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CHAIN Update Report #43



**Drug Use and Service  
Utilization among People  
with HIV in NYC:  
Barriers to Care and Low  
Threshold Services**

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**C.H.A.I.N. Report**

## CONTENTS

{ TOC \O "1-3" \H \Z }

### Tables

Table 1. Correspondence of “Low Threshold” Components to CHAIN Measures .....	10
Table 2. Self-Rated Overall Health Status, by Drug Use History .....	11
Table 3. Expressed Reasons for HIV Testing, by Drug Use History .....	14
Table 4. HIV Test Site Utilization, by Drug Use History .....	15
Table 5. Referral Patterns to First HIV Treatment, by Drug Use History .....	17
Table 6. Source of First HIV Treatment, by Drug Use History .....	18
Table 7. Importance of Benefits in Service Enrollment, by Drug Use History .....	18
Table 8. Insurance Status, by Drug Use History .....	19
Table 9. Use of Health Services over 6 Months Preceding Baseline Interview, by Drug Use History .....	20
Table 10. Use of Health and Social Services in 6 Months Before Study Intake, by Drug Use History .....	21
Table 11. Barriers to Health and Social Services, by Drug Use History .....	24

### Figures

Figure 1. Conceptual Map of Influences of Drug Use on Service Utilization .....	6
Figure 2. Typology of CHAIN Sample (N=968) Drug Use Patterns .....	9
Figure 3. Transitions in Drug Use Between Wave 1 and Wave 2 .....	12

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## 1. INTRODUCTION

Assuring access to HIV-related services for people who use drugs has consistently been recognized as a major problem in HIV service delivery, both by NYC studies and bodies of research elsewhere. Drug users are at substantial risk of a number of poor health outcomes, including those connected to unhealthy lifestyles and lack of healthcare, as well as those connected with the specifics of drug use, and a number of infectious diseases (including HIV, HBV, and HCV) transmitted through drug use or associated behaviors. Nonetheless, a number of analyses (Chitwood et al. 1999; Power, Hartnoll and Chalmers 1992) have shown serious gaps in healthcare for these high-need populations.

Weiss, Kluger and McCoy (2000) summarized the relatively sparse research on drug users' health and health care utilization by pointing out that providers have little understanding of drug use as a chronic and relapsing condition, generally dislike and avoid drug users as patients, and that most drug users are well aware of the feelings of their providers and regard them with fear and suspicion. Research on utilization has pointed to their high levels of emergency room use and use of acute rather than preventive or primary health services.

“Low threshold services” (meaning services with as few barriers as possible) are often advanced as a model of how to meet the needs of these populations. Research on outcomes of low threshold service models has been limited, largely for methodological reasons centering around finding appropriate outcome measures and ensuring sample sizes adequate to detect relatively modest differences in outcomes. Prior CHAIN research has identified drug users as an underserved group within the HIV-infected population, but generally not explored the differences among subgroups that are related to service utilization, and has not examined the potential role of low-threshold services in increasing enrollment and engagement of drug users in the service system.

This report examines a number of aspects of HIV-related medical and social service care, among PLWHs with different drug use histories. Different levels of drug use are associated with different service utilization patterns, including those of HIV testing and engagement with medical and social services. Finally, it explores the perceived barriers to service use, showing how individuals with different drug use profiles experience different barriers to care, and suggests how elements of a “low threshold” service model might diminish the impact of these barriers.

This report has four major parts:

1. We categorize the CHAIN sample into a more refined typology of types of drug users which may affect service utilization, and examine the interrelations of these groups over time.

2. Using this typology, we examine aspects of the initial “pathway” to care, including testing and referral to services, and how they are associated with types of drug use.
3. We show differences in utilization of HIV-related and general medical services by drug use type.
4. Using an existing typology of barriers, we examine barriers to services. Relating the experience of service barriers to type of drug use, we show that those aspects that are particularly prominent among the higher-intensity drug users are precisely those that components of the “low threshold” service model described by the membership of the AOD Workgroup, attempt to address.

## 2. KEY FINDINGS

The report is based on the division of the sample into four patterns of past and present drug use, including “Never,” “Past,” present “Lower Frequency” and present “Higher Frequency” users. When we classify PLWHs by their drug use pattern we find that:

1. There is substantial movement of individuals among the categories. During any 6-9 month period, approximately 25% of the cohort with some past drug use history will undergo a change in their drug use patterns, whether in the direction of “relapse” or of “recovery.”
2. There are significant differences among subgroups in all parts of the “pathway” to care or process of service enrollment and engagement, from HIV testing through service enrollment and utilization. The higher-intensity and more recent the drug use, the less likely members of the cohort are to access services that provide continuity and follow-up, and the less likely to be engaged in services generally, with the notable exception of having an HIV-related medical provider.
3. Those with little or no drug use history are significantly more likely to have undergone initial HIV testing in settings already connected to the medical system, and which can provide some continuity of care. In contrast, many high-frequency drug users are tested in non-medical settings that are less likely to provide that continuity. They are also less likely to have had testing recommended by medical personnel.
4. Those with no history of drug use rate their general health significantly higher than those with a history. They also make the initial transition to services more smoothly, waiting a shorter time after initial diagnosis before seeking care, and being more likely to have a referral rather than having to seek out services on their own.

5. These differences are also reflected in utilization patterns. Higher levels of drug use are associated with less use of primary care, more use of emergency room care, and higher use of case management services. Higher levels of drug use are also associated with lack of medical insurance and not being a DASIS client.
6. Those who report current drug use, especially at higher-frequency levels, are more likely to experience each of a number of barriers to getting care. These barriers include difficulties with transportation, getting information about services, and anticipating poor experiences with services. Current and especially higher-frequency drug use is also associated with social comorbidities including lower mental health functioning, problem drinking, and unstable housing, as well as a past history of unsuccessful drug treatment attempts. These comorbidities also contribute to drug users' difficulty using services.
7. Higher-frequency and more recent drug users experience substantial cumulative disadvantages in service entry, referral, utilization, and ease of access to care and medical treatment. These disadvantages are concentrated especially in a subgroup of high-frequency users, who are particularly difficult to reach with existing service models.

