

NYC CHAIN Report
2005_2



Delayers, Drop-outs,
the Unconnected, and
“Unmet need”

Angela Aidala
Elizabeth Waddell
Jo Sotheran

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

**HRSA Contract H89 HA 0015-15, MHRA
Contract CFH2003-01 and PE06Y11
October, 2005**

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, PhD, and Angela Aidala, PhD, of Columbia University's Mailman School of Public Health, TRT members include Mary Ann Chiasson, DrPH, MHRA (chair); Susan Abramowitz, PhD, Planning Council Needs Assessment Committee; Kenneth Butler, PWA Advisory Group; Judy Sackoff, PhD, NYCDOHMH; Grace Moon, NYCDOHMH Office of AIDS Policy Coordination; JoAnn Hilger, NYCDOHMH; Julie Lehane, PhD, Westchester County DOH; and Jennifer Nelson, MHRA.

This research was supported by grant number H89 HA 0015-15 from the US Health Resources and Services Administration (HRSA), MHRA contract CFTH2003-01 and PE06Y11, 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.

Following is a summary of the major findings from a number of CHAIN Project investigations undertaken to better understand ‘unmet need’ in light of HRSA’s emphasis on persons who are aware of their HIV status but are not engaged in ongoing HIV primary care. A comprehensive report is being prepared with the title, “In Care, Out of Care, Marginal and Unconnected: Engagement and Disengagement with HIV Medical Care in New York City,” by Angela A. Aidala, Elizabeth Needham Waddell, Jo Sotheran, Gunjeong Lee, Mailman School of Public Health, Columbia University.

Summary of Findings

- It is misleading to focus on a simple in care/ out of care dichotomy when attempting to understand “unmet need” for medical care among persons living with HIV/AIDS. At any point in time the population HIV infected person includes individuals who have never received any HIV medical care, persons who consistently maintain regular medical visits for monitoring and treatment of HIV infection, persons who initiated continuous care after a period of substantial delay, persons who had entered care and stopped or dropped out, and those who continue to have a precarious or inconsistent relationship with HIV medical services over time. In the recently recruited new CHAIN study cohort, 39% of participants currently in care had delayed initial entry into HIV care and/or reported one or more periods of dropping out of care.
- Those outside or marginal to HIV care and those better integrated into the care system do not differ with regard to basic demographics (gender, race/ethnicity, age). They are most distinguished by contextual factors and life situations: active drug use rather than a history of use, current mental health difficulties, homelessness or unstable housing, recent incarceration, little social support, and for delayers, characteristics of their testing site. The strongest predictor of timely entry into HIV care is the extent to which the testing site actively facilitates accessing care.
- Those outside of care tend to be in better health than other PLWH. Delayers, those with prior episodes of dropping out of care as well as HIV infected persons currently out of care say that they do not feel the need to seek care when they are not experiencing symptoms.
- Finding the currently unconnected has become increasingly more challenging. HIV positive persons and undiagnosed persons engaged in high risk behaviors are relatively easy to locate in a range of community settings. However, the success of outreach and other programs designed to remove barriers to accessing care by locating low threshold health and social service facilities in high risk neighborhoods and/or the use of mobile units was apparent in the frequency with which persons on the street mentioned these sources of care, and in the relatively low percentage of persons encountered having no contact at all with medical services.
- The currently unconnected are more likely to be dropouts than delayers. Very few persons living with HIV who are currently not receiving medical care have never seen a physician for HIV care. Only 2 individuals among the 25 interviewed (8%) have never seen a medical provider for HIV. This contrasts with previous investigations when 60% of the currently unconnected had never seen a medical provider for HIV.

- Persons living with HIV/AIDS who are not receiving medical care are significantly more likely than others to have multiple non-medical needs. Three-fourths report that they need housing, and over half report the need for other concrete services such as food, clothing, or transportation. Rates of service need for all ten service areas examined are highest among those currently outside of care.
- A large proportion of persons not in medical care, as well as those at risk for dropping out of care have had significant contact with other aspects of the HIV service system that have been less productive for service integration. Providers and PLWH are especially critical of policies that place many homeless persons with HIV in single room occupancy (SRO) housing. Tenants are typically required to leave before 28 days, after which they acquire some tenants' and occupancy rights. Any attempt to engage SRO residents in care, and to provide services to address their multiple needs, are frustrated by the transiency and vulnerability that surrounds tenants.
- Intensive individual outreach is needed to reach individuals unaware, unmotivated, or unable to access community based services, and where such services are absent or limited. Continuing a trend seen in 1999, there are proportionally more chronic homeless and seriously mentally ill among the currently unconnected. Aggressive community policing has meant fluid and largely hidden venues where such individuals might be found. There are also increasing numbers of persons from less well defined service populations: heterosexually infected women with no IDU or other drug abuse history and non-gay identified MSM of color.
- The unconnected are not enticed by the promise of new treatments for their HIV infection. In fact, the desire to avoid medications was a common theme in reasons given for delayed entry as well as for discontinuing care. Myths and misconceptions about medications and the role of medications in management of HIV disease persist among many subgroups infected with HIV or at high risk of infection.

Recommendations

- Multi-pronged strategies are required to reach and engage the currently unconnected and to maintain PLWH marginally connected to the service system. Outreach and service readiness programs should be aware of the differences between individuals who are at different stages in the continuum of engagement with the health care system. Some individuals are at a stage when they are ready to begin to manage their HIV illness, and will seek services although their motivation and capacity to access and maintain care may be limited. Other individuals have not yet developed an awareness of the need nor intention to access care. The first group can be served by community based services that facilitate client initiated access. The later group require active, individual outreach to reach them where they gather or would be motivated to come for other reasons than medical care. Attempts to pressure the unconnected into care do not appear to be effective.
- Outreach and community based services appear necessary not only for first entry into HIV care but to maintain continuity of care for many persons infected with HIV. While more individuals

enter care relatively soon after diagnosis than at earlier stages of the epidemic, for many, their engagement with services is tentative and fleeting and they remain marginal to the care system. Staff in conventional clinic or office based settings are likely to have few incentives to maintain treatment contact. Storefront clinics, mobile units, health providers seeing clients at soup kitchens and SROs have become not only the 'entrance ramp' to conventional care, but the primary source of care for increasing numbers of persons living with HIV/AIDS.

