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Top Client Indentified
Unmet Needs for Medical and Social Services

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TOP CLIENT IDENTIFIED UNMET NEEDS FOR MEDICAL AND SOCIAL SERVICES

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I. INTRODUCTION

This report will examine the top unmet needs for medical and social services experienced by persons living with HIV/AIDS in New York City. A number of different approaches to defining “unmet need” will be used. We will focus on client self-reports or perceptions of unmet needs for services that they consider important for their health and overall well-being. In addition, for a number of service areas, we will also examine a number of objective indicators of unmet need for services, regardless of whether or not the individual client shares this judgement. In the areas of drug addiction, for example, or mental illness, part of the condition itself is often a failure to recognize impairment and the utility of treatment or services. For medical care of HIV, clinical standards recognize the importance of early entry into care and ongoing outpatient visits, as well as implementation of treatment protocols that may not be equally known to all individuals living with the virus.

Needs for medical services, for mental health and alcohol or drug treatment services, and for a range of social and support services will be examined to answer the following questions: What are the current “top” unmet needs, that is, service areas in which CHAIN study participants are experiencing problems or difficulties accessing services, and/or areas where problems continue despite service utilization (lack of problem resolution). We will examine both quantitative as well as qualitative, open-ended descriptions of the nature of unmet needs or service gaps experienced by HIV positive clients. For both medical and social service areas, we will assess to what extent the prevalence and nature of respondents’ top unmet needs have changed over time, in the approximately 24 months since baseline interview and most recent (Time 4) survey.

We will analyze differences in patterns of unmet needs by client characteristics and identify the client subgroups among whom service gaps are most common.

Key Findings

- When asked directly, sizeable proportions of CHAIN study participants report some unmet need for medical services - that they did not get, delayed getting or had some problem with medical care in the six months prior to interview. However the proportion of clients who describe unmet needs and problems has declined over time from almost half (49%) of all persons interviewed 49% at baseline to slightly less more then one-third (34%) of those interviewed most recently.

- Almost all CHAIN study participants throughout the study period have had access to medical care in that they consistently report that they have a doctor or other medical person whom they consider in charge of their HIV care, and over 90% report regular outpatient visits.

- However, when we consider the extent to which medical care can be characterized by features associated with good primary care (coordination, comprehensiveness, and access)
we find that 40% do not have such care. Access to antiretroviral drug therapies has been 
increasing but sizeable proportions of the sample (27%) are currently not on any 
combination therapy although their low CD4 T-cell counts indicate they would be candidates 
for initiation of such therapy.

- Overtime, client access to comprehensive primary care appears to have increased and the 
perception of unmet needs for medical services has declined. However, client characteristics 
associated with perception of unmet need for medical care and access to comprehensive 
primary care have remained fairly constant. Minority ethnic status, low income, unstable 
living arrangements, active drug use, and type of insurance decrease the likelihood of access 
to comprehensive primary care.

- In-depth analysis of respondent open-ended discussions of the nature of unmet needs for 
medical care indicates that the predominant theme is one of “quality of care” - clients 
expressed the need for a better quality of medical services, in particular for finding a doctor 
who is caring, understanding and whom they can trust. Relatively few clients report access 
problems other than those associated with limits on care and treatment due to insurance 
restrictions.

- When considering mental health and alcohol and drug (AOD) treatment services, we 
examine both client self-perceptions and more objective measures of unmet need for 
services. Low scores on a standardized measure of mental health functioning indicate likely 
need for mental health services. Approximately 45% of all CHAIN study participants have 
scores in the range indicating clinically relevant symptoms. Of these, only slightly more than 
half are receiving any mental health services indicating a sizeable service gap.

- About 30% of CHAIN respondents are currently using heroin, crack/cocaine, or drinking at 
a level indicative of abuse or dependence. Slightly more than one-half of active drug users 
are receiving any AOD services. Of those who are active users and not receiving any 
treatment, we find considerable treatment readiness; more than half say treatment is 
important to them.

- Almost all (90%) of CHAIN study participants have had to struggle with some unmet need 
for social services, defined as a need that has continued for at least six months without 
resolution. Across all waves of the study, need for housing services and for financial 
assistance have been the top unmet needs faced by the respondents. However, even for 
these most intractable of problems, rates of unmet need have decreased over time. For 
example, at baseline interview, almost half of all persons interviewed reported that they had 
an unmet need for financial assistance compared to 25% at the time of most recent interview 
(approximately 24-30 months later).

