INFRASTRUCURE WORK GROUP REPORT

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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. The infrastructure report draws on both qualitative and quantitative data regarding available services and barriers to accessing services. Some tables and discussion have been previously presented in other CHAIN Technical Reports. As documented in other technical reports available from the CHAIN project, clients in general are satisfied with the continuum of services available to them in New York City. Clients report a high degree of contact with medical and social service providers, and providers report a high degree of personal contact with clients. This study reports on problems that the cohort of 698 HIV-positive informants reported in accessing medical and social services, and in self-reported barriers to care. People living with HIV are forced to negotiate a complicated system of entitlements and services to address their medical and social service needs. Although most respondents are satisfied with the AIDS care system, this report emphasizes the qualitative comments about problems with the system to point toward areas of improvement and suggestions for strengthening it. This report is intended to summarize existing problems and make statements about the HIV/AIDS care system to facilitate services to the HIV-positive population in New York City. The body of the infrastructure report provides an analysis of problem resolution and characterizes the successful resolution of problems by both organizational and personal/sociodemographic variables.

Key Findings

Barriers to Services

Access to all types of social services appears to be more problematic than access to medical care.

Key informants at agencies as well as respondents all note that the AIDS care system is complicated to maneuver.

Agency staff report relying on a network of personal contacts and agency contacts to obtain necessary services for clients.

Overall, 20% of the total sample reported experiencing difficulties because it took too long to get an appointment with a medical provider, although only 13% of the sample expressed a similar concern with social service providers.

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Out of a subsample of 288 participants, 13% reported delays in either getting a medical appointment and/or seeing a doctor, 10% reported difficulties with Medicaid and other types of insurance coverage, and 8% reported problems with the quality of medical care they receive. (These percentages refer to a representative subsample of 288 Wave 1 study participants on which we conducted rigorous qualitative and quantitative analysis.)

The principal barriers to medical care reported by respondents were transportation, fear of what one's doctor/service provider might say, inattentive staff and cost (21%, 15%, 14% and 12%, respectively). The major barriers to social services were individual uncertainty as to where to find services, transportation, staff inattentiveness, and staff who lacked understanding (17%, 15%, 15% and 12%, respectively).

In an analysis of transportation barriers by borough of the respondent, there were notable differences between respondents expressing transportation barriers in accessing medical care in Staten Island (29%), Brooklyn (36%), Bronx (23%), Manhattan (15%), and Queens (13%). There were no borough differences related to transportation barriers in accessing social services care.

Problem Resolution

Participants report that only a small percentage of social service problems they experience are resolved to their satisfaction.

There is no difference between males and females in terms of probability of problem resolution in social or medical services.

Respondents who reported that staff were insensitive to their needs were less likely to report problem resolution than respondents who had no concerns regarding staff sensitivity.

Respondents who reported concerns about staff competence were less likely to report resolution of their problems than respondents who had no concerns regarding staff competence.

Problem resolution was not tied to client satisfaction with services rendered in most social service settings. Many respondents whose problems were ongoing reported a high level of satisfaction with services.
I. INTRODUCTION

Although most respondents are pleased with the array of services and entitlements available, problems continue. A few vocal respondents report problems in accessing necessary medical and social services. Understanding barriers or perceived barriers to accessing care is critical in planning and implementation of HIV/AIDS services to meet the needs of the HIV positive population in New York City. This report will provide general information about problem resolution and detailed information about the most prevalent problems (housing, finances and transportation).

The analysis of self-reported barriers to medical care and social services is based on Wave I interviews. For the purposes of this report, “Barrier” was defined as “the biggest difficulty respondents encountered when they attempted to get medical care and/or assistance in resolving any of their non-medical problems.” We also included in the definition of a barrier any obstacle that lead to the delay of an appointment with a medical and/or social service provider. The data on barriers were, primarily, from answers to open-ended questions where respondents had the opportunity to elaborate on any difficulty they faced in the medical and social service system. Wherever appropriate, the respondent’s answer was enriched by information available in the Social Services section of the interview.

Additional qualitative information was provided by the previous Personnel Needs Study, also funded as part of the Ryan White Title II Evaluation. In the PNS, open-ended information was gathered from personal interviews with providers working in HIV/AIDS care. Providers’ interviews provide rich detail about the informal network of information and contacts critical to obtaining client services and entitlements. In the analysis, we hypothesized that there exists an “invisible” care system of the linkages and referrals among the various agencies providing services to HIV/AIDS individuals, and, given that it does exist, we look at how effective it is and how it can be improved.

