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## **The Unconnected Revisited: A CHAIN Briefing Paper**

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## **I. Introduction**

The hope offered by new treatments makes the problem of assuring access to appropriate health care and support services for people living with HIV even more of a compelling challenge than at earlier stages of the epidemic. Current standards of care recommend that HIV-positive individuals enter into care as early after infection as possible. Treatment with combination antiretroviral therapy prior to the development of symptoms is generally recommended and once initiated, treatment must be maintained to ensure good clinical outcomes and to avoid development of drug resistant strains of HIV. Thus all persons with HIV should be in a system of care that monitors their condition and provides treatment and supports necessary to maintain treatment when appropriate.

However, not all persons who are HIV positive are in care. The aim of this report is to provide a descriptive analysis of HIV infected individuals who are aware of their serostatus but remain outside or marginal to the health care and social service system serving the HIV/AIDS population in New York City. With the advent of new treatments that have been shown to prolong life and improve the quality of physical functioning there has been an assumption that individuals who previously had delayed seeking medical care until they were symptomatic may now actively seek care at an earlier stage. In addition, programs funded to actively outreach to individuals who may have been less motivated to seek care or less well served by traditional hospital or office-based medicine have removed at least some barriers to accessing care. A CHAIN study completed in 1995 concluded that an estimated 8,000 individuals aware of their HIV status were unconnected to services - operationally defined as persons diagnosed with HIV/AIDS but having no regular source of HIV medical care, and no HIV case management services (Aidala et al. 1995). They were found to differ from clients of HIV provider agencies in systematic and significant ways.

### Study Questions

A number of questions remain: Are there currently individuals who remain unconnected to services? Who are these individuals and how might they be located? How do they compare to persons better integrated into the HIV care system? How do they compare to persons who were outside of the HIV care system in the era prior to the advent of protease based treatments? What program or policy recommendations can be made for reaching individuals outside of or marginal to the HIV care system and facilitating their timely entry into care?

This report suggests that the challenge of engaging an “unconnected” population still persists; that such individuals still represent a large, difficult-to-reach population; and that agencies charged with reaching and serving this population have successfully expanded their strategies but will need continued support for multiple strategies to draw the unconnected into care and maintain treatment contact.

### The Study Sample

Several decades of research addressing problems of sampling “hidden and hard-to-reach” populations directed our attention to a number of established methodological strategies to pursue as we attempted to locate and recruit individuals unconnected to services (see recent review by Heckathorn 1997; also NIDA Monograph 97). A starting point is to find “relational outcroppings,” geographically bounded places where such individuals are likely to gather (Lee, 1993). Based on prior CHAIN and other research, HIV positive individuals most at risk for remaining outside of care include the

homeless, mentally ill, or chemically dependent. Logical sites to locate such individuals involve places where they might go to obtain food, temporary shelter, a place to tend to basic needs such as using the bathroom, places where individuals are engaged in income-producing activities, and places where individuals obtain or use drugs. This suggests soup kitchens, homeless “drop-in centers,” areas where drug sales take place, areas frequented by prostitutes, crack houses and shooting galleries, and needle exchange outposts.

As part of the 1998 CHAIN study effort to recruit a supplementary sample of unconnected individuals, we replicated the strategies we employed for our 1995 effort. We used the “acquaintance sampling” technique of asking current CHAIN participants whether they knew individuals who were HIV positive but unconnected to services, and whether they could assist in recruiting such individuals into the study. In addition, CHAIN interviewers accompanied outreach workers from agencies targeting sex workers, substance users, the homeless, and other groups with a high risk of HIV. In 1995, 48 individuals were located and successfully interviewed using such strategies in approximately three months of field effort. The same strategies in 1998, after six weeks of effort, yielded only 10 individuals unconnected to care.

Our field observations as well as discussions with outreach providers suggested a change in the extent and problem of “unconnectedness.” There appeared to be fewer individuals who remained outside the system of care once they knew their serostatus. In part this was a measure of the success of outreach programs for marginalized populations and the removal of organizational barriers to access by out stationing health and social services at facilities in high risk neighborhoods, having longer service hours, and removing such requirements as specific documentation and fixed appointments prior to seeing a medical or other service provider. Nonetheless, there remained a population entirely outside of care who did not come into services, no matter how low the threshold or how conveniently located the agency. These individuals, it seemed, could only be found through aggressive street outreach.

Based on this, the CHAIN study launched an ethnographic approach to finding individuals truly unconnected to care. A number of locales that were identified by collaborating outreach agencies were visited -- areas where high risk individuals were known to congregate, such as sex worker “strolls,” drug purchasing “cop spots,” shooting galleries, and soup kitchens. As with all ethnographic work with hard-to-reach and suspicious populations, the effort required multiple visits to specific locales, talking to many people, and completing many screening interviews before locating HIV-positive individuals unconnected to care. Approximately six weeks of pursuing this strategy yielded an additional 14 eligible respondents.

In addition to the these 24 unconnected individuals, we have supplemented this report with findings from 26 individuals who were interviewed in the course of our screening efforts. Although these individuals did not meet our formal criteria for being unconnected, they do represent a group only a step away from “unconnectedness.” Most of these individuals had been referred to us by outreach workers who considered them unconnected to care and many had been unconnected to care for a period of time. They differed, in part, from the truly unconnected in their willingness to come to services offered at an outreach facility, and in the depth of their connection to the outreach agency, often availing themselves of case management services located there which helped them negotiate and maintain some connections to care. The existence of this “marginally connected” group suggests different stages of a continuum of engagement with the health care system.

Because of the small number of individuals involved in this project, *we advise great caution in the*

*interpretation of the quantitative interview data.* These numbers suggest trends and highlight differences; they are not meant to be generalizable to a larger population. Equally important is the qualitative information we gathered -- the stories and insights that clients and providers told us, and the settings we observed. Taken together, all these pieces of information begin to tell a story of individuals presently unconnected or marginal to the HIV care system.

### Summary of Findings

Among this report's findings are the following:

- The unconnected are more likely to be homeless or unstably housed, chemically dependent, mentally ill, or a combination of the three, than individuals in CHAIN's agency-based cohort; mental illness co-occurring with substance abuse is even more of a problem for those currently unconnected than among individuals unconnected to care in the 1995 study.
- The unconnected live a marginalized existence. The press of survival needs predominates their daily lives. The economics of survival and street activity even influenced health behaviors and care-seeking activities. For example, a fair number of individuals reported that the reason they agreed to be tested for HIV initially was because they were paid to do so. Several individuals reported that although they were prescribed HIV medications they chose to sell the drugs on the black market rather than take them as prescribed.
- The unconnected are not enticed by the promise of new treatments for their HIV infection. In fact, myths and misconceptions about HIV and its transmission persist among this population. For example, several individuals and outreach workers spoke of the practice among intravenous drug users of mixing Crixivan (a protease inhibitor) with heroin in the belief that it reduced the transmission of HIV if the needles were shared.
- As with the individuals unconnected to care in the 1995 CHAIN project, the current unconnected population appear to be at an earlier stage of HIV infection and physically healthier than individuals currently within the HIV care system. The perception and experience of good health is the reason most often given by individuals who remain outside of care: "I feel fine" is a typical response as well as statements indicating a wait and see approach to disease management.
- Unlike the earlier unconnected cohort, who had reported that HHC facilities were likely to be their first provider of any HIV medical care, the current group of unconnected were more likely to report prisons and drug treatment programs as their first source of care, suggesting a more developed "institutional capture" among this population.
- It appears that there are fewer individuals aware of their HIV status who remain outside of care than at earlier stages of the epidemic. However, the currently unconnected appear to be even more difficult to reach and more difficult to engage. Our findings suggest there are both client characteristics and service system or provider characteristics that serve as barriers. There are proportionally more "hard core" homeless, chemically addicted and seriously mentally ill among the currently unconnected. They have often been excluded from mainstream services, in part because they do not comply with expected help-seeking behaviors. In addition, their multiple, serious problems are poorly addressed by agencies

who as a result of funding, licensure, or mission, focus on a single rather than multiple diagnoses.

