

**CHAIN TECHNICAL REPORT #15**  
**Columbia School of Public Health**  
**June 26, 1996**

**ACCESSING MEDICAL AND SOCIAL SERVICES:  
BARRIERS AND STRATEGIES FOR IMPROVING HIV CARE INFRASTRUCTURE**

**Prepared by:**

**Lyndon Haviland, MPH**  
**Helen-Maria Lekas, MPhil**  
**Gregg Weinberg, MA**  
**Peter Messeri, Ph.D.**

**Peter Messeri, PhD, Principal Investigator**  
**Cheryl Heaton, DrPH, Co-Principal Investigator**  
**Angela Aidala, PhD, Co-Investigator and Field Director**

This research was supported by grant numbers BRH890015-05 and BRX620002-95 from the U.S. Health Resources and Service Administration (HRSA). This grant is funded through Title I of the Ryan White Comprehensive AIDS Resources Emergency Act of 1990 through the New York City Department of Health to the Medical and Health Research Association of New York City, Inc. Its contents are solely the responsibility of the Columbia University School of Public Health and do not necessarily represent the official views of the funders.

TABLE OF CONTENTS

EXECUTIVE SUMMARY ..... 1

I. INTRODUCTION ..... 3

II. METHODS ..... 3

III. BARRIERS TO MEDICAL SERVICES ..... 6

IV. BARRIERS TO SOCIAL SERVICES ..... 9

V. PREVALENCE AND RESOLUTION OF SOCIAL SERVICE PROBLEMS ..... 10

VI. GENERAL PROBLEM SOLVING STRATEGIES ..... 17

VII. COMMUNITY LEVEL ANALYSIS: INTER-AGENCY LINKAGES ..... 17

VIII. CONCLUSION ..... 20

## **EXECUTIVE SUMMARY**

The infrastructure study is one of a series of analyses being conducted by the Community Health Advisory and Information Network (CHAIN) Project of Columbia School of Public Health for the work groups of the Ryan White Care Act Title I Health and Human Services Planning Council. This study reports on the obstacles encountered by persons living with HIV when they attempt to access the health and social services delivery system. The experiences of providers of medical and social services to the HIV-positive population are also incorporated into this analysis. The infrastructure report is based on data from a cohort of 698 persons living with HIV (CHAIN Client study) and on additional data from the Personnel Needs Study (PNS), a study also funded as part of the Ryan White Title I Evaluation consisting of in-depth interviews with providers working in HIV/AIDS care in New York City.

As documented in other technical reports available from the CHAIN project, participants report moderate to high levels of satisfaction with the continuum of services available to them in New York City. However, people living with HIV negotiate a complicated system of entitlements and services to address their medical and social service needs. Although most respondents are satisfied with the HIV care system, this report compiles qualitative comments about problems with the system of care that point toward areas of improvement and suggestions for strengthening it.

### **Key Findings**

- The majority of clients are satisfied with the medical and social services they are receiving. 73% of those connected to the service delivery system reported complete satisfaction with their primary medical provider, while 76% reported complete satisfaction with their primary case manager.
- Among all participants (N=698), the most frequently mentioned difficulties in obtaining medical care were delays in getting an appointment (21%) transportation (21%), fear of what one's doctor/service provider might say about one's health status or entitlement to assistance (16%), inattentive staff (14%) and cost (13%). The major barriers to social services were uncertainty as to where to find services (18%), transportation (15%), staff inattentiveness (15%) and staff's lack of understanding (12%).
- Other service delivery issues participants tended to report were delays in getting an appointment with a social service provider, difficulties with Medicaid and other types of insurance coverage, problems with the quality of medical care, bureaucratic errors attributed to incompetent and inattentive staff, and fragmentation of the social services delivery system.
- Finances and housing are the most common problems for which participants require the

## **CHAIN TECHNICAL REPORT #15 -INFRASTRUCTURE - June 20, 1996**

---

help of social service agencies. Out of 298 participants who experienced a financial difficulty only 14% reported having their problems resolved or making a great deal of progress toward resolution, whereas out of 248 reporting a housing difficulty 23% reported resolution or a great deal of progress.

- Problem resolution is not necessarily tied to client satisfaction with services rendered in most social service settings. Many CHAIN participants whose problems were far from resolved were quite satisfied with the received services based on the polite and caring manner with which they were treated by the staff.
- Some participants viewed the system of care as highly fragmented. They wished to have providers who were knowledgeable about a broad range of services and could help them to navigate through the maze of agencies and act as forceful advocates on their behalf when attempting to obtain services and entitlements.

## **I. INTRODUCTION**

Understanding barriers to accessing medical and social services is critical in the planning and implementation of HIV/AIDS services designed to meet the needs of the HIV infected population in New York City. This report will provide information on the most prevalent obstacles people face when they attempt to access services and on the most successful strategies in overcoming these barriers. We will analyze the relationship between participants' sociodemographic characteristics and the existence of barriers. We will also explore whether there exists an association between barriers to care and the type of agency providing assistance. By looking at the linkages and referrals among different agencies, we will attempt to determine the existence and efficiency of an interorganizational care system offering services to the HIV-positive population in New York City. We will conclude this report with the recommendations made by clients and providers that might help to overcome the barriers to the provision of health and social services.

## **II. METHODS**

### **Study Participants**

The infrastructure report is based on data from two different studies, the CHAIN Client Study (CCS) and the CHAIN Personnel Needs Study (PNS), both funded by the Ryan White Title I Evaluation. The CHAIN Client Study is intended to provide a profile of the need for, utilization and impact of the HIV health and social services system in New York City from the perspective of persons living with HIV. Data for the present analysis were obtained from the first round of interviews, conducted between October 1994 and August 1995. Participants conveyed information on their encounters with service providers and their physical, mental and social well being. Study participants are being re-interviewed at approximately six- month intervals.