- It is important to more widely disseminate realistic information about HIV treatment and the importance of continuous engagement with medical care for persons living with HIV – in advance of testing or the need for treatment HIV-positive individuals need to be better educated about the benefits of early intervention and the role of medications in management of HIV disease. Providers need to become better informed about prevailing myths and fears about HIV treatments and address these directly.
- There are many ways in which HIV infected individuals have contact with existing services and these should be reviewed with the goal of increasing the potential for improved linkages with medical care, and the removal of barriers to initiating and maintaining care among persons with multiple needs.
- An important point of intervention would be at the testing site. Increased testing must be used in conjunction with pre and post-test counseling that adequately prepares the client for a preliminary positive result. Post-tests efforts to facilitate entry of HIV positive persons into appropriate care should expand beyond providing written referrals to include actively attempting to facilitate entry of HIV positive persons into appropriate care, such as provision of patient escorts or direct telephone contact between the test site and medical treatment facility, especially for persons at risk for delay or dropout.
- AIDS housing policies should be reviewed with an understanding of the negative effects of homelessness and housing disruptions on access to and continuous engagement with medical care among persons living with HIV/AIDS in New York City.

Introduction

While HRSA has defined “unmet need” as individuals with HIV who are aware of their serostatus but not receiving regular HIV primary medical care, it is more appropriate to see unmet need as a dynamic process that goes beyond the simple in care/ out of care dichotomy. At any point in time the population of persons living with HIV/AIDS includes persons who have never received any HIV medical care, persons who consistently maintain regular medical visits for monitoring and treatment of HIV infection, persons who initiated continuous care after a period of substantial delay, persons who had entered care and stopped or dropped out, and those who continue to have a precarious or inconsistent relationship with HIV medical services over time. For the present study:

- Delayers are defined as persons who wait 6 or more months after the diagnostic HIV test to present for treatment evaluation or are diagnosed with HIV at the time of presentation for care with fewer than 200 CD4 cells indicating an advanced state of disease.
- Dropouts are defined as persons who have had one or more times after they first saw a medical provider for HIV when they stopped going to the doctor and did not have any medical appointments for six months or more.
- The Unconnected, are PLWH/A currently outside of care, defined as those who have had no HIV-related medical care (no doctor visits, no CD4 or viral load tests) for six months or more, regardless of whether or not they have ever seen a physician for HIV.
- While it is impossible with the data at hand to give an estimate of the numbers of PLWH currently aware of their status and not receiving regular medical care, the following rates are informative. More than one-fourth (26%) of the 2002 agency recruited cohort had delayed entry into medical care for 6 months or more (median delay 12 months). One in five, 21%, reported dropping out of care one or more times for at least 6 months with an about half remaining outside of care for one year or more. Overall, 39% of the sample reported either an initial delay or dropping out of care one or more times during the course of their HIV.

Data Sources

- A mixed methods strategy was used for the analysis of delayers, dropouts and the unconnected, drawing upon both quantitative and qualitative data sources provided by persons living with HIV/AIDS, HIV service providers, and community stake holders.
- The ongoing CHAIN cohort study provides information about delayed entry into HIV care after infection, and patterns of drop-out or continuity of care over time. A total of 968 PLWH were interviewed during 1994-2001, and another 684 new study participants were interviewed in 2002-2003. The sample was designed to be representative of the HIV-infected population receiving publicly funded medical and social services in New York City

- Demographics, health status, service need/utilization data were collected as well as narrative descriptions providing detailed information about how PLWH became aware of their HIV status, when and how they first got HIV medical care, and discussions of any episodes of discontinuing medical appointments or dropping out of care for 6 months or more.
- At each phase of CHAIN cohort recruitment, a separate data collection effort using ethnographic field methods was undertaken to locate and interview a small sample of HIV positive persons aware of their serostatus but not receiving any medical care - the 'unconnected.' A total of 48 PLWHs not in care were interviewed in 1995, 24 in 1998, and 25 in 2004.
- In 2003-04 informant interviews were conducted with 32 medical and social service providers working with different risk groups and populations where problems of delayed entry into care and/or dropping out of care have been significant: MSM of color, substance users, high risk youth, homeless persons, immigrants, ex-offenders.
- We also conducted 7 client focus groups to specifically discuss issues and barriers to HIV testing, entry into care, and engagement with care over time among different subpopulations at risk: MSM of color, transgender-experienced, active substance users, addicts in recovery, ex-offenders, women at risk, and the homeless or unstably housed.
- A Community Advisory Board with expertise in medicine, research, service administration, and social-service provision to HIV positive populations helped with research design, interpretation of findings, and formulation of policy recommendations reported here.

Finding the Unconnected

Finding the unconnected has become increasingly more challenging. In 2004 we replicated the strategies we employed for our 1995 and 1998 efforts. Our primary approach to recruiting PLWH currently outside of care has been to accompany outreach workers from programs targeting groups with a high risk of HIV and visiting locales where such individuals were known to congregate - drug purchasing "cop spots", near shooting galleries and crack houses, sex worker "strolls," homeless drop-in centers, soup kitchens. See Table 1 for summary of "unconnected" outreach efforts.

- A total of 299 individuals completed brief screening interviews during the four months of recruitment effort. All persons completing the screener who reported they had not received any medical care for six months or more were invited to complete a longer interview. Of the 74 individuals who completed the longer interview, 58 disclosed that they were HIV positive, and of these, 23 were found to be currently outside of care indicated by no medical visits or no diagnostic tests for six months or longer. Half of these had not seen a medical provider for HIV for 12 months or longer.
- Thus the "yield" of unconnected PLWHs for the outreach effort was 23/299 or 7.7% of all persons screened, and 23/58 or 39.7% of all persons self-disclosed as HIV positive.

- Of the 299 persons screened, 74% had received some type of medical care within the prior six months (Table 2). This includes care received at emergency rooms and at substance abuse or housing related facilities, as well as visits to hospital based or free standing clinics.
- HIV positive persons and others engaged in behaviors putting them at high risk of infection were relatively easy to locate in a range of community settings (see Table 3). However, the success of outreach and other programs designed to remove barriers to accessing care by locating low threshold health and social service facilities in high risk neighborhoods and/or the use of mobile units was apparent in the frequency with which persons on the street mentioned these sources of care, and in the relatively low percentage of persons encountered who had had no contact at all with medical services.
- Increasing numbers of persons in high risk, historically underserved communities are being served directly by medical personnel incorporated into outreach efforts, clinical operations established in social service settings (homeless drop in centers, needle exchange programs) or mobile medical units. By client and provider reports, the absence of such outreach and patient navigation programs would mean the loss of whatever tenuous connection to HIV care that clients currently maintain.
- There are unknown numbers of PLWH who are truly unconnected. Intensive individual outreach is needed to reach individuals unaware, unmotivated, or unable to access community based services, and where such services are absent or limited. This task has become more challenging. Continuing a trend seen in 1999, there are proportionally more chronic homeless and seriously mentally ill among the currently unconnected. Aggressive community policing has meant fluid and largely hidden venues where such individuals might be found. There are also increasing numbers of persons from less well defined service populations: heterosexually infected women with no IDU or other drug abuse history and non-gay identified MSM of color.