There seems to be a difference between the expectations clients hold for medical providers and social services providers. Clients make both greater demands and hold higher expectations in their interactions with social service providers, and clients also report a higher level of dissatisfaction with such providers. This gap between the two types of services has to be interpreted in light of the fact that HIV/AIDS is incurable, and doctors do perform critical services for clients. It may also be emblematic of systematic barriers to care that alleviating physical pain by providing a pain killer is usually easier than trying to find housing in the inundated New York City housing market.
II. METHODS

Study Participants

The present analysis is part of the CHAIN Project. The CHAIN project is intended to provide a quantitative profile of the need for, utilization and impact of the HIV health and services system in New York City. Data for the present analysis was obtained from interviews, conducted between October 1994 and August 1995. The individuals interviewed are the participants in an ongoing study of the service needs of persons living with HIV, 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 second round of interviews began in July 1995 and was completed in spring 1996. A third round of interviews began in March 1996. The quantitative data reported here is taken from the 698 persons interviewed in Wave 1. The qualitative data comes from a representative sample of 288 Wave 1 interviews.

Study variables

Variables: Interview data were used to characterize supports for problem solving with respect to agency type, respondent income, respondent access to insurance.

Participants were asked to discuss barriers to obtaining necessary social and medical services. The issue of barriers to services becomes clear in an analysis of problems obtaining services, and in distinguishing socio-demographic variables or organizational variables linked to resolution of problems. For each person interviewed the following information was obtained:

- Problems in accessing medical and social services
- Degree to which problem was resolved
- Respondent satisfaction with assistance
- Insurance status
Text Box 1
Measuring Perceived Staff Competence As a Potential Barrier

At any time in the last six months, did you ever delay or not get the assistance that you thought you needed because the staff at the office...?
(A “yes” to any of the following):
Because you weren’t sure that staff at the office or clinic would understand your problems?
Because you felt that the staff is not good at listening to your problems or needs?
Because the staff at the office or clinic are often not polite, are disrespectful, or are insensitive to your needs?

On the basis of qualitative information, two additional variables were created to measure perceived barriers to care. The first variable was “provider attitude”. Respondents were asked if they had experienced difficulties or delays because of perceived staff attitude. This was measured as a “yes” to any of three separate questions describing client and provider exchanges. Text Box 1 provides more detailed information about the “provider attitude” index.

Text Box 2 Measuring Perception of Staff Incompetence as a Barrier to Care

At any time in the last six months, did you ever delay or not get the assistance that you thought you needed because the staff at the office...?
(A “yes” to any of the following):
Because you didn’t trust the providers to be confidential about your HIV status?
Because you felt that the staff was not competent to deal with your problem?

The second index which was created to examine perceived barriers to care deals with perceived “provider incompetence”. The variable is a combination of two questions. Both of these index variables were analyzed to see if there were correlations between perception of staff sensitivity or staff competence and problem resolution. In addition, the variables were cross-tabulated to study socio-demographic correlates of negative staff perceptions.
Qualitative Methodology

The qualitative data come from 288 Wave 1 interviews which constitute a subsample of the Wave 1 CHAIN interviews. As we have indicated in our previous reports, an attempt was made to equally represent in our CHAIN sample all groups of individuals who are HIV-positive regardless of gender, race/ethnicity, risk of exposure and stage of illness. A similar effort was made when we gathered our subsample of 288 participants.

All qualitative data is derived from open-ended questions throughout the questionnaire, where study participants have the chance to offer their own perceptions of problems they have faced while accessing and navigating through the medical and social services system in New York City. As a general rule, in our analysis of the content of the answers to open-ended questions we take into consideration a participant’s socio-demographic profile, health profile, and economic resources, thus creating a context within which we can understand a participant’s view of the service delivery system.

