in emergency room usage, and a modest decline in in-patient utilization.

- Levels of self-reported "appropriate medical care," that is primary HIV care that meets minimum practice guidelines (see the appendix for specifics on how this is measured), has also leveled off at around 70% after several years of more intensive primary medical care utilization. It is probably not coincidental that the period of greater primary care usage occurs during the period of 1996-2000 when antiretroviral medication regimens required even closer medical supervision than they do today.

### Figure 5. Service Utilization Trends



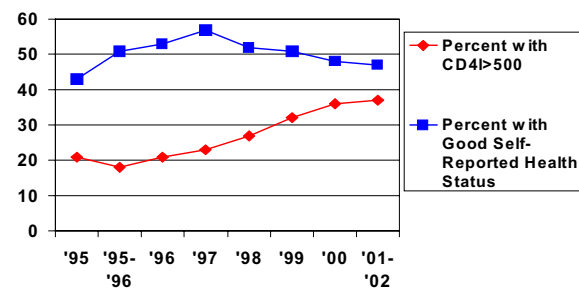
## Issue Area: Health Status Measures

Over the course of the study period we have used two strategies for measuring an individual's health status: one has involved an effort to identify a clinical health marker, such as a CD4 count or a viral load, and the other has been predicated on an individual's perception of his or her health. Throughout many of the reports, we have used these types of measures as factors that might explain a particular outcome. For example, in Update Report 25, a report on work, we considered how both the perception and self-reported clinical health status of an individual affected one's interest in returning to work, and we looked at the effects on HIV medication use and adherence in Update Reports 1, 12, 14, 19, 20, 23, 34, 38. We have also used these measures as outcomes in and of themselves in Update Reports 21 and 39, which explored trends in health status.

### Key Findings

- Overall, as illustrated in the figure to the right, the "clinical" measure of CD4 counts has been steadily on the rise since 1997, in step with increases in use of antiretroviral medications. Twice as many respondents in the last wave reported CD4 counts over 500 compared with the second wave in 1996. This despite the fact that the proportion of respondents who had ever had an AIDS diagnosis increased from approximately 65% in the first wave to 80% by the eighth wave. It should be noted that individuals with an AIDS diagnosis can have CD4 counts over 500, since a respondent may have a CD4 count below 200 at one point in time and an AIDS diagnosis will persist even as the CD4 count rises above 200.
- In contrast to the steadily increasing CD4 counts, however, self-reported health status, as measured by the Medical Outcome Study physical component summary score, has declined since 1997. Although this may be due to the natural aging of the cohort (particularly one suffering from an often debilitating chronic disease in which the effect of other comorbidities may be heightened), it may also be a consequence of the HIV medications themselves. In addition to the side effects experienced by individuals who use antiretroviral therapies, there may also be a shift in expectations among the cohort. As the burden of a previously terminal diagnosis is shifted to the onus of managing a complex chronic disease, people's expectations for better health and improved clinical markers may not match how they feel.

Figure 6. Health Status Trends



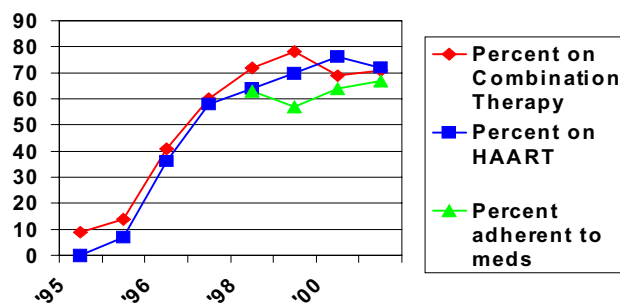
## Issue Area: Antiretroviral Therapy & Adherence

Respondents in the CHAIN Study first began reporting use of protease inhibitors in late 1995. Beginning in April 1997, we reported on the introduction of combination therapies to HIV medical care (Update Report #1), and since then we have reported on trends related to antiretroviral therapy (Update Reports #12, 14, 19, and 20), patterns of adherence (Updates 20, 23, 34, 38), the relationship of combination therapies to outcomes (Updates 26, 34), and an exploration of whether ancillary services are associated with increased adherence (Update 38).

### Key Findings

- As illustrated in the figure to the right, there was steep uptake of combination therapies and HAART after the third wave in 1996-1997, which leveled off by 2000.
- Statistically significant racial/ethnic disparities in initial access to antiretroviral therapies in 1996-1998 had diminished by 2000-2002, in that black and Latino respondents had equivalent rates with white respondents.
- Several sociodemographic characteristics are significantly associated with adherence – men, individuals over 50 years old, participants with greater than a high school education, and individuals more recently diagnosed are all more likely to be adherent than comparable groups.
- All the ancillary services – housing, drug treatment, professional mental health, case management – are significantly associated with increased reporting of appropriate HIV medical care. Housing and professional mental health treatment, as well as certain case management models, are also associated with increased use of antiretroviral therapy.
- None of the ancillary services was associated with increased adherence to HIV medications. Ancillary services may have secondary effects on health outcome “processes,” such as appropriate medical care, but that factors relating to adherence may be too complex to be responsive to services designed to meet other objectives (i.e., finding housing, securing drug treatment, etc.).

Figure 7. HIV Meds & Adherence



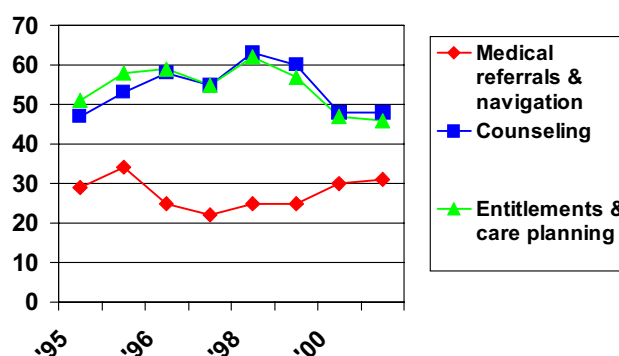
## Issue Area: Case Management

Case managers have long been the cornerstone of New York City's HIV care system, particularly in the era prior to the introduction of combination therapies. As in other urban areas hard hit by AIDS, case managers were employed to shift the burden and the locus of care from intensive (and expensive) hospital units to community-based care. Since our earliest reports we have examined trends in use of case management (Technical Reports 7R, 17), attempted to describe various models of case management (Technical Report 11, Update Report 7), and explored the relationship between these models of case management and various health outcomes and service trends (Update Reports 24, 30, 35, 38).