Comparing Delayers, Dropouts, and the Currently Unconnected

To better understand people and contexts associated with remaining outside of HIV medical care, we will compare PLWH who are currently unconnected to medical care, as well as PLWH in care who delayed initial entry into care, and who have had one or more episodes of dropping out of care for six months or more (whether or not they were delayers), to persons who entered HIV care in a timely fashion, and have maintained regular visits over the course of their illness (the Engaged, Connected to Care) . Results of these comparisons are presented in Tables 5 through 10.

Demographics and Risk Exposure (Table 5)

- As in earlier stages of the epidemic, persons who are outside of care, or who have a history of intermittent engagement with care do not differ by basic demographics such as gender, age, or race/ethnicity from persons better integrated into the HIV medical care system.

- There are differences by risk exposure category. Injecting drug users are less likely to maintain continuous engagement with care; 36% of those currently outside of care are IDUs and with the same proportion among the delayers and dropouts, compared to 26% among the continuously connected.
- Examining gender and race/ethnicity within risk exposure category, there are important differences from earlier samples of PLWH unconnected to care. Women among the currently unconnected are less likely to be IDUs. Two-thirds (66%) of unconnected women interviewed in 1999 were IDUs compared to 27% among current sample. There is a lower proportion of MSM among HIV infected persons not in medical care, and all men reporting MSM experience in the current sample were persons of color, none of whom identified as “gay or homosexual” which contrasts with patterns seen in 1995 and 1999.

Economic and Housing Resources (Table 6).

- Some of the biggest differences among PLWH with different patterns of engagement with the medical care system are found when we examine economic resources and housing status (Table 6). Only about one-third (36%) reported currently living in their own apartment compared to 80% of persons continuously connected to care; 60% of the unconnected had spent one or more nights homeless during the six months prior to interview.
- Almost half of the unconnected were living in an SRO at the time of interview and several others had recently resided in SROs. While the CHAIN study team did accompany outreach teams that visited SROs, we only recruited 4 individuals directly from these facilities. It appears that many PLWH unconnected to medical care have some connection with SRO facilities, often, through HASA sponsored programs. Unlike in prior years, the CHAIN effort to locate persons outside of the HIV care system did not exclude persons with HIV case management, (previously HASA/DASIS clients were considered ‘connected’).
- PLWH currently unconnected to medical care are as likely as others to be working or to have received rental assistance. They are less likely to be receiving other forms of entitlements or income supports.
- The currently unconnected are almost five times as likely to have been in jail during the six months prior to interview than other CHAIN study participants (16% compared to 5%, OR 4.66, CI 1.5-14.4).

Mental Health and Substance Abuse Needs and Service Utilization (Table 7)

- PLWH currently unconnected to care are distinguished by high rates of mental illness and co-occurring substance abuse. We administered a standardized measure of mental health functioning (MOS-SF36, Stewart, Hayes & Ware 1988) and present the proportion of respondents who score below 42.0 on this scale, the cut point indicative of clinically-relevant mental health symptoms, and those who score below 37.0, the mean score seen in psychiatric inpatient populations.

Almost all, 91% of those currently outside of care score below this level. As a comparison, approximately 12% of the general U.S. population have mental health scores at this low level.

- Problem drug use was indicated by non-experimental use of heroin, crack or cocaine, methamphetamine, or problem drinking as defined by a standardized scale (CAGE; Ewing 1984). Three-fourths (76%) of PLWH outside of care have a history of problem drug use and almost all of them are using at the present time. Rates of substance use are high among the entire sample but rates of active drug use are much lower. Only 20% of the continuously engaged are problem drinkers or currently using heroin/cocaine/crack or other drugs compared to 33% of the delayers, 36% of drop outs and 73% of those currently outside of HIV medical care.
- Despite high need for mental health services, the unconnected are much less likely to have had contact with any type of mental health services - visits with a mental health professional, supportive counseling from social worker or religious counselor, or participation in a support group.
- More than half of PLWH outside of HIV medical care have had some contact with drug treatment services in the six months prior to interview. Detox and participating in self-help groups (AA, NA) are more common than other types of treatment experience. Few are methadone maintenance patients although several others have been on methadone some time in the past.

Health Status and Use of Health Services (Table 8)

- The currently unconnected report better physical health than CHAIN study participants more integrated into the HIV care system, although differences are not as striking as seen in earlier investigations of PLWH outside of medical care. Their mean scores on a standardized instrument measuring physical health functioning (MOS-SF36) are higher, they are less likely to score below 45.0, a score consistent with disability sufficient to interfere with regular employment (Stewart, Hayes & Ware 1988), and none of them have had any opportunistic infections. CD4 counts are comparable among those who reported test results. However several of the unconnected could not remember CD4 tests from long ago and 2 of them have never seen a physician or gotten diagnostic tests for their HIV.
- There are important differences in health services utilization by type of engagement with HIV primary care. PLWH who have been consistently connected to medical care, and those who

became engaged with care after an initial period of delay have lower rates of emergency room use and hospital inpatient stays than those who have a history of dropping out of care as well as those currently outside of the HIV medical care system. For example 44% of the unconnected and 41% of dropouts report emergency room visits in the six months prior to interview compared to 32% of the continuously connected and 24% of the initial delayers.

- Note that about one-fourth (26%) of PLWH who have not seen a medical provider for HIV care did have one or more clinic visit in the six months prior to interview. This often represented mandatory screenings for jail, drug treatment, or homeless shelter admission, but includes clinic visits for non-HIV illness or injury, at times provided by a mobile unit.
- Three individuals (12%) among the unconnected report that they currently have a prescription for antiretroviral medications although none are consistently adherent. None of the unconnected are on HAART regimens.

HIV Diagnosis and Entry into Care (Table 9)

- All CHAIN participants are asked about reasons for HIV testing and multiple responses are recorded. Individuals currently outside of care are distinguished by the relatively high proportion (20%) who became aware of their HIV status through a test that was mandated or expected as a part of drug treatment, jail or other program, and low rates (8%) of testing because a medical provider recommended it. They are as likely as other CHAIN study participants to report that awareness of risky behavior was a reason for them to get tested.
- Those currently unconnected to care are among the more recently diagnosed. They are somewhat less likely than others currently in care to have experienced health problems at the time of diagnosis
- In contrast to PLWH unconnected to care interviewed in either 1995 or in 1999, very few persons living with HIV who are currently not receiving medical care have never seen a physician for HIV care. In other words, the currently unconnected are more likely to be dropouts than delayers. Only 2 individuals among the 25 interviewed (8%) have never seen a medical provider for HIV. This contrasts with previous investigations when 60% of the currently unconnected had never seen a medical provider for HIV.
- The unconnected are much less likely than others to be unattached to medical care prior to HIV infection. Fewer than 10% reported having a regular source of medical care prior to HIV infection
- PLWH currently unconnected to medical care were less likely than those in care to have gotten their first HIV medical care at an HHC facility and more likely to have received care in a setting such as drug treatment, a social service agency, or jail. The specific facilities were examined where first care was provided. It appears that clinical care received at voluntary hospitals was

at hospitals that had more extensive networks of community based care sites, often related to drug treatment, housing, or corrections programs.