- A summary index was created to measure the experience of unmet need for social services 
over the entire study period. Individual client characteristics associated with greater and
more persistent unmet for services are race/ethnicity, low income, housing instability, and active substance involvement. In addition, household composition appears to have an impact on rates of unmet need for social services; respondents with children in the household (more often women) have higher scores on the index.

II. THE CHAIN SURVEY AND DATA

The Columbia School of Public Health is responsible for conducting the CHAIN Project surveys and reporting on findings from the survey data in collaboration with the New York City Department of Health, the Medical and Health Research Association of New York City, Inc. (MHRA) and the Mayor’s Office of AIDS and Policy Coordination. 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 change in physical, mental and social well-being. This information is specifically prepared for the HIV Health and Human Services Planning Council of New York City 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 to equally represent medical care and social service sites that were and were not recipients of Title I grants. At 30 sites, staff contacted a random sample of clients. Clients indicating an interest in participating were contacted by CHAIN staff and interviews arranged. An open enrollment procedure was implemented at the remaining 13 agencies. All eligible clients present on a small number of recruitment days were invited by agency providers and CHAIN staff to participate in the study. Interviews were scheduled with interested clients. A total of 648 individuals recruited from participating agencies completed baseline interviews. This sample was supplemented with 48 interviews conducted with individuals who were outside or only marginally connected to HIV medical and social services (the “unconnected”). 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).

Subsequent interviews were conducted at approximately 6-9 month intervals. At Time 2, we conducted follow-up interviews with 568 participants, at Time 3 with 480, and at Time 4 with 419 participants completed by December, 1997. The most recent total number of interviews completed (N= 420) represents 82% of the overall cohort who have not died or moved away from New York City. Fewer than 3% of participants have refused to participate in the follow-up interviews.

All CHAIN interviews were conducted in person by trained interviewers. Interview topics include sociodemographic characteristics, mental and physical health functioning, access and use of medical and social services and quality of life. At each wave of interviews, study participants were asked a series of questions about specific features of their medical care such as whether their provider offers primary care characterized by coordination (single doctor or medical person “in charge of
overall HIV care”), comprehensiveness (indicated by the provision of “routine check-ups, vaccinations, and medical tests” as well as being a place they could go for “information or advice about a health concern”) and access (whether they can “call up 24 hours a day” their provider, in case of a medical emergency). These features of coordination, comprehensiveness, and access have been established as characteristics of “good” primary care (Flocke et al. 1995) that patients can reliably report upon. We will use this as an indicator of a number of characteristics of primary care that have been shown to be associated with differences on the measure (see CHAIN Report on Primary Care).

Study participants were also asked about any problems or difficulties or need for help or assistance in each of ten service areas (housing, financial matters, food etc), whether or not they sought assistance from an agency or paid provider, and the extent to which problems were resolved or a great deal of progress made toward resolution during the six month prior to interview. Answers to these questions comprise quantitative measures of service need, demand for services, and resolution of problems as perceived by the respondent him or her self. In addition, respondents provided detailed descriptions of unmet needs and problems with medical and social services in response to open-ended questions.

III. FINDINGS

A. UNMET NEED FOR MEDICAL SERVICES

The first analysis will be an examination of client perceptions of unmet needs for medical care. As part of every CHAIN study interview, study participants were asked if at any time in the six months (length of time) since prior interview, “did you delay or not get the assistance you thought you needed” with regard to medical services. They were also asked about the “biggest difficulty” they have had getting the medical care they needed during the same time period. Answers to these questions provide the data for our analysis of top client identified unmet needs for medical services. In addition, we will examine several measures of access to HIV primary care and access to current treatments as a way of comparing self-perceptions with more objective measures typically used to characterize care received.

Indicators of Unmet Need for Medical Services (Table 1)

- Table 1 demonstrates that unmet need for medical care as reported by clients has declined over time. The first thing to notice is that rates of self-report unmet need for medical care are relatively high, especially compared to other indicators of need for medical care also reported in Table 1. However, a clear decreasing trend is evident over time with about half (47-49%) at Time 1 and Time 2 as opposed to 34% at Time 4 interviews stating that they experienced some unmet need for medical care. (Below we examine respondents’ descriptions of perceived unmet needs).