### Key Findings

- We identified three functions performed by case managers – providing medical referrals and assisting clients in navigating the medical care system (often equivalent to providing a gatekeeper function); counseling clients on personal issues; and providing social service care planning and assistance with entitlements and benefits.

Figure 8. Case Management Functions



- As illustrated in the figure above, the majority of case management functions reported by respondents have been care planning and counseling, with about half as many reports of medical case management.
- Receipt of case management was consistently associated with improved outcomes – including entry and retention in medical care as well as reported use of antiretroviral therapies and HAART (the latter specific to Ryan White-funded case management).

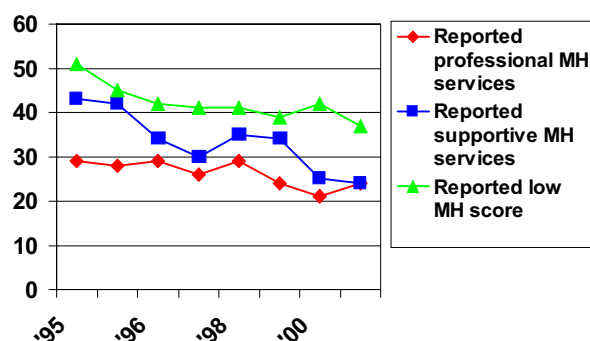
## Issue Area: Mental Health

A number of CHAIN reports have included measures of mental health need and service utilization as components in multi-factorial analyses. Four reports, in particular, focused exclusively on mental health: Technical Report 16, and Update Reports 9, 29, and 40. These reports have established the prevalence and trends over time of mental health service utilization, characterized as either professional mental health services (i.e., psychiatrist, psychologist, or therapist), or supportive services (i.e., support groups, case managers, or clergy) and have also distinguished between two expressions of need for mental health services – one that relies upon a client’s “demand” or stated interest in receiving such a service, and the other that is predicated upon a mental health summary score. The score is based upon a nationally standardized survey instrument, the Medical Outcome Study’s Short Form 36 (SF-36), which has been replicated and validated many times. The reports have also examined the effect of these measures of mental health on various outcomes (such as being on HIV medications and being adherent), the impact of co-located services, and pathways to mental health services, among other issue areas.

### Key Findings

- As illustrated in Fig. 9, supportive mental health service utilization and the percentage of the cohort with low mental health scores have declined over time.
- Respondents with very low mental health scores were more likely to lose benefits, particularly income support. This loss was less likely to be related to eligibility criteria and more likely to be associated with a respondent’s inability to comply with such administrative rules as maintaining adequate documentation or keeping appointments.
- Clients who received any type of mental health service, including such supportive services as support groups, reported less impairment and more effective functioning over time, were more engaged with medical care, had lower rates of risky sex and drug behaviors, were more stably housed, and scored higher on measures of overall adjustment to living with HIV.
- Although respondents with very low mental health scores were as likely as individuals with higher mental health scores to be on antiretroviral therapy, they were less likely to be adherent to their medication regimens.

Figure 9. Mental Health Trends



**Issue Area: Alcohol & Other Drugs (AOD)**

CHAIN reports have looked at AOD issues from a number of vantage points. On one level, reports have described the population of HIV+ AOD users (Technical Reports 9 and 12), characterized respondents’ frequency of drug and alcohol use (Update Report 43), and assessed people’s engagement in high-risk behaviors (Rapid Response Report 3). From the perspective of the health and social service system, CHAIN reports have also explored the need for services among AOD users (Update Report 8) and the barriers to AOD care experienced by CHAIN respondents (Update Report 43). In virtually every CHAIN report, AOD use has been considered as a factor that relates to service utilization, use and adherence to HIV medications, as a social “co-morbidity” with an independent effect on various health outcomes, and as a potential “destabilizing” force in an individual’s life that has many consequences.

**Key Findings**

**Table 4. History of Frequent Alcohol or Other Drug Use**

	Percent reporting frequent AOD use (n=968)
<i>Ever used cocaine or crack 3+ times per week</i>	<b>57%</b>
<i>Ever used heroin 3+ times per week</i>	<b>50%</b>
<i>Ever a problem drinker</i>	<b>20%</b>

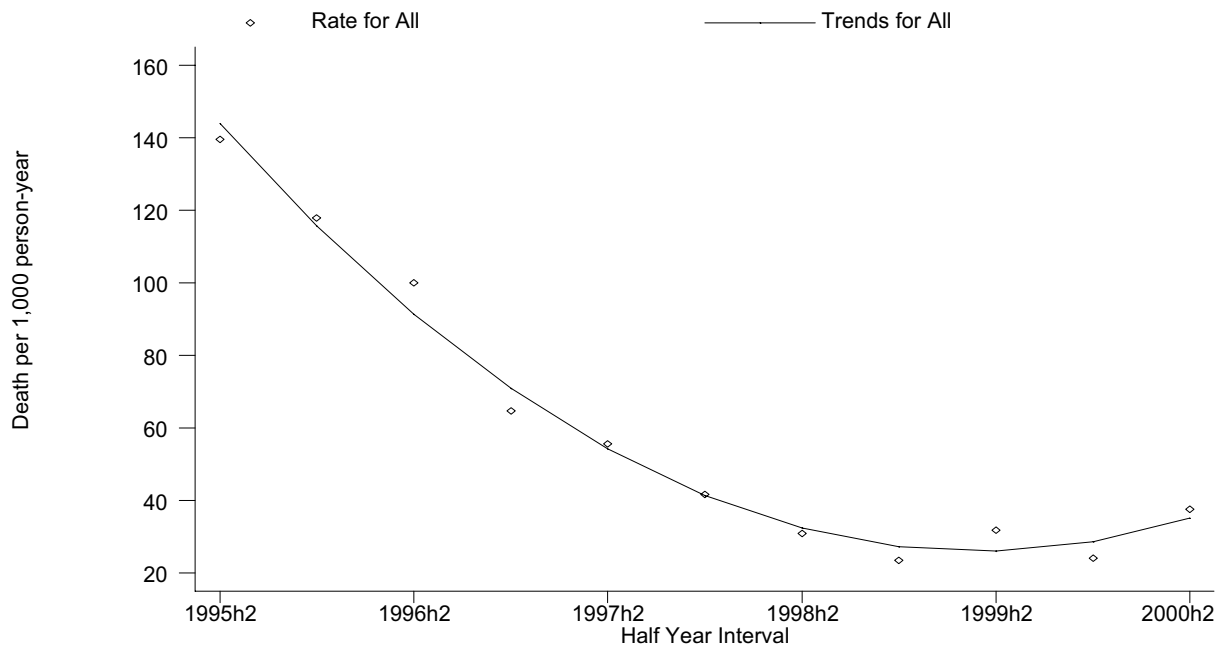
- Substance use is widespread among CHAIN respondents. Almost 90% of respondents reported use of one or more illicit drugs in their lifetime, over half reported a history of frequent cocaine, crack, or heroin use, and 20% indicated they have been a problem drinker at some point in their life (see Table 4).
- In terms of their pathways in to medical care, substance users with the most frequent drug use (i.e., daily cocaine, crack, or heroin use) were far more likely to delay entry in to medical care after learning their initial HIV status, and were also more likely to have learned their serostatus at social service agencies and drug treatment programs rather than in health care settings.
- The refresher cohort recruited in 1998 was less likely to report current or former drug use than was the baseline cohort recruited in 1994-1995. Eighteen percent of the refresher group reported current drug use, compared to 33% of the baseline group surveyed three years earlier.
- Receipt of drug treatment services was associated with a number of positive outcomes: respondents who reported therapeutic drug treatment were more likely to access and retain primary medical care; clients who participated in self-help drug treatment were more likely to be in stable housing; and current drug users in therapeutic or self help treatment were more likely to report appropriate HIV medical care.