Non-Medical Needs and Service Utilization (Table 10)

- Persons living with HIV/AIDS who are not receiving medical care are significantly more likely than others to have multiple non-medical needs. Three-fourths (74%) report they need housing, about half (48%) describe the need for financial assistance, and over half (52-61%) report the need for other concrete services such as food, clothing, or transportation. Rates of service need for all ten service areas examined are highest among those currently outside of care.
- Those unconnected to medical care, however, do have recent experience with social service providers. They are as likely as others to have at least one contact with a social service agency in the six months prior to interview. Forty percent (40%) have had contact with a case manager or social worker although for many this was a visit to determine or maintain eligibility for services rather than engagement in service planning and coordination.

Social Support (Table 11).

- PLWH outside of care appear to have smaller social networks than others connected to care; however they are not socially isolated.
- Those unconnected to medical care are no less likely to be married or to be living with a partner as married; about the same proportion currently live alone.
- The unconnected have fewer close friends and fewer family members whom they see at least occasionally or speak with on the phone. One-third (32%) of the unconnected report they have no close friends and 28% have no family members or other relatives with whom they are in regular contact.

Why They Delay, Drop Out, Remain Unconnected (Table 12).

Answers to open-ended questions about reasons for delayed entry into HIV medical care and/or discontinuing care provided in surveys and in focus groups offer insight into individual motivations and rationales to remain outside of care. Answers were transcribed and coded according to themes that emerged from respondent narratives.

- The most common reason given for delayed entry into HIV medical care was ‘denial’ - the desire to avoid thinking about and accepting “*being an AIDS person*” and the for the most part the unknown life changes that diagnosis entails. Key among these are concerns around stigma and rejection, and around costs and benefits in relation to possible sanctions. One third of delayers

gave explanations such as “Cause I just couldn't believe it, couldn't deal with at the time” and “I wanted to hide, put it under the rug .”

- Denial contributes to delayed testing but also delayed entry into medical care since accepting medical care is admitting HIV positive status to yourself as well as to others. In the words of one respondent, “*The really important thing is that once you know [that you're positive]...you can never, never again not know. And you have to think about that before you decide to 'know.'*” “Denial was also given as a reason for discontinuing HIV medical care.
- It is difficult to deny HIV infection for persons who are symptomatic. Not experiencing symptoms was frequently heard as a reason for delayed entry into medical care, and for dropping out of care once initiated: “*I was feeling ok, I didn't have anything to be worried about.*” Some version of “*Because I don't feel that I need it*” was a common explanation given by persons currently unconnected to medical care.
- Another theme found in explanations for discontinuing care was ‘tired of it.’ Discussions sometimes were related to issues of denial: “*Because I didn't want to hear anything about that [HIV] anymore.*” Some were also expressions of treatment exhaustion - being tired of or wanting a break from medical appointments and taking medications: “*I just didn't want to go and also I feel tired of going.*”
- Avoidance of medications was mentioned by delayers, by drop outs, and by PLWH currently outside of medical care. Fear of side effects was raised much more often than the actual experience of side effects as a reason to avoid care. Concerns such as effects on personal appearance (e.g. turns your fingernails black) as well as incompatibility with other medications (methadone) were raised. More common were references to toxicity: “*I didn't want to take the medications for a long time.... I heard that they were so toxic that they killed people faster.*” A general lack of understanding of the role of medications for managing HIV disease was apparent. For many PLWH, seeking medical care results in medication and if you don't want or think you need medications, you avoid medical visits. A dropout explained: “*Because my health was good - I did not want to risk myself to medication.*”
- Active drug use, and the extent to which “*chasing after drugs*” takes over all other concerns is another common reasons given for delayed entry as well as for dropping out of care: “*The drugs came first.*” Drug relapse was mentioned by many as a reason for dropping and staying out of care, not only for the disorganizing effect on the drug taker's life but because of the response to relapse by medical providers: “*You feel lousy and guilty and miserable and hate yourself enough already when you're using - the last thing you want is somebody who's going to try to make you feel even worse. But they [doctors] all do. So you just stop going to doctors unless you absolutely have to.*”
- Competing life concerns - especially dealing with homelessness or unstable housing are described as explanations for delaying, dropping out, or remaining outside of HIV medical care: “*Got locked up 2000-2001... Got out, moved in with Dad - running the streets, staying w/friends, never*

followed up... restricted Medicaid.” Others point to loss of housing as a triggering event, diminishing time and resources needed to deal with treatment “I just stopped going 8-9 months ago - had rats in the apartment so left that apartment. Now it's cold [out here].”

- Another set of contextual factors described by PLWH who have discontinued care refer to disruptions caused by programs closing, eligibility changes, physicians leaving, patients moving or, among those in housing programs, being relocated. The following description illustrates the extent to which program changes further challenge those with limited resources to manage their HIV disease: *“I had a doctor when I was in the [Needle Exchange] program. Dr. Ann Baxter - she was great, really cared, helped me. Even came to where I was staying. Then the program ended and I had to see a regular doctor... I went a couple of times to Mt. Sinai - tried to get an appointment. They said one month. Im out here on the streets. I forget!”*
- A related set of factors had to do with experiences - or expected experiences - of poor treatment by medical providers. Individuals who lack insurance, who have a history of substance abuse, homelessness, and/or mental illness, have often experienced rejection or been excluded from mainstream services. A history of poor treatment in the past often discourages people from using or seeking treatment at all, in anticipation of being treated badly again. Medical care experienced as indifferent or disrespectful results in dropping out of care.