- Multi pronged strategies are required to reach and engage the currently unconnected population. Street outreach where workers actively seek out individuals, are an important compliment to strategies based in storefront or mobile clinic operations in which agencies wait for clients to seek out the service. Intense, individual client involvement may be necessary as an enabling service to facilitate not only initial entry but sustained relationships between these individuals and those who offer medical and other necessary support services and care.

## **II. Methods: Finding the Unconnected**

In order to supplement the agency-based longitudinal sample in CHAIN's fifth wave with individuals who were unconnected or marginally connected to the HIV care system we adopted a multi-pronged recruitment strategy. Similar to the strategy we used in the first wave, this unconnected recruitment strategy involved (1) using the "acquaintance sampling" strategy of soliciting names of unconnected individuals from respondents in the agency-based CHAIN survey and (2) working with outreach agencies whose clientele was more likely to be unconnected to services. In addition, as described below, we have enhanced the recruitment strategy with a direct field outreach effort that extended beyond agency-mediated contacts.

Our strategic approach was guided by our prior research findings as well as current program efforts to reach those outside of care (see e.g. HOPWA, 1997). First is that there's a spectrum of "unconnectedness" ranging from individuals who are unaware of their HIV serostatus, to those individuals who know their HIV serostatus but have not sought any medical or social support services, to those who engaged the HIV care system episodically (and with little or no continuity of care), or those who receive limited HIV care services. A second assumption was that individuals along this spectrum of unconnectedness are often (1) at an early stage of HIV illness, or have no overwhelming HIV health needs, (2) living lives in which other needs predominate (e.g., finding shelter, obtaining drugs, meeting economic needs through street activity), (3) struggle with substance abuse or mental disability that impairs their ability to seek care, or (4) a combination of the prior three. The third assumption is that many of these individuals congregate in particular areas of the city around specific activities, which may include meeting basic needs (food at a soup kitchen, housing at a homeless shelter), receiving targeted services (needle exchange, condom distribution), or engaging in street-level activities (obtaining drugs, sex work).

Using recruitment criteria similar to those used in the first wave, we defined an unconnected individual as: (1) having an HIV-positive diagnosis, (2) being aware of one's serostatus for at least 3 months; (3) having no regular medical provider in the six months prior to CHAIN contact, (4) having no case manager coordinating HIV-related services in the 6 months prior to CHAIN contact and (5) not being a client of DAS/DASIS. Only adults (age 20 or older) were accepted into study. Note that respondents were not excluded from the unconnected sample if they had contact with a provider in conjunction with receipt of TANF, foodstamps or other publicly available entitlements, as long as

services were limited to matters concerning the benefits provided by these programs.

We employed three distinct recruiting efforts: (1) acquaintance sampling, (2) an agency-mediated strategy, and (3) a field outreach strategy.

### Acquaintance Sampling Strategy

Respondents in the CHAIN cohort are asked at every interview whether they know anyone who is HIV-positive and not receiving any services. A staff member contacted this “index” case in order to make contact with the unconnected individual being referred to us. Given limited resources, we were only able to recontact 15 of these respondents to see if they would be able to assist us in screening their acquaintance and if eligible, recruit them into the study. Of the 15 we contacted, 8 determined that their acquaintance was in fact connected to care and 7 could not or would not make that determination. Thus, as illustrated in Table 1 below, although 25 clients in the CHAIN agency sample (approximately 4% of those asked) initially indicated they knew an individual who was unconnected to services, we were not able to follow the acquaintance strategy to positively identify, contact, and recruit any into the CHAIN Unconnected study. While acquaintance referral strategies hold promise for locating individuals unconnected to care, considerable time and resources would be needed to mobilize and follow up on leads. For example, we were only able to contact potential intermediaries by phone; those who know truly unconnected persons are most likely similar to them with regard to unstable living arrangements, erratic schedules, no phone in household etc.

**Table 1. Acquaintance Sampling Strategy**

	Wave 5	Wave 6	Total	
Number of CHAIN respondents who said they know someone unconnected to care	21	4	25	100%
Among those...				
<i>Referred person was in fact connected to care</i>	7	1	8	32%
<i>When recontacted for further information, CHAIN respondent was unsure whether referred person was connected to care or how to reach the individual</i>	5	2	7	28%
<i>CHAIN could not reach referred individual or insufficient contact information available</i>	9	1	10	40%

## Agency-mediated Strategy

We began with two agencies that had worked with us in recruiting unconnected individuals in the first wave, and whose primary mission was to conduct outreach and provide “low threshold” entry to services. They had no or few demanding eligibility or administrative criteria that had to be met in order to serve clients, and/or provided the services in such a way that clients may remain anonymous. One of the agencies, the Streetwise Harm Reduction Center<sup>1</sup>, is a needle exchange program located in a storefront in lower Manhattan, and the other, Safe Haven, is an outreach agency targeting sex workers in all five boroughs. Both agencies have expanded their programs since our 1995 recruitment efforts, and have incorporated such Ryan White funded services as case management and HIV counseling and testing among their service offerings. This has split their programs into components which actively work with clients who have some motivation to engage with the HIV care system and those components which still provide low threshold, first contact, outreach services. We added a third agency, Project Renaissance, that provides health and social work services to individuals at soup kitchens and homeless shelters. In addition, we conducted a single-day recruitment at a large Manhattan soup kitchen, one that serves lunch to approximately 700- 900 people a day. Table 2 below illustrates the results of these agency-mediated efforts, grouped together as “community sites” since each involves clients approaching the agency at a storefront or mobile van that regularly visits fixed locations.

Table 3 has further information broken down by agency. At these sites, potentially eligible clients were referred to CHAIN interviewers by agency liaisons. Teams of 3 -5 interviewers were present. Of approximately 2,092 people using these sites (a duplicated count since our field staff made 9 site visits and the same individual might have been encountered twice), 759 people were referred by the agency liaisons to the CHAIN team. Of those, 252 completed a screener; 13 individuals were deemed ineligible without having to complete a screener. Of the 252 people screened, the majority were not (or did not identify as) HIV-positive. Of the 36 people who were HIV positive, 10 proved to be truly unconnected .

**Table 2. Contact & Recruitment Rates of CHAIN Outreach Efforts**

	Contact Rate		Recruitment Rate	
	# contacted / # people present	%	# unconnected / total # screened	%
<b>Agency Mediated/ Community Site</b>	759 / 2092	36.3	10 /252	4.0
<b>Field Outreach</b>	113 / 1660	6.8	21 <sup>1</sup> / 104	20.2
<b>TOTAL</b>	872 / 3752	23.2	31 <sup>1</sup> / 356	8.7

<sup>1</sup> Includes 7 unconnected individuals who were interviewed as a group at one site

## Field Outreach Strategy

In addition to the agency mediated strategy described above, we instituted an independent field outreach strategy as well. Using informal service networks and personal connections, one CHAIN outreach interviewer made contact with staff at soup kitchens and housing service agencies to learn

<sup>1</sup> To protect confidentiality , pseudonyms are used for names of all agencies and individuals.

where to best search for HIV positive individuals unconnected to care. The field outreach interviewer spent a considerable amount of time in “reconnaissance,” assessing street and community settings -- speaking with people, offering coffee or food to single individuals as an incentive to meet with her and begin the process of gaining trust and access. Where appropriate and feasible, she completed screeners and completed interviews. She was joined on a number of site visits by another CHAIN interviewer as well, and also broadened her scope to include a number of street visits to “high risk” spots. As illustrated in Table 3, the field outreach team made a total of 32 site visits, almost four times as many recruitment visits as used in the storefront/ community site strategy. There were fewer people present at these field sites as had been encountered in the agency mediated effort (1,660 compared with 2,092) and the field outreach team spoke with fewer individuals (113). However, a high proportion of these (104) were screened, and interviews were completed with 14 unconnected individuals. As noted in Tables 2 and 3, there were also seven unconnected individuals at one site who were interviewed as a group. Interestingly, in comparing the “community site strategy” with the “field outreach strategy” in Table 2, it is evident that we were able to recruit twice as many unconnected individuals using a more ethnographic, field outreach effort. The time required to find the individuals to screen, however, is considerably longer and the effort far more intensive.