### **3. BACKGROUND AND METHODS**

#### **3.1. INSIGHTS FROM RESEARCH ON PATHWAYS TO HEALTH CARE**

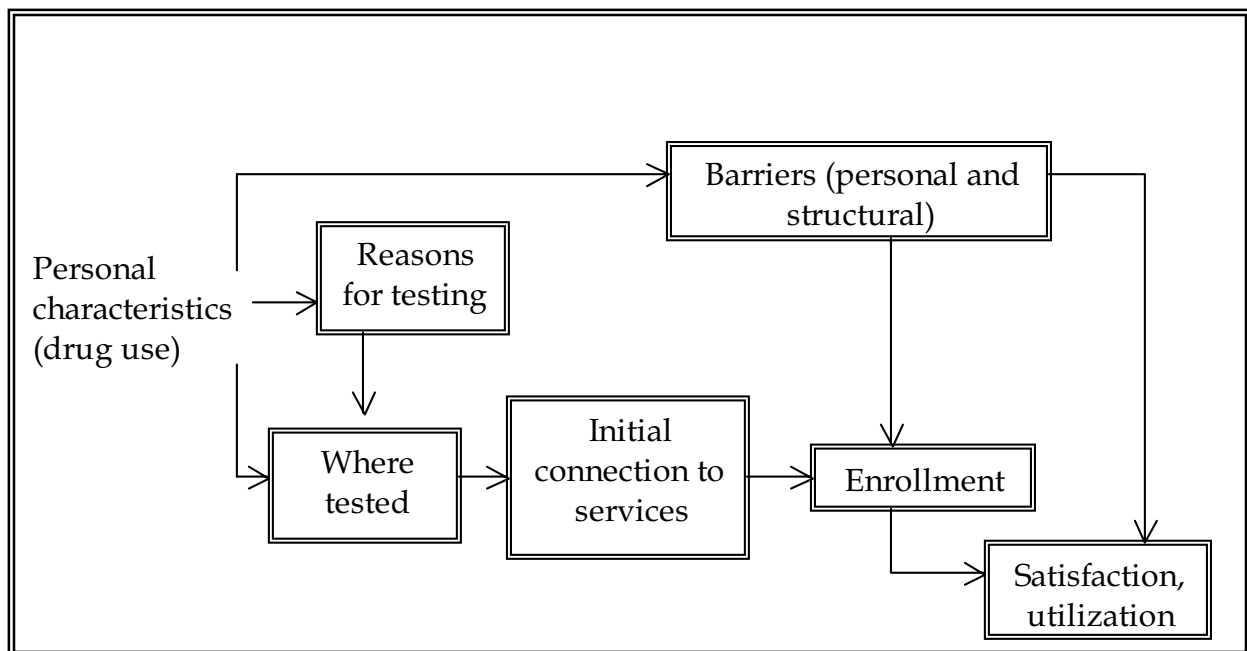
Research into the general area of help-seeking for health and social services portrays a complex process, influenced by both individual and social factors. Two general frameworks from this literature structure the approach taken here.

1. Health service utilization outcomes can be influenced by the objective *need* (health status) for services; *predisposing* factors or characteristics of the *individual* (for example needs, knowledge, behavior), and *enabling* factors or characteristics of the *services* themselves that make them more or less receptive to certain categories of people (Aday and Awe 1997; Andersen 1995). *In this report, we examine the ways in which types of drug use are related to an array of personal characteristics and attitudes that may influence the tendency to seek and use services.*
2. Later patterns of service utilization often depend on how and where individuals enter the “system,” as the entry point channels people into different treatment paths that may lead to different outcomes (Rogler and Cortes 1993; Pescosolido, Gardner, and Lubell 1998). This general observation has been borne out in analyses of “pathways” of HIV medical care within the CHAIN cohort, showing that most participants continue in the pathway in which they entered the system (Abramson and Sanger 2001) and that there is a high level of continuity with the

same provider, once in the “system” (Messeri et al. 2000). This implies that the initial stages of entry to the system, including linkages and referrals to initial care, can influence long-term differences in outcomes, and points to the importance of examining the entry points into the system. *In this report, we examine drug use characteristics in relation to aspects of the HIV testing process in the context of testing as the initial stage of entry into care.*

These frameworks are not contradictory. Rather, they emphasize that an important characteristic like level of drug use can both influence the entrance to and thus the pathway through services, *and* continue to influence outcomes at each stage of the service pathway.

**Figure 1. Conceptual Map of Influences of Drug Use on Service Utilization**



### 3.2. CHAIN SURVEY AND DATA

The Mailman School of Public Health at Columbia University is responsible for conducting the CHAIN Project surveys and reporting on findings from the survey data in collaboration with the NYC Department of Health and the Medical and Health Research Association of New York City, Inc. (MHRA). The purpose of this study is to provide longitudinal information on study participants’ needs for health and human services, their use of health care and social service organizations, their satisfaction with services, and the impact of these services on physical, mental and social well being. This information is specifically prepared for the NYC HIV Health and Human Services Planning Council to assess the full spectrum of services for HIV infected persons in

NYC. The study was undertaken through a subcontract from MHRA with the authorization of the NYC Department of Health and the HIV Planning Council.

The CHAIN Project followed a recruitment procedure designed to yield a broadly representative sample of people living with HIV in New York City. Study recruitment was conducted in 43 agencies that were selected so that there would be roughly equal numbers of medical care and social services sites and representation from sites that were and were not recipients of Title I grants. At 30 sites, staff contacted a random sample of clients. The names of clients who indicated an interest in participating were turned over to CHAIN staff for interviews. A sequential enrollment procedure was implemented at the remaining 14 agencies. All eligible clients present on a small number of recruitment days were invited by agency providers and CHAIN staff to participate in the CHAIN study. Interviews were then scheduled with interested clients. A total of 648 individuals recruited from participating agencies completed baseline interviews. The agency-based sample was supplemented with 50 interviews conducted with HIV+ individuals with little or no connection to medical and social services. These individuals were contacted at outreach sites and through nominations from CHAIN participants. More detailed information on sampling strategy and recruitment may be obtained upon request from MHRA (CHAIN Technical Report #1, 1995).

Subsequent interviews were conducted at approximately six to nine month intervals. Round 2 interviews were completed with 568 participants, 92% of the cohort still alive and not known to have moved outside of New York City. Round 3 interviews were conducted with 480 of the CHAIN participants, 88% of the cohort who was alive and still residing in New York City. Round 4 interviews were conducted with 420 CHAIN participants or 82% of the surviving cohort. In an effort to replenish the CHAIN sample, which had lost a number of participants to death and other factors, in 1998 an additional 267 individuals were added to the study, using the same agency and community sources. These individuals constituted the "refresher" sample and joined the 385 CHAIN continuing participants who have been involved in the project since its inception in 1994, bringing the total number of people interviewed in Round 5 to 652. In Round 6, slightly over 500 study participants were interviewed, 80% of those eligible.

All CHAIN interviews are conducted in person by interviewers recruited from communities throughout New York City and trained specifically for the study. Interviewers are matched to respondents as much as possible with regard to gender and race/ethnicity. Approximately one-third of the field staff are themselves HIV positive. Interview topics include sociodemographic characteristics, the full range of experiences with access and use of medical and social services, and quality of life. At each round of interviews participants are asked about their current living situation, their recent health and social services utilization, and perceptions of quality and satisfaction with that utilization.

For this report, except where otherwise noted, we use the full number of 968 interviews collected in 1994 and 1998 available for baseline characteristics.<sup>1</sup>

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<sup>1</sup> Minor discrepancies are attributable to missing data for particular variables.