Table 1 Summary of CHAIN “UNCONNECTED” Outreach Efforts, 2004

OUTREACH SITE	TOTAL POPULATION SCREENED					INTERVIEW RESPONDENTS: HIV+ AND UNCONNECTED TO CARE (N=23) ²	
	# Site Visits	# Persons Screened	% With No Medical Visit 12+ Months ¹	# Reported Having HIV Test	% of Persons Screened Disclosed HIV+ Status	# With No HIV Medical Care 6-11 Months	# With No HIV Medical Care 12+ Months
SRO Outreach: Bronx (Day/Night)	3	8	13%	100%	100%	3	1
SRO Outreach: Harlem (Night)	2	4	25%	100%	100%	1	1
Street Outreach: Harlem	3	18	39%	100%	44%	4	3
Street Outreach: Harlem (Night)	1	3	33%	100%	33%	0	0
Street Outreach: Brooklyn	3	20	25%	95%	30%	1	0
Van-Based Street Outreach: Brooklyn (Night)	1	16	0%	81%	31%	0	0
Harm-Reduction Drop-In Center (Bronx)	1	63	2%	100%	29%	2	2
Street Outreach: Queens	1	17	0%	94%	18%	1	0
Street Outreach: Bronx	3	34	30%	94%	9%	2	0
Van-Based Street Outreach: Harlem	1	26	8%	85%	5%	1	1
Soup Kitchen: Chelsea	2	27	30%	89%	4%	0	0
Mobile Med Van Outreach: Lower East Side	3	26	31%	77%	0%	0	0
Street Outreach: Bronx (Night)	2	37	14%	92%	0%	0	0
TOTALS	26	299	16%	92%	19%	15	8³

1. Including mandatory screenings for jail, shelter, or drug treatment, or care received in emergency room or mobile van
2. 23/299 = 7.7% of all persons screened; 23/58 = 39.7% of persons self-disclosed as HIV positive
3. 8/299 = 2.6% of all persons screened; 8/58 = 13.8% of persons self-disclosed as HIV positive

Table 2.
CHAIN Outreach Screened Sample

<i>Total screened (n=)</i>	<i>(299)</i>
Demographics	
Sex	
Male	68%
Female	32
Transgender	<1
Ethnicity	
White	7%
Black	50
Latino	41
Other/ mixed	2
Age	
Range	23 - 69 yrs
Mean (sd)	43.12 (8.1)
Medical Conditions	
TB	
Ever tested for TB	96%
Volunteered test result ¹	
Positive	27%
Negative or don't know test result	73%
Hepatitis C	
Ever tested for Hepatitis C	79%
Volunteered test result ¹	
Positive	74%
Negative or don't know test result	26%
HIV	
Ever tested for HIV	92%
Volunteered test result ¹	
Positive	40%
Negative or don't know test result	60%
Contact with Health Care System	
Last visit to any medical provider²	
Within past 6 months	74%
6 - 11 months	20
12+ months ago	16

1. Among persons who were tested and volunteered test result: for TB n=52 , HebC n=53, HIV n=276.

2. Including mandatory screenings for jail, homeless shelter, or drug treatment or care in emergency room or mobile van.

Table 3.
Self-Reported Health Risks among CHAIN Outreach Sample
with No Medical Care for 6+ Months (HIV+ and High Risk)

Self-Reported Health Risks		
	Disclosed HIV Positive	All others ¹
<i>Total short form (n=)</i>	<i>(23)</i>	<i>(47)</i>
Smoked cigarettes	87%	98%
Problem drinking	44%	53%
Been homeless	74%	89%
Victim of violence	35%	51%
Used cocaine/ crack	74%	75%
Used needle to inject drugs	39%	41%
MSM unprotected sex	17%	10%
Heterosexual unprotected sex	44%	60%
Exchanged sex for money or drugs	34%	39%
Had lots of different sexual partners	44%	57%
Any health risk	87%	100%
Any HIV risk ²	78%	87%

Note: None of the differences between disclosed HIV+ and others are statistically significant

1. Self-report HIV negative or unknown status
2. Used needle, MSM unprotected sex, heterosexual unprotected sex, used coke/crack, exchanged sex or had lots of different sexual partners.

Table 4. Engaged and Unengaged in Medical Care among the New CHAIN Cohort Sociodemographics

	Agency Recruited Sample			
	Engaged Connected to Care ¹	Delayed Entry into Care 6+ months ²	Dropped Out of Care 6+ months ³	Currently Outside of Care ⁴
Total Sample (n=)	(413)	(125)	(144)	(25)
Gender				
Male	59%	66%	56%	56%
Female	40%	32%	44%	44%
Transgender	1%	2%	0	0
Race				
Black, non-Hispanic	55%	53%	47%	40%
Latino/Hispanic	37%	35%	39%	52%
White, non-Hispanic	7%	10%	13%	8%
Other	2%	2%	1%	0
Age				
20-30	8%	8%	8%	0%
31-40	24%	32%	31%	44%
41-50	43%	40%	46%	40%
51+	30%	26%	19%	16%
Sexual orientation				
Straight, heterosexual	73%	69%	67%	80%
Lesbian, gay, homosexual	18%	17%	19%	0%
Bisexual	8%	11%	10%	16%
Other	2%	3%	3%	4%
Risk category				
MSM	23%	26%	22%	16%
IDU	26%	36%	35%	36%
MSM/IDU	4%	6%	2%	0%
Heterosexual/ Other	46%	32%	40%	48%

1. Engaged - entered HIV care within 3 months of diagnosis, and never experienced period when 'dropped out of care' for 6 months or more
2. Delayed Entry into HIV care 4+ months after diagnosis but never "dropped out" after initiating medical care
3. Dropped Out of HIV care for one or more 6+ month period after initiating medical care. May also have delayed initial entry into care after diagnosis
- 4 Currently outside of care - no HIV medical care or CD4 or viral load tests for 6+ months.

**Table 5. Engaged and Unengaged in Medical Care among the New CHAIN Cohort
Housing and Economic Resources**

	Agency Recruited Sample			
	Engaged Connected to Care	Delayed Entry into Care 6+ months	Dropped Out of Care 6+ months	Currently Outside of Care
Total Sample (n=)	(413)	(125)	(144)	(25)
Current Housing				
Own Apartment	80%	74%	65%	36%
Doubled-up with others	3%	4%	6%	4%
SRO or Shelter	9%	14%	13%	48%
AIDS housing	3%	5%	10%	4%
Drug treatment	2%	1%	4%	0%
Street, public place	<1%	1%	0%	8%
Other	2%	1%	2%	0%
Homelessness/ Housing Instability past 6 months				
Stable housing	76%	73%	67%	28%
Unstable Housing: Doubled up, in Temporary/ Transitional Housing	9%	10%	12%	12%
Homeless: Street, shelter, SRO	15%	18%	21%	60%
Sources of Income & Public Assistance¹				
Income from wages	16%	26%	16%	20%
Soc security disability (SSDI)	24%	22%	18%	12%
Soc security supp income (SSI)	43%	46%	45%	31%
TANF/AFDC	23%	22%	20%	8%
Other public assistance	8%	8%	6%	0%
Food stamps	71%	74%	78%	44%
Rental subsidy, DASIS, Sect 8	51%	44%	43%	44%
Incarceration Experience				
Jail or prison past 6 months	2%	2%	5%	16%