The participants in the CHAIN Client Study are broadly representative of all persons living with HIV in New York City. They were recruited in one of four ways. The largest number, 390, were selected through a two-stage random sampling process in which 30 HIV health and social service agencies were selected at random from a list of about 300 providers in New York City. With assistance from the CHAIN project staff, agency personnel contacted a random sample of their clients, who had given permission for the contact, to ask if they would participate. Another 258 individuals were recruited through an open enrollment process at 8 agencies; all persons who visited the clinic or agency on a specific day during a limited time period were invited to join the study. The random selection and sequential recruitment strategies were intended to minimize the tendency of agencies to refer their most satisfied and/or easier to reach clients.

A smaller group of 50 individuals who had minimal or no connection to HIV service providers are also included in this study. Persons eligible for the "unconnected" sample had to be aware of their HIV positive status for at least three months, did not have a regular source of medical care, and were not receiving HIV case management services. To recruit respondents outside of HIV

## **CHAIN TECHNICAL REPORT #15 -INFRASTRUCTURE - June 20, 1996**

---

care institutions, the research team utilized chain referral or acquaintance sampling and street outreach efforts. Unconnected participants were referred by participants in the agency sample who were asked to identify and then contact acquaintances of theirs who they believed were not currently in services. Unconnected participants were also recruited through outreach efforts. CHAIN staff accompanied street outreach workers from several AIDS service organizations who through their work came into contact with individuals known to be HIV positive but were not receiving services. Persons who were reached through either the acquaintance or outreach procedures completed a screener questionnaire to confirm their eligibility before completing the full interview. (The interested reader is directed to CHAIN Technical Reports #7R and #9 for detailed information on sample design and characteristics of study participants)

Interview data on experiences with accessing medical and social services were collected through questions with structured response (Did you experience...? Yes or No) and amplified through questions with open ended answers (Describe the problem you experienced). Open ended questions were a rich source of information on infrastructure issues. Open-ended questions give participants the opportunity to describe in their own words and categorize the problems they experience in navigating the medical and social service system in New York City. It permits them to illustrate the barriers to care they confront and how they overcome these barriers.

Abstracting and organizing qualitative data is quite time consuming. Therefore, in this study we have analyzed the answers to open-ended questions for about half the sample. Open-ended responses were abstracted for the first 300 completed interviews as well as all 41 unconnected participants who had no regular source of medical care or case manager. We believe the open ended responses for this sample are indications of likely responses for all CHAIN participants. This group encompasses the full range of participants in the cohort. A check on the open-ended answers for a small number of the last participants to be interviewed found similar responses to those for the first 300.

Data on infrastructure are also presented from the provider perspective. As part of a study of HIV personnel needs, in-depth interviews were conducted with 86 randomly sampled providers from 29 randomly sampled HIV/AIDS service agencies located throughout New York City. The "Personnel Needs Study" analyzes the stresses and satisfactions experienced by health care and social service providers working in HIV/AIDS services, and moreover, the obstacles confronting these providers in serving their HIV-positive clients. Data from the Personnel Needs Study (PNS) were used in the analysis of the inter-organizational links among different agencies and in the section of recommendations made for improving the quality of care. (The interested reader is directed to CHAIN Technical Report #6 for information on sample design and characteristics of personnel need study providers)

**Measuring Barriers to Services:**

Two complimentary approaches were taken to eliciting information on barriers to services: first, a structured check list of potential barriers to care, and second, open-ended questions eliciting qualitative responses. The “predefined” list of barriers included: (1) *language*, (2) *cost*, (3) *violation of confidentiality*, (4) *staff incompetence*, (5) *not knowing where to go for services*, (6) *transportation*, (7) *staff disrespect*, (8) *staff lack of understanding*, (9) *staff not listening to their client’s problems*, (10) *lack of child care*, and (11) *being nervous or afraid of what one’s provider might say about one’s health or social service needs*. A quantitative analysis is based on the frequency with which participants say they experienced each type of barriers to medical and social assistance.

*Quantifying Barriers to Services*

We used some of the above predefined barriers to create a *provider attitude* measure designed to capture *perceived negative aspects of a health or social service provider’s attitude towards the clients* that may have impeded clients from getting the assistance they felt they needed. Participants were asked if at any time in the last six months they had delayed or not gotten the medical and/or social service assistance they thought they needed because:

- a. They *didn’t trust the provider* to be confidential about their HIV status
- b. *The staff at the office or clinic are often not polite*, are disrespectful, or are insensitive to their needs
- c. They *weren’t sure that the staff at the office or clinic would understand* their problems
- d. They felt that the *staff is not good at listening* to their problems

A participant is considered to have encountered a provider with a negative attitude if he or she answered “yes” to any of the above questions.

*Qualitative Responses: Participant defined Barriers to Services*

We also asked participants to provide their own definitions of a barrier by asking them what they perceived as “*the biggest difficulty they have encountered in getting medical care and/or assistance in resolving any of their non-medical problems.*” Participants had a further opportunity to define a barrier by identifying, *any obstacle that led to the delay of an appointment with a medical and/or social service provider*. We analyzed these self-reported barriers for the subsample of 341 participants which we defined earlier. Wherever appropriate, we supplemented this qualitative data on self-defined barriers with reasons participants gave for not seeking services or why problems with the service delivery system were not resolved. We also reviewed the participants’ responses regarding improvement of the HIV care delivery system both for insights regarding barriers they may have experienced and for suggestions they make for transcending these barriers and enhancing the HIV services. Specifically, we asked participants “*If you could change one thing that is or is not available to persons living with HIV, what would that be?*”

### III. BARRIERS TO MEDICAL SERVICES

This section surveys the type of difficulties CHAIN participants encountered in obtaining medical services during the six months that preceded baseline interviews. We begin with a quantitative overview of the frequency with which participants say they have experienced eleven “barriers to care” predefined in the interview schedule. We then summarize recurrent themes that emerge from responses to open-ended questions when participants were asked to describe barriers to care in “their own words”.