## Outcome Area: Mortality Analysis

Through the end of 2000, a total of 214 CHAIN participants, 31 percent of the original cohort, are known to have died. A review of the cause of death from 142 death certificates available for the decedents indicated that AIDS was the most commonly cited cause of death. A small number of death certificates listed lymphomas or other cancers (7), drug use (5) and coronary heart disease (3) as the primary cause of death. For Update Report 26, an examination of outcomes, we analyzed the impact of antiretroviral therapy on reducing mortality, and considered whether death rates differed within certain subgroups, such as by race/ethnicity, by gender, or by whether an individual is an intravenous drug user. [This report was revised and expanded, and is published in the March 2003 journal *Medical Care*.] As illustrated in the figure below, Mortality rates for the CHAIN cohort dropped sharply during the study period. Mortality rates peaked at the start of the study, reaching a high of 140 per 1,000 person-years for the second half of 1995. Mortality rates consistently declined in each successive half-year period through the first half of 1999, and remained at historically low levels through the end of 2000. Mortality rates remained below 40 deaths per 1,000 person-years, less than a third of the rate experienced during 1995, for every half-year interval from the second half of 1998 onward.

**Figure 10. Mortality Rate**

### Key Findings



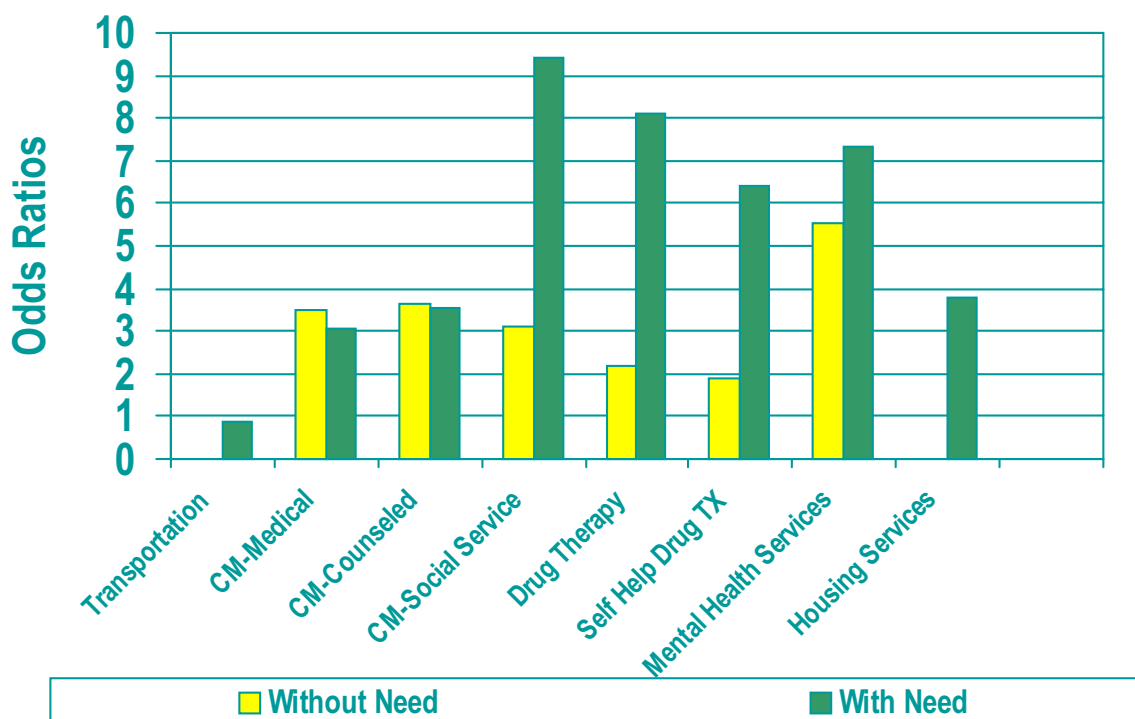
- After adjusting for CD4 count, age, gender, and race/ethnicity, we found that HAART combination therapies exerted strong and significant effects on lowering mortality risk ( $P < .01$ ). Triple combination therapy was associated with a 50 percent reduction in mortality risk. In contrast, PCP prophylaxis and non-HAART combinations were associated with modest but statistically non-significant reductions in mortality risk.
- To illustrate the public health significance of these findings, we projected the number of additional deaths that would have occurred had mortality rates between 1997 and 2000

remained at the rates observed for 1995 and 1996. We estimated that 110 CHAIN participants were alive in December 2000 who would otherwise have died had the pre-1997 mortality rates persisted. This works out to an additional 157 survivors as of December 2000 per thousand people living with HIV at the start of 1995. Extrapolating these results to the 28,157 surviving New York City AIDS cases at the beginning of 1995, suggests that approximately 6,300 individuals were still alive at the end of 2000 because of the widespread administration of antiretroviral therapy and other improvements in medical care.