### 3.3. MEASURING TYPES OF DRUG USE AND COMPONENTS OF “LOW THRESHOLD” SERVICES

Present or past drug use is common within the CHAIN cohort. Aidala, Weinberg and Ho (1997) identified approximately 1/3 of the sample as “problem drug users,” defined as any heroin, cocaine, or crack cocaine use within the preceding 6 months, or “as problem drinkers” as identified by a standardized scale. However, this analysis did not consider the implications of the differences among parts of this overall group of “problem drug users,” nor specifically compare the impact of service utilization barriers along the full spectrum of drug use categories. To better examine the relationships between drug use patterns and health services utilization, we categorized the sample into four categories based on information provided by their baseline interview at entry to the CHAIN study.

These categories are based loosely on the concept of “careers” in drug use, which divides an individual’s use into periods based on different types and intensities of use.

- **“Never”** users reported either no lifetime use of crack, cocaine, or heroin at all, or fewer than 5 lifetime uses. In practical terms, fewer than 5 uses qualifies as experimental usage, so these experimental users are behaviorally similar to, and were merged into the category of “never” users.
- **“Past”** users reported more than 5 lifetime uses of crack, cocaine, or heroin, suggestive of an ongoing past pattern of use, but no use within the 6 month period preceding baseline interview. These, then, are individuals with substantial past drug use who have stopped that use sometime prior to the 6 months preceding baseline interview.
- **“Lower Frequency”** users are those with 5 or more lifetime uses of crack, cocaine, or heroin, and who have *continued* to use during the 6 months preceding interview, but at a relatively Lower Frequency level (less than daily use). This is a level of use which often allows the user to continue a relatively normal life, and is often transitional to either ceasing altogether or becoming a more frequent user.
- **“Higher Frequency”** users are those with 5 or more lifetime uses of crack, cocaine, or heroin, and who report continuing to use during the 6 months preceding interview, at least once per day. At this level of use, serious addiction (defined as continuing drug use despite negative social, behavioral, or other consequences) often sets in, and the activities of drug use (finding money, finding drugs, using them) begin to dominate the user’s life while the social consequences of the use increase in severity.

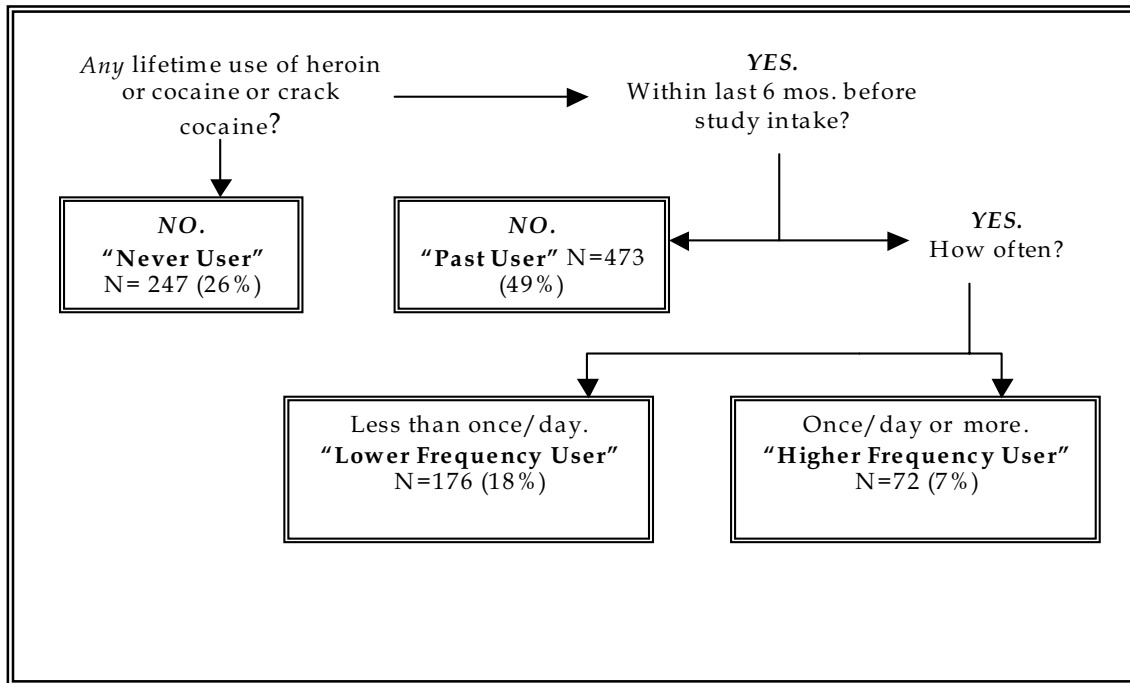


Figure 2. Typology of CHAIN Sample (N=968) Drug Use

At intake, the CHAIN cohort’s drug users were dominantly (almost 50%) either Past Users or (18%) Lower Frequency Users. The very fact that so few Higher Frequency Users were captured by the dominantly institutional recruitment for the CHAIN sample is indicative of the general lack of connection of the higher-intensity drug users to the service system.

**3.4. ANALYTIC STRATEGY**

There is no single standard measure or definition of “low threshold” services. Using elements suggested by the workgroup as components of a “low threshold” approach, we have in turn selected a particular element of the CHAIN data to use in examining how categories of drug use are distributed along this element. The following table shows the correspondence of the components of “low threshold” services and the measures we used to approximate how need for these elements might be distributed across drug use types.

**Table 1. Correspondence of “Low Threshold” Components to CHAIN Measures**

Workgroup “low threshold” component:	CHAIN measure:
1. No criteria for “clean time” from alcohol or other drugs	1. Prevalence of existing use, changes in status over time
2. Provides intake and assessment for services	2. HIV testing as introductory phase of assessment and intake
3. Referral and linkage to case management and basic services	3. Initial service engagement and referral patterns
4. No fee for providing services	4. Financial constraints: insurance
5. Assistance establishing eligibility for HIV services	5. Initial motivation for service engagement, use of case management services
6. No time limit for services	6. Delay in seeking services

#### **4. BACKGROUND HEALTH STATUS OF THE SAMPLE**

To examine the effects of differences in drug use on service utilization, we ensured that there were no major demographic differences among the drug-use groups. At study intake, there were no statistically significant differences (measured as chi square  $p < .05$ ) among the four sample groups on the dimensions of race/ethnicity or gender. Predictably, Past Users and Lower Frequency Users are slightly older than Never Users or Higher Frequency Users, and are significantly ( $p < .001$ ) less likely to be under 35 years old. Source of study recruitment was not a serious source of bias. The four groups are relatively evenly distributed across the general categories of medical v. social-service study recruitment sites.

Health status, as it indicates a “need” for services, is one of the key components of actual service utilization. As background, we examined current health status at intake. We would expect health status to influence health and social service utilization by creating a real or perceived “need” for it. If needs are different across groups, differences in utilization may owe more to differences in need than to barriers to access. (See, for example, Abramson and Sanger 2001, which found that differences in health outcomes by service pathway were related more to population differences among the pathways than to the effects of service differences in the pathways.)