Tables 1 through 7 show the percentage of participants by major sub-groups that experienced each of the eleven barriers to medical services. Taken one at a time, the experience of barriers are reported at relatively low frequencies. At most, little more than 20% of the entire cohort of 698 participants reported experiencing any single barrier, and all but two barriers are reported by fewer than 15% participants. In descending order, the most frequently mentioned obstacles to getting medical services were problems with transportation, being nervous or afraid about what a provider might say, staff inattentiveness, and cost. About 20% of the participants mentioned one or more of the four “provider attitude” barriers. There is variation by borough of residence in the percentage of participants experiencing transportation as a barrier in accessing medical services: Staten Island (29%), Brooklyn (26%), Bronx (23%), Manhattan (15%), and Queens (13%).

#### **Barriers to Medical Services**

Total sample: 698

#### Most Frequent Barriers Experienced:

- Transportation: 21%
- Nervous of Afraid: 16%
- Staff didn't listen: 14%
- Cost: 13%
- Staff lacked understanding: 12%
- Didn't know where to go: 12%

When we compared participants connected to services with those who are unconnected, not surprisingly, we found that the latter were more likely to encounter barriers to medical care. Although the frequency with which unconnected participants report barriers are substantially higher, the rank ordering of barriers is similar for both the unconnected and those connected to services. The unconnected reported transportation (29%) being nervous or afraid about what a provider might say (28%) as the most frequent barriers (compared to 21% and 15% respectively for those connected

to services). Furthermore, relatively high percentages of unconnected participants reported not knowing where to go for medical services and encountering negative provider attitudes (Table 1).

There are only small differences between men and women. Women are somewhat more likely to have transportation problems than men, whereas men are slightly more likely to report cost as an obstacle to care when compared to women (see Table 2).

There are some interesting racial/ethnic differences in barriers to medical services (Table 3). Whites are three times more likely to report cost as a barrier to medical care (31%) when compared

## CHAIN TECHNICAL REPORT #15 -INFRASTRUCTURE - June 20, 1996

to Latinos (10%) or blacks (8%). Latinos and blacks are more likely than whites to encounter transportation problems. Whites are more likely to complain about medical staff incompetence and insensitivity when compared to blacks and Latinos. When the provider attitude barriers are combined, 29% of whites complain about staff attitudes compared to 19% of blacks and 23% of Latinos (Combined Percent not shown).

When participants are classified by risk exposure group, *men who have sex with men* are twice as likely as the *problem drug users* and those who belong to the category of *heterosexual & other* to mention cost as an obstacle to medical care (Table 4). Differences are small for all other barriers.

As individuals move from an *asymptomatic to a symptomatic stage* they become increasingly more nervous/afraid about what their medical provider might say and, more importantly, this fear becomes an obstacle to getting the medical care they need (see Table 5). Individuals who are symptomatic reported the highest rates of staff inattentiveness, and lack of understanding compared to those who are asymptomatic or who have AIDS. When provider attitude barriers are combined, 27% of symptomatic participants report such complaints compared to 23% of participants with AIDS and 16% of asymptomatic participants.

Persons with income below \$10,000 are twice as likely as those with income above \$10,000 to report transportation as a barrier to accessing medical services (26% versus 13%). In other respects, including the cost of services, income does not make a difference in reported barriers to services (Table 6).

The small percentage of participants without either public or private insurance coverage (7%) generally reported more barriers to care (see Table 7). Not unexpectedly, the largest difference between the insured and uninsured was cost. However, uninsured status was also associated with a higher frequency of reports of not knowing where to go and transportation difficulties. There were also some noteworthy differences between privately and publicly insured participants. Those with private insurance were twice as likely as those with public insurance (19% vs. 10%) to report cost as a barrier. On the other hand transportation was much more of an issue for publicly insured than privately insured individuals.

An in-depth qualitative analysis of the **self-defined barriers to medical care** mentioned in the subsample of the 341 interviews provided insights into ongoing difficulties clients experience as they attempt to obtain critical medical services.

We find that delays in either getting a medical appointment and/or seeing a medical provider (mentioned by 13% of the 341 participants), difficulties with Medicaid (mentioned by 10%) and other types of insurance coverage, and problems with the quality of medical care (mentioned by 8%) they receive are the most frequently mentioned “self-defined” obstacles facing the HIV-positive individuals (see sidebar).

The qualitative finding that many clients encountered delays when accessing the medical

system is also supported by the quantitative finding that 21% of our total sample of 698 participants reported that it took too long to see a medical provider.