- Table 1 also indicates that across all four waves the overwhelming majority of respondents (over 90%) have access to basic medical care, that is, to a medical provider in charge of their overall HIV care. At time 4, only 1% of the respondents were without a medical provider.
An overwhelming majority, in all four waves of interviews, reported making at least one outpatient visit in the six months prior to the interview. In the most recent round of interviewing, CHAIN study participants reported on average between 7 and 8 outpatient visits since the last interview (6-9 months) indicating that most study participants visit a medical provider approximately once a month (see CHAIN Update Report #12).

The rates of comprehensive primary care have increased over time. Using a measure of “comprehensive primary care” that classifies clients as to whether or not they have care that is coordinated, comprehensive, and accessible on a 24 hr basis vs. medical care lacking one or more of these features, we see that at Time 1, over half of the participants reported lacking medical care that meets this standard. At time 4, the proportion without comprehensive primary care dropped to 40%.

We examined use of antiretroviral drug therapy as another important indicator of access to HIV medical care. Since treatments were only approved for use late in 1995, we compare information from wave 3 and wave 4 interviews only. Sixty percent in wave 3 compared to 39% in wave 4 mentioned that they were not on any antiretroviral drug therapy. Trend analyses not shown here (see Update Report #12) show increasing rates of involvement with treatment regimens involving combination therapy. Nonetheless, we discover that at wave 4, almost one third of the participants who, according to the HHS guideline should be using these medications, are not.

Indicators of Unmet Need for Medical Services by HIV Disease Status (Table 2)

Stage of disease is likely to affect both self-identified needs for medical care and service utilization. However, early entry into care as soon as possible after infection and regular outpatient visits are standards for HIV care. Examining perception of need for services as well as objective indicators of service use by stage of illness can shed some light on the extent to which the service system is responsive to those at earlier as well as later stages of HIV/AIDS.

There are significant differences in self-identified unmet need for medical services at Time 1 by stage of illness with the symptomatic respondents showing the highest rates (63%) compared to the AIDS diagnosed (50%) and the asymptomatic (40%). Differences in perceived unmet need for medical care between the symptomatic and AIDS diagnosed has diminished over time.

Examining the objective indicators of unmet need for medical care, we see the same pattern of sharp differences in the first wave of interviewing by stage of illness. In the first round of interviews, for example, over 1/5 of the respondents who were asymptomatic reported that they did not have a medical provider, and about the same proportion had not a single outpatient visit during the six months prior to interview. This compares to 5-6% of the AIDS diagnosed who did not have regular care.
Nonetheless, the differences by stage of illness decreased dramatically across the waves, not only in having a source of care and regular visits, but also on the indicator of comprehensive care. Sixty-three percent in the first wave compared to 30% in the fourth wave of asymptomatic respondents did not have comprehensive primary care as measured by our three indicators. Symptomatic and AIDS diagnosed respondents also experienced a decrease in the proportion without comprehensive primary care, but the difference was not as pronounced.

By the time of Wave 4 interviewing, there were no statistically significant stage of illness differences in access to basic medical care, or self-perceived unmet need for care. These experiences of CHAIN study participants should alert us to the continued need to facilitate easy and early engagement with care.

Indicators of Unmet Need for Medical Services by Client Characteristics (Table 3)

Table 3 is based on the most recent CHAIN interview data. There are some sociodemographic differences when we examined unmet need as expressed in not having comprehensive primary care and in self-reported unmet need. Minority ethnic status, current drug using, low income, unstable housing arrangement and being uninsured increase the likelihood of not having access to comprehensive primary care.

Table 3 is based on the most recent CHAIN interview data. There are some sociodemographic differences when we examined unmet need as expressed in not having comprehensive primary care and in self-reported unmet need. Minority ethnic status, current drug using, low income, unstable housing arrangement and being uninsured increase the likelihood of not having access to comprehensive primary care.