The specific qualitative data used in the following analysis stem from the open-ended questions in the Barriers and Social Services sections of the CHAIN questionnaire. We focused on the questions which asked about “the biggest difficulty” a study participant has encountered while attempting to get medical care and social services. The open-ended nature of these questions gave the opportunity to the participants to offer their own definitions of obstacles to care and, moreover, to elaborate on particular episodes of facing and overcoming barriers to care.

| Text Box 3 |
| Open-ended Questions on Barriers to Care |

- What has been the biggest difficulty you have ever had getting the medical care you have needed?
- Have you experienced this difficulty in the last six months?
- What has been the biggest difficulty you have ever had resolving or getting help with non-medical problems you have had?
- Have you experienced this difficulty in the last six months?
The answers to these questions regarding problems obtaining services in the last six months were complemented by the participants' responses regarding improvements to the HIV care delivery system. Through this question we collected invaluable suggestions by the participants about improving the service delivery system which has an immediate effect on their lives. Time and again, the social sciences literature has demonstrated the importance of incorporating into policy-making the views of the people who are actually affected by these policies and who have an intimate understanding of the everyday implementation of public policies.

Text Box 4
Respondent suggestions regarding improvement and changes in the service delivery systems to meet their needs

If you could change one thing about help that is or is not available to persons living with HIV, what would that be?

Wherever appropriate, we supplemented the data from the Barriers section with data from the Social Services section. The detailed information by problem area (Housing, Finances, Transportation etc) in the Social Services section provided the context in which the barriers answers were analyzed. When, for example, a participant mentioned in the Barriers section that she was faced with serious obstacles while trying to receive housing assistance, we used the data she offered in the Housing subsection in order to better interpret her barrier to housing assistance.

Text Box 5
Problem Area Reported

- Housing
- Finances
- Transportation
- Employment
- Food/Meals
- Psychological
- Legal

What Problems Are Reported/Resolved

Overall, respondents reported 938 social service problems in various stages of resolution, including problems in housing, transportation, finances, child care, employment, food/groceries, household items. Respondents sought help from both private and public agencies in attempting to resolve their social service problems. Of the problems reported, housing problems were
the most frequently reported, followed closely by financial problems. Problem resolution did not always relate to the agency type where assistance was sought, although there was some variation by problem type.

Overall, 22% of housing problems were resolved, 12% of financial problems were resolved and 13% of transportation problems.

III. ANALYSIS OF FINDINGS:

With the caveat that most clients were satisfied with the services which they received, we turn to a detailed discussion of the qualitative results from a review of a representative sample of 288 respondents. The qualitative data clearly indicate that housing and finances are the two most problematic areas affecting participants' lives. Participants often encountered obstacles when attempting to get housing and financial assistance. Most participants who reported transportation problems reported that they did not have enough money to go places or to go from place to place, and had few suggestions to overcome this obstacle. Additional comments related to transportation, to dealing with one's psychological state (depression), and one's legal affairs were also reported, however, the cases were so few that no conclusive results could be reached.

Housing Problems

<table>
<thead>
<tr>
<th>Text Box 6 Housing Problems (Quantitative Data)</th>
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<tbody>
<tr>
<td>266 reported a housing problem</td>
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<tr>
<td>84% of those reporting a problem sought assistance</td>
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<tr>
<td>22% of the problems reported were resolved or great progress was made</td>
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<tr>
<td>37% of respondents were “very” satisfied with assistance they received</td>
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Thirty eight percent of the total sample reported housing problems. Housing is an area where respondents with problems sought assistance. Respondents were aware of their entitlements with regard to housing and reported using a variety of case managers and organizations to obtain housing. As in most areas of problem resolution, more clients were “very” satisfied with the assistance that they received than resolved their problems.
The qualitative data reveals the variety of issues confronted by respondents in our study. Nineteen percent of our subsample of 288 participants reported serious difficulties in dealing with their housing issues. Housing issues ranged from facing eviction and from being doubled up with relatives and needing an apartment of one’s own, to 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 respondents who reported that they preferred living in an apartment. Being unable to cook their own meals in a welfare hotel was viewed as compromising their physical health, and living in a SRG “full of junkies” while struggling to remain clean and sober was perceived as hazardous to one’s physical and mental health. Some of the SRO/welfare hotel residents requested from DAS or from some other 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. However, short supply of low-income housing units in New York City, the slow paced and insufficient housing assistance offered by DAS, and the low financial assistance for housing were major obstacles in moving out of the SRO/welfare system and into an apartment.