## Outcome Area: Ancillary Services

Ancillary services – an umbrella term encompassing a broad range of services designed to address the social and psychological needs of individuals and groups affected by HIV – generally deal with non-medical problems, such as inadequate or unstable housing, mental illness, substance use, or lack of transportation. Update Report 30 explored the impact of specific ancillary services on entry and retention into medical care. We considered that ancillary services could increase access or retention to medical care in one of several ways: (1) by overcoming or addressing specific logistical barriers that prevent an individual from getting to a doctor, such as lack of transportation or child care; (2) by overcoming or addressing more complex problems, such as unstable housing, mental illness, or substance abuse; (3) by helping clients navigate the health and human services system with the aid of a case manager; or (4) by having a preventive effect in addressing issues before they develop into significant problems or reducing the number of competing needs that an individual has to address. In this study, we also considered whether ancillary services could address disparities in access to medical care that have historically plagued certain groups within the larger population.

Figure 11. Increasing the Odds of Entering Medical Care



Note: As illustrated above, for example, individuals with a need for case management -- social services who receive that service are over 9 times as likely to enter into medical care as similarly needy individuals who don't receive the service. By comparison, individuals *without* a need for case management social services who receive that service are 3 times as likely to enter into medical care as similarly low-need individuals who don't receive the service.

## **Key Findings**

- The study's principal findings are that, (1) receiving such specific ancillary services as substance abuse treatment, mental health care, housing services, and case management do increase an individual's likelihood of entering medical care and maintaining appropriate medical care services for HIV, and (2) these services have their greatest effect when they address a corresponding need. For example, as illustrated in the figure above, individuals with a need for case management services who received such services were over 9 times as likely to enter into medical care as were similarly needy individuals who did not receive case management services.
- Case managers clearly serve as the principal coordinators within a comprehensive care system, and our results suggest that their effect is felt both directly (i.e., by providing a specific service) and indirectly (i.e., by assisting an individual in obtaining a service through an interagency coordination or referral mechanism). The finding that social services provided by a case manager in a prior time period have an effect on later entry or retention in primary medical care supports this notion of facilitation.
- Ancillary services that meet complex needs – such as housing instability and mental illness – may have an even greater impact on getting individuals into care than in maintaining them in care (although they have a positive impact on both). This suggests that such ancillary services are particularly important in engaging hard-to-reach populations. Our findings also suggest that efforts to begin addressing complex needs first, before focusing exclusively on medical care, may assist individuals in accessing and retaining ongoing medical care.
- One can estimate the need for services (and their potential effect on increasing access and retention among HIV-positive populations) with several simple self-reported measures: housing instability, mental health scores as measured in the MOS SF-36, the presence of a primary medical provider at the time of initial diagnosis, and a history of substance use (or current use).

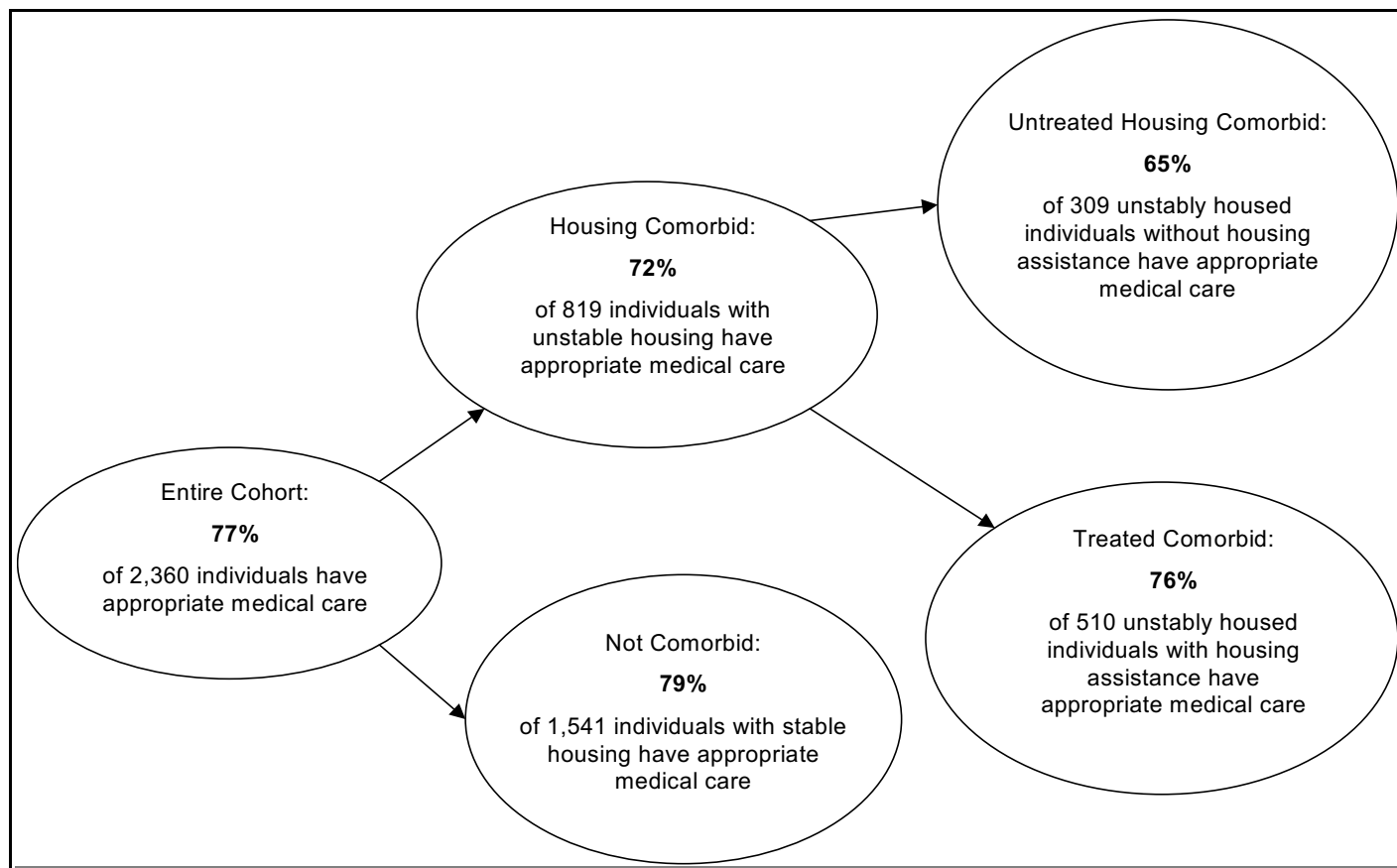
## Outcome Area: Social Comorbidities

HIV/AIDS is associated with a number of social as well as clinical comorbidities. Poverty, substance use, mental illness, and unstable housing are among the problems that often plague those living with HIV/AIDS, and as such, pose as much of a “comorbidity” as do clinical expressions of disease. CHAIN examined the epidemiology of several clinical and social comorbidities among the CHAIN study group (Update Report 24), the relationship of such comorbidities to access and receipt of medical care among people living with HIV/AIDS in New York City (Update 30), and the impact of treating such comorbidities on specific health outcomes. Clearly, both social and clinical comorbidities have independent effects on an individual apart from HIV. An individual with unstable housing has a need for housing services regardless of his or her HIV serostatus. On the other hand, there may be a synergistic effect of HIV and comorbidities. Among HIV-infected individuals the disability, illness, or chaos resulting from such comorbidities may be magnified, making both housing needs and medical needs more acute. We hypothesized that an individual with such complex needs would need a comprehensive care system capable of handling these intertwined demands.