Insofar as we can measure it, objective health status at study intake was broadly similar among the four groups at study intake. As measured by the self-reported most recent CD4 cell count (a rough index to overall immune status, which we would expect to be reflected in differences in infections and other disease manifestations), the groups were roughly similar. There was also little difference in how long the subsamples had known about their HIV diagnosis: over 70% of each group had known for 5 or fewer years,

suggesting that the groups had roughly similar periods of time in which to seek out services.

Despite this rough similarity of objective “need” for HIV-related services, there were significant differences in how the sample *perceived* and described their health in general (Table 2). Never users were over twice as likely to rate their overall health as “excellent” or “very good” as were Higher Frequency users; Higher Frequency users were distinctive in the high proportion who acknowledged that their overall health was only “fair” or “poor.” The generally poor objective health status – even apart from HIV -- of regular drug users is well understood from prior research. This analysis merely indicates that they also *perceive* their health as lower. The lower evaluation of personal health in general suggests that *the higher the level of drug use, the greater the actual and/or perceived need for health services.*

**Table 2. Self-rated Overall Health Status, by Drug Use History**

Percent of sample rating health as	Drug use history subsamples (p<.004)				Overall sample N=962
	Never N=245	Past N=469	Lower Freq N=176	Higher Freq N=72	
“Excellent” or “very good”	44%	33%	31%	19%	34%
“Good”	25%	28%	34%	36%	29%
“Fair” or “poor”	31%	39%	35%	44%	37%

If the objective needs of drug users for services are high, and their perception of their general health is only adequate, this suggests that they might be candidates for services. The next series of analyses asks whether different types of cohort members actually *accessed* services.

## **5. DRUG USE PATTERNS AND NEED FOR LOW-THRESHOLD PROGRAM COMPONENTS**

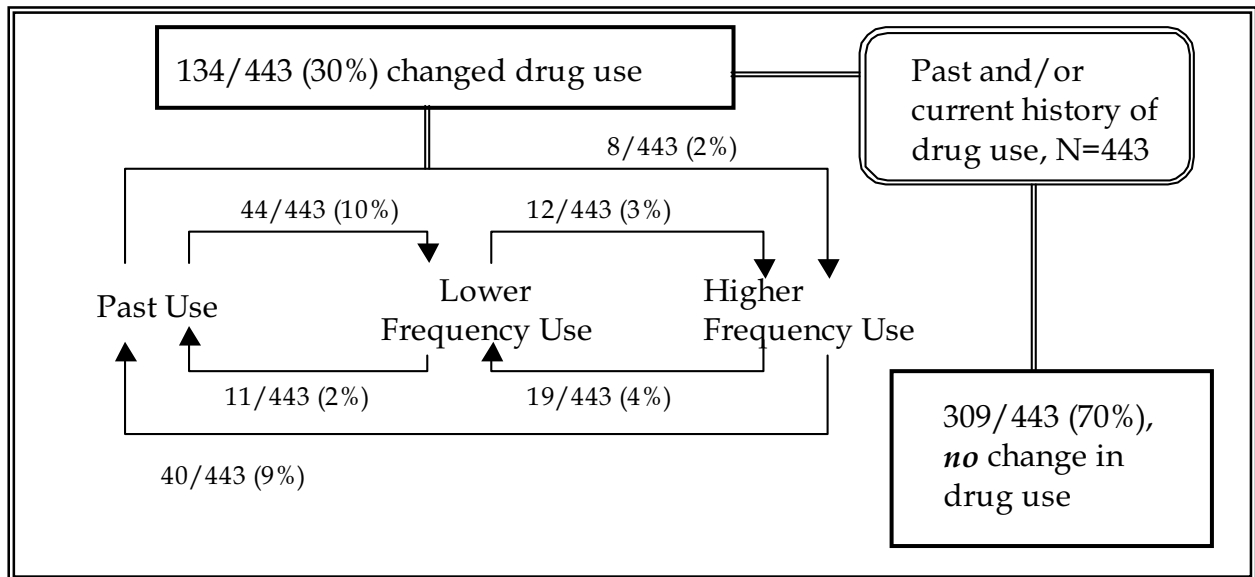
### **5.1. Absence of Requirements for Substance Abstinence**

Despite broadly similar health status and demographic profiles, there are sharp differences in all aspects of recruitment to and utilization of HIV-related and other services, among the three categories with any admitted history of drug use. It is important to understand the relationship of these categories to each other over time, because the concepts of “relapse” and “recovery” have implications for effective service provision.

Substance use is quite common among members of the CHAIN cohort. A previous report (Aidala, Weinberg, Ho 1997) noted that almost three quarters (74%) of the original (1994) CHAIN cohort reported a history of cocaine or crack use, and 43% a history of heroin use. Almost 1/3 reported some use of these drugs or problem drinking within 6 months preceding entrance to the study and baseline interview.

This report estimated that at any point in time, approximately 1/3 of the clients in care were active heroin or crack/cocaine users and/or problem drinkers. (Active users were defined as those who had been continually active since a prior interview as well as those who relapsed from a prior period.) Noting that rates of cessation of drug use in the short term (6-14 months) were relatively low, it concluded that *although the proportion of active substance users in the cohort was relatively constant over time, different individuals made up that proportion, and many individuals shifted over time between use to non-use.*

**Figure 3. Transitions in Drug Use Between Wave 1 and Wave 2 (N=443 with Past and/or Current History of Drug Use)**



Our analysis has similar findings. Drug use is a chronic, relapsing condition. An individual may move between several stages of it over many years. This has major implications for services that are conditioned on being “drug free,” especially for a lengthy period of time, as an individual’s drug-use status changes over time. To show the extent of transition among *all three* major drug-use categories, we examined the changes between Wave 1 (baseline intake) and Wave 2 (first followup interview), 6-9 months later. This analysis was restricted to the 443 who had some past (more than 6 months preceding interview) and/or current (6 months preceding interview) history of drug use, and for whom followup data for Wave 2 was available.

Of the 443 people with some history of drug use at intake and available followup data, *fully 30% had made a change within 6-9 months of re-interview.* The number and percent of those who had been using at intake but had ceased by Wave 2 (51/443, 12%) was almost identical to the number and percentage (52/443, 12%) who had *not* been using in the period preceding intake, but had returned to use by Wave 2.<sup>2</sup> Most of these transitions were in small increments (from Low Frequency to Past use, or High Frequency to Low Frequency), illustrating the gradual pace of many transitions in and out of drug use patterns.

Abstinence vs. non-abstinence is not the only type of change in the population. There is also substantial interchange between segments of the drug-using population, often over relatively brief periods of time. As illustrated in Figure 3, a number of different transitions are possible and represented in the sample. Few people cease higher frequency use overnight, and few move from no use to heavy use without an intervening period of lower frequency use. A lower frequency user may be someone who is slowly cutting down from heavy use, *or* a never-user who is just starting to use. As later analysis will show, there are substantial differences in service utilization patterns between the Lower Frequency and the Higher Frequency users, generally to the disadvantage of the Higher Frequency users.