Qualitative data from the in-depth analysis of 341 interviews show study participants having to wait for a long time, up to six months, in order to get a medical appointment. Dentists appear to top the list of hard-to-reach specialists. However, dermatologists, optometrists, psychologists, arthritis specialists, and MDs at big city hospitals and community clinics alike were also included in this list. A 33-year-old man, for example, was given an appointment with a doctor who went on vacation and, as a result, he had to wait one

month in order to get a new appointment, while a 32-year-old man was told, by a big city hospital with a designated AIDS unit, to wait seven to eight weeks before getting an appointment with a doctor. Tired of waiting for a scheduled appointment, or faced with an health crisis occurring between their sparsely scheduled medical visits, some clients end up visiting emergency rooms, only to encounter long waits. Participants had to wait up to thirteen hours to be seen in an ER. A 30-year-old man, who had fever and “*was scared that it was PCP*” had to wait for 7 hours in the ER before seeing a doctor, while a 49-year-old woman was told by the hospital clinic she attends regularly to go to an ER, and had to wait for thirteen hours before seeing a doctor. Even when they had a scheduled appointment, some participants still encountered long waits. A 53-year-old man had to wait for four hours to see a nutritionist, while a 45-year-old woman expressed her dissatisfaction with long waits by saying that “*It is exhausting to access (medical) care...the long waits at clinics are a disability*”. A 48-year-old man summarized the experience of many when he exclaimed, “*The waiting time to see a doctor discourages a lot of people; a day at the clinic is really time consuming. (I have) wasted days to see a doctor*”.

Several participants reported that they had a difficult time trying to get their Medicaid cards, that some private doctors do not accept Medicaid card holders as their patients, and that Medicaid does not cover the expense of vitamins and alternative therapies. It should be noted that a few participants commented on similar restrictions imposed by private insurance companies. A 47-year-old man who applied for his Medicaid card described the whole process as “*frustrating*”, and added that he had to wait, at times, for one-half hour on the phone before being able to talk to a “real” person; while a 35-year-old woman lost her Medicaid coverage “*due to a computer error*”, and was left without coverage for two months.

**Self-Defined Barriers to Medical Services:**

Delays and difficulty in getting a medical appointment, especially with specialists, including long waits in the ER.

Difficulty using the Medicaid card

Problems with the “quality of medical care”:  
Specifically:

- a. Difficulty in establishing a personal rapport with the doctor
- b. Health providers fearful of HIV- positive patients
- c: Symptoms (especially pain) not taken seriously by health providers.

#### IV. BARRIERS TO SOCIAL SERVICES

Tables 8 through 13 report on frequency of predefined barriers to social services experienced in the six months before baseline interviews. No more than 20% of all participants mentioned any single barrier to accessing social services. The most frequently mentioned barrier was not knowing where to go, mentioned by 18% of participants, followed closely by transportation (15%) and the four provider attitude barriers. When the provider attitude items are combined, they collectively form the most prevalent barrier--22% of participants mentioned one or more of these barriers (see sidebar).

When compared to those in care, unconnected participants generally experienced more difficulties in obtaining social services (Table 8), although the rank ordering of barriers were similar for both groups of participants. Among the unconnected, provider attitudes were the leading form of barrier followed by not knowing where to go and transportation. Cost was rarely mentioned as a barrier by either group of participants.

There were no substantial differences related to gender (Table 9), but whites were generally more likely to report barriers than either blacks or Latinos (Table 10). Whites were more critical of provider competence and attitudes than minority participants. When all four provider barriers are compared, 29% of whites reported at least one such barrier, compared to 19% of blacks and 22% of Latino participants. Transportation was the one barrier that was more likely to be mentioned by minority participants (16%) than by whites (8%).

There were no meaningful differences in the pattern of barriers with respect to risk exposure group (Table 11). However, when we turn to stage of disease we find that symptomatic participants were generally more critical of provider attitudes than either asymptomatic participants or those with AIDS (Table 12). When all four attitudes are combined, at least one was mentioned by 31% of asymptomatic participants, 22% of those with AIDS diagnoses and 14% of asymptomatic participants.

Finally when participants are divided by income, transportation and not knowing where to go are more than twice as likely to be mentioned by those who had annual incomes of less than \$10,000 than those with income about this level (Table 13). No other barrier including cost was related to an individual's income.

##### **Barriers to Social Services**

###### Most Frequently Mentioned Barriers

Didn't Know Where to Go 18%  
Staff Didn't Listen 15%  
Transportation 15%  
Staff Insensitive 12%  
Staff lack understanding 12%  
Staff Incompetent 11%

Provider attitude (combining: lack of trust, of understanding, staff insensitivity and inattentiveness) 22%

When participants were asked to describe in their own words the obstacles they encountered in attempting to obtain services, they most often framed their experiences with reference to efforts to get assistance with housing and financial problems. When participants discussed transportation as an obstacle, they typically referred to the fact that they did not have enough money to go places or to go from place to place, and they had few suggestions for overcoming this obstacle. Dealing with one's psychological state (depression), and one's legal affairs were also reported as barriers, however, the cases were so few that no broader generalizations could be drawn.

## **V. PREVALENCE AND RESOLUTION OF SOCIAL SERVICE PROBLEMS**

A second line of inquiry for exploring participants' experiences with accessing social services involved a sequence of questions in which individuals were asked to describe problems, if any, they were having in ten areas. For each area in which they experienced a problem, we further asked about the type of agencies they turned to for help, their satisfaction with the assistance provided, and their assessment of progress towards resolving the problem. Satisfaction with services was rated on a four-point scale from very satisfied to very dissatisfied with the assistance provided. Because responses were heavily concentrated on the satisfaction end of the scale, we have chosen to look at the proportion of participants who were very satisfied. The problem resolution rating was a five-point scale ranging from "the problem is currently resolved" to "the problem is getting worse". For this analysis we present data on the percentage of respondents who said the problems they had experienced were either currently resolved or a great deal of progress had been made towards resolving them. Table 14 summarizes the percentage of participants with problems in each of the ten areas, their satisfaction with the help received, and assessment of progress in resolving the problem.