The slow pace of getting an apartment, in general, was a complaint voiced by clients who resorted to DAS or other agencies for their housing issues and was attributed, primarily, to “the way the system works”. As one respondent explained, the New York City Housing Authority had approved his application but “the waiting list is too long.” A 36-year-old Latino 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, clients 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 reactance could be caused by their disappointment with DAS and the whole network of agencies providing social services to the HIV/AIDS population. A 33 year-old Latino man who got through DAS a ‘horrible apartment with serious electrical problems’ explained that 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 often caused housing problems. The most frequently mentioned complaints were that DAS delayed in sending the rent money, send 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 respondents, at times, locate through their own efforts.

Strategies for transcending barriers to housing assistance: The strategy adopted by most respondents in dealing with DAS was to ask for assistance from other agencies, or try to work things out with DAS on their own; the latter was a frustrating and usually unsuccessful tactic. All types of agencies public and private were contacted by respondents trying to overcome the housing difficulties created by DAS.

Individuals who had attempted to get a decent place through DAS and were still dissatisfied with their living situation at times resorted 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 respondents 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 Latino 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 white 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.

When landlords became the source of housing problems, clients used their DAS worker and/or case managers from other agencies as mediators. 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.

Financial problems

Overall, 314 respondents 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 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 for some respondents. Twenty five percent of our subsample of 288 respondents claimed to have encountered serious obstacles in resolving their financial issues. These obstacles occurred on both the macro/policy level and the organizational level. Specifically, respondents 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 respondent 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 our respondents from having a decent quality of life. Respondents 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 DAS and other state and federal agencies who are supposed to establish and provide financial benefits. One fourth of our subsample of 288 participants 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 clients from keeping their medical appointments.
On an organizational level, DAS and other public assistance agencies were the most frequently mentioned barriers to establishing, getting, and preserving financial benefits. It appears that getting financial benefits from DAS and/or public assistance was a real bureaucratic odyssey for many of our respondents. Clients complained about having their case closed and having to work to reopen it. A regular complaint 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 black woman’s records she was left for 4 months without any income. On another occasion, a 49 year-old black woman reported to be “fighting with DAS about money for the last 3 years”, as they keep opening and closing her case, and although she won the fair hearing, she still has not gotten any money.

Participants considered the runaround to different offices in order to determine one’s eligibility for benefits a major barrier. A 33 year-old Native American woman who had her food stamps cut off without any notice complained that HRA had her “running back and forth between agencies”. Another client who is trying to get her SSI benefits explained that she “keeps getting the runaround … 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”. Some respondents felt that their health care workers and case managers were uncaring and lacked the necessary knowledge concerning their benefits. A vocal minority of our clients mentioned that some employees at DAS and the Public Assistance offices seem to treat our clients with lack of concern, even disrespect.

The minority of clients who were dissatisfied with their services made comments about their perception of staff attitudes.

Text Box 9
Qualitative information regarding financial problems

- Financial policies tied to specific T-cell counts
- Benefits inadequate to meet basic needs
- Obtaining benefits from agencies can be an arduous and slow process
- DAS staff suffers from high turnover rate
- Clients need some backup system for financial support

1These interviews and cited responses took place before the re-organization of DAS.
"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," reported one man, while another man said about his case manager at DAS: "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."

More importantly, clients complained that their DAS workers did not know enough about benefits, and often were not able to provide proper assistance. DAS workers were accused of "not offering clear information about eligibility, procedure, and consequences of financial assistance," of being "not devoted and clueless". Clients remarked on the seemingly high turnover rate of DAS workers, an impediment to the development of client - worker rapport. In describing the high rate of turnover among DAS workers, a client called them "ping pong workers". The appeal for "better communication between client and DAS case manager", was echoed throughout the interviews.

These findings were corroborated by our analysis which was based on the two variables of "provider attitude" and "provider incompetence", defined earlier in boxes 1 and 2 (page 6). Specifically, we found that 30% of the total sample reported that their medical or social services provider's attitude was an obstacle in receiving care; while 21% of the total sample mentioned that their provider's incompetence obstructed their access to either the medical or the social services care system.

Another common complaint was that the process of getting financial assistance was too slow. Time and again, our respondents 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. As one client, who was dissatisfied with his case manager and felt guilty about asking for assistance, reported, "they (DAS and welfare) make it such a battle to get financial help."