This means that “using” or “not using” drugs are, for any given individual, potentially transient and temporary states. There is a substantial probability that a person who is abstinent now will be using again within 6 months to a year, while a counterpart who is using may have ceased, at least for the time being. Conditioning services on abstinence, especially long-term abstinence, both serves as an initial barrier to use and encourages service dropout as even clients who are abstinent when they start utilizing the service may not be within a matter of months. A lower-threshold approach which does not demand abstinence as a condition of service is able to attract those who are currently using drugs, as well as provide a “safety net” for those who were abstinent when they entered the service but may have relapsed while enrolled.

## ***5.2. Providing Intake and Assessment Procedures (Through HIV Testing)***

HIV testing is a key aspect of the basic assessment for HIV needs and services. As a diagnostic procedure, HIV testing is the “vestibule” or “funnel” to treatment for HIV, and is often promoted as a means of case-finding and entry to the service system. All CHAIN study participants have by definition been HIV tested at some point. However, that testing can differ on dimensions of why the testing was done, where it was carried out, whether referrals to care were made, and how long before the individual followed

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<sup>2</sup> 40/443 (9%) had shifted from Lower Frequency to Past use, combined with the considerably smaller number, 11/443 (2%) who shifted from High Frequency to Past use, to total 51/443 or 11% of the group had ceased drug use. In the other direction, 44/443 (10%) relapsed from Past to Lower Frequency use; combined with 8/443 (2%) who relapsed from Past to Higher Frequency Use, a total of 52/443 (12%) Past users had relapsed to drug use again.

up on the referrals. All of these may be influenced by drug use patterns, which influence the type of testing available to individuals.

**5.2.1. Reasons for Testing**

The most common reason for being HIV tested, among all categories was, understandably enough, one’s own past risk behavior. Individuals with a drug-use history were significantly more likely to report this than were those without. However, when we examine the *second* most common reason – the recommendation of another person – there are noticeable and significant differences. As the level of drug involvement increases, the proportion that had testing recommended by a *health care provider* decreases. This probably reflects the lower initial levels of access to basic and primary health care among people with frequent drug involvement found by other studies (Weiss, Kluger and McCoy 2000), as well by this report. However, the proportion who were recommended to test by someone *other* than a medical person – such as a case manager or counselor – *rises* as drug involvement increases. This probably reflects the drug users’ lower utilization of primary health care, accompanied by higher exposure to drug treatment and social services where HIV testing is routinely recommended to and sometimes required of, people with drug use histories.

**Table 3. Expressed Reasons for HIV Testing, by Drug Use History**

	Drug use history subsamples				Overall sample N=968	
	Never N=247	Past N=472	Lower	Higher		
			Freq N=145	Freq N=72		
I engaged in risky behaviors, was curious	36%	41%	52%	46%	p<.01	42%
Doctor or other health care provider/counselor recommended it	34%	36%	27%	22%	p<.04	33%
Someone else recommended it	6%	8%	11%	19%	p<.01	9%

**5.2.2. Use of HIV Counseling and Testing Sites**

Besides differences in why participants were tested, there are differences in *where* participants were tested. This question is important because of its connection to the low threshold component of being able to provide linkages and referrals to needed services. Through the facilities and referrals linked to the testing site, the testing site represents a potential set of structural and systemic barriers to referral and followup care, as well as the entrance to the treatment “pathways” detailed in other reports. Although New York

State’s HIV testing protocol lends some standardization to the process, there are still differences across testing-providers, depending on the institutions they are embedded in. Some of these differences – especially the linkages of the testing provider to other services – have implications for enrollment and retention in services after initial diagnosis.

Few participants reported use of the anonymous test site system. Hospitals were the most common test site among all groups; this category probably includes both clinic and inpatient settings, and it probably includes testing at clinics by referral or arrangement from another provider. However, there were significant differences in the utilization of *other* types of test sites, especially private doctors, clinics, and drug treatment or prison testing settings.

**Table 4. HIV Test Site Utilization, by Drug Use History**

	Drug use history subsamples (p<.0001)				Overall sample N=700 *
	Never N=162	Past N=335	Lower Freq N=145	Higher Freq N=58	
Where HIV tested:					
Anonymous test site	9%	6%	8%	2%	7%
Private doctor	15%	9%	7%	3%	10%
Community or public clinic	27%	22%	20%	15%	22%
Hospital	24%	24%	26%	31%	25%
Inpatient hospital	13%	14%	18%	9%	14%
Rehab or prison	3%	21%	19%	36%	18%
Family planning or other	9%	3%	1%	3%	4%

\* Question asked only of original cohort

Reflecting their greater attachment to primary care and more frequent testing recommendation from health care providers, the Never users were significantly more likely to have been tested at private doctors’ offices or in community clinics. The drug users (past or present), on the other hand, were significantly more likely to enter testing through either prison or a drug rehab program. This is strikingly true of the Higher-Frequency users, who are over *10 times* as likely to have been tested in these settings than the Never Users. These differences in test site have two implications.

1. One is for individual *motivation and behavior*. Testing in drug rehabs and prisons, although perhaps officially voluntary, can be effectively involuntary. It is reasonable to suppose that there might be less real interest in being tested, and less follow-through on the results, among people tested in such settings, because of the circumstances surrounding testing. Studies of drug users’ health care utilization have shown that prison-based health care is widely disliked and that

- many drug treatment programs present testing as a routine part of treatment (Weiss, Kluger and McCoy 2000). In either case, individual motivation for testing and followup might be less strong in people tested in these settings.
2. The second implication is for *structural barriers* to treatment. Private physicians and even clinics not only are able to offer better linkages and referrals to medical services, but are also settings in which participants can remain indefinitely. Prisons and drug rehabs are less likely to have an easily accessible and convenient set of referrals available. Perhaps even more important, their limited and finite length of stay, accompanied by distance from residents' homes, presents a major structural barrier to follow-through on linkages, even by those who desire to follow through.

In general, then, as level of drug use increases, there is less likelihood of being tested through referral by the medical system, and more by referral from a social service or other provider. There is also a far higher probability of being tested in an environment which may not provide optimal referral and linkage to further services. Thus, even at the testing stage, higher levels of and more recent drug use are associated with disadvantages in progressing to the next stage, that of referral and linkage to needed treatment.

HIV testing is the most basic type of assessment for HIV needs and services. The higher frequency and more recent drug users are significantly more likely to be tested in settings which offer relatively little continuity of care. The lower threshold programs' component of providing this assessment could contribute to greater continuity of care, especially for this group, by carrying out HIV testing in a setting that was familiar to the individual and to which s/he may return for other needed services, or simply by providing referral and linkage services to those already tested elsewhere.