**Table 14:  
Social Service Problems**

<b>Problem Area</b>	<b>% Participants Reporting Problem</b>	<b>Among participants with problems</b>	
		<b>% Very Satisfied with Help Received</b>	<b>% Experiencing Progress in Resolving Problem</b>
<b>Housing</b>	38%	36%	21%
<b>Finances</b>	45%	46%	13%
<b>Legal Matters</b>	20%	49%	26%
<b>Employment</b>	9%	25%	8%
<b>Home Care</b>	9%	36%	16%
<b>Mental Health</b>	25%	66%	24%
<b>Household Items</b>	23%	35%	8%
<b>Child Care</b>	3%	22%	5%
<b>Transportation</b>	21%	32%	13%
<b>Food, Nutrition</b>	25%	36%	15%

The most frequent areas in which participants reported experiencing problems were housing (38%) and finances (45%). A second tier of problems was reported by between 20% and 25% of participants. These included legal matters, mental health concerns, need for household items, transportation and food and nutrition. The percent of participants who said they were very satisfied with the help they were receiving in each area generally fell in the 30 to 40 percent range. Respondents were most likely to be satisfied with the assistance they received for mental health services, as 66% of those with mental health problems reported being very satisfied with the assistance they received in this area. Close to half of participants reporting financial or legal problems were also very satisfied with the help they received. The relatively few participants who reported problems related to employment and child care were least likely to be satisfied with the services they received in these areas. The level of satisfaction with help received for social service problems was generally 20 to 30 percentage points below satisfaction ratings for medical services (See CHAIN TECHNICAL REPORT #7R). Compared to the moderate levels of satisfaction reported for social service providers, ratings for problem resolution was typically rated still lower. For instance, although 46% of participants were very satisfied with the assistance they were receiving for obtaining financial support, only 13% felt that a great deal of progress was being made in resolving their financial difficulties. For housing, 21% of participants in this area felt they were making a great deal of progress. In some areas, the percentage of participants who reported progress in resolving problems was less than 10% (employment, household items, and child care).

In the remainder of this section, we examine in more detail the qualitative responses to the

type of problem and approaches to problem resolution in the two most prevalent problem areas, housing and finances. However, before proceeding, a caveat is in order: the frequency with which DAS is mentioned, both as an obstacle and a resource, reflects the fact that the majority of the participants resort to DAS for most of their issues, and moreover, that DAS is the most commonly used agency among HIV-positive individuals. Consequently, it is not surprising that DAS will bear the bulk of criticism compared to other public and private agencies.

### **Housing Problems**

#### **Housing Problem Summary**

38% reported a housing problem

84% of those reporting a problem sought assistance

21% of the problems reported were resolved or great progress was made

36% of respondents were “very” satisfied with assistance they received

reported housing problems, 19% of participants where qualitative data were abstracted could be classified as having housing problems that are serious. These included facing eviction, being doubled up with relatives and needing an apartment of one’s own, and being unable to get their landlord to fix the broken windows and appliances in one’s apartment. Living in an SRO or welfare hotel was considered undesirable by most participants. Being unable to cook their own meals in a welfare hotel was viewed as compromising their physical health, and living in a SRO “full of junkies” while struggling to remain clean and sober was also perceived as hazardous to one’s physical and mental health. Participants were aware of their entitlements with regard to housing and reported using a variety of case managers and organizations to obtain housing. Some of the SRO/welfare hotel residents

The qualitative data reveals a variety of housing issues confronted by participants in our study. Although 38% of the total sample

#### **Qualitative responses to barriers/housing issues**

Living in an SRO/Welfare Hotel

Long Wait to get an apartment

Fear/reluctance to leave one apartment for a “better” place

DAS delays in paying rent

DAS paperwork

Landlords who take advantage of Section 8 benefits

had agency assistance in moving out of what one client called, “*the terrible hotel system with roach infested rooms and drug inspiring environment*” and into an apartment. The short supply of low-income housing units in New York City, the slow pace of service provider agencies, and the low financial assistance for housing were mentioned by participants as major obstacles in moving out of the SRO/welfare system and into an apartment.

About two-thirds of participants with a housing problem were less than completely satisfied with the assistance they received. The slow pace of getting an apartment in general was a complaint commonly voiced by participants and was attributed, primarily, to “*the way the system works*”. As one participant explained, the New York City Housing Authority had approved her application but “*the waiting list is too long.*” A 36- year-old man, who was temporarily doubled up with his father while waiting for an apartment, spoke for many participants when he stated that “*housing should be given to people with HIV earlier and not when they are on the brink of death.*” In many instances, participants explained that they would prefer a “better” apartment, that is, one in a cleaner building with an elevator, or in a safer neighborhood, but appeared to be reluctant to attempt to find another place. We suggest that this reluctance could be caused in some cases by their disappointment with the whole network of agencies providing social services to the HIV/AIDS population. A 33- year-old man who secured housing through DAS complained that it was a “*horrible apartment with serious electrical problems*” but he was “*afraid to ask for assistance from DAS because my worker gets angry whenever I ask for more benefits*”. Similarly, a 26- year-old Latino man who lived in an apartment with broken windows and plumbing problems and requested housing assistance from a case manager in his drug treatment program described his experience:

*“They tell you they will call and get back to you. When you go back they don’t have anything; they tell you they forgot or some other story”.*

DAS delays sometimes caused housing problems. Ten percent of the 341 participants whose open-ended questions were analyzed reported experiencing difficulties with DAS in relation to their housing problems. The most frequently mentioned complaints were that DAS delayed in sending the rent money, sent the rent to the wrong landlord, and delayed or mishandled the paperwork for housing assistance. On one occasion, for example, DAS was sending the rent to the client’s old landlord for 9 months, and, finally, a lawyer from the a non-profit agency providing legal services had to intervene in order to correct the mistake. DAS mistakes have resulted in evictions and the loss of prospective apartments which the participants, at times, locate through their own efforts.