### Provider Observations on Reaching the Unconnected

The providers we interviewed, based on their target populations, devise distinct strategies for finding, contacting and linking those who are currently outside the care system to medical and social services. The Streetwise Harm Reduction is a storefront, needle exchange agency located in the lower East Side of Manhattan serving primarily homeless, intravenous drug users. The agency engages in a variety of strategies to facilitate clients coming to their community site. Venetian blinds cover the large display window and the agency’s entrance as a means of protecting the clients’ identity. The agency is open from nine in the morning to nine in the evening, and there are constantly clients crowding the main entrance room, where street-weary clients often take a nap on the couches and chairs available in this space. The fact that Streetwise allows its clients to doze off on its couches and chairs comes in contrast with the way many hospitals and clinics treat individuals who are intravenous drug users, mostly homeless, and therefore, often unkempt and sleep deprived. This difference was mentioned by the agency’s director: *“We talk to places [hospitals, clinics] and they tell us that they are willing to take our clients [HIV positive, intravenous drug users], but then they don’t allow them to nod on the chairs in the waiting room - when they don’t even know whether the nodding is from drugs or from the medications.”*

Clients come to the storefront to get clean “works”, case management services, attend support groups, or just chat with the agency’s case manager and get some respite from the streets where many live. Paul, the agency’s director, mentioned that getting their HIV positive clients into medical care is a slow, not always linear process. Streetwise’s role is to provide the necessary services and support when the HIV positive intravenous drug users seem ready to get treatment. In many instances, a crisis in people’s life, such as being turned out by their family, results in their revealing to the Streetwise staff that they are HIV positive. The next step is to *“allow them very slowly to deal with the whole thing. For example, I tell them, ‘Go into my office (for privacy) call this place, it is completely anonymous, and find out about medications and the disease in general.’”* Streetwise, like the rest of the agencies that reach out to socially marginalized groups, is very sensitive to the fact that most of its clients have had negative experiences with social institutions, and therefore, the staff explicitly avoids what might be perceived as coercive actions.

Safe Haven is an outreach agency that operates primarily out of a van which visits different locations in low-income neighborhoods where individuals at high risk for HIV tend to congregate, such as sex worker “strolls” and drug purchasing “cop spots.” We joined the van and its outreach workers as they were stationed under an overpass, a spot where sex workers (mostly women) often solicit their business. The van provides HIV testing and counseling, referrals for medical and drug treatment, HIV education and prevention, clean works for intravenous drug users, condoms, weekly support groups and a temporary haven from the harsh street life to many of the clients who come on the van to get a glass of juice, a bag of snacks and to chat with the van’s workers. By talking casually with the women the workers begin to build rapport with these clients. We witnessed how the outreach workers provided harm reduction assistance by artfully leading a conversation with clients from the topic of favorite foods, to gaining and losing weight because of excessive crack use. During this discussion, for example, one women revealed that she was just released from jail where she spent 21 days for a misdemeanor, while another woman explained that she had gained some weight because she decreased her use of crack, she had “*slowed down,*” as she put it. When asked how accessible HIV services are nowadays for their target population compared to 1995 (year of the first CHAIN unconnected project), Safe Haven workers explained that these days, because of intensive outreach efforts, services are more widely available. As Janet, one of the workers, stated: “*Today more people [outreach workers] are coming out here and it makes a difference, a big difference. They [clients] don’t have to come to us, we are coming to them.*” However, as Janet concluded, there is still work to be done among folks unconnected to services. Based on the outreach workers’ estimate, one out of two female sex workers who come to the van remain outside the service system.

Our experiences with ethnographic field outreach were echoed by members of an MTA-affiliated outreach team who scour public transportation facilities in their search for individuals unconnected to services. The only way they can find their target population is by patiently spending time, getting to know the physical and social characteristics of their site, and gaining entree and establishing rapport with individuals who gather there. Workers walk around subway and bus stations, at all hours of the day or night, and approach individuals who seem to be homeless. Accompanying this outreach team on one of its rounds at Penn Station, we realized how familiar the outreach workers were with the layout of the facility and, more importantly, with the homeless individuals who are living in different parts of the station. For example, Darryl, one of the outreach workers, knew the woman who stays at the end of a narrow corridor that leads to a dead end, and provided details about this prospective client: “*She is always there with a six pack. The other day she had 105° fever and she was taken to the intensive care.*” Darryl knows the first names of most homeless individuals who frequent Penn Station and many recognize him and walk up to him just to chat. He simply approaches most of them, introduces himself, and attempts to begin a conversation. The next step is to offer to buy the prospective client a coffee and a donut and to start on the difficult path of building rapport. “*I am not playing favorites. You have to treat everybody [clients] the same,*” is how Darryl describes the strategy this team follows in order to make contact with its target population. This approach, along with repeated efforts to “*engage the clients into conversation,*” can eventually result in bringing individuals into the care system. Following the team around Penn Station during rush hour, Darryl and his co-worker engaged people in conversation who appeared disheveled or disoriented, who were either standing in the middle of a pathway, or sitting in a corner surrounded by filled plastic bags. We recognized that this team was attempting to make contact with those individuals the rest of the commuters were systematically avoiding.

**Table 3. Summary of CHAIN Outreach Efforts, 1998-1999**

SITE	# SITE VISITS <sup>1</sup>	EST # PEOPLE PRESENT <sup>2</sup>	# REFERRED TO, OR ENGAGED BY CHAIN <sup>3</sup>	# SCREENED <sup>4</sup>	# HIV+: UNCONN (short) <sup>5</sup>	# HIV+: UNCONN (long) <sup>6</sup>	#HIV+: CONN (short) <sup>7</sup>
<i>Agency Mediated / Community Site<sup>8</sup></i>							
Needle exchange	2	120	30	30	3	1	12
Mobile med van	4	100	59	59	2	2	10
Soup kitchen <sup>9</sup>	1	672	650	156	1		2
Mobile med van	2	1200	20	7	1		2
<b>Community Site SUBTOTAL</b>	<b>9</b>	<b>2092</b>	<b>759</b>	<b>252</b>	<b>7</b>	<b>3</b>	<b>26</b>
<i>Field Outreach<sup>10</sup></i>							
Needle exchange outreach	4	50	12	6		5	
Homeless outreach	10	150	10	7	(7)*		
Soup kitchen <sup>11</sup>	2	1400	50	50	1	3	
Street <sup>12</sup>	7	60	41	41	2	3	
<b>Field Outreach SUBTOTAL</b>	<b>23</b>	<b>1660</b>	<b>113</b>	<b>104</b>	<b>3</b>	<b>11</b>	
<b>TOTAL</b>	<b>32</b>	<b>3752</b>	<b>872</b>	<b>356</b>	<b>10</b>	<b>14</b>	<b>26</b>
					Total unconnected: 24		Marginally connected: 26
* These seven interviews refer to “group interviews” in which individual answers have not yet been disaggregated, and which have not been included in the column total							

<sup>1</sup> The number of distinct CHAIN recruitment efforts at each site. Site visit teams were composed of one to six CHAIN interviewers, depending on the site