1. Multiple responses possible

**Table 6: Engaged and Unengaged in Medical Care among the New CHAIN Cohort
Mental Health and Substance Use Involvement**

	Agency Recruited Sample			
	Engaged Connected to Care	Delayed Entry into Care 6+ months	Dropped Out of Care 6+ months	Currently Outside of Care
Total Sample (n=)	(413)	(125)	(144)	(25)
MENTAL HEALTH FUNCTIONING				
Self-Report emotional/ psychological Problems	11%	15%	16%	39%
Mental health functioning^{1,4}				
Mean (sd):	43.69 (12.3)	43.14 (11.6)	40.48 (12.8)	32.40 (9.6)
Score 42.0 or lower ²	44%	49%	56%	91%
Score 37.0 or lower ³	34%	30%	41%	91%
SUBSTANCE USE				
Ever Problem drug user ⁵	42%	56%	54%	76%
Ever IDU	31%	42%	38%	36%
Currently problem drug user	20%	33%	36%	73%
TREATMENT EXPERIENCE⁶				
Mental health treatment past 6 mos	56%	57%	62%	26%
Alcohol or drug treatment past 6 mos	19%	29%	36%	52%

1. MOS SF-36 Mental Component Summary Scale (MCS). Higher values indicate better functioning

2. Cut point indicative of clinically relevant symptomology.

3. Mean score for patients with psychiatric diagnosis.

4. Case base for unconnected sample (n=11).

5. Use of heroin, crack/cocaine, or problem drinking. Current use refers to past 6 months.

6. Includes any treatment including participation in self-help groups or support groups.

**Table 7: Engaged and Unengaged in Medical Care among the New CHAIN Cohort
Current Health Status and Use of Health Services**

	Agency Recruited Sample			
	Engaged Connected to Care	Delayed Entry into Care 6+ months	Dropped Out of Care 6+ months	Currently Outside of Care
Total Sample (n=)	(413)	(125)	(144)	(25)
GENERAL HEALTH FUNCTIONING				
Self-Report good/ excellent health	63%	68%	62%	57%
Physical health functioning ^{1,3}				
Mean (sd)	42.14 (11.3)	41.58 (11.7)	41.02 (10.7)	46.16 (11.3)
Score below 45.0 ²	56%	58%	62%	36%
RECENT T-CELL COUNT				
Below 200	19%	26%	31%	30%
201 - 500	49	32	41	22
500 or higher	31	38	26	26
Don't know/ never had test	1	4	1	22
NUMBER AIDS CONDITIONS ³				
None	84%	81%	83%	100%
1 Opportunistic infection	12	13	15	0
2+ Opportunistic infections	5	6	3	0
USE OF HEALTH SERVICES				
Hospital in-patient past 6 mos	16%	19%	27%	30%
Emergency room visit past 6mos	32%	24%	41%	44%
Any type clinic visit past 6 mos	92%	90%	92%	26% ⁴
HIV MEDICATIONS				
Any HIV meds currently prescribed	77%	72%	72%	12%
HAART	65%	61%	65%	0%

1. MOS SF-36 Physical Component Summary Scale (PCS). Higher values indicate better health functioning

2. Scores below 45.0 indicate significant physical impairment (e.g. inability to maintain regular employment).

3. Case base for unconnected sample (n=11).

4. Includes mandatory screening for jail, shelter, or drug treatment, or care received in mobile van. No visits for HIV care.

Table 8. Engaged and Unengaged in Medical Care among the New CHAIN Cohort HIV Diagnosis and Entry into Care

	Agency Recruited Sample			
	Engaged Connected to Care	Delayed Entry into Care 6+ months	Dropped Out of Care 6+ months	Currently Outside of Care
Total Sample (n=)	(413)	(125)	(144)	(25)
Self Report Reason for HIV test¹				
Engaged in risky behavior	28%	34%	39%	28%
Recommended by provider	18%	12%	21%	8%
Sex or IDU partner was HIV+	12%	11%	11%	16%
Required/ expected in jail or drug treatment	4%	6%	7%	20%
Health at time of diagnosis				
Health problems at time of HIV diagnosis	27%	29%	23%	13%
Year of HIV Diagnosis				
1980-1990	28%	53%	56%	32%
1991-1995	29%	27%	20%	28%
1996-2003	43%	20%	24%	40%
Time from diagnosis to HIV care				
0-3 months	98%	0%	60%	68%
4-6 months	2%	12%	7%	0%
Over 7 months	0%	88%	33%	25%
Never saw medical provider for HIV	0%	0%	0%	8%
Had MD prior to HIV diagnosis				
Had regular source of care	43%	38%	44%	9% ²
No source of medical care	58	62	56	91
Provider of first medical care³				
HHC	22%	18%	21%	4%
Voluntary hospital	42%	57%	55%	61%
CHC/neighborhood clinic	14%	9%	11%	4%
Private practice/ HMO	7%	4%	6%	9%
Drug treatment or social service agency	8%	9%	3%	13%
Prison or jail	6%	3%	4%	9%

1. Multiple responses possible

2. Case base for 2004 unconnected sample (n=11).

3. For those who have seen medical provider for HIV

**Table 9. Engaged and Unengaged in Medical Care among the New CHAIN Cohort
Non-Medical Needs and Service Utilization**

	Agency Recruited Sample			
	Engaged Connected to Care	Delayed Entry into Care 6+ months	Dropped Out of Care 6+ months	Currently Outside of Care
Total Sample (n=)	(413)	(125)	(144)	(25)
NEED FOR NON-MEDICAL SERVICES				
In past 6 months needed help with...¹				
<i>Housing</i>	33%	33%	41%	74%
<i>Financial matters</i>	23%	23%	24%	48%
<i>Food, groceries, meals</i>	6%	7%	15%	52%
<i>Household items, clothing</i>	9%	6%	14%	52%
<i>Transportation</i>	8%	8%	13%	61%
<i>Employment, job training</i>	7%	6%	13%	44%
<i>Emotional problems</i>	11%	15%	16%	39%
<i>Legal matters</i>	11%	10%	14%	26%
<i>Home care</i>	3%	5%	8%	22%
<i>Child care</i>	1%	1%	0%	4%
CASE MANAGER ²				
Any contact with any case manager or social worker in past 6 months	64%	71%	55%	40%
CONTACT WITH SERVICE PROVIDERS				
Any contact with social service agency in past 6 months	37%	42%	49%	56%