**Strategies for transcending barriers to housing assistance:** The strategy adopted by most participants in dealing with housing problems was to ask for assistance from other agencies, to intercede on their behalf. All types of agencies, public and private, were used by respondents to negotiate with DAS or with any other agency they were encountering problems.

Individuals who had attempted to get a decent place through DAS and were still dissatisfied with their living situation at times turned to other agencies for assistance, a strategy which often proved successful. Case managers in city hospitals, private non-profit organizations, federal and state agencies were used by clients in their attempt to get a livable apartment. A few participants

used a number of different agencies in dealing with their housing difficulties. In order to regain her Section 8 certificate, for example, a 47- year- old woman recruited the help of the community-based social service agency and of a case manager in a community clinic she attends, while a 45- year- old man went to his community's district board, to his local political representative, to a private non-profit organization, and to his neighborhood's coalition in order to avoid eviction.

Although DAS caused problems for some participants, the agency was an invaluable resource for others. When landlords, for example, became the source of housing problems, clients used their DAS worker as a mediator. Landlords were accused of denying to rent apartments to DAS clients, of renting substandard "shoddy" apartments to DAS clients, and of raising the rent to match the tenants' rent entitlement. "Landlords take advantage of our illness. They raise the rent when they realize that the rent money is coming from the government," explained a 47 year-old white man who lost his Section 8 certificate. On another occasion, DAS provided a room in a welfare hotel to a 43-year-old homeless man who had been unsuccessfully asking for housing assistance from a variety of other city agencies; as he put it "DAS took me off the street".

### **Financial Problems**

Overall, 314 participants reported financial problems (46%). Similar to respondents with housing problems, more respondents reported satisfaction with the assistance that they received in resolving their financial problems. Financial problems, as the clients' comments indicate, influenced problems in other social services areas including transportation, food/meals, and household items.

A review of the open-ended responses to questions about finances reveals that money problems are particularly intractable. Twenty-five percent of our qualitative subsample claimed to have encountered serious obstacles in resolving their financial issues. These obstacles occurred on both the policy level and the organizational level. Specifically, participants claimed that the financial benefits offered to people with HIV/AIDS were inadequate, and moreover, that the policy regulation which determines one's eligibility for assistance according to one's T-cell count was disastrous. As one participant poignantly commented on the association of one's T-cell count and benefits, "In this country, you almost have to be dead...to get real financial support.... Why don't they help people while they are still healthy."

Of those who reported financial problems (N=314) only 14% reported either solving the problem or making great progress toward resolving it. The qualitative data make it clear that a lack of money was considered a major factor in preventing people from having a decent quality of life.

#### **Financial Problem Summary**

45% of participants reported financial problems

61% of those who reported problems sought help from an agency

46% of those who reported problems were satisfied with the assistance they received

14% of those with problems resolved their problems, or made great progress towards resolution of their problems

Participants reported two main obstacles in establishing financial security: a low standard of benefits provided to people with HIV/AIDS, and a set of difficulties associated with city, state and federal agencies who are supposed to establish and provide financial benefits. One fourth of our qualitative subsample reported monetary obstacles which ranged from not having enough money to buy food to their being unable, for years, to establish their SSI eligibility. However, on only a very few occasions did a lack of money prevent participants from keeping their medical appointments.

On an organizational level, public assistance agencies were the most frequently mentioned barriers to establishing, getting, and preserving financial benefits. A complaint, voiced by 8% of the 341 participants, was that due to some bureaucratic error clients had their case closed and were left without any benefits, at times for up to six months. When the HRA lost a 51-year-old woman's records she was left for 4 months without any income. A 49-year-old woman reported "*fighting with DAS about money for the last 3 years,*" as they keep opening and closing her case. Although she won the fair hearing, she still has not received any money.

**Qualitative barriers concerning financial problems**

Benefits inadequate to meet basic needs and therefore, participants need some backup system for financial support

Financial policies tied to specific T-cell counts

Obtaining benefits from agencies can be an arduous and slow process

Participants considered the process to determine one's eligibility for benefits a "run-around" to different offices, and therefore, a major barrier. A 33-year-old woman who had her food stamps cut off without any notice complained that HRA had her "running back and forth between agencies". Another participant, trying to get her SSI benefits, explained that she "*keeps getting the run-around ...taking papers (at various offices) while her paperwork got lost*", and added, "*People (at the public assistance office) are not concerned, and they keep making excuses*".

A few participants mentioned that some employees at DAS and the Public Assistance offices seem to treat their clients with lack of concern, even disrespect.<sup>1</sup> As one man put it "*The way they talk to you. It's like they think they are on a pedestal and any one who needs help is not worthy*"; while another man said about his case manager : "*his caseload doesn't allow him to give individual attention (to his clients)...He (case mgr) doesn't stop to say how are you or do you need anything. I feel like I'm talking to a wall*".

These comments were corroborated by our quantitative finding that 30% of the total sample reported that their medical or social services provider's attitude was an obstacle in receiving services.

---

<sup>1</sup>These interviews and cited responses took place before the re-organization of DAS.

## CHAIN TECHNICAL REPORT #15 -INFRASTRUCTURE - June 20, 1996

Another common complaint was that the process of getting financial assistance was too slow. Time and again, our participants reported that they had to wait several months in order to get SSI, SSD, or food stamps, and that often a bureaucratic mistake had resulted in having to go through the whole process again to have their benefits reinstated.