### Key Findings

- Overall, all of the comorbidities under investigation showed a general decline over time among members of the CHAIN cohort, but when measured by their **persistence** across time there were substantial numbers of individuals with comorbidities that persisted for at least two or three consecutive waves of interviewing (approximately a year and a half).
- The social comorbidities of unstable housing, drug use, and mental illness were more persistent – thus more “entrenched” or possibly untreated – than the clinical comorbidities of STDs or TB.
- As illustrated in the figure on the following page, there was a significant impact on certain health outcomes (in this case, the reported receipt of appropriate medical care) by treating specific social comorbidities. Among the entire cohort and across several waves of interviewing, 77% of respondents reported having appropriate medical care. When we split the cohort based on whether someone was unstably housed, 72% among those with this housing “comorbidity” reported appropriate medical care compared with 79% without the housing comorbidity. When we further examined whether “treating” the housing comorbidity made a difference, we found that only 65% of the untreated group reported appropriate medical care, compared with 76% of the treated group. In this illustration, it appeared that treating a housing comorbidity raised the outcomes to be equivalent to those without the comorbidity.

**Figure 12. Proportion of HIV-Positive Adults with Appropriate HIV Medical Care, Among Individuals with Housing Comorbidities, NYC CHAIN Data**



**Notes on Figure 1**

(1) The differences in the proportions of the groupings pictured above are statistically significant. Overall, 77% of respondents have reported receiving medical care that appears to meet preferred practice guidelines. When distinguished by whether individuals have a housing comorbidity, only 72% report appropriate medical care as compared to 79% of the individuals who are not experiencing the comorbidity. Furthermore, among individuals with the comorbidity who are not treated, only 65% report appropriate medical care, compared to 76% of the comorbid individuals who did receive treatment.

(2) A housing comorbidity is defined as any unstable housing experience in the 12 months prior to an interview, such as living in a shelter, on the street, or doubled-up.

(3) Treatment for the housing comorbidity is defined as receiving supportive housing or rental assistance during the period in which the unstable housing was experienced or in the subsequent 6-12 months, or supportive housing services (such as referrals to housing agencies) that have been preceded by supportive housing or rental assistance.

(4) “Appropriate HIV Medical Care” is defined as medical care that meets certain minimal practice guidelines, such as the number of primary care visits within a six-month period, a complete physical exam, a blood work-up, and a minimum of one CD4 check. These guidelines are based on NYS AIDS Institute primary care protocols and on interviews with key AI program staff.

(5) The numbers of individuals represent repeated observations of 967 respondents interviewed over six interview rounds between 1994 and 2000. 700 individuals were recruited into the CHAIN cohort in 1994-1995 and an additional 268 were recruited in 1998.

## Outcome Area: Impact of Ryan White CARE Act

Estimating the impact of Federal health policies on individuals affected by such policies has long been an objective of the policy and research communities. In Update Report 35 our analysis capitalized on three distinct data streams: client-level data from the longitudinal CHAIN cohort; administrative contract data on Ryan White-funded services in the city, across all Ryan White titles, by site and type of service; and an agency database of over 2,800 service providers. By mapping these data sets to one another we identified when and where CHAIN cohort participants received specific services funded through the Ryan White CARE Act. With this, we established three comparison groups – (1) individuals receiving specific services from a Ryan White-funded provider; (2) individuals receiving specific services from a non-Ryan White funded provider; and (3) individuals not receiving these services. We compared selected health outcomes among these three groups, controlling for the sociodemographic, health, and risk characteristics that might otherwise explain the differences in health outcomes. Using this approach we explored a fundamental question: *Does the Ryan White CARE Act make a difference in individual health outcomes?* After conducting a series of analyses we have concluded that Ryan White CARE Act funding is significantly associated with improved health outcomes.

As the table below illustrates, individuals with a Ryan White-funded medical provider were 1.7 times as likely as a similar individual with a non-Ryan White funded provider to report appropriate medical care, and 1.5 times as likely to report being on HAART. Similarly, individuals with Ryan White funded case managers were 1.8 times as likely to report appropriate medical care and 1.4 times as likely to report being on HAART as their counterparts receiving care from non-Ryan White funded providers.

**Table 5. Estimating the Impact of Ryan White on Health Outcomes**

<i>Among individuals with a Ryan White funded...</i>	<i>What are the increased...</i>	
	<b>Odds of Appropriate Medical Care</b>	<b>Odds of being on HAART</b>
Primary medical care provider	<b>1.7***</b>	<b>1.5*</b>
Health care (other than 1 <sup>o</sup> care)	<b>1.8***</b>	1.0
Housing service	0.7	1.1
Alcohol or drug treatment	1.1	0.8
Professional mental health	0.8	0.7
Supportive mental health	1.1	<b>0.1***</b>
Case management or client advocacy	<b>1.8***</b>	<b>1.4†</b>
Food and nutrition	1.1	0.7
Dental services	0.8	1.8

† p < .10

\*p < .05

\*\* p < .01

\*\*\* p < .001

Note: Adjusted odds ratios and coefficients have been controlled for gender, race/ethnicity, age, education, substance abuse history, CD4 count, unstable housing, and low mental health

## Appendix 1. ESTIMATING THE UNCONNECTED

*[From Technical Report #9, "The Unconnected: Service Needs of HIV-positive Persons Who Are Outside or Marginal to the Service Delivery System," March 22, 1996]*

To make some crude estimates of the minimum numbers of persons who are outside the care system, we will draw upon what we have learned about relationships between connected and unconnected persons, as well as other research about social networks of HIV positive persons, especially substance users, who are more likely than others to know persons not in care (Neaigus et al, 1994; Page, et al. 1993; Pivnick et al. 1994). We found that approximately 10% (.097) of the agency recruited sample reported that they personally knew someone who was HIV positive, but not receiving either medical or social services related to HIV. In collecting these nominations we learned that those in services tend to know several other persons who are HIV positive but relatively few who are completely outside of the service system. When we were able to follow up nominations, screening interviews revealed that approximately one-third of individuals nominated as unconnected were in fact receiving some type of HIV related services. The nominees were most often more marginal to the service system than the friend who nominated them; however they did not qualify as unconnected according to our strict eligibility criteria. Thus the proportion of agency-recruited respondents whose network connections contain at least one "truly unconnected" is estimated at .065 (.097 nominated x .667 of nominees who pass screener = .065).