<sup>2</sup> This is a duplicated estimate of the total number of clients engaged by an agency at all site visits, or the number of people involved in a particular street activity at site visits (such as prostitution or drug activity)

<sup>3</sup> The number of individuals referred by agency intermediaries or approached by CHAIN to participate in the study

<sup>4</sup> A brief screening to determine eligibility was conducted with every individual referred to or engaged by CHAIN

<sup>5</sup> Although the short interview was intended for HIV+ individuals who were “connected” to care, a number of “unconnected” people were unable or unwilling to conduct the longer CHAIN interview. In the interest of gaining information while the person was present, the short interview was administered

<sup>6</sup> This represents unconnected individuals who completed the full interview

<sup>7</sup> This represents individuals believed to be unconnected by agency mediators who did not meet the formal criteria for being “unconnected to care”

<sup>8</sup> Services were delivered to individuals who sought out the storefront or mobile clinic/van

<sup>9</sup> Based on one-day recruitment effort at Manhattan soup kitchen

<sup>10</sup> Individuals were sought out by outreach workers, who then offered and provided services

<sup>11</sup> CHAIN interviewers recruited individuals at several soup kitchens in Manhattan and Brooklyn

<sup>12</sup> CHAIN interviewers recruited individuals at selected street areas where high risk activity was prevalent (i.e., drug activity and prostitution)

### III. Findings

Table 4 through 10 represent information gathered from both short and long interview forms. Wherever possible, we conducted the full CHAIN study interview. In situations where this was not feasible, or where a respondent was unwilling or unable to sit for the full interview (which takes approximately two hours to complete), the interviewer used a shortened form of the questionnaire. This short interview form contains certain key questions regarding sociodemographics, resources, health and social service needs, and service utilization. We compared those unconnected in 1995 (n=48) with the unconnected recruited in 1998 (n=24), and also added individuals interviewed as part of the current unconnected recruitment project who proved to have some connection with the health care system (we have labeled them “marginally connected” in order to distinguish them from the agency-based cohort). The final column represents the full agency-based cohort of 638 individuals, composed of 385 individuals from the original cohort recruited in 1995 and 253 individuals who were added to the sample in 1998. Individuals who were originally recruited as unconnected in 1995 have been included in the full cohort. There are only 18 of the original 48 who remain in the cohort and all are presently connected to care.

We reiterate the importance of caution in the interpretation of the quantitative interview data because of the small number of unconnected individuals we were able to systematically interview. Whenever possible, these findings are supplemented by the qualitative data we gathered -- the experiences and insights that clients and providers shared with us, and the settings we observed.

#### Who are the Unconnected?

The unconnected, in New York City, are mostly individuals in their thirties, of both genders, primarily African-American and Latinos. Most are homeless, or unstably housed, and extremely poor. The overwhelming majority of the unconnected support themselves in the irregular economy, exchanging sex for money or drugs, peddling street drugs and prescription medications, stealing or fencing stolen goods and panhandling. Consequently, the predominant risk behaviors many engage in are illegal drug use and survival sex. Mental illness is one more challenge facing many of the persons with HIV/AIDS who are unconnected to care. Life stories describe multiple problems and multiple social disadvantages including traumatic events, incarceration, few close friends, and nonexistent or fragile relationships with family members.

According to the providers, the unconnected are the socially marginalized who fall into three broad categories: homeless, mentally ill, substance using. Often they are “multiply diagnosed” - struggling with homelessness, mental illness and chemical dependency (or all three) as well as their HIV infection. *“These people [the unconnected] are marginally housed. They live in welfare hotels, in shelters, on the street,”* a case manager on an outreach van providing medical care to a homeless population explained, while the medical provider working on the same van said about the unconnected: *“Some are paranoid, psychotic, there is a lot of mental illness. Some who have tested positive think they don’t have it [the virus].”* The majority of the unconnected, all providers agreed, are substance users, *“Those who use drugs, alcohol and all other kinds of drugs,”* was how one outreach worker defined those likely to be outside of care.

These observations are supported by our survey data. Table 4 and Table 5 present demographic and economic resource characteristics of the currently unconnected, marginally connected, and agency samples. Some of the key points that emerge from the tables:

**Table 4. Sociodemographics of the Unconnected**

	<b>Unconnected recruited at Wave 1 1995</b>	<b>Unconnected recruited at Wave 5 1998</b>	<b>Marginally Connected recruited at Wave 5</b>	<b>Agency Cohort at Wave 5</b>
n=	(48)	(24)	(26)	(638)
<b>Gender</b>				
Male	69%	50%	50%	58%
Female	31%	50%	50%	42%
<b>Race</b>				
Black, non-Hispanic	58%	71%	74%	58%
Latino/Hispanic	29%	17%	26%	28%
White, non-Hispanic	13%	8%	0%	13%
Other	0%	4%	0%	1%
<b>Age</b>				
20-30	21%	21%	4%	10%
31-40	35%	42%	38%	36%
41-50	31%	21%	38%	41%
51+	13%	17%	19%	14%
<b>Sexual orientation</b>				
Straight, heterosexual	82%	83%	70%	72%
Lesbian, gay, homosexual	9%	0%	13%	21%
Bisexual	9%	8%	17%	6%
Other	0%	8%	0%	1%
<b>Risk category</b>				
MSM	8%	13%	17%	20%
IDU	65%	75%	30%	41%
MSM/IDU	8%	4%	13%	8%
Heterosexual/ Other	19%	8%	39%	32%

**Table 5. Resources of the Unconnected**

	Unconnected recruited at Wave 1 1995	Unconnected recruited at Wave 5 1998	Marginally Connected recruited at Wave 5	Agency Cohort at Wave 5
n=	(48)	(24)	(26)	(638)
<b>Current Housing</b>				
Own Apartment	49%	29%	44%	74%
Doubled-up with others	9%	13%	9%	6%
SRO, welfare hotel	2%	8%	22%	5%
AIDS housing	0%	0%	9%	9%
Drug treatment	0%	0%	9%	3%
Shelter	9%	4%	4%	1%
Street	31%	38%	4%	0%
Other	0%	8%	0%	2%
<b>Housing instability past 6 months</b>				
Stable housing	35%	13%	46%	77%
Doubled up with others	6%	13%	8%	10%
Unstable: Street, shelter, SRO etc.	58%	74%	46%	13%
<b>Sources of Income &amp; Public Assistance<sup>1</sup></b>				
Income from wages	20%	0%	5%	18%
Soc security disability (SSDI)	6%	13%	12%	24%
Soc security supp income (SSI)	21%	25%	31%	46%
Soc security retirement	2%	0%	4%	4%
TANF/AFDC	13%	17%	23%	16%
WIC	2%	0%	0%	3%
Food stamps	36%	33%	46%	64%
General assistance, Home Relief	8%	13%	12%	8%
Rental subsidy, DASIS, Sect 8	4%	25%	23%	57%

1. Multiple responses possible

- The unconnected at both study periods are more likely to be black and Latino, and IDUs (see Table 4) than the agency-based cohort
- The unconnected are more likely to be currently living on the street or in shelters (42%) than are the marginally connected (8%), and have a longer history of housing instability. Only 13% of the unconnected have been stably housed throughout the six month period prior to interview compared to 46% of the marginally connected and 77% of the agency sample (Table 5).
- The unconnected have few economic resources, similar to the marginally connected. The currently unconnected are less likely to be working but appear to have more access to public assistance than unconnected individuals from 1995, particularly regarding rental subsidies (Table 5).