**Strategies for transcending barriers to financial assistance:** In the effort to get financial assistance, the most commonly used strategy was to employ the services of several agencies. Quite a few participants mentioned that by visiting another agency and asking for help they resolved the problems created by an inefficient, uncaring or rude DAS or welfare worker. Community organizations providing specialized AIDS services, community-based multi-services agencies, city hospitals, and community clinics were some of the alternative places participants used in attempting to get their financial issues resolved. The participants tend to visit a number of medical and social services agencies, and whenever they find a caring and competent worker/case manager -at times even an MD- and they establish a rapport with him/her, they use this person in order to resolve most of their social services needs.

Many times during the interview our participants spoke of a worker/case manager who *"is like a friend"*, who *"goes beyond the call of duty"* calling at the participant's home just to check on him, or giving participant's money for tokens out of her own pocket, and who manages to meet all of the participant's needs for social services.

Relatives and friends often provided financial support when the formal network of agencies failed to do so, as, for example, in the case of a 46- year-old man whose benefits were delayed for several months and who borrowed money from friends and relatives in order to survive. Food pantries and churches were used as last resorts by participants when they ran out of money for food, clothing, even furniture, and after they had exhausted all other sources of support.

Participant criticisms of DAS, summarized above, should be assessed in a broader context in which this agency operates. As mentioned earlier, DAS is likely to be the target of much of the criticism of the system simply because it is the largest and central agency in determining eligibility for housing and financial assistance. 23 participants out of 341 criticized DAS in relation to their financial problems. We should also stress that the interviews were

oriented towards finding out what was wrong with service delivery and less of an emphasis on what is right. We should also add that when participants were asked about satisfaction with DAS case management services, satisfaction ratings were below those received by other case management services, but the majority of participants were still very satisfied with DAS case management services.

Among the negative criticisms directed at DAS and public assistance, we should point out that there were some positive comments. Our participants referred to caring and efficient workers/case managers were found at DAS and other agencies. Moreover, participants were able to distinguish between an inefficient worker and an inefficient system assigning too heavy caseloads to workers at DAS. As a 35- year-old woman, who reported that she is "*looked over by the (DAS) system*" and who needs assistance in the financial, legal, home care, transportation, and food areas explained: her case manager is "*a good guy, trapped in a terrible system*". On balance, DAS was struggling before and presumably will continue to struggle with making difficult decisions about eligibility for housing and social welfare program after its reorganization. Participants' comments about difficulties they have experienced are important inputs on areas for improvement, but they should not be the sole basis for deciding the overall quality of agency performance.

## **VI. GENERAL PROBLEM SOLVING STRATEGIES**

CHAIN participants often reported a high level of satisfaction with case managers or with a social worker from an agency to which they went for assistance despite the fact that their problems weren't resolved. The CHAIN study reinforces the literature on patient satisfaction, which indicates that perceived interpersonal and communication skills account for a large part of patient satisfaction. Therefore, a polite, caring and understanding worker may leave a lasting good impression on the clients and help in alleviating some of the stress they may be experiencing, even when the clients' needs/problem remain unresolved.

The participants resort to using different organizations for different needs but they oftentimes may try to have all their needs met by an understanding and efficient worker even when the request falls outside this worker's jurisdiction. Interviews with HIV care providers conducted for the Personnel Needs Study supported this finding by providing instances in which case workers report that on occasion they go beyond their normal responsibilities trying to accommodate their clients' needs, for example by making phone calls in order to get relevant information, accompanying a client to the appropriate agency, even paying for tokens for the client out of their own pocket.

## **VII. COMMUNITY LEVEL ANALYSIS: INTER-AGENCY LINKAGES**

The main question we attempt to answer, in this section, is whether there exists an informal HIV/AIDS service delivery system composed of linkages among the different agencies designed to provide services to the HIV-positive population in New York City. We will also address the issues of accessibility and effectiveness of this network of agencies by using data from interviews

## CHAIN TECHNICAL REPORT #15 -INFRASTRUCTURE - June 20, 1996

with HIV infected persons and providers of HIV care conducted for the Personnel Needs Study. We will conclude our analysis by making some suggestions on how to enhance the communication and collaboration among the different organizations, thus improving the delivery of services to the HIV-positive community of New York City.

Our analysis is based on data from 19 in-depth interviews of case managers and social service providers working in public and private agencies in the New York City area, and from the compilation of open-ended questions for 341 participants in the first round of the Client Study interviews. Participants had the opportunity to express their views on the interorganizational network when they discussed their efforts in engaging agencies to help resolve social service problems they were experiencing.

A content analysis of the comments of participants and providers in the HIV/AIDS service delivery system indicates that multi-agency informal service delivery networks emerge out of the cooperation and referrals that develop between agencies. However, the interorganizational ties are tenuous, as the communication among providers is often poor, and their collaboration limited, and is often plagued by antagonism among agencies.