### ***5.3. Providing Linkages and Referrals to Treatment***

These relative disadvantages that accompany higher levels of drug use are reflected in three other aspects of the process of seeking initial HIV medical care and linkages to other services.

First, drug users (especially Higher Frequency users) were significantly *less* likely to have the advantage of a referral (which usually smoothes the path in social service agencies) and more likely to have sought out and accessed treatment on their own.

Second, consistent with lack of referral, they waited longer after diagnosis to start using HIV medical care. Higher-frequency and more recent drug use was significantly and consistently related to having waited a year or more after initial diagnosis. These findings are consistent with our earlier finding that the heavier and more recent drug users are more likely to have been tested in settings which provide minimal referral and linkage, leaving the infected person to access care independently, and thus delay care. The low-threshold component of relaxed time limits on services speaks directly to this

tendency to greater delay in the heavier drug-using subpopulations, who may be “screened out” of services when time limits are imposed.

**Table 5. Referral Patterns to First HIV Treatment, by Drug Use History**

	Drug use history subsamples				Overall sample N=700 *
	Never N=162	Past N=335	Lower Freq N=145	Higher Freq N=58	
Waited 1 year or more before seeking HIV treatment	9%	12%	15%	25%	p<.01 13%
Was referred for care (rather than went on own)	71%	72%	66%	49%	p<.05 68%

\* Question asked only of original cohort  
\*\* Question asked only of those who got new provider after testing

Third, they initially accessed *different* kinds of settings for HIV medical care. Higher-frequency or more recent drug users were significantly *less* likely to seek their first help from a medical provider or health plan which might offer continuity of care and linkage to primary care. Almost none of the Higher Frequency users sought their first care in such settings. They were far more likely to visit a clinic of some type. All types of drug users were far more likely than Never users to have sought their first care in some type of “other” setting, perhaps clinics associated with treatment programs or correctional institutions, reflecting the greater role of these settings in the testing process.

The greater use of clinics and multi-service settings by drug users may also relate to *reasons* for seeking care. Recognizing the importance of care for one’s health was the leading reason for seeking care reported by all categories. On all the categories of reasons to seek care, there were only trivial differences among drug use categories, with the exception of one. The only one on which the drug use categories differed significantly was that of seeking treatment to “get the benefits or entitlements that people with HIV or AIDS are eligible for.” A higher proportion of all types of drug users reported this as “important” or “somewhat important.” This interest may have been one of the reasons to seek care at designated AIDS centers or other multi-service settings where benefits enrollment and other social services are offered, as opposed to a private medical provider where they are generally not.

**Table 6. Source of First HIV Treatment, by Drug Use History**

	Drug use subsamples (p<.0001)				Overall sample N=654 *
	Never N=152	Past N=319	Lower	Higher	
			Freq N=133	Freq N=50	
Family practice, healthplan, other medical provider	24%	13%	6%	2%	14%
Hospital clinic	45%	55%	58%	72%	54%
Government clinic	22%	13%	16%	8%	15%
Emergency room	4%	1%	2%	0%	2%
Other	5%	18%	17%	18%	15%

\* Asked only of those receiving HIV treatment

**Table 7. Importance of Benefits in Service Enrollment, by Drug Use History**

	Drug use subsamples (p<.001)				Overall sample N=669 *
	Never N=157	Past N=325	Lower	Higher	
			Freq N=136	Freq N=51	
“Get benefits or entitlements” is “important” or “very important”	36%	46%	59%	43%	46%

\* Asked only of original cohort

#### 5.4. Providing Free or Affordable Services

The CHAIN system does not offer any measure of whether agencies offer their services free of charge. We approach this question by examining the ability of the participant to afford care, through type of insurance coverage.

The impact of financial considerations on service utilization is often reflected in the levels and types of insurance. These influence whether care is available at all, and perhaps more important, what choices in care are available. Medicaid and other publicly-funded insurance plans (ADAP, etc.) are by far the largest insurers of medical services for the HIV-infected. However, the secondary sources differ sharply and significantly by drug use type. Even in New York City, where access to Medicaid is relatively broad compared to other cities and states, and financial considerations appear

to play only a modest part in access to HIV services, a substantial proportion (22%) of Higher Frequency users were totally uninsured, a far larger proportion than in the other categories. A Higher Frequency user is over 5 times more likely to be completely uninsured than a Never user, and 5 times less likely to have access to private insurance and the greater range of choices it provides. We can expect this “insurance gap” to widen with changes in public assistance and Medicaid eligibility in recent years.

**Table 8. Insurance Status, by Drug Use History**

	Drug use subsamples (p<.0001)				Overall sample N=968
	Never N=247	Past N=473	Lower Freq N=176	Higher Freq N=72	
Insurance:					
Private	17%	8%	7%	3%	10%
Medicaid or other publicly-funded	66%	81%	78%	71%	83%
None	4%	4%	12%	22%	7%

Differences in insurance status at study intake probably *understate* the differences in insurance when participants were first diagnosed and entered care, as many participants have acquired insurance – especially Medicaid -- in the course of being diagnosed and gaining entitlements, but before entering the CHAIN study. Nonetheless, differences in insurance at study intake illustrate a trend: Private insurance is concentrated among the Never users, totally uninsured status – and the limitations in choice of treatment it entails -- among the Higher Frequency users. One of the components of the lower threshold model – that of helping to gain benefits and providing services inexpensively or free of charge – is directly helpful in improving access for drug-using subpopulations.

## 6. PATTERNS OF SERVICE UTILIZATION

So far, we have shown that a difference in type and history of drug use is significantly related to the HIV testing process: motives for testing and type of test setting both vary significantly. The Higher Frequency drug users are far more likely to have been recommended to have the HIV test by non-medical personnel, and to have been tested in institutional settings (prisons and drug treatment). By their nature, both prisons and drug rehabilitation programs are temporary settings with fixed terms of stay. We would expect that it would be far easier for linkages made through these settings to be broken later, as people are released, move, and have other changes in their lives associated with reintegrating into their communities

We asked what services participants had used in the 6 months preceding entry to the study. Indeed, the more frequent or recent the drug use, the lower proportion had used

a private doctor, dental care provider, other medical services, or alternative medical provider. In contrast, the higher the level of drug use, the more likely respondents were to have used emergency rooms for their care. This finding is consistent with other studies of health care utilization among drug users, and reflects the lack of primary care and other acceptable alternatives to emergency rooms to a large fraction of the HIV+ population. Emergency rooms are a particularly undesirable form of health care utilization both because of their greater cost to the health care system, and because their care is episodic and generally unconnected to sources of ongoing care.

**Table 9. Use of Health Services over 6 Months Preceding Baseline Interview, by Drug Use History**

	Drug use history subsamples				Overall sample N=967	
	Never	Past	Lower Freq	Higher Freq		
	N=247	N=472	N=176	N=72		
Emergency room	32%	40%	39%	50%	p<.03	38%
Private doctor	21%	13%	7%	4%	p<.001	13%
Dental care	42%	48%	39%	26%	p<.003	43%
Other medical practitioners	35%	32%	27%	14%	p<.01	31%
Alternative health services	16%	18%	11%	8%	p<.06	15%

We also asked whether participants had a provider for HIV medical care, routine medical care (vaccinations, check-ups, etc.), case management or assistance in getting services, and mental health services (including peer support groups but excluding specifically drug-related groups such as NA).