1. Multiple responses possible

Table 10: Engaged and Unengaged in Medical Care among the New CHAIN Cohort Social Support

	Agency Recruited Sample			
	Engaged Connected to Care	Delayed Entry into Care 6+ months	Dropped Out of Care 6+ months	Currently Outside of Care
Total Sample (n=)	(413)	(125)	(144)	(25)
MARRIAGE AND PARTNER RELATIONS				
Marital status:				
Currently married	10%	7%	10%	16%
Formerly married	33	27	31	34
Never married	57	66	60	50
Has spouse or partner ¹	46%	47%	47%	43%
LIVING ARRANGEMENTS				
Lives alone	54%	54%	51%	60%
Alone in institutional setting ²	6	6	15	4%
Lives with others	40	39	35	36%
FRIENDS AND FAMILY				
No close friends	16%	16%	18%	32%
Mean (sd) Number of close friends	4.69 (7.5)	4.48 (6.9)	4.33 (7.4)	3.80 (5.6)
No family members or other relatives in regular contact	9%	14%	15%	28%
Mean (sd) Number of family members	6.82 (9.3)	6.19 (8.8)	4.63 (6.4)	4.70 (6.4)

1. Resident or non-resident spouse

2. Group home, transitional shelter, drug treatment housing etc.

3. Case base for 1998 unconnected (n=14).

Table 11. Thematic Coding of Open-Ended Descriptions of Reasons for Delayed Entry into HIV Medical Care and Reasons for Dropping Out of HIV Medical Care

Reasons for Delayed Entry into HIV Medical Care¹	
<i>Total Sample of Delayers (n=)</i>	<i>(157)</i>
In denial about HIV - couldn't/ didn't want to believe was infected	33%
Doing drugs, relapsed	18%
Felt fine, wasn't sick, no symptoms	14%
Fatalism - believed was going to die anyway	9%
Was homeless / had no money (competing needs)	7%
Fear, uncertainty	7%
Did not want HIV medications	6%
Did not know where to go	6%

Reasons for Dropping Out of HIV Medical Care²	
<i>Total Sample of Dropouts (n=)</i>	<i>(124)</i>
Doing drugs, relapsed	27%
Did not care about treatment, just stopped	19%
Disruption in care - program closed, doctor left, I moved or was moved	13%
In denial about HIV - couldn't/ didn't want to believe was infected	11%
Did not want HIV medications / wanted to discontinue medications	11%
Tired of it, was fed up, wanted a break	9%
Did not like doctor, services were poor	8%
Felt fine, wasn't sick, no symptoms	7%

1. Multiple responses possible. Answers to the question: After finding out their HIV status, some people go to get services right away while others let some time go by. Why did you delay in getting medical services?

2. Multiple responses possible. After you first say a medical provider for HIV, was there ever a time that you stopped going to the doctor or just didn't have any medical appointments for 6 months or more? IF YES, Please explain.

Table 12. Thematic Coding of Open-Ended Descriptions of Reasons for Never Receiving Medical Care for HIV, or for Dropping Out of HIV Medical Care among PLWH Currently Not in Care

Reasons for Never Receiving or Dropping Out of HIV Medical Care	
<i>Total Sample Currently Outside of Care (n=)</i>	<i>(25)</i>
Homeless/ competing needs	24%
Feel fine, not sick, no symptoms	20%
Doing drugs, relapsed	16%
Do not want HIV medications / want to stop medications	12%
Tired of it, was fed up, wanted a break	12%
Disruption in care - program closed, doctor left, I moved or was moved	8%

1. Multiple responses possible. Answers to the question: Why have you never seen a medical provider for HIV? Or Why did you stop going to the doctor or not having any medical appointments for HIV?

APPENDIX

Comparing the Unconnected: PLWH/A Outside of Medical Care in 1995, 1998, and 2004

Note: Strict comparison of the most recent (2004) and earlier samples of persons outside of care are not possible due to the change in the operational definition of ‘unconnected.’ In 1995 and 1998, persons who had not received any medical services but who reported some contact with HIV case management services in the six months prior to interview would not be considered “unconnected.” The definition of ‘unconnected’ used in 2004 considered only lack of contact with a medical provider for HIV care or HIV diagnostic tests (CD4, viral load) for six or more months prior to interview as the indicator of ‘unconnected’ status.

Table 1. Sociodemographics of the Unconnected

	Unconnected recruited in 1995	Unconnected recruited in 1998	Unconnected recruited in 2004
Total Sample (n=)	(48)	(24)	(25)
Gender			
Male	69%	50%	56%
Female	31%	50%	44%
Race			
Black, non-Hispanic	58%	71%	40%
Latino/Hispanic	29%	17%	52%
White, non-Hispanic	13%	8%	8%
Other	0%	4%	0%
Age			
20-30	21%	21%	0%
31-40	35%	42%	44%
41-50	31%	21%	40%
51+	13%	17%	16%
Sexual orientation			
Straight, heterosexual	82%	83%	80%
Lesbian, gay, homosexual	9%	0%	0%
Bisexual	9%	8%	16%
Other	0%	8%	4%
Risk category			
MSM	8%	13%	4%
IDU	65%	75%	36%
MSM/IDU	8%	4%	0%
Heterosexual/ Other	19%	8%	48%

Table 2. Resources of the Unconnected

	Unconnected recruited in 1995	Unconnected recruited in 1998	Unconnected recruited in 2004
Total Sample (n=)	(48)	(24)	(25)
Current Housing			
Own Apartment	49%	29%	36%
Doubled-up with others	9%	13%	4%
SRO, welfare hotel	2%	8%	44%
AIDS housing	0%	0%	4%
Drug treatment	0%	0%	0%
Shelter	9%	4%	4%
Street	31%	38%	8%
Other	0%	8%	0%
Homelessness/ Housing Instability past 6 months			
Stable housing	35%	21%	28%
Unstable Housing: Doubled up, in Temporary/ Transitional Housing	6%	7%	12%
Homeless: Street, shelter, SRO	58%	71%	60%
Sources of Income & Public Assistance¹			
Income from wages	20%	0%	20%
Soc security disability (SSDI)	6%	13%	12%
Soc security supp income (SSI)	21%	25%	31%
TANF/AFDC	13%	17%	8%
Food stamps	36%	33%	44%
General assistance, Home Relief	8%	13%	0%
Rental subsidy, DASIS, Sect 8	4%	25%	44%
Incarceration Experience			
Jail or prison past 6 months	19%	11%	16%