It is not uncommon for the participants in our study to employ more than one case manager in order to deal with their social services needs. As our report on HIV case management services indicates, 56% of participants had case managers, and moreover, 36% of the case managed participants reported working with case managers from two or more different agencies in the six months prior to the interview. Participants resort to different agencies for different needs or when they encounter particularly intractable problems, especially in the area of housing and finances. The fact that participants do employ different case managers suggests that there exists a flow of information about the availability of services among clients and/or an interorganizational referral system consisting of social service providers. Participants reported using a number of case managers from different agencies in order to resolve their social service problems. A 42-year-old man, for example, used three case managers from three different agencies in order to get his financial benefits. However, it took him six months to get his benefits, and as he put it, *"The time it took me to get my money...I had to exhaust everything; they made me into a pauper."* A 32-year-old man, who was dealing with a variety of problems, visited the public assistance office and a private multi-service agency for help with his finances, Legal Aid because he was facing bankruptcy, and a church-based charity organization to get clothing for his son. On some occasions, participants use case workers affiliated with private agencies as mediators and/or advocates whenever they run into problems with their case manager from a public agency. As a 33-year-old woman explained, when her worker at the public assistance office had her *"run back and forth between agencies"* in order to get her financial benefits, she asked for assistance from the social worker at her drug treatment program who was able to resolve her problem. Interviews with social service providers confirmed this finding that workers in private agencies often play the role of a mediator and/or advocate on behalf of their HIV positive clients, *"an intermediate"* as one case manager put it. A social service provider of a small private social services agency explained that she had to accompany her client to the public assistance office and wait for six hours in order to see the welfare worker and *"have an argument"* with her because "she wasn't doing her job" and was refusing to fill in an application

for her client. A case manager affiliated with a community health center explained her role as an advocate as follows:

*“So what I do is I encourage the client, when you go to your appointment, this is what you have to tell your case manager, these are the services that you need. So what I do is I empower them.”*

The provider interviews further support the existence of an interorganizational service delivery system. As a case manager in a community organization explained, *“We refer (our clients) to these specific city hospitals because we have some communication with the social workers there so we know that they will help us get on the right course”*. A housing case manager in a community agency stated that even after the housing issues of her clients are resolved she asks them about other problems they might be facing and consequently, refers them to other programs. Providers appear to be well aware that the HIV-positive population is a population with multiple needs, and they do strive to meet these needs to the best of their abilities. However, they do admit that there exists antagonism between the different agencies and that often the interorganizational communication is poor. One provider called the antagonism between agencies “territorial”. Another provider mentioned that some case managers decline to help their clients when they find out that their clients have asked for help from other agencies, whereas he encourages his clients to use other agencies in order to get their benefits since the system moves so slowly. Many providers talked about the frustration caused by trying to get their clients’ needs met through the interorganizational service system. As one case manager put it: *“It is difficult to try to help (her clients) when you are trying to get them certain things,...working with different agencies that are so disorganized and not together.”* This same provider called draining and frustrating the attempt to *“access the system(the service delivery system). Talk about a system that is not even there...”*

The experiences of participants also suggest that the antagonism and poor communication among agencies is frustrating and constitutes a serious barrier in accessing and using the interorganizational service delivery system. A 32- year-old man, for example, who was facing eviction and asked for help from a community multi-service agency, discovered that his initial case manager refused to cooperate with the worker from the community agency. Similarly, another 32-year-old white man, after resorting to four different agencies in order to resolve his financial problems stated: *“Agencies are working against each other, instead of working together; each agency, for example, has different rules.”* A 44- year-old man, who was facing serious housing and financial problems spoke for many participants when he exclaimed, *“Communication among non-medical providers is poor.”*

Participants made specific suggestions about how to improve the service delivery system and overcome most of the barriers to care. Some of their suggestions included eradicating fragmentation of social service agencies by organizing one centralized agency, providing patients’ navigators who will help the participants deal with the different agencies, providing a “readable and understandable welfare manual”. One participant recommended that “all social services should be put under one roof”, while another suggested that the city should “Centralize one gigantic agency with various components; housing and medical (care) combined.” A 43- year-old man, who was

unable to get housing assistance from DAS, defined his patient navigator as a “caring person that would help people through the bureaucracy”, while a 39- year- old woman stated that “*Agencies should organize outreach workers, to prepare people to go to DAS or to go with them.*” The overarching perception of the participants is that there exists an “interorganizational care system” but that it lacks in accessibility and effectiveness. As one participant characteristically said, “*There is help out there, but it is difficult for people to know what they need and how to get assistance.*”

## **VIII. CONCLUSION**

In this study, we have summarized both quantitative and qualitative information on how a broadly representative sample of people living with HIV view the organization and delivery of medical and social services for HIV-related health and social conditions. The findings in this report should be taken as a piece of a larger collection of data on agency performance. It is not possible to draw overall judgements as to how well or poorly service providers are meeting their service objectives simply based upon the frequency distribution and summary of comments provided in this report. Instead, this information should supplement other data on service delivery performance. It should be used to take into account the voice of HIV patients and clients. It should be used to inform efforts to set priorities on elements of the service delivery system most in need of improvement.

Overall, most CHAIN participants express satisfaction with the services available to them through the extended network of HIV/AIDS providers. This is consistent with our findings that the frequency with which any single barrier was mentioned seldom exceeded 20%. Given a fixed list of barriers transportation and a collective measure of provider attitudes were the most frequently mentioned barriers to services. From the qualitative data, we found that to some participants the HIV service delivery system appears to be fragmentary and lacking in coordination between agencies. Participants feel that they need more information and guidance in obtaining their entitlements and accessing medical and social services. Moreover, participants and providers made some excellent recommendations in transcending most of the barriers to care. Using patient/client navigators is one way of assisting HIV-positive people in accessing the service delivery system, and thus eliminating the frustration experienced by some participants who got lost in the “bureaucratic maze”. Strengthening the linkages between agencies by recruiting caring, competent providers and by making the establishment of interorganizational relations a priority among the HIV/AIDS agencies was a suggestion made by both participants and providers. Case managers also reported that smaller caseloads will result in the improvement of the quality of services. The adoption of these recommendations is bound to improve the HIV/AIDS service delivery system and to contribute to the understanding and smooth navigation of what one participant called, “the maze of AIDS service organizations”.