There were significantly lower levels of *all* types of provider utilization among those with a history of past or more frequent drug use than among the Never users. The vast majority of the sample report having an HIV medical provider, and the differences among drug use categories are far smaller in this area than for any other provider type. The high proportion using HIV care is not surprising, partly because the sample were recruited from HIV-related services and members were by definition HIV-infected. In addition, previous CHAIN reports have emphasized the relatively higher use of HIV related services than other types of services. What sheds the most light on the relatively high utilization of HIV care among the drug using subsamples is the recent study of drug users’ perceptions of health care (Weiss, Kluger and McCoy 2000). It found that users regarded HIV services far more favorably than any other type of medical service, citing such characteristically low-threshold features as more flexible scheduling and higher levels of personal concern and acceptance than found in other parts of the health care system.

The picture is quite different when we examine use of primary care (defined as a provider who can be used for such services as immunizations and routine check-ups). The drug using subsamples, especially the Higher Frequency users, are significantly less likely (and by a wider margin than in the case of HIV care) to have a primary care provider. This is consistent with prior findings that access to primary care was lower among participants who were non-White, lower income, less educated, in less stable housing, Medicaid-insured rather than privately-insured, and drug users. This is of concern for health status in general as the same study showed that access to primary care was associated with less use of emergency rooms and continuous access to primary care with improvements in self-perceived global health status (Messeri et al. 2000).

The only service type used by a significantly larger proportion of higher-frequency or more recent drug users was *case management*. This is consistent with the earlier findings that drug users are more likely to have been tested in non-medical settings (which might provide social services more routinely), more likely to have initially sought care in multi-purpose settings, more likely to need insurance (and probably other benefits) and more likely to have been concerned with accessing benefits. Thus they are more likely to *both* need and make use of case management services. This is especially the case because they are also significantly less likely to be DASIS clients at study intake.

**Table 10. Use of Health and Social Services in 6 Months Before Study Intake, by Drug Use History**

	Drug use history subsamples					Overall sample N=968
	Never N=247	Past N=472	Lower Freq N=176	Higher Freq N=72		
HIV medical provider	98%	97%	91%	76%	p<.0001	95%
Routine medical provider	96%	91%	81%	65%	p<.0001	88%
Case management	28%	61%	59%	50%	p<.02	64%
Mental health provider	22%	33%	23%	17%	p<.01	28%
Client of DASIS	42%	52%	49%	31%	p<.002	47%

## 7. BARRIERS TO SERVICE UTILIZATION

Not surprisingly and reflecting other studies, higher levels of drug involvement are associated both with greater *perceived* barriers, basically interpersonal in nature, and with greater *objective* barriers to services.

To examine perceived barriers, we asked if at any time in the preceding 6 months respondents had difficulty getting medical and/or social services they needed, because

of various barriers. We categorized a “yes” response to one or more of the questions on medical services barriers, social services barriers, or both types of barriers, as representing perception of a barrier.

For *all* of these perceived barriers, the proportion reporting having experienced them increased systematically as drug use increased.<sup>3</sup> This is true *across all categories* of the typology of service needs and barriers in accessing medical care, developed by Messeri et al. (2000). These barrier types and the corresponding questions we examined, include:

1. **“Logistical.”** These are practical, instrumental, “objective” obstacles, such as transportation or child care. Among “logistical” barriers, we see that inability to find transportation is significantly related to level of drug use, and increases along with level of drug use. Language barriers, financial affordability, and childcare needs were cited by relatively few respondents of any category so are not analyzed further.
2. **“Coordinative.”** These are obstacles involving information, and are expressed as needs for assistance identifying providers, navigating the care system, or securing insurance or referral resources. Once again, we see that expressing these information needs (“not sure where to go”) is modestly, though significantly, associated with higher and more recent drug use. This is understandable when we remember that higher levels of drug use are also associated with lower levels of connection to the medical system, greater use of relatively impersonal and episodic sources of care, and greater interest in and use of, case management.
3. **“Individually-mediated.”** These are individual characteristics (such as substance use or mental health difficulties) that impair the individual’s ability to access services. Most of the remaining barriers we inquired about can be grouped under this heading, for convenience. In fact, any of these questions can be regarded as individually-mediated *or* socially-mediated when substance users are involved. They are *individually*-mediated in the sense that past or current substance use contributes to difficulties at the individual level in dealing with the medical system. We can include the individual’s difficulties in time management and suspicion of providers under this heading. However, these questions are also *socially*-mediated in that the response of the *medical system* to drug users is usually highly negative. We categorize these barriers as “individually-mediated” largely for the sake of convenience, as it is impossible to disentangle how much of the responses reflect individual respondents’ perceptions and how much the reality that they experience. Again, on all of these questions, more recent or more frequent drug use is significantly associated with perception of a barrier.

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<sup>3</sup> Only in the case of a few barriers were these differences statistically significant. We show results for a larger set of barriers, to illustrate that the direction of the differences is consistent, even if not always statistically significant.

The potential complexity of drug use as a barrier is illustrated by three other individually-mediated factors.

- a. The increasing severity of drug use as it becomes more recent and frequent across categories, is reflected by the increasing proportion who have some prior experience in drug treatment.<sup>4</sup> This reinforces the point made earlier about statuses in drug use being relatively transient, as well as points to the existence of a subpopulation which has not been successful in drug treatment. For them, the need to be abstinent or even to enter treatment may present a serious barrier to use of HIV-related services.
  - b. A substantial proportion (over half) of the higher-frequency drug users are *also* potential problem drinkers, reporting alcohol consumption three or more times per week. A co-existing alcohol problem can not only intensify the usual difficulties of care-seeking (keeping appointments, interacting with providers), but can also be a disqualification for certain services and treatments, including some types of drug treatment.
  - c. Finally, impaired mental health functioning is more common among the current drug users, especially the Higher-Frequency users. Using a standardized measure, the Mental Component Summary Scale (MCS) of the MOS SF-36, over 65% of the Higher-Frequency users scored below the cut-point of 42 on the scale. Scores below this cutpoint indicate clinically relevant mental health symptoms, or those that would profit from mental health services. Over 48% of Higher-Frequency users scored below the more stringent cutpoint of 37 that is characteristically found among clinical mental health populations, those with more severe or persistent disorders. Low mental health function has been associated with a number of poor outcomes for HIV-positive people, including difficulties maintaining medication adherence and navigating the services system more generally. (For more extended discussion, see Aidala 1997, Aidala 2000.)
4. **“Socially-mediated.”** These barriers are affected by community or social forces, such as housing supply and accessibility. We examined housing, because of its influence on a number of dimensions of care-seeking and care utilization. The more recent and more frequent the drug use, the less likely are participants to live in a relatively stable housing situation (owning or renting one’s own living quarters), and significantly more likely to be living in types of housing we could classify as unstable or inherently transient (doubling up, AIDS / welfare / drug treatment housing), or abject homelessness (streets, shelters). In prior CHAIN

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<sup>4</sup> We classified this as formal drug treatment, excluding self-help modalities such as NA.