We next examined mental health and substance use. All respondents were asked to report on emotional or psychological difficulties, including relationship problems or need for counseling. In addition, we administered the Medical Outcomes Survey (MOS-36) health functioning instrument which provides a summary of both physical and mental health functioning (Stewart, Hayes & Ware 1988). We present the proportion of respondents who score below 42.0 on this scale, the cut point indicative of clinically-relevant mental health symptoms, as well as those who score below 37.0, a score consistent with psychiatric diagnosis. Problem drug use was defined as non-experimental use of heroin, crack or cocaine, or problem drinking as defined by a standardized scale (CAGE; Ewing 1984).

- Both the currently unconnected and marginally connected are more likely to self-report emotional or psychological problems than the agency sample or individuals unconnected to services in 1995.
- The mean score on the mental health scale for those unconnected to services is well below the cut-point consistent with psychiatric diagnosis indicating that the majority are experiencing clinically relevant symptoms and/or significant impairment in mental health functioning. The extent and apparent severity of mental health problems distinguish current from formerly unconnected as well as contrasts sharply with scores and rates found among the agency sample.
- Those currently unconnected are even more drug involved than the unconnected sample studied in 1995. All have a history of problem drug use; all but one individual interviewed report current heroin use, crack use, problem drinking or all three. Over half of the unconnected sample are current problem drug users as well as scoring below the cut point on the scale indicating mental illness (the dually diagnosed or MICA population).
- The unconnected have comparable rates of drug treatment as the agency sample however unconnected at both study points are far less likely than individuals better integrated into the HIV care system to have had any mental health treatment or services, despite their apparent greater need.

**Table 6: Mental Health and Substance Use Involvement**

	<b>Unconnected recruited at Wave 1 1995</b>	<b>Unconnected recruited at Wave 5 1998</b>	<b>Marginally Connected recruited at Wave 5</b>	<b>Agency Cohort at Wave 5</b>
<b>Total Sample (n=)</b>	(48)	(24)	(26)	(638)
<b>MENTAL HEALTH FUNCTIONING</b>				
<b>Self-Report emotional/ psychological Problems</b>	10%	34%	42%	7%
<b>Mental health functioning<sup>1,4</sup></b>				
<b>Mean (sd):</b>	44.79 (10.2)	31.67 (10.6)	na	43.95 (11.4)
<b>Score 42.0 or lower<sup>2</sup></b>	56%	79%	na	40%
<b>Score 37.0 or lower<sup>3</sup></b>	44%	64%	na	26%
<b>SUBSTANCE USE<sup>4,5</sup></b>				
<b>Ever Problem drug user</b>	93%	100%	na	75%
<b>Currently problem drug user</b>	73%	93%	na	24%
<b>Used heroin or crack/coke daily</b>	59%	79%	na	49%
<b>Ever IDU</b>	51%	77%	47%	45%
<b>DUAL DIAGNOSIS<sup>4,6</sup></b>				
<b>Low low mental health functioning and current problem drug use</b>	31%	57%	na	8%
<b>TREATMENT EXPERIENCE<sup>4,7</sup></b>				
<b>Mental health treatment since HIV diagnosis</b>	29%	21%	na	53%
<b>Ever alcohol or drug treatment</b>	50%	57%	na	55%

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

<sup>2</sup> Cut point indicative of clinically relevant symptomatology.

<sup>3</sup> Mean score for patients with psychiatric diagnosis.

<sup>4</sup> Case base for unconnected samples W1 (n=41) W5 (n=14)..

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

<sup>6</sup> MCS score 37.0 or lower and heroin use, crack/cocaine use, and/or problem drinking past 6 months.

<sup>7</sup> Includes any treatment including participation in self-help groups or support groups.

As we found in the earlier investigation, the unconnected are at an earlier stage of illness and appear physically healthier than individuals well connected to the care system. The marginally connected appear to be in between on indicators of physical health functioning (Table 7).

- Only 13% of the unconnected have received an AIDS diagnosis compared to 69% of the agency sample. However, caution must be exercised when interpreting these findings. Since relatively few have had any contact with medical providers, it is possible that health conditions may have been missed.
- Consistent with the interpretation that the unconnected are at an earlier stage of HIV disease, we find they score higher on the standardized measure of health functioning. The ability to function becomes increasingly impaired as symptoms become manifest (see CHAIN Report, #7R, 1995).
- The unconnected are as likely as the agency sample to perceive their health as good or excellent. The perception and experience of good health is the reason most often given by individuals who remain outside of care: “I feel fine” is a typical response as well as statements indicating a wait and see approach to disease management: “I am not thinking about it (the virus). If I ever get sick and I have to go to the hospital, I will deal with it then”.

#### HIV Testing and Entry into Care

The unconnected and the marginally connected describe different trajectories into testing as well as different experiences with the medical care system after diagnosis of HIV infection.

- In reporting reasons for taking the initial HIV test, a number of the unconnected indicated they took the test (and returned for results) because they were paid to do so, or because they were in jail or drug treatment. None of them took the test because it was recommended by a doctor or other medical provider.
- A distinguishing characteristic of the unconnected at both study times is the lack of a regular source of medical care prior to as well as subsequent to HIV diagnosis, suggesting that they have had poor health care for much of their lives.
- The majority of the unconnected have never seen a doctor or other medical provider for HIV care. This contrasts sharply with the agency sample, with only 2% never having seen a doctor for HIV. The vast majority (80%) of the agency sample enter care within three months of diagnosis.
- Unlike the earlier unconnected cohort, who had reported that HHC facilities were likely to be their first provider of any HIV medical care, the current group of unconnected who have had contact with the HIV health system were more likely to report prisons and drug treatment programs as their first source of care, suggesting a more developed process of “institutional capture” whereby care is brought to individuals in institutionalized settings.

**Table 7: Current Health Status and Functioning**

	<b>Unconnected recruited at Wave 1 1995</b>	<b>Unconnected recruited at Wave 5 1998</b>	<b>Marginally Connected recruited at Wave 5</b>	<b>Agency Cohort at Wave 5</b>
<b>Total Sample (n=)</b>	(48)	(24)	(26)	(638)
<b>GENERAL HEALTH FUNCTIONING</b>				
<b>Self-Report good/ excellent health</b>	<b>46%</b>	<b>68%</b>	<b>43%</b>	<b>67%</b>
<b>Physical health functioning <sup>1,3</sup> Mean (sd)</b>	<b>44.78(10.2)</b>	<b>49.28 (10.0)</b>	<b>na</b>	<b>46.71(10.1)</b>
<b>Score 45.0 or higher <sup>2</sup></b>	<b>46%</b>	<b>79%</b>	<b>na</b>	<b>60%</b>
<b>RECENT T-CELL COUNT</b>				
<b>Below 200</b>	<b>9%</b>	<b>0%</b>	<b>29%</b>	<b>27%</b>
<b>201 - 500</b>	<b>8%</b>	<b>26%</b>	<b>38%</b>	<b>42%</b>
<b>500 or higher</b>	<b>16%</b>	<b>21%</b>	<b>19%</b>	<b>27%</b>
<b>Don't know/ never had test</b>	<b>59%</b>	<b>53%</b>	<b>14%</b>	<b>4%</b>
<b>NUMBER AIDS CONDITIONS <sup>3</sup></b>				
<b>None</b>	<b>78%</b>	<b>86%</b>	<b>na</b>	<b>48%</b>
<b>1 Opportunistic infection</b>	<b>10%</b>	<b>14%</b>		<b>30%</b>
<b>2+ Opportunistic infections</b>	<b>12%</b>	<b>0%</b>		<b>22%</b>
<b>STAGE OF HIV DISEASE <sup>4</sup></b>				
<b>AIDS Diagnosis</b>	<b>22%</b>	<b>13%</b>	<b>24%</b>	<b>68%</b>
<b>Not AIDS Diagnosed</b>	<b>78%</b>	<b>87%</b>	<b>76%</b>	<b>32%</b>

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

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

<sup>3</sup> Case base for unconnected samples W1 (n=41) W5 (n=14)