There are some interesting differences between self-report unmet need for medical care, and lack of basic medical care such as no provider or no regular outpatient visits. It is noteworthy that, white respondents have the lowest rates of unmet need for comprehensive care, and the highest rates of self-reported unmet need when compared to both black and Hispanic study participants. This finding agrees with the other research studies which indicate that race/ethnicity plays a role in verbalizing one’s dissatisfaction with the medical service system, and that whites seem to report more often dissatisfaction or unmet need for services.

Falling into the category of being currently a problem drug user seemed to be associated with the highest rates of not having comprehensive medical care (50%) compared to being categorized as a former problem drug user (37%) or as an individual who never had a drug use problem (31%). However, this same group of current problem drug users has the lowest rate of self-reported unmet need (although the intergroup differences are small), which could point to a reluctance to express the need for services by a stigmatized and often disenfranchised group.

Participants with unstable housing report higher rates of both measures of unmet need for medical services when compared to participants who live in stable housing. Half of the unstably housed respondents self-reported unmet need for medical care compared to less than one third (29%) of those living in stable housing.

Manhattan and Bronx residents reported the highest percentages of not having comprehensive
medical care (46% and 45% respectively) and Staten Island was at the other end of the spectrum with the lowest rate (22%). When analyzing the self-reported unmet need, Brooklyn had the highest rate (44%) and Staten Island the lowest (17%).

The Nature of Unmet Needs for Medical Services Among those who Self-Report Unmet Needs or Problems with Medical Care

To gain a better understanding of the nature of unmet needs among study participants, a sub-sample of cases was selected for more in-depth analysis of qualitative, open-ended discussions of problems and needs for services. We focused on individuals who self-reported an unmet need for medical services, social services, or both and randomly selected 100 cases from among these and examined statements and narrative descriptions they provided when asked about encountering any obstacles while getting or attempting to get services. We also analyzed respondents’ responses to the question: “If you could change one thing about help that is or is not available to persons living with HIV, what would that be?” which provides another perspective to assess the nature of service gaps as perceived by clients. The sample was selected to be proportionally representative of gender, race/ethnic, and risk groups in the larger CHAIN sample. We compared the results of this analysis from the results of content analysis of responses to the same questions provided by CHAIN study participants in their first interviews. This provides the opportunity to examine possible changes over time.

Biggest Difficulty Getting Medical Services (Table 4)

- Content analysis of answers to open-ended questions supports our conclusion that by the time of their fourth CHAIN study interview, the overwhelming majority of study participants seem to have access to basic medical care (regular provider, outpatient visits). However, a significant number of individuals expressed the need for better quality of medical services, in particular, for finding a doctor who is caring, understanding and whom they can trust. In 44 of the 100 cases examined, respondents answered that they did have some unmet medical need. Of these, 30% explained that although they do have a medical provider they lack a “quality” provider. “Making contact with my doctor (is a problem). He has no bedside manners and he is sympathetic.”

- A comparable percentage (27%) answered that they need an HIV doctor or a specialist (gynecologist, dentist) but upon closer examination it was found that more often than not, these were also people who had access to care but were dissatisfied and looking for a different
provider. As one respondent explained, he needs a doctor “who is decent, someone who cares.”

- Another difficulty or problem for clients is quality of the clinic or medical facility - 23% of those who were experiencing difficulties in getting medical services pointed to problems or perceived inadequacies of the place where they got their care. “Provider attitude” (e.g. “nurses are rude”) was named as problematic for clients as well as bureaucratic rigidity (they require the same paperwork over and over) and incompetence (test results got lost).

- Problems of access to care appeared to center around issues with insurance or benefits. While very few respondents in the sample do not have any insurance, several individuals pointed to the lack of coverage for procedures or treatments that they felt they needed as well as administrative delays and errors with insurance payments as problems for them. Two individuals mentioned restrictions associated with managed care as problematic for them. Transportation is also an access problem but named by several individuals. Fewer than one in ten say they don’t know where to go to get the care they need.

- An issue for a subset of respondents is the need for mental health and/or drug treatment services. Only one individual mentioned needing to find a therapist or psychiatrist; the others referred to symptoms and associated distress but, for the most part, did not seek assistance from professional providers. (Unmet need for mental health and drug treatment services will be discussed below).

- Relatively few, 7%, of those who say they did not get care they need were referring to issues relating to medications.