**Strategies for transcending barriers to financial assistance:** In the "battle" to get financial assistance, the most commonly used strategy was to employ the services of other agencies. Quite a few respondents 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 respondents used in attempting to get their financial issues resolved. We suggest that often our respondents 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.
Numerous times throughout the interview our respondents spoke of a worker/case manager who "is like a friend", who "goes beyond the call of duty" calling at the respondent's home just to check on him, or giving the respondent money for tokens out of her own pocket, and who manages to meet all of the respondent's needs for social services. Despite the negative criticism directed at DAS and public assistance, we should point out that such caring and efficient workers/case managers were found in all agencies, and moreover, that some clients 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 black 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".

Relatives and friends provided invaluable financial support whenever the formal network of agencies failed to do so, as, for example, in the case of a 46 year-old white 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 respondents when they ran out of money for food, clothing, even furniture, and after they had exhausted all other sources of support.

Problems Obtaining Medical Services

Although barriers to medical care were less frequent than barriers to social services, they were equally important in determining the quality of life of our respondents. The majority of our respondents were satisfied with their medical services and reported frequent provider-client encounters (for a full discussion of frequencies of medical contact, see CHAIN Technical report on Medical Care.) However, a small percentage 27% of our total sample reported not being completely satisfied with their primary medical provider. The qualitative responses of our subsample of 288 participants, provide insights into ongoing difficulties that respondents experience as they attempt to obtain critical medical services. Of those reporting

Text Box 10
Qualitative responses to barriers in obtaining medical care

- Difficulty using the Medicaid card
- Providers fearful of HIV positive patients
- Difficulty in obtaining appointments with specialists (including dentists)
- Difficulty in establishing a personal rapport with the doctor
- Long waits for appointments
- Symptoms (especially pain) not taken seriously

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difficulties. 13% reported delays in either getting a medical appointment and/or seeing a medical provider, 10% reported difficulties with Medicaid and other types of insurance coverage, and 8% reported problems with the quality of medical care they receive.

Among our respondents who reported difficulty in obtaining medical services, some described having to wait for a long time, up to six months, in order to get a medical appointment. As one of our respondents put it, “it takes forever to get an appointment at a hospital clinic”. 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 Latino 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 Native American 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 in the emergency rooms. Respondents had to wait up to thirteen hours to be seen in an ER. A 30 year-old white 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 white 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 clients still encountered long waits. A 53 year-old black man had to wait for four hours to see a nutritionist, while a 45 year-old white 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 black 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).”

Respondents reported that they had a difficult time trying to get their Medicaid card, that some private doctors do not accept Medicaid cardholders as their clients, and that Medicaid does not cover the expense of vitamins, and alternative therapies. A 47 year-old white man who applied for his Medicaid card while suffering from dementia described the whole process as “frustrating”, and added that he had to wait at times, for half hour on the phone before being able to talk to a “real” person; while a 35 year-old black woman lost her Medicaid coverage “due to a computer error”, and was left without coverage for two months. A couple of respondents mentioned that they were unable to see the doctors they wanted because they did not accept Medicaid coverage, and ten respondents complained about the fact that Medicaid does not cover alternative therapies and/or the purchase of vitamins. Since most of our respondents are covered by Medicaid, the majority of the obstacles reported concern this particular type of coverage. However, a few clients complained that their private insurance programs also do not
Although it is difficult to measure "quality of care" through the open-ended responses to the Client Interview, respondents did comment on their difficulty in accessing "quality care." Complaints ranged from being unable to establish a personal rapport with one's doctor, to coming across a dentist who refused to remove the respondent's braces, due to his HIV status. A 38-year-old Latino man said that, during his stay at a big city hospital, the "care givers fear HIV so much, that they would leave the food outside my door, and, by the time the nurse or my family came to bring in the food, it was cold"; while a 45-year-old white man explained that the medical providers at another city hospital "were uncomfortable with treating a person with HIV," and that he had to be "very aggressive in getting proper care." Respondents also mentioned that their complaints about symptoms were not taken seriously and that, as a 42-year-old black woman characterizedly said, "Doctors don't understand your needs".

**Strategies for transcending barriers to medical care:** Apart from resorting to emergency rooms, and occasionally changing clinic and/or medical provider in search of better care, our respondents do not seem to have a strategy for transcending their barriers to medical care. Contrary to what occurs in the area of social services, clients do not employ the services of alternative hospitals and/or providers. Our data do not provide an explanation for this lack of strategy, however, our hunch is that the power of medical authority and the incurability of the disease may account partly for the reluctance to seek out a variety of different medical providers.