<sup>4</sup> Based upon CDC classification or client self report

**Table 8. HIV Diagnosis and Entry into Care**

	Unconnected recruited at Wave 1 1995	Unconnected recruited at Wave 5 1998	Marginally Connected recruited at Wave 5	Agency Cohort at Wave 5
n=	48	24	26	638
<b>Reason for initial HIV test<sup>1</sup></b>				
Engaged in risky behavior	38%	29%	50%	36%
Baby tested positive	4%	0%	0%	2%
Recommended by provider	17%	0%	12%	32%
Partner was HIV+	23%	8%	12%	13%
Required by insurer/employer	0%	0%	0%	1%
In jail or drug treatment	na	29%	19%	3%
<b>Year of HIV Diagnosis</b>				
1980-1990	27%	8%	27%	6%
1991-1995	73%	33%	35%	46%
1996-1997	na	33%	35%	44%
1998	na	25%	4%	4%
<b>Time from diagnosis to HIV care</b>				
0-3 months	25%	29%	62%	80%
4-6 months	0%	4%	4%	3%
Over 7 months, or unknown	19%	8%	23%	15%
No medical care for HIV	56%	58%	8%	2%
<b>Had MD prior to HIV diagnosis</b>				
Had regular source of care	17%	21% <sup>2</sup>	na	51%
No source of medical care	83%	79%	na	49%
<b>Provider of first medical care</b>				
HHC	82%	15%	11%	17%
Voluntary hospital	7%	54%	39%	50%
CHC/neighborhood clinic	4%	0%	17%	11%
Private practice	2%	0%	6%	11%
Drug treatment	2%	8%	22%	10%
Prison	4%	23%	6%	0%

1. Multiple responses possible

2. Case base for W5 unconnected sample n=41.

We examined open-ended discussions of the testing experience to see if this initial encounter with the HIV service system might shed some light on why some individuals move quickly into regular care and others remain outside the care system. Most of unconnected respondents did not report any negative experiences at the sites where they were tested for HIV. They received counseling, confidentiality of test results was protected, and most often they were given referrals to HIV clinics and other places providing medical or social services.

However, a significant subset of individuals reported that they were tested in what they experienced as coercive situations and/or did not receive adequate information about the disease and about the medications related to HIV. It seems that individuals who were tested in prison and drug treatment programs, what is being referred to as “institutional capture,” were more likely to express their dissatisfaction with their testing experience. Anthony, an African-American male client, who got tested in prison responded to the question, “Why did you take the test then?”, as follows:

*“It is required in jail. They tell you that it is an option, but they are full of it. As soon as they find out you are positive, they are ready to pump you with medications, no questions asked.”*

Similarly, Wayne, another client who also got tested in jail talked about the absence of any real choice and about breach of confidentiality:

*“In jail you don’t have a choice. They take the test and they tell you the results. If you are positive, they start giving you medicine right in front of everybody, so everybody knows.”*

Some drug treatment programs require their clients to get tested and this was an issue several study participants mentioned. “Testing was part of the program” or “They were testing everybody,” as a couple of the clients stated. The interviews clearly indicate that the clients who were tested without freely and deliberately seeking to know their HIV status consider this a negative experience and, in some cases, this experience may have deterred them from seeking services once they left the institution where they tested. As Eric, a white non-Hispanic man who got tested at a drug treatment program said: “I took the test because I had to. They took the test and told me. It was awful. I am never going back to rehab again. I don’t care if I die even with a needle in my arm.” Wayne describes his reasons for not receiving medical services as follows:

*“All the doctors want to do is get paid by stuffing you with medication. The meth [methadone] doctors give you meth, the other doctors give you pills. So what are they actually for? Nothing!”*

Alternatively, there were unconnected study participants who were satisfied with their testing experiences. They reported being given pre- and post-test counseling, and being treated with respect: “They were nice. They talked to me first, then took the test. When I went back I already knew. I was OK,” said Ellen, an African-American IDU sex worker, of her testing experience in a city hospital. “She gave me respect,” was what Melissa, another sex worker, said about the outreach worker she spoke to when she went to get tested on the van. When asked why they did not access the medical or social services system, these study participants talked about the lack of documentation papers which stops them from getting Medicaid and other kinds of benefits, and about the fear of disclosure..

Fewer respondents had any complaints about their testing experience among individuals unconnected to services in 1995. However, they were more likely to initiate testing for their own personal reasons, and thus, perhaps, more ready to deal with the diagnosis.

#### Service Need and Service Utilization

Each respondent was asked whether he or she needed help or assistance in the past six months regarding specific services -- housing, financial matters, legal matters, employment, emotional or psychological difficulties, household items or clothing, child care, transportation, food or meals. Respondents were further asked whether they sought services and if their problems were resolved.

- As a group, the unconnected expressed a great deal of service needs, particularly when compared with the agency-based cohort. There are relatively fewer differences between the unconnected and the marginally connected in their need for services; in some instances the marginally connected express greater need (Table 9). However the marginally connected have more often made some attempt to access services than individuals more completely outside the HIV services system (data not shown).
- The hierarchy of needs is the same for both unconnected and those better integrated into the service system. The need for basic, concrete services such as housing, food and financial assistance predominate; fewer individuals express a need for employment or job training, legal matters, or childcare assistance.
- The unconnected report fewer instances of taking any HIV medications or any type of combination therapy. While their relatively early stage of HIV disease and good health (e.g. none reported t-cell counts below 200 - refer to Table 7) might indicate that lack of combination therapy is clinically appropriate, there are prophylaxis treatments that would be most likely recommended under usual standards of care.

Analysis of qualitative data indicate that individuals unconnected to services are far from enticed by the promise of the newer protease based medications. In fact conceptions and myths regarding medications for HIV infection are widespread among the unconnected, and were mentioned along with the futility of seeking medical care for a fatal illness. *“I’ve seen my brother [who is also HIV positive] being pumped up with pills and the doctors didn’t know what they were doing,”* one unconnected woman said. Another woman associated her decision not to seek medical treatment with the fear that she might have adverse drug interactions between her methadone and her HIV medication:

*“I heard bad rumors of people taking medication for the HIV while they are taking methadone. I don’t want to chance it to get sick.”*

Provider interviewers confirmed that there are numerous misconceptions and myths about HIV, the nature of the disease and the function of the antiretroviral medications. Providers emphasized the importance of outreach education and explained that there are several myths about HIV medications which their clients believe, *“There are myths out in the street. People on methadone are less likely to take protease inhibitors. The thought is that methadone slows the progression of the disease and that protease inhibitors interfere with methadone,”* Slim, one of the outreach workers, mentioned. Similarly, Dr. Silver, one of the medical doctors who works with an outreach team said that some of her patients who come to the van know about protease inhibitors, but some *“think that if you mix Crixivan with heroin and you shoot it you don’t get HIV.”*

**Table 9. Service Needs & Utilization, HIV Medication**

	Unconnected recruited at Wave 1 (1995)	Unconnected recruited at Wave 5	Marginally Connected recruited at Wave 5	Agency Cohort at Wave 5
n=	(48)	(24)	(26)	(638)
<b>In past 6 months needed help with...*</b>	46	24	21	638
<i>Housing</i>	54%	50%	81%	26%
<i>Financial matters</i>	48%	63%	67%	20%
<i>Legal matters</i>	11%	17%	24%	9%
<i>Employment</i>	20%	17%	24%	4%
<i>Home care</i>	0%	4%	5%	1%
<i>Emotional problems</i>	15%	34%	43%	7%
<i>Household items, clothing</i>	22%	33%	33%	11%
<i>Child care</i>	0%	4%	10%	1%
<i>Transportation</i>	22%	33%	48%	8%
<i>Food, groceries, meals</i>	36%	42%	33%	9%
<b>In past 6 months has used...*</b>				
<i>Hospital</i>	13%	0%	35%	24%
<i>Emergency room</i>	33%	38%	52%	34%
<i>Clinic</i>	21%	17%	77%	82%
<b>HIV Medication</b>				
<i>Currently takes HIV meds</i>	6%	8%	50%	76%
<i>On any combination therapy</i>	0%	8%	33%	47%

\* Multiple responses possible

## Social Support

The last table (Table 10) looks at social support. Often needs can be met through assistance provided by family and friends. In addition, a major factor predicting use of services for high need populations such as the homeless mentally ill is social support for help seeking. If individuals are not able or willing to negotiate the service system, a concerned helper often facilitates both entry and maintenance in treatment (see e.g. Susser et al. 1997).