1. Multiple responses possible

Table 3: Mental Health and Substance Use Involvement

	Unconnected recruited in 1995	Unconnected recruited in 1998	Unconnected recruited in 2004
Total Sample (n=)	(48)	(24)	(25)
MENTAL HEALTH FUNCTIONING			
Self-Report emotional/ psychological Problems	10%	34%	39%
Mental health functioning ^{1,4}			
Mean (sd):	44.79 (10.2)	31.67 (10.6)	32.40 (9.6)
Score 42.0 or lower ²	56%	79%	91%
Score 37.0 or lower ³	44%	64%	91%
SUBSTANCE USE			
Ever Problem drug user ⁵	93%	100%	76%
Ever IDU	51%	77%	36%
Currently problem drug user	73%	93%	73%
TREATMENT EXPERIENCE ⁶			
Mental health treatment past 6 mos	29%	21%	26%
Alcohol or drug treatment past 6 mos	50%	57%	52%

1. MOS SF-36 Mental Component Summary Scale (MCS). Higher values indicate better functioning

2. Cut point indicative of clinically relevant symptomology.

3. Mean score for patients with psychiatric diagnosis.

4. Case base for unconnected samples 1995 (n=41) 1998 (n=14) and 2004 (n=11).

5. Use of heroin, crack/cocaine, or problem drinking. Current use refers to past 6 months.

6. Includes any treatment including participation in self-help groups or support groups.

Table 4: Current Health Status and Use of Health Services

	Unconnected recruited in 1995	Unconnected recruited in 1998	Unconnected recruited in 2004
Total Sample (n=)	(48)	(24)	(25)
GENERAL HEALTH FUNCTIONING			
Self-Report good/ excellent health	46%	68%	57%
Physical health functioning ^{1,3}			
Mean (sd)	44.78(10.2)	49.28 (10.0)	46.16 (11.3)
Score below 45.0 ²	54%	21%	36%
RECENT T-CELL COUNT			
Below 200	9%	0%	30%
201 - 500	8%	26%	22%
500 or higher	16%	21%	26%
Don't know/ never had test	59%	53%	22%
NUMBER AIDS CONDITIONS ³			
None	78%	86%	100%
1 Opportunistic infection	10%	14%	0
2+ Opportunistic infections	12%	0	0
USE OF HEALTH SERVICES			
Hospital in-patient past 6 mos	13%	0%	30%
Emergency room visit past 6mos	33%	38%	44%
Any type clinic visit past 6 mos ⁴	21%	17%	26%
HIV MEDICATIONS			
Any HIV meds currently prescribed	6%	8%	13%

1. MOS SF-36 Physical Component Summary Scale (PCS). Higher values indicate better health functioning

2. Scores below 45.0 indicate significant physical impairment (e.g. inability to maintain regular employment).

3. Case base for unconnected samples 1995 (n=41), 1998 (n=14) and 2004 (n=11).

4. Including mandatory screenings for jail, shelter, or drug treatment, or care received mobile van

Table 5. HIV Diagnosis and Entry into Care

	Unconnected recruited in 1995	Unconnected recruited in 1998	Unconnected recruited in 2004
Total Sample (n=)	(48)	(24)	(25)
Self Report Reason for initial HIV test¹			
Engaged in risky behavior	38%	29%	28%
Baby tested positive	4%	0%	0%
Recommended by provider	17%	0%	8%
Sex or IDU partner was HIV+	23%	8%	16%
Required/ expected In jail or drug treatment	na	29%	20%
Health at time of diagnosis			
Had health problems at time of HIV diagnosis	32%	na	13%
Year of HIV Diagnosis			
1980-1990	27%	8%	32%
1991-1995	73%	33%	28%
1996-2003	na	58%	40%
Time from diagnosis to HIV care			
0-3 months	25%	29%	68%
4-6 months	0%	4%	0%
Over 7 months, or unknown	19%	8%	25%
Never saw medical provider for HIV	56%	58%	8%
Had MD prior to HIV diagnosis			
Had regular source of care	17%	21%	9% ²
No source of medical care	83%	79%	91%
Provider of first medical care³			
HHC	82%	15%	4%
Voluntary hospital	7%	54%	61%
CHC/neighborhood clinic	4%	0%	4%
Private practice/ HMO	2%	0%	9%
Drug treatment or social service agency	2%	8%	13%
Prison or jail	4%	23%	9%

1. Multiple responses possible

2. Case base for 2004 unconnected sample (n=11).

3. For those who have seen medical provider for HIV

Table 6. Non-Medical Needs and Service Utilization

	Unconnected recruited in 1995	Unconnected recruited in 1998	Unconnected recruited in 2004
Total Sample n=	(48)	(24)	(25)
NEED FOR NON-MEDICAL SERVICES			
In past 6 months needed help with...¹			
<i>Housing</i>	54%	50%	74%
<i>Financial matters</i>	48%	63%	48%
<i>Food, groceries, meals</i>	36%	42%	52%
<i>Household items, clothing</i>	22%	33%	52%
<i>Transportation</i>	22%	33%	61%
<i>Employment, job training</i>	20%	17%	44%
<i>Emotional problems</i>	15%	34%	39%
<i>Legal matters</i>	11%	17%	26%
<i>Home care</i>	0%	4%	22%
<i>Child care</i>	0%	4%	4%
CASE MANAGER²			
Any contact with any case manager or social worker in past 6 months	12%	19%	40%
CONTACT WITH SERVICE PROVIDERS²			
Any contact with social service agency in past 6 months	29%	19%	56%

1. Multiple responses possible

2 In 1995 and 1998, no contact with HIV case manager or social service provider but possible contact with social worker at public entitlement agency (e.g. food stamps). No restriction on type of case manager or social service contact in 2004.

Table 7: Social Support

	Unconnected recruited in 1995	Unconnected recruited in 1998	Unconnected recruited in 2004
Total Sample (n=)	(48)	(24)	(25)
MARRIAGE AND PARTNER RELATIONS			
Marital status:			
Currently married	10%	10%	16%
Formerly married	29%	23%	34%
Never married	56%	66%	50%
Has spouse or partner ¹	20%	29%	36%
LIVING ARRANGEMENTS			
Lives alone	43%	78%	60%
Alone in institutional setting ²	9%	4%	4%
Lives with others	48%	17%	36%
FRIENDS AND FAMILY			
No close friends	33%	64% ³	32%
Mean (sd) Number of close friends	2.69 (3.9)	2.71 (2.1)	3.8(5.6)
No family members or other relatives in regular contact	19%	50% ³	28%
Mean (sd) Number of family members	6.19 (10.6)	2.44 (3.5)	4.70(6.4)

1. Resident or non-resident

2. Group home, transitional shelter, drug treatment housing etc.

3. Case base for 1998 unconnected (n=14).