**General Problem Solving Strategies**

Qualitative information from agencies indicate that there is poor communication and cooperation among the various agencies striving to serve the HIV/AIDS population. Time and again, case managers had to make an effort to find another social worker working for a certain hospital, or a DAS worker in order to have their client’s needs met. The lack of communication among the different agencies was reported as a source of frustration by case managers who, however, acknowledged that DAS is understaffed, but also that there are people in the field of HIV/AIDS service system who do not care about their clientele.

One of the most effective strategies adopted by most clients was to resort to a case manager from another agency who would intervene on their behalf and attempt to communicate with another case manager and have their case re-opened. The same agencies had both positive and negative evaluations from clients which point to the fact that usually what makes a difference is the individual worker and her qualifications, dedication and caring which make her into an effective server.
Clients often reported a high level of satisfaction with case managers or with a social worker from an agency to which they were 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 more of the variation in 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 however, due to limited resources and/or breakage in system communication the clients’ needs/problem might yet remain unresolved.

The clients seem to resort to use various organizations for their different needs and 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. Also reported in the Personnel Needs study: case workers on occasion go beyond their call of duty 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. Given that resorting to a variety of interlinked providers and/or agencies, that is, a network of providers and/or agencies, is the most common strategy followed by our study participants in overcoming their barriers to care, we conclude our report by presenting an analysis of the linkages between different providers and/or agencies.

Community Level Analysis: Invisible Links Between Agencies/Providers

The main question we attempt to answer, in this section, is whether there exists an “invisible HIV/AIDS service delivery system” 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 both the clients’ and 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.

The significance of the social networks that emerge from the relationships among organizations has been demonstrated by numerous studies. The strength and the number of linkages connecting the different organizations, and the frequency and intensity of communication and cooperation channeled through these linkages have been associated with the effectiveness of an interorganizational network (Leinhardt, 1977; Burt and Mioor, 1983; and Wellman and Berkowitz, 1988). In our analysis, we will attempt to define the factors that contribute and those that inhibit the creation of successful linkages between organizations.
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 open-ended questions of 288 Wave I interviews with HIV-positive individuals who constitute a subsample of the CHAIN agency sample. Clients had the opportunity to express their views on the interorganizational network in the Social Services and Barriers to Services sections where they spoke about using a variety of agencies to get their problems resolved and about the obstacles they encountered.

A content analysis of the comments of clients and providers in the HIV/AIDS service delivery system indicates that an "invisible care network" arises out of the cooperation and referrals 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 the total CHAIN agency sample have a case manager, 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 (Messer, Healon, and Aidala, May 1996). Clients 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 and an interorganizational referral system. Clients reported using a number of case managers from different agencies in order to resolve their social service problems. A 42 year-old black 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 white 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, clients use case workers affiliated with private agencies as mediators and/or advocates whenever they run into problems with their case managers from a public agency (mainly DASS). As a 33 year-old Latino 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 that 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 providers' interviews further support the existence of an invisible 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;" while 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," while another mentioned that some case managers decline to help their clients when they find out that their clients has 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 interorganization 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 clients 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 Native American 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 Latino man
who was facing serious housing and financial problems spoke for many clients when he exclaimed, "Communication among non-medical providers is poor."

Clients made specific suggestions about how to improve the service delivery system and overcome most of the barriers to care. Rpadicating the fragmentation of social services by organizing one centralized agency, providing patients' navigators who will help the clients deal with the different agencies, providing a "readable and understandable welfare manual" were some of these suggestions. One client 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 white 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 39 year old black 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 clients is that there exists an "invisible care system" but that it lacks in accessibility and effectiveness. As one client characteristically said, "There is help out there, but it is difficult for people to know what they need and how to get assistance."

CONCLUSION:

Overall, clients are satisfied with the services available to them through the extended network of HIV/AIDS care developed by the HIV Planning Council, however an analysis of the ongoing problems experienced by some respondents reveals a fragmentation of services and a lack of coordination between agencies. Clients feel that they need more information and guidance in obtaining their entitlements and accessing medical and social services. Moreover, clients 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 clients 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 clients and providers. Case managers also reported that "smaller caseloads" will result in the improvement of the quality of services. The "creation of a central agency" which one participant called "an information boutique", and which would provide information on both medical and social services to the HIV population was another recommendation made by clients. 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".
BIBLIOGRAPHY:
