

THE CULTURE AND POLICY INSTITUTE

Providing Services for those in Need: The Politics of AIDS in Bexar County Texas

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TABLE OF CONTENTS

TABLE OF CONTENTS	1
BACKGROUND INFORMATION	3
Introduction	3
AIDS: Prevalence and Incidence	4
AIDS and the General Population: Current Knowledge and Awareness	5
Trends in Heterosexually Transmitted HIV	8
Cumulative Texas AIDS Surveillance Data: San Antonio EMA	11
Cumulative Texas Aids Surveillance Data: State of Texas	12
Needs Assessment: Quality Improvement Evaluations	12
Needs Assessment Processes	13
The 1993 USCM Technical Report	15
OTHER NEEDS ASSESSMENT FINDINGS WITHIN TEXAS	17
TDH Region 8 Health Services Delivery Area (HSDA)	17
Greater Houston EMA	22
NEEDS ASSESSMENTS OUTSIDE OF TEXAS	25
St. Petersburg/Tampa	25
Seattle EMA	30
SUMMARY OF NEEDS ASSESSMENT REPORTS	32
NEEDS ASSESSMENT RESEARCH METHODOLOGY	33
SAMPLE PROFILE	35
Demographic Characteristics	36
How do you classify your gender or sex?	37
Race and Ethnicity	37
Living Arrangements	40
HIV STATUS	42
Age of Diagnosis	43
Source of infection	44
Multiple Sources of Infection	45
REPORTS OF MULTIPLE SOURCES OF HIV INFECTION AMONG MALES 17-75 YEARS OLD	46
Homosexual Sex and Shared Needles	46
Heterosexual Sex and Shared Needles	46
FEMALES 17-75 YEARS OLD	46
Homosexual Sex and Shared Needles	46
ASSESSING THE IMPACT OF THE TWO PART SAMPLE DESIGN	47
RACE/ETHNICITY OF RESPONDENTS BY SOURCE OF INTERVIEW	48
RACE/ETHNICITY OF RESPONDENTS BY RANDOM/CONVENIENCE SELECTION	48
SELF REPORTED HIV STATUS BY RANDOM/CONVENIENCE SELECTION	49
TOTAL MONTHLY INCOME BY RANDOM/CONVENIENCE SELECTION	50
OVERALL SATISFACTION BY RANDOM/CONVENIENCE SELECTION	50
OVERALL SATISFACTION BY TYPE OF INTERVIEW	51
OVERALL SATISFACTION BY LANGUAGE OF INTERVIEW	51
ECONOMIC STATUS OF RESPONDENTS	52
INCOME AVAILABILITY AND LEVEL BY SOURCE	53
INCOME INFORMATION BY AGE	55
INCOME INFORMATION BY RACE AND ETHNICITY	56
INCOME INFORMATION BY CD4 LEVEL	56
INCOME INFORMATION BY SELF-REPORTED HIV STATUS	56
INCOME INFORMATION BY YEAR TESTED	56
INCOME INFORMATION BY EDUCATION	57
RENTAL ASSISTANCE	57
OVERALL SATISFACTION WITH SERVICE AGENCIES	61
SERVICE UTILIZATION AND SATISFACTION	68

Case Management.....	68
Medical and Dental Services/Needs.....	73
Alternative Health Treatments	79
Counseling Services	80
Household Necessities	81
Housing Services	82
Financial Assistance	83
Nutritional Assistance	84
Legal Services.....	85
Transportation Services	86
Child and Adult Care.....	87
EXTENT OF SERVICE UTILIZATION.....	88
OVERALL UTILIZATION	89
AVERAGE CD4 LEVELS BY EXTENT OF SERVICES USED	91
AVERAGE SERVICE USAGE BY USE OF CASE MANAGEMENT	92
AVERAGE NUMBER OF SERVICES USED BY MONTHLY INCOME LEVEL	92
Use of Counseling Services.....	93
CLIENT NEEDS	95
MEDICAL ASSISTANCE/NEEDS.....	96
SPECIAL MEDICAL NEEDS	97
MEDICAL SERVICES PROBLEMS.....	99
FACTORS IMPORTANT TO CLIENTS	100
HIGH RISK SEXUAL BEHAVIOR.....	101
HAVE UNPROTECTED SEX BY LEVEL OF GENDER, AGE, EDUCATION	103
AND SELF-DESIGNATED HIV STATUS	103
UNPROTECTED SEX BY USUAL SOURCE OF HIV SERVICES INFORMATION	104
UNPROTECTED SEX BY TYPE OF CAREGIVER.....	107
CONFIDENCE IN INSTITUTIONS AND TRUST IN PEOPLE.....	110
Local, State and National Institutions	110
Comparing Sample and National Responses.....	110
Confidence in Institutions.....	111
Trust in People	112
Trust in People.....	113
Summary.....	113
WOMEN'S NEEDS	116
Demographic Profile	116
Economic Profile	116
Overall Satisfaction	117
Other Needs.....	118
Summary	118
PEDIATRIC NEEDS.....	119
Demographic Profile	119
Economic Profile	119
Overall Satisfaction	120
Other Needs.....	121
Summary.....	121
CLIENTS WITH CD4 COUNTS UNDER 200	121
Demographic Profile	121
Economic Profile	122
Overall Satisfaction	123
Other Needs.....	123
Summary	124
RECOMMENDATIONS FOR FUTURE DATA COLLECTION	125
CONCLUSIONS.....	128
REFERENCES.....	131

BACKGROUND INFORMATION

Introduction

Faculty from the University of Texas San Antonio and the Ryan White Needs Assessment HIV/AIDS Planning Committee united in a collaborative effort to design and implement a needs assessment survey that would evaluate the health and social service needs of its clients.

As required by Title I of the Ryan White Comprehensive AIDS Resources Emergency Act of 1990, in order to become eligible for grant funding, an HIV Health Services Planning Council was established. Under Title I of the Ryan White Act, the Planning Council is directed to prioritize funding allocations, develop a comprehensive plan that oversees the delivery of health services and to assess the administrative mechanism for distribution of funds and monitor services (within the eligible metropolitan area). In addition to pursuing federal requirements for funding, in 1993, the States Region 8 HIV Consortium formally established a Needs Assessment Committee made up of community representatives and clients from participating agencies, and service provider organizations.

In 1991 the Texas legislature mandated that all health care services programs shall make available reports and analyses relating to AIDS and HIV “in a timely and accurate manner.” Information regarding the incidence and prevalence of AIDS/HIV cases by region, age, sex, gender, race/ethnicity and transmission route must also be represented in state-based project reports. In addition to the routine collection of demographic and epidemiological information, health care services must compare Texas-based data with national data in order to fulfill public policy objectives set by federal, state and local agencies.

Since the inception of the Needs Assessment Committee, general goals consisted of editing and distribution the survey instrument and collecting and analyzing data. Unlike the 1993 project, the current instrument benefited from further revisions, has been translated into Spanish and uses random sampling for portions of the data collection process.

AIDS: Prevalence and Incidence

Centers for Disease Control surveillance data indicate that a total of 573,800 persons in the USA aged 13 or older were reported having AIDS between 1981-1996 (Neff and Crawford, 1998). While this shows an overall decline of about 13% between 1995-1996 there are pockets of increases among specific groups, particularly minority males and females. Notably, by 1995 the rate of AIDS among African Americans (22.1) was 18 times the rate for non-Hispanic whites (1.2) and the rate for Hispanics (8.1) was about seven times that for non-Hispanic whites (Neal, et al., 1995). Of course AIDS impacts populations worldwide. In 1991, the World Health Organization (WHO) estimated that by 1994, over 4 million acquired immune deficiency syndrome (AIDS) cases would have