We discovered a difference over time in client open-ended descriptions of unmet need for medical services. In Wave 1 interviews, clients who reported an unmet need for medical care were more likely to refer to a need to find an HIV medical provider or a specialist such as a dermatologist or gynecologist (see CHAIN Baseline Report, Technical Report #9). It appears that, by Wave 4, most of the sample are integrated into the medical care system, however, the quality of services they receive in some instances is not acceptable, according to their own standards. If we combine individuals who describe their unmet needs for medical care as needing a more caring or competent doctor or medical facility, about half of all descriptions of unmet needs for medical services concern issues of quality of care from the patients perspective.

B. UNMET NEED FOR MENTAL HEALTH AND ALCOHOL AND DRUG SERVICES

As stated in the introduction, when considering unmet need for mental health and alcohol and drug (AOD) treatment services, it is important to examine both client self-perceptions and more objective measures of unmet need for services. All CHAIN study participants completed the MOS SF-36, a standardized instrument for measuring physical and mental health functioning. Low scores (below 42.0) on the MCS, or Mental Component Summary Scale, indicate clinically relevant symptoms and likely need for mental health services. In addition, we ask a direct question about experiencing psychological problems or emotional difficulties and the felt need for counseling. Similarly, we use
reports of actual substance use: used heroin, crack/cocaine, or problem drinking during the six months prior to interview, as a measure of need for AOD services. A separate set of questions asks about perceived problems associated with substance use and how important it is now for the respondent receive treatment for AOD problems.

**Indicators of Unmet Need for Mental Health and AOD Services (Table 5)**

- The first thing to note is that, in all four waves, the percentages of CHAIN study participants who have scores on the mental health measure indicating clinically relevant symptoms are relatively high. Unlike the situation with medical care, there are no drastic shifts over time in the proportion of those with likely need who are receiving services. In all study waves, only slightly more than half of clients with low scores are receiving any mental health services indicating a unmet need for these services.

- Among those with low scores who are not receiving any services, the great majority (78-88%) do not perceive that they have any psychological problem or need for services.

- Rates of active substance use have gone down slightly over the study period (34% to 28%). At each wave of interviewing, slightly more than one-half of these are receiving any AOD services. However, in contrast to the relationship between what might be considered objective vs self-perceived need for services, among active drug users who are not receiving any treatment, we find considerable treatment readiness. More than half say treatment is important to them. This rate is high in comparison to general samples of substance users.

**Intergroup differences in unmet need for mental health services and AOD services**

The interested reader can refer to several prior CHAIN study reports for more detailed investigation of inter-group differences in unmet need for mental health services and entry into mental health care (see e.g. Update Report #9). Similarly, two prior reports on need for and utilization of AOD services are available (e.g. CHAIN Update Report #8). Findings will be summarized here.

- Race/ethnicity and insurance status are the strongest predictors of unmet need for mental health services. At time 1, Blacks and Latinos with low scores are less likely than white respondents to be receiving any type of mental health treatment. Race/ethnic differences in differential utilization of services diminished somewhat over time (data not shown).

- Respondents with low mental health scores who had private insurance or other public (primarily Medicare) were more likely than Medicaid or those with no insurance to access mental health care. An important over time difference is that at baseline, 24% of individuals with low mental health scores and no insurance were nonetheless receiving some type of treatment. Fewer persons are without insurance at the present time but none of the 9 individuals with mental health symptoms but no insurance are receiving any treatment (data
not shown).

- Insurance status is also associated with higher rates of unmet need for AOD services, but here, the only differential is between those who have no insurance and everyone else, and there are no differences over time in the relationship between insurance and access to treatment. Lack of insurance appears to be a barrier to accessing AOD services, even for those who want help (data not shown).

- In the most recent wave of interviewing, males were more likely than females to access AOD services. Respondents who are homeless or precariously housed are less likely than those with stable housing to be in AOD treatment despite higher rates of substance involvement. The drug use history is also associated with differences in rates of treatment. Those who are primarily crack/cocaine users are less likely than heroin dominant users to remain outside of treatment (data not shown).

- Prior differences by borough appear to have diminished over time. In the baseline survey, a greater proportion of drug users living in Manhattan were not in treatment (22%) compared to their counterparts in the other boroughs. At time 4, there are no significant differences between boroughs.

In subsequent tables, we will examine individuals who self-report need for mental health or AOD services, regardless of their scores on the “objective” measures.