- The unconnected appear to be more socially isolated than individuals better connected to the HIV service system. On several indicators, they appear to be even more socially isolated than individuals who were unconnected to care in 1995.
- The unconnected are no less likely than those in the agency sample to be married or in a marriage like partner relationship, but they are considerably more likely to live alone.
- The unconnected have fewer friends than either the marginally connected or the agency sample. The biggest difference is with regard to family relationships. The unconnected report far fewer on average than any other group; they appear to be more estranged from family relationships than individuals in the prior unconnected sample. Over one-third of unconnected respondents do not have a single family member or relative that they are in contact with and an even greater number have no family members aware of their HIV status (data not shown).
- Case managers can often perform social support functions, not only referring and advocating for clients but also providing some degree of emotional support for persons in need. Few of the unconnected have had any contact at all with any case manager or social worker in the six months prior to interview. Almost two-thirds (73%) of the agency sample have regular contact with a case manager even though for many, they may have fewer service needs than those unconnected to care.

## Barriers to Accessing Services

In this final section, we discuss what appear to be both individual and service system or provider barriers to timely entry into care among the unconnected. Most of the unconnected exist on the margins of society, and their experiences with the medical and social service system have been shaped by their histories of multiple social disadvantage. Moreover, their prior experience with the system may be one of the primary obstacles keeping them unconnected. Our interviews indicate that negative encounters with providers discourage clients from accessing services. For example, Peter, a white non-Hispanic man who is living with his wife in an apartment with no utilities explained why he is not even attempting to get help for his financial problems: *“I didn’t think anybody could get me the help I need because I had been treated so bad in the past when I asked for money.”* Similarly, Mark, an African-American man associated a social worker’s indifferent attitude with his decision not to reveal his HIV status:

*“She cannot relate to me. Everything in our society interacts with money...The agencies want to keep names in their system to get paid. They have nothing to do with the real concerns of my well-being. They are there, they ask you, ‘How you’re feeling?’ and when you start telling them it is like talking to an empty space.”*

**Table 10: Social Support**

	Unconnected recruited at Wave 1 1995	Unconnected recruited at Wave 5 1998	Marginally Connected recruited at Wave 5	Agency Cohort at Wave 5
<b>Total Sample (n=)</b>	(48)	(24)	(26)	(638)
<b>MARRIAGE AND PARTNER RELATIONS</b>				
<b>Marital status:</b>				
<b>Currently married</b>	11%	10%	5%	14%
<b>Formerly married</b>	29%	23%	46%	32%
<b>Never married</b>	60%	66%	50%	55%
<b>LIVING ARRANGEMENTS</b>				
<b>Lives alone</b>	43%	78%	55%	42%
<b>Alone in institutional setting<sup>1</sup></b>	9%	4%	10%	85%
<b>Lives with others</b>	48%	17%	36%	50%
<b>FRIENDS AND FAMILY</b>				
<b>Number of close friends     mean(sd)</b>	2.62 (3.9)	2.71 (2.1)	3.17 (3.7)	5.56 (8.7)
<b>Number of family members or other     relatives in contact with     mean (sd)</b>	6.19 (10.6)	2.44 (3.5)	5.83 (10.7)	6.62 (9.3)
<b>CASE MANAGER</b>				
<b>Any contact with any case manager     or social worker in past 6 months</b>	12%	19% <sup>2</sup>	59%	73%

<sup>1</sup> Group home, transitional shelter, drug treatment housing etc.

<sup>2</sup> No HIV case manager but contact with social worker at public entitlement agency (e.g. food stamps)

Several clients characterize the social services system as being disrespectful and ineffective. Kathy, when attempting to receive welfare benefits, indicated that her social worker appeared disdainful; *“She screamed at me to bring these papers. Why does she treat me that way? Just because she’s sitting on the other side of the desk?”* Another study participant expressed the system’s delay in providing timely housing assistance: *“I live on a bus with others...I signed up for a case manager at (a drop-in homeless shelter), I am still waiting.”*

Stigma and fear of disclosure was brought up by several unconnected study participants, primarily women, as a barrier to getting services. Being stigmatized and treated poorly due to HIV serostatus and intravenous drug use was perceived by female clients as a barrier to seeking services. In most instances, the fear of being treated poorly stems from prior encounters with service providers. *“The fear of being ridiculed. Them treating me differently, bad, because of my HIV,”* Melissa gave as her reason for not accessing services. She also admitted that when she accompanied a friend who is also HIV positive to social services, *“They [social workers] just blurted out her business about her HIV.”* Another female client, while discussing her experience with a doctor in an emergency room where she gets care concluded: *“I just don’t like the way they look at you when they know you use drugs.”* In two instances, doctors were perceived as treating unconnected female clients in a patronizing and disrespectful manner, which dissuaded them from regularly accessing the medical care system. It is noteworthy that stigma and having an unpleasant experience with a medical provider were reported more often by women than by men as barriers to seeking care.

We also asked staff of outreach agencies to describe the barriers to accessing medical and social services among the clients they serve. Both program directors and outreach workers cited some of the same weaknesses of the service system reported by their clients. Specifically, the providers spoke about their clients’ social marginalization, associated with their chronic poverty, homelessness, substance use and mental illness. They also discussed some of the system inadequacies which tend to discourage an already vulnerable population from accessing care.

Some of the providers confirmed that clients’ lack of documentation papers, such as, birth certificates and social security cards often proves to be a barrier to getting medical and social benefits. Having to get these personal documents is the first stumbling block many of the unconnected face. As Janet, one of the outreach workers, explained the lack of documentation is often a serious obstacle:

*“A lot of the women we deal with [sex workers, drug users], don’t have an ID, they can’t keep an ID out here [in the street] because it is stolen, or they lose it, or it is taken away by one of the police officers. And they need an ID to get an ID. You can’t get a social security card unless you have an ID, you can’t get a birth certificate unless you get an ID.”*

To overcome this barrier some of the outreach agencies have permission to fill out an application to request a client’s social security card, the agency keeps the original and gives the client a photocopy which she can then use to begin her journey for getting benefits. However, the law grants this permission only for individuals who were born in New York State. Lack of personal documents is a difficulty ex-offenders usually have, as Antonio, one of the outreach workers, mentioned:

*“I always wonder about these people [ex-offenders], they can’t get their papers, they have to go back [to the correctional facility] for their papers. Nobody wants to go back...Just having the inmate card. Where can you go with that?”*

Clients agree with providers that the cost and procedure for acquiring personal documents is a problem they are facing, “Damn, it costs money to get these papers. Fifteen dollars,” one female client said, while another woman, whose welfare benefits were discontinued, expressed the wish that the process for getting documents was easier.