However, once we successfully interviewed someone who was not receiving services, when we repeated the nomination and recruitment procedure, we found that a much higher proportion (.386) of those who are truly unconnected can nominate others similarly situated. A higher proportion (.75 - .80) of nominees passed screening as truly unconnected by our strict definition. Unfortunately, we did not pursue the chain referral process to completion. Had we done so, it is possible that networks with an even greater density of unconnected individuals would be found. Using a conservative approach and assuming that rates of knowing an unconnected acquaintance remain constant, we estimate that .309 (.386 nominated x .80 of nominees who pass screener = .309) of the second links of the chain referral are truly unconnected.

Given these ratios of connected to unconnected, and drawing on other research about social networks of HIV positive persons, especially substance users who are more likely than others to know persons not in care, we can make some very crude estimates as to the minimum numbers of persons who are unconnected to services as we have defined it. We estimate that excluding special populations, undocumented residents, adolescents, and the untested, there are a minimum of approximately 5,000 individuals currently living in New York City who are HIV positive, have been aware of their serostatus for at least three months, and have no regular source of HIV primary care and no HIV case management services. We arrive at this minimum estimate in the following manner:

1. Estimated number of persons receiving HIV primary care services in 1995: 49,000 - 53,000.<sup>2</sup>

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<sup>2</sup> Health Systems Agency of New York City estimate for 1995 (HSA 1995).

2. Number of those in care estimated to know at least one unconnected individual: 3,185 - 3,445 (49,000 - 53,000 x .065).
3. Number of "1st link" individuals who know at least one other unconnected person: 984-1,065 (3,185 - 3,445 x .309).
4. Number of "2nd link" individuals who know at least one other unconnected person: 304-329 (984 - 1,065 x .309).
5. Number of "3rd link" individuals who know at least one other unconnected person: 94-102 (304 - 329 x .309)<sup>3</sup>.
6. Estimate of the unconnected (excluding untested and special populations): 4,567 - 4,941 (2 + 3 + 4 + 5 above).

*[From personal communication with Derek Hodel, Sept 21, 2001, in reference to NY EMA Reapplication for Ryan White CARE Act Title I funds]*

#### Available Evidence

1. There are approximately 48,000 unduplicated individuals who have filed an HIV-related Medicaid claim in 1999
2. The payor mix on all HIV-related hospital discharges in 1999 was 2/3 Medicaid (67%) and 1/3 all else
3. The first CHAIN report on Unconnected in 1995 estimated that 6.5% of HIV-positive individuals in care were unconnected to care. This group could be considered the most marginalized and disengaged HIV+ population.
4. The Ryan White Impact Study (excerpted as Update Report 35) found that 3.5% of the CHAIN cohort between 1997-2000 indicated that at any given moment they did not have a primary medical provider. These individuals are episodically disengaged or disconnected from medical care.

#### Assumptions

*Assumption 1:* It's possible to extrapolate from the Medicaid and hospital discharge data to estimate the total numbers of individuals in care in NYC. Given that the Medicaid payors represented twice as many hospital discharges as non-Medicaid, we would estimate that the total number of individuals in care is equal to the 48,000 Medicaid + 24,000 non Medicaid = 72,000 HIV-positive individuals who know their serostatus and are in care. This estimate assumes that the distribution of people in care is essentially equivalent to the distribution of people who have been hospitalized.

*Assumption 2:* The lowest number that one would estimate as being unconnected would be (72,000) x (.035), representing the 3.5% who are episodically disengaged from care = 2,520

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<sup>3</sup> A constant rate of .309 is assumed. Our estimate allows for three links away from the index agency respondent since beyond this, it is likely that networks may begin to overlap one another.

individuals.

*Assumption 3:* A middle number could be estimated as  $(72,000) \times (.065)$ , representing the 6.5% who are more marginalized and more "permanently" disengaged from medical care = 4,680 individuals.

*Assumption 4:* The higher end of the estimate would be a combination of those episodically disengaged from care (2,520) + those more chronically disengaged from care (4,680) = 7,200 individuals.

Given the above assumptions and data sources, we are estimating that there is a range of 2,520 to 7,200 individuals in NYC who know their HIV-positive serostatus but are unconnected from primary medical care, either chronically or episodically.

## Appendix 2. CHAIN STAFF, 1994-2002

- Senior Team:** Peter Messeri (Principal Investigator), Angela Aidala (Co-PI and Study Director), David Abramson (Co-Investigator and Project Director), Jo Sotheran, Cheryl Heaton (former Co-PI), Joyce Moon Howard
- Analysts:** Maurice Sahar, Gregg Weinberg, Mei Ching Chou, Gunjeong Lee, Tasha Stehling
- Field Directors:** Yasmin Davis, M. Lyndon Haviland, Helen Maria Lekas, Natasha Davis, Barbara Bennet, Elizabeth Needham
- Research Staff:** Grace Roegner Freedman, Jeff Natt, Kelly Larson, Rachel Milligan Ferat, Bernadette Brusco, Chinarro Kennedy, Wanda Bonilla, Dahlia Bovian, Rachel Blum, Antonios Likourezos, Ann Denise Brown, Marcus Cotto, Cynthia Severe, Sandra Smartt, Fleur Lee, Nealia Khan, Nina Sanger, Dave Hunter, Evelyn Mejia, Thurka Sangramoorthy, Maya Rom, Laura Kozek
- Admin. staff:** Jennifer Ho, Eleanor Read, Narine Malcolm, Janice Spatcher
- Interviewers:** Latreece Miller, Leslie Sadler, Nadine Nader, Jerome Easterling, Kurt Gottschalk, Catherine Simon, Darlene Saulter, Maria Elena Ramos, Sonia Severe, Carolyn Kovac, Craig Miller, Audrey Grandy-Lampk, Selena Lee, Hendricks Vanderbilt, Karen Saulter, Barbara Burch, Mercedes Chavez, Yvonne Robinson, Mary Floyd, Margaret Contreras, Jacqueline Johnson, Juana Cuello, Michele Peake, Rita Jones, Jeff Natt, Arlana Girven, Narine Malcolm, Rose Rivera, Crystal Sloan.
- Technical Review:** Dorothy Jones Jessop, Kathy Nelson, Deisha Jetter, Kim Fox, Les Hayden, Jo Ann Hilger, Ravi Patur, Ashley Williams, Mary Ann Castle, Rebecca Tiger, Arturo Llerandi-Phipps, Mary Ann Chiasson, Jennifer Nelson, Jeanne Kalinoski, Ryan Chavez, Richard Peterson, Clay Keene, Julie Lehane, Kevin Garrett, Tom Sentell