**Unmet Needs for Alcohol or Drug Services**

The problem of client and provider under recognition of the need for mental health services and other factors that help us understand the patterns of unmet need for mental health care have been addressed in several prior CHAIN Study Reports (see e.g. CHAIN report #16; CHAIN Update Report #9). As discussed in these reports, use of HIV-specific mental health services appear very low in comparison to likely need, and client recognition of need for services appears to be a major contributing factor. However, screening for mental health problems is not routinely done by HIV providers. It is likely that the limitations of the current service delivery system interacts with client attitudes and apprehensions to place serious barriers to the utilization of mental health services among those who need them.

To better understand the patterns of unmet need for alcohol and drug treatment, we undertook a careful examination of CHAIN Study Participants who are currently problem drinkers and/or problem drug users who mention that alcohol/drug treatment is important to them, but are not receiving any

- A content analysis of Wave 1 and Wave 4 interviews with problem drinkers and/or problem drug users revealed four possible reasons for not receiving alcohol/drug treatment services despite considering such treatment important: disenchantment with treatment programs, facing overwhelming and interconnected social problems, not having a case manager which
could be an indicator of either lack of access to case management or resistance to case management based upon alienation from service institutions, and being distrustful of service providers.

- By the time of their first CHAIN study interview, most of the problem alcohol/drug users have had some experience with AOD treatment and quite a few reported being dissatisfied with the type of assistance they had received. Respondents who were previously enrolled in methadone maintenance programs reported that these programs did not offer counseling which they considered an integral part of drug treatment. “Just come in, drink methadone, and that is it” was how one participant recalled his visits to a methadone program and went on to complain about the lack of caring counselors and support meetings. Others attributed their reluctance to seek treatment to prior negative experiences with “unconcerned” alcohol/drug counselors, regardless of the type of drug treatment program they attended. Like with medical providers, alcohol/drug counselors were evaluated based on whether they were thought of as “caring” and “understanding”: “My counselor seems unconcerned, it is as though I am talking to myself,” one respondent characteristically explained.

- Another group of participants who reported their prior experience with treatment programs as a reason for currently avoiding treatment were those who have been in short term detoxification programs and questioned the effectiveness of solely physical detoxification without counseling and relapse prevention. “I felt they didn’t do anything for me except get the drugs out of my system, no meetings or groups,” one respondent stated, while another current drug user described his cycling in and out of detoxification clinics and explained how futile this had been for his drug addiction recovery.

- Encountering a variety of pressing social problems constitutes another reason for not receiving AOD treatment despite considering it important. An analysis of the open-ended statements of problem alcohol/drug users who are not in treatment revealed that many are facing a host of serious social problems, such as, the lack of adequate and affordable housing, and the lack of income to cover their basic necessities. It appears that these respondents who are in need of AOD treatment although they acknowledge the importance of alcohol/drug treatment they tend to regard their other needs for services as more pressing. For example, a mother who is a problem alcohol drinker who is not receiving treatment described her efforts to ensure guardianship for her three young children and it appears that this task constitutes her priority as opposed to participating in an alcohol treatment program. Similarly, a participant who has no place to live and is temporarily “doubled up” with a relative considers his homelessness as his number one priority and it seems that AOD treatment is of secondary importance.

- Quite a few of the problem alcohol/drug users who recognize the importance of treatment but are not receiving any reported not having a case manager. A suggestion can be made that lacking a case manager is an indicator of being alienated from the service delivery system in general. A caveat must be made, that not having a case manager could be the result of being a problem alcohol/drug user not in treatment and not the cause. Nevertheless, it seems that the lack of a case manager in combination with the lack of trust toward the service system constitutes a reason for abstaining from treatment. Other CHAIN study investigations have
found that have a case manager is strongly associated with accessing professional drug treatment services (CHAIN Update Report #8).

UNMET NEEDS: SOCIAL SERVICES

Table 8

Table 8 is a summary table that presents self-reported need for services and lack of problem resolution in 11 different service areas. The first column shows the percent of all CHAIN Study participants who reported a problem or need for service in the area of AOD services, financial need, housing, psychological or emotional problems, etc. The second column shows the percent among those with a self-defined need for services who actually got their problem resolved. The final column shows the rate of unmet need among the entire CHAIN sample (Time 1: N=700; Time 4: N=420).