Providers also point to legal barriers facing the clients, such as, outstanding warrants and illegal immigration status. Individuals who are engaging in illegal activities are often afraid that any contact with either the medical or the social service system will result in incarceration. Given New York City’s aggressive policy of enforcing “quality of life” statutes that affect people who live on the streets, outstanding warrants for misdemeanors also keep individuals outside the care system, “*People are dying in the streets because of misdemeanors. We hired a lawyer to help our clients clean up minor things, like quality of life offences,*” Paul, the director of Streetwise explained. HIV positive women who are drug users, often have a different concern. Many do not access services out of fear that they will be viewed as unfit mothers, due to their drug use, and their children will be placed in foster care. As Miriam, an outreach worker, put it: “*Women who are using drugs are afraid to go for benefits because they fear that they system will take away their children.*” This gender-specific obstacle in part explains why many of the providers said that women tend to stay outside the service system longer than men. Another group of HIV positive individuals who also do not get services in order to avoid any contact with the legal authorities are the undocumented immigrants, as Martin, a director of one of the outreach vans mentioned.

One of our respondents, an African-American man in his sixties, who suffers from arthritis, diabetes, and a heart condition explicitly said that his legal problems are preventing him from getting medical care, “*I can get no benefits because I skipped parole. I figured I would go back to jail and they wouldn’t help me there.*” As a result, this HIV positive unconnected man goes to any emergency room for his diabetes, buys insulin on the street, and gets his needles at a needle exchange program.

A barrier to care that was apparent in the earlier investigation as well as the present study of individuals outside of care points to unresponsiveness, and at times discriminatory treatment, by the service system. There are multiple manifestations of the problem. One type of difficulty is structural - individuals with multiple problems often ‘fall through the cracks’ of a service system oriented primarily to serving individuals with a single diagnosis. Individuals with serious substance abuse problems are often ineligible for treatment in mental health treatment settings, homeless providers may not have staff expertise or facilities licenses to respond to multiply diagnosed individuals, and HIV primary care providers may appropriately focus on physical health issues when mental health, drug addiction, and desperate social straights are more salient issues for the client to address. Both HRSA and HUD/ HOPWA have established programs to begin to address the system and provider considerations necessary to serve HIV individuals who also struggle with homelessness, mental illness and chronic chemical dependency.

Another type of provider barrier results from the disjuncture between life on the margins that characterizes multiply diagnosed individuals and the requisites of mainstream service provision. As we have seen, such individuals may not manifest expected help-seeking behavior. They are often apprehensive about seeking professional assistance when in need or accept any care or treatment offered. All providers agree that one of the most intractable problems socially marginalized HIV positive individuals face when they access services is the way in which the service system responds to their needs. Some of this response may be due to a general societal response to social outcasts - those who use drugs, are homeless, mentally ill or sex workers. Martin, the director of one of the

outreach teams targeting primarily homeless, intravenous drug users, explained the multiple rejections facing his HIV positive clients: *“Our society, which is conservative, doesn’t want to deal with substance users in the first place. Then most are black and Latinos, and on top of this they have HIV.”*

Outreach workers provided instances where their clients were discriminated against and treated poorly by social service and medical providers. Dr. Silver, one of the medical doctors who has been working with an outreach team for the last fifteen years, explained the difference between a medical outreach van and other medical centers, *“We don’t care if people don’t smell nicely, or have lice. We are very non-threatening.”* To the statement made by one of her co-workers that most doctors, *“treat homeless people like shit, inhumanely, because they think they are somebody and they treat poor people like nobody”* Dr. Silver added that some hospitals tend to attract doctors who are more sensitive to socially disadvantaged patients. *“Certain doctors who want to work with certain populations, like the poor and the homeless, go to work for city hospitals. If you want to treat the rich and to make money you go to work for a private hospital.”*

Providers described discriminatory treatment often encountered by intravenous drug users in medical facilities. *“Over and over again, an IDU who is pregnant goes to a clinic and instead of having somebody sit down and talk to her seriously, they immediately suggest an abortion,”* the director of one of the outreach teams stated. Emergency room doctors often neglect patients who are substance users and downplay their physical needs, *“When you are a doctor in the ER and an addict comes in, you put them on a bed, take care of everybody else, and in the end you treat them, hoping that maybe your shift will be over by then,”* as one outreach worker mentioned. One of the workers who runs a support group for women who are intravenous drug users stated that the stories women share in the group reveal that some were tested for HIV without giving their permission, while some were told they are HIV positive because of their drug use without even being tested. Given that emergency rooms are often the only source of medical care, and more importantly, the gateway into the medical care system for many of the unconnected, these negative encounters with doctors become obstacles in accessing and staying in the medical care system.

Populations targeted by outreach agencies can also experience poor treatment from social service agencies. Miriam, an outreach worker, who often accompanies clients to social service agencies mentioned delays and impolite treatment as barriers to accessing the social service system. She mentioned a recent incident where she waited with the client for the social worker, after calling him twice and explaining that she had an apartment lease for this HIV positive, homeless client. Finally, *“the social worker comes down walking like a bum and slouches on his chair. Then he said that they don’t give checks for rent, only vouchers. I explained the situation and I asked him for a Xerox copy of the documents. He sneered and didn’t give me the copy.”* One of the providers in explaining the impersonal way in which some social service agencies operate saw them as *“a deli where they call out numbers.”* Delays in social service agencies often prevent HIV positive, homeless individuals from becoming housed. Another obstacle in securing housing for persons living with the disease is the attitude of several landlords who do not want to work with social services agencies or who do not want to lease their property to persons living with HIV/AIDS.

Most of the respondents who are currently outside of the service system mentioned that they did come into contact with either medical or social services at some point after their diagnosis. It appears that they were unable to keep appointments, or they lost patience with the bureaucratic rules, or experienced rejection by providers such that they gave up the attempt. Lifestyle constraints, the regular experience of social rejection, and use of mind altering substances, tend to make multiply

diagnosed persons impulsive and impatient in dealing with others, and poorly prepared to negotiate the service delivery system. From a provider perspective, these characteristics make them less desirable as patients and clients.

#### **IV Recommendations**

Many of our recommendations for engaging the unconnected with HIV care and services remain essentially the same as those put forth based on our prior analysis.

1. Since those who delay their management of HIV illness tend to be marginalized populations such as the homeless, substance users, and sex workers, there is a continued need to support and expand outreach efforts, especially high intensity efforts, that attempt to engage such populations with HIV-related services.
2. Outreach appears necessary not only for first entry into HIV care but to maintain continuity of care. While more individuals enter care relatively soon after diagnosis, for many, their engagement with services is tentative and fleeting and they remain marginal to the care system. Clinic or office based staff are likely to have few incentives to maintain treatment contact. Enabling services that extend access further into the community are necessary.
3. It is important to continue to develop and refine very low threshold "service readiness" programs (based on models of recovery readiness) that directly address housing, financial need and other concrete problems in a supportive, non-judgmental way that does not require prior commitment to abstinence from drugs or other major behavioral changes. A "stages of change" approach to engagement with HIV medical care would appear necessary for the hardest to reach unconnected. Outreach and provision of services that address basic survival needs can be seen as necessary intermediate and enabling services. These services can attract those outside of care to the agency where they can receive information and establish a trusting relationship with service professionals who are then in a position to facilitate change in awareness, intention, and behaviors regarding HIV disease management and service utilization.
4. Development of such 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.
5. HIV-positive individuals need to be better educated about the benefits of early intervention. It is especially important to provide accurate, culturally appropriate, and accessible information about the benefits of antiretroviral treatments and the importance of exact adherence to regimens. Providers need to become better informed about prevailing myths and fears about HIV treatments and address these directly.
6. There is a persistent need to educate HIV providers as to who the "unconnected" are, as well as to

sensitize providers to the perceived barriers (unwelcomeness, bureaucratic rules) that often dissuade individuals from pursuing services at earlier stages of illness.

7. Given that those unconnected to services tend to know people who are receiving services, agency could be enlisted to assist outreach agencies in developing techniques to reach further into unconnected populations through acquaintance networks.

8. Develop mechanisms and infrastructure for outreach agencies to share strategies and develop a “trusted network” for the hardest-to-reach populations.

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