**Table 11. Barriers to Health and Social Services, by Drug Use History**

	Drug use history subsamples				Overall sample N=957
	Never N=244	Past N=469	Lower Freq N=174	Higher Freq N=70	
<b>Logistical:</b>					
◆ Difficult to get transportation	16%	16%	20%	31%	p<.01 18%
<b>Coordinative:</b>					
◆ Didn't know where to go, unsure	15%	18%	19%	24%	ns 18%
<b>Individually-mediated :</b>					
◆ Staff is not good at listening to my problems or needs	14%	20%	21%	23%	ns 19%
◆ Weren't sure the staff would understand my problems	11%	16%	16%	17%	ns 15%
◆ Thought staff was not competent to deal with my problem	11%	16%	16%	19%	ns 15%
◆ Staff are often not polite, are disrespectful or insensitive to my needs	13%	15%	18%	24%	p<.08 15%
◆ Was nervous or afraid of what provider might say	14%	12%	14%	26%	p<.02 14%
◆ Concerned about confidentiality	6%	7%	7%	13%	ns 7%
◆ Low mental health functioning	44%	48%	52%	65%	p<.01 49%
					N=474
◆ Alcohol use within preceding 6 mos.: 3 or more times / week	10%	13%	27%	51%	p<.0001 20%
◆ Past history of drug treatment	5%	66%	65%	86%	p<.0001 57%
<b>Socially-mediated:</b>	Drug use history subsamples				p<.0001)
◆ Current housing	Never N=246	Past N=473	Lower Freq N=176	Higher Freq N=72	Overall sample N=967
Own or rent own place	88%	76%	64%	47%	81%
Doubled up	6%	5%	10%	3%	6%
Welfare, AIDS housing, drug program	5%	16%	16%	25%	14%
Shelters, streets, public places	0%	2%	9%	22%	4%
Other	0%	1%	1%	3%	1%

analysis, unstable housing has been associated with lower levels of appropriate HIV medical care (Abramson et al. 2001), as well as with less timely entry into medical care generally, lower retention in it (Messeri et al. 2000), and more frequent shifting among health care providers and pathways (Abramson and Sanger 2001). Whatever the cause-and-effect relationships between heavy drug use and lack of stable housing, lack of housing poses a much higher barrier to service utilization among the heavier and more frequent drug user subpopulations.

The extent of the barriers posed by drug use, especially among the Higher Frequency users, is shown by the high proportions that have already had some drug treatment. The Higher Frequency users are in fact *more* likely than the other groups to have had prior treatment.

A number of the barriers fall into dimensions of perceived competence and perceived understanding and sympathy on the part of providers. Drug users are no different than the general population in basing much of their satisfaction with medical care on quality of interaction with the providers (Weiss, Kluger and McCoy 2000; Lekas and Aidala 1998). However, people who use drugs face an additional set of barriers to finding competent care and achieving a good professional interaction with providers.

First, the patients' perception of providers' lack of competence or inability to understand their problems is not solely a problem of perception. In fact, drug users have a specific set of health and treatment problems about which providers frequently understand little and for which medical education offers little preparation. This has been noted particularly in the area of pain management (Weiss, Kluger, and McCoy 2000) but also applies to areas such as pharmacological interactions, the role of sedatives, effects of drug withdrawal syndromes, and interactions between multiple medical problems characteristic of drug using populations.

Second and at least equally important, health practitioners usually share the distaste of and stigmatizing attitudes toward drug users that are common in society at large. Drug users' anticipation that they will be treated poorly has considerable foundation. Even former users often suffer from the effects of *stigma*, as it has been found that the stigma associated with a condition often adheres to a person with it long after the condition itself has been cured or ameliorated (Link et al. 1997).

This is the area in which the low-threshold model component of not making services contingent on abstinence is most important. In using such agencies, drug users need not fear being "found out," and can be relatively open about their history and needs without compromising their access to services. Perhaps even more important, the more an agency embraces this stance, the more accepting the staff are likely to be, and thus be more accessible and sympathetic to their drug-using clients. Some clue to how acceptable low-threshold services can be is found when we examine the modest number of respondents (34 Lower Frequency and 38 Higher Frequency users) who admitted to injecting drugs within the preceding 6 months. Almost 50% in each category reported using a syringe exchange to get their syringes. This has implications for providing services to many drug users, as all New York City syringe exchanges also provide a

range of health-related and social services, also available on a very low threshold basis, and can refer to many others.

## 8. SUMMARY AND CONCLUSIONS

This report had examined aspects of HIV-related medical service utilization among four subsamples of the CHAIN sample differentiated by their past and present drug use, or lack of use. The major finding is a pattern of cumulative disadvantages and barriers that are lowest among the Never users, increase among the Past users and Lower Frequency users, and reach their highest prevalence among the Higher Frequency users. All of these barriers are addressed by some component of a low-threshold model of care.

One set of disadvantages relates to the *pathways to care*. Starting from the initial diagnostic HIV testing and continuing through connection to primary care and other non-HIV medical and social services, there is a consistent pattern of cumulative disadvantages in medical and other care associated with respondents' drug use, especially heavier or more chronic drug use. These include undergoing initial testing in settings with less continuity of care, lower levels of referral and follow-up to services manifesting in longer delays to service enrollment, lower levels of insurance coverage, differences in source of HIV treatment. These disadvantages are reflected in *utilization patterns* which include lower levels of access to primary care and greater use of episodic and emergency room care. The sole exceptions to this generalization are enrollment in specifically HIV-related medical care, which is relatively similar across groups and use of case management services, which is more common among the drug using subpopulations, who both require it more and probably have greater access to it.

A second set of disadvantages is found in *barriers to care*. Significantly greater barriers are reported by the heavier and more recent drug users, whether the barriers belong to the logistical (practical), coordinative (information and referral), individually-mediated (personal characteristics) or socially mediated (social or community influenced characteristics) types. Particularly noticeable are differences in a set of barriers related to stigma, discrimination, ignorance, and poor treatment by providers.

Many of these barriers are not amenable to easy solutions, as they combine both individual and systemic aspects. However, all of these barriers are likely to be ameliorated by programs based on elements of the "low threshold" approach to services, which does not demand total abstinence as a condition of services, attempts to remove barriers to affordability, and seeks to render services in as flexible and user-friendly manner as possible. Particularly for the higher-frequency drug users in the HIV-infected population, adoption of this approach is recommended as a way to improve utilization of testing and the services to which it leads.

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