- Fewer than 10% of all CHAIN study participants have not had to struggle with some unmet need for social services, defined as a need that has continued for at least six months without resolution.

- In all study waves, the top unmet service needs have been for financial assistance, housing, and AOD services. At baseline survey, 46% of respondents had a financial problem and the vast majority of them (93%) did not see their problem resolved nor a great deal of progress toward resolution. Thus 39% of the entire sample had a problem with financial support that was not resolved within the six month study period.

- The percentage of clients interviewed at Time 4 who reported a need for housing assistance was lower than baseline rates (26% compared to 38%), and rates of problem resolution were higher, but housing is still the top unmet need. This finding is consistent with what we know from qualitative data sources.

- A simple summary scale adding together all the areas of service need described by the client is presented at the bottom of the table, along with an index of the total number of service areas for which the client received no problem resolution. These summary indices also indicate an aggregate reduction in unmet needs over time. A score of 2.27 indicates that the average CHAIN study participant had difficulties or need for services in more than two service areas. The second score, 1.97, shows the average number of service areas with unresolved problems.

Figure 1 & Figure 2

- Fig 1 and Fig 2 show the general downward trend of unmet need for services over the course
of the study period. The sharpest decline appears to be in the area of financial assistance; over time, fewer clients have a need for assistance, and a greater proportion of those with need get assistance. In other analyses not shown here, we determined that for several of the service areas with high rates of unmet need (financial assistance, housing) problems were not easily resolved but persistence in attempting to secure help on the part of client and/or case manager, along with sheer time in the service system, contribute to eventual problem resolution. It is also the case that with time, clients advance in their stage of illness and become eligible for more services when AIDS diagnosed.

Table 9
- The trend line showing diminishing of unmet need for services over time presents aggregate trends. We also need to examine persistence or diminishing of needs within the same individual. Again we see that need for financial assistance, and housing are the most common, and most persistence of unmet needs experienced by persons living with HIV in New York. Two-thirds of all clients needed financial assistance at least one interview period, and over half had a housing problem at least once and for almost half of these, their problem was present during at least two interview periods suggesting persistence of the problem for at least 12 months.

Table 10
- A summary index of unmet need for social services was created: additive scale scoring one point for each service area (up to 12) for each interview (up to 4) during which the client reports a problem or service need but no resolution of problem during the six months prior to interview. Individual client characteristics associated with greater and more persistent unmet need for services are race/ethnicity, low income, housing instability, and substance use. In addition, household composition appears to have an impact on rates of unmet need for social services; respondents with children in the household (more often women) and those living alone have higher scores on the index than other respondents.

Table 11
- We examined several data sources in the attempt to better understand reasons for unmet need for services, especially persistence of need over time. It is important for planning purposes to understand what portion of unmet need results from access problems - clients with need do not utilize services - and what part from ineffective services - clients seek assistance but the help available does not resolve all difficulties.
- In Table 11 we present a summary of problems of access and problems of resolution of social service needs among clients interviewed at Time 1 and most recently at Time 4. We can see there are relatively high rates of both problems of access, failure to use-agency based or other professional services, and problems with ineffectiveness or difficulties of problem resolution.
For service areas such as transportation, needing clothing or household items, employment services, close to one-half of those who had the problem did not seek agency assistance.

- An equally common, and in some service areas, more common problem contributing to unmet needs for services appears to be lack of problem resolution. Rates of problem resolution are uniformly low across all service areas examined. About half of all clients who seek assistance with a service need report that no progress or only little progress toward problem resolution is made within the six month reporting period.

- There appears to be some improvement in effectiveness in problem resolution over the three years of the study period (10/95 - 9/97), but not wide differences. For example, 53% of those who sought assistance with financial problems reported no resolution or only a little progress toward resolving their needs at time 1 interview. The proportion with no resolution dropped to 45% during the fourth wave.

- “Don’t know where to go” was the most common reason given by respondents who experienced a problem but did not seek services or assistance from a paid provider. When these answers were examined more closely they included people who felt that they were not eligible for the services they knew about, as well as people who had tried to get help but given up and don’t know where to go beyond where they have already attempted to secure assistance.