*Note:* Rather than list staff alphabetically, we have elected to list people chronologically – by when they joined the CHAIN staff. There are two exceptions to this rule. Current members of the Senior Team are listed prior to former members, and in the case of the interviewing staff we have restricted the list to those individuals who completed 30 or more interviews. The interviewers are listed in descending order of completed interviews, beginning with Latreece Miller (570) and Leslie Sadler (404). Although we did not list interviewers who completed fewer than 30 interviews, we acknowledge their work and effort, since every interview counts.

### Appendix 3. CHAIN EVALUATION REPORTS

REPORT#	DATE	TITLE
<b>TECHNICAL REPORTS</b>		
Tech #1	8/31/94	SAMPLE DESIGN FOR STAFFING NEEDS AND CLIENT SURVEY STUDIES
Tech #2	7/5/94	SURVEY OF PERSONNEL NEEDS OF HIV/AIDS AGENCIES: RECRUITMENT & RETENTION DIFFICULTIES AND PERSONNEL INCENTIVE PROGRAMS
Tech #3	9/27/95	TRAINING FOR HIV/AIDS SERVICE AGENCIES
Tech #4	3/1/95	SUMMARY TABLES FOR CLIENT SURVEY - THE FIRST 100 CASES
Tech #5	8/2/95	A TRI-COUNTY SURVEY OF THE PERSONNEL NEEDS OF HIV/AIDS SERVICE AGENCIES
Tech #6	8/2/95	THE PERSONNEL NEEDS STUDY PART II: DELIVERY
Tech #7R	12/14/95	SUMMARY TABLES FOR BASELINE CLIENT SURVEY
Tech #8	10/20/95	THE ADOLESCENT HIV STUDY: NEEDS, UTILIZATION AND BARRIERS FOR MEDICAL CARE, SOCIAL SERVICES AND PREVENTION EDUCATION
Tech #9	11/17/95	THE "UNCONNECTED" - SERVICE NEEDS OF HIV POSITIVE PERSONS WHO ARE OUTSIDE OR MARGINAL TO THE SERVICE DELIVERY SYSTEM
Tech #10	5/10/96	HOUSING & HIV/AIDS IN NEW YORK CITY
Tech #11	5/12/96	HIV CASE MANAGEMENT SERVICES IN NYC: QUALITY AND OUTCOMES
Tech #12	5/22/96	SUBSTANCE USE & HIV AIDS IN NEW YORK CITY
Tech #13	6/3/96	THE INFRASTRUCTURE WORK GROUP REPORT
Tech #14	6/10/96	HIV HEALTH CARE SERVICES IN NEW YORK CITY: UTILIZATION AND QUALITY
Tech #15	6/16/96	ACCESSING MEDICAL AND SOCIAL SERVICES: BARRIERS AND STRATEGIES FOR IMPROVING HIV CARE INFRASTRUCTURE
Tech #16	6/18/96	NEED FOR MENTAL HEALTH SERVICES AND SERVICE UTILIZATION IN NEW YORK CITY
Tech #17	10/4/96	SUMMARY TABLES TIME 2 CLIENT SURVEY
Tech #18	04/24/00	CLIENT OUTCOMES
<b>RAPID RESPONSE REPORTS</b>		
Rap Resp#2	4/21/97	ECONOMIC SECURITY & INCOME CHARACTERISTICS OF THE BASELINE SAMPLE
Rap Resp#3	4/14/00	HIGH RISK BEHAVIORS: UNPROTECTED SEX & NEEDLE

REPORT#	DATE	TITLE
<b>BRIEFING PAPER</b>		
Briefing Paper#1	4/29/99	THE UNCONNECTED REVISITED: A CHAIN BRIEFING PAPER
<b>UPDATE REPORTS</b>		
Update Rep#1	4/21/97	THE INTRODUCTION OF COMBINATION THERAPIES
Update Rep#2	4/21/97	MIGRATION TO SERVICES
Update Rep#3	4/28/97	FAMILY CONSTELLATIONS AND NEED FOR SOCIAL SERVICES
Update Rep#4	4/24/97	MANAGED CARE AND HEALTH SERVICES FOR PEOPLE LIVING WITH HIV
Update Rep#5	5/30/97	CONTINUITY AND CHANGE IN HOUSING PROBLEMS & NEED FOR HOUSING SERVICES
Update Rep#6	5/09/97	ACCESS TO PRIMARY AND CHANGE IN HEALTH PROBLEMS & NEED FOR HOUSING SERVICES
Update Rep#7	5/30/97	MATCHING CLIENT NEEDS AND INTENSITY OF CASE MANAGEMENT: A METHODOLOGY FOR PLANNING AND EVALUATION
Update Rep#8	6/17/97	SUBSTANCE USE AND NEED FOR ALCOHOL & DRUG SERVICES
Update Rep#9	12/97	NEED FOR MENTAL HEALTH SERVICES AND SERVICE UTILIZATION
Update Rep#11	3/4/98	UNDERSTANDING MIGRATION TO SERVICES
Update Rep#12	4/15/98	TRENDS IN USE OF HIV ANTIRETROVIRAL THERAPY
Update Rep#13	4/24/98	SATISFACTION AND DISSATISFACTION WITH MEDICAL AND SOCIAL SERVICES
Update Rep#14	4/27/98	INDIVIDUAL INITIATION AND CESSATION OF ANTIRETOVIRAL THERAPY
Update Rep#15	2/18/98	TRENDS IN MANAGED CARE PLANS AND PEOPLE LIVING WITH HIV
Update Rep#16	5/1/98	TOP CLIENT IDENTIFIED UNMET NEEDS FOR MEDICAL AN SOCIAL SERVICES
Update Rep#18	4/12/99	COHORT COMPARISON: ASSESSING CHANGES & TRENDS BETWEEN THE 1994 AND1998 CHAIN COHORTS
Update Rep#19	5/03/99	TRENDS IN CURRENT USE OF HIV ANTIRETROVIRAL THERAPY-1998
Update Rep#20	5/19/99	PATTERNS OF ADHERENCE TO ANTIRETROVIRAL MEDICATION
Update Rep#21	5/12/99	TRENDS IN HEALTH STATUS
Update Rep#22	5/18/99	NEEDS ASSESSMENT FOR WORK-RELATED SERVICES AMONG PERSONS LIVING WITH HIV/AIDS
Update Rep#23	5/1/00	PATTERNS OF ADHERENCE TO ANTIRETROVIRAL MEDICATIONS, 1995-1999
Update Rep#24	4/27/00	COMORBID CONDITIONS: INTERSECTING NEEDS AMONG THE CHAIN COHORT

REPORT#	DATE	TITLE
Update Rep#25	4/27/00	FACTORS INFLUENCING INTEREST IN EMPLOYMENT AMONG PERSONS LIVING WITH HIV
Update Rep#26	4/28/00	DECLINING MORTALITY RATES AND SERVICE INTERVENTIONS
Update Rep#27	4/27/00	COMPLEMENTARY AND ALTERNATIVE MEDICINE: RATES OF UTILIZATION AMONG THE CHAIN COHORT
Update Rep#28	4/21/00	WOMEN'S NEED FOR AND UTILIZATION OF SERVICES BY FAMILY TYPES
Update Rep#29	6/2000	MENTAL HEALTH SERVICES & TREATMENT NEEDS
Update Rep#30	4/12/00	THE IMPACT OF ANCILLARY SERVICES ON ENTRY & RETENTION TO HIV MEDICAL CARE IN NEW YORK CITY
Update Rep#32	4/17/00	HOUSING ASSISTANCE AND HOUSING STABILITY AMONG PERSONS LIVING WITH HIV/ AIDS
Update Rep#33	3/28/01	DENTAL SERVICES FOR HIV+INDIVIDUALS IN NYC'S CHAIN COHORT
Update Rep#34	8/16/01	MEDICATION ADHERENCE AND PATIENT OUTCOMES
Update Rep#35	5/23/01	ASSESSING THE IMPACT OF RYAN WHITE CARE ACTON ON HEALTH OUTCOMES N NYC: EXECUTIVE SUMMARY
Update Rep#35a	5/23/01	RYAN WHITE IMPACT TECHNICAL TABLES
Update Rep#36	7/25/01	PATHWAYS TO MEDICAL CARE
Update Rep#37	7/25/01	HOUSING AND MEDICAL CARE AMONG PERSONS LIVING WITH AIDS
Update Rep#38	7/31/01	ANCILLARY SERVICES AND ADHERENCE
Update Rep#39	7/24/01	TRENDS IN HEALTH STATUS, UPDATED
Update Rep#40	12/01	PATHWAYS TO MENTAL HEALTH SERVICES
Update Rep#41	11/13/01	HOUSING STATUS AND HEALTH OUTCOMES AMONG PERSONS LIVING WITH HIV/AIDS
Update Rep#42	12/12/01	GEOGRAPHIC DISPLAY OF THE CHAIN COHORT AND SERVICE UTILIZATION
Update Rep#43	12/19/02	LOW THRESHOLD AOD PROGRAMS
Update Rep#46	7/25/02	CHRONIC DISEASES AND CLINICAL COMORBIDITIES
Update Rep#47	1/15/03	CHAIN RETROSPECTIVE: 1994-2002

REPORT#	DATE	TITLE
<b>BRIEF COMMUNICATIONS</b>		
2002-1	7/24/02	TRAUMA & VIOLENCE
2002-2	4/16/02	DRUG HOLIDAYS
2002-3	8/10/02	FOOD & NUTRITION
<b>MEMOS</b>		
2002-1	7/25/02	PATTERNS OF MEDICAL CARE AND SUBSTANCE USE PROVIDERS
2002-2	7/25/02	PARTNER NOTIFICATION
2002-3	7/25/02	MEDICAL CARE VISITS
2002-4	11/20/02	PEOPLE OVER 50 YEARS OLD
<b>TRI-COUNTY REPORTS</b>		
2002-1	11/13/02	COHORT CHARACTERISTICS
2002-2	11/13/02	HEALTH STATUS & HEALTH SERVICE UTILIZATION
2002-3	11/13/02	STIGMA & SOCIAL ISOLATION
2002-4	11/13/02	FIELD NOTES
2002-5	11/13/02	SUPPORT GROUPS
2002-6	11/13/02	BASELINE NEEDS ASSESSMENT

#### Appendix 4. CRITERIA FOR DETERMINING APPROPRIATE HIV MEDICAL CARE

Step	Criterion	Coded as Appropriate/Preferred Practice
<b>1</b>	<b>Number of visits to primary care provider in past 6 months, Rounds 1 &amp; 2 (pre-1996)</b>	
		<i>If asymptomatic = 1 visit/6 months</i>
		<i>If symptomatic or AIDS diagnosis = 2 visits/6 months</i>
<b>2</b>	<b>Number of visits to primary care provider in past 6 months, Rounds 3, 4, 5 (post-1996)</b>	
		<i>If asymptomatic, not on antiretroviral therapy (ARV) = 1 visit/6 months</i>
		<i>If on ARV or symptomatic or AIDS diagnosis = 2 visits/6 months</i>
		<i>If CD4 count &lt; 500 and viral load &gt; 10,000 = 2 visits/6 months</i>
<b>3</b>	<b>Specific services received from primary care provider in past 6 months</b>	
		<i>Minimum of one CD4 check</i>
		<i>Respondent reported both a physical exam and a blood test/work up</i>

**Note:** Depending on time period, either steps 1 + 3 (pre-1996) or steps 2 + 3 (post-1996) have to be present to qualify for meeting preferred practice guidelines. Sources include New York State AIDS Institute “Protocols for the Primary Care of HIV/AIDS in Adults and Adolescents (Nov 1995), on the latest edition of “Criteria for the Medical Care of Adults with HIV Infection” by the AIDS Institute (Mar 1998), and on personal interviews with key program staff at the AIDS Institute.