- Another possible barrier to seeking care is perceived provider attitude: the client reports that people at the clinic or agency are rude or disrespectful, not good at listening, or do not understand my problems. This is a theme that has emerged from a number of data sources and we see it here also.

Table 12

- We again examined answers to a check list type of question asking respondents to check off reasons they might have delayed or not gotten social services they might have needed. We compared the obstacles facing respondents in wave 1 and 4 and we found a lessening of transportation problems and of not knowing where to go for services as reasons for delaying or not getting assistance. For example, 31% of respondents in wave 1 mentioned transportation as a barrier and currently 15% affirm this as a barrier to care.

- The respondents’ perceptions about service providers attitudes toward them appears to play a role in seeking or not seeking services from an agency for social service needs, as well as perceiving problems with assistance received. In some instances respondents have explicit experiences to describe; in other cases, there appears to be general apprehension about social service personnel, perhaps based upon experiences with agency personnel prior to becoming HIV positive (e.g. at welfare offices, unemployment offices, etc).

**Unmet Needs for Social Services**
Biggest Difficulty Getting Social Services (Table 11)

As discussed earlier, we also reviewed 100 cases randomly selected from all the respondents interviewed in Wave 4 and conducted an in-depth analysis of the statements study participants made when asked about unmet needs and barriers encountered while getting or attempting to get both medical and social services.

- The overwhelming majority, that is, 72% of the 100 respondents whose statements were analyzed mentioned some unmet social service need or problems with getting services, at the fourth round of interviews. Similarly to the quantitative analysis just presented, housing, problems with entitlements, and financial issues were the three areas most frequently mentioned by study participants as problematic in the open-ended discussions of need for services.

- Forty seven percent of the 72 respondents who mentioned any difficulty with social services reported facing a housing problem. When discussing their housing problems study participants explained that they need to move to another apartment, that they need a more affordable housing or rental assistance, or that they live in poor quality apartments, “Finding a nice and affordable apartment” is a characteristic request made by respondents.

- Problems with entitlements were mentioned by more than one fifth (22%) of the 72 individuals who described any difficulties with social services. These respondents recounted instances of being “caught into the bureaucracy” of both public and private agencies, or discussed the obstacles they faced when applying for, getting and keeping their benefits. “Just getting someone to help me or to find out what to do (is a problem)”, was how one man talked about experience of being lost into the service system. “Not being sick enough to qualify for assistance” was another concern expressed by a number of clients.

- The need for more financial assistance was an issue for 17% of these 72 respondents. Their open-ended statements indicated that lack of funds influences the quality of their nutrition, transportation to medical appointments, and getting job training. As the respondents’ narratives demonstrate these three areas of problems are interrelated, since intractable problems with entitlements result in financial problems and/or housing problems.

How to Improve the HIV Service System: From the Clients’ Perspective (Table 12)

To complement our understanding of unmet need we analyzed the answers respondents gave when asked: “If you could change one thing about help that is or is not available to persons living with HIV, what would that be?” and included the findings in this last part of the report.

- Expanding housing opportunities was the request most frequently mentioned. Thirty percent of the 89 respondents who provided an answer to the “change” question asked for a wider
housing selection, in terms of location and price, and commented on the lack of quality housing for HIV positive individuals. “There are so many empty apartments in the city, but I am unable to get a place” was how one client who lives in an SRO put it, while another spoke about delays in getting housing “Try to give housing to those with HIV earlier and not when they are on the brink of death.” Clients even suggested ways of securing housing for HIV positive individuals. As one respondent said: “We could help the communities by renovating abandoned buildings.”

- Twenty four percent of the 89 respondents requested an increase in financial support and described how the lack of money affects their lives. “It is impossible to live on the amount of money we receive” one client mentioned, while another explained that more money is needed for basic necessities such as “utilities and clothing.”

- It is noteworthy, that an expansion of HIV/AIDS information and education was requested by 18% of the respondents who answered the “change” question. Specifically, respondents asked for more education targeting HIV positive people, their providers and the larger public. Clients felt that wider dissemination of information on HIV/AIDS will lessen the public’s fear of the disease and will decrease stigmatization and discrimination still associated with the disease. “I would change the way people think and act toward people who are HIV positive and make them more sensitive towards people’s feelings” one respondent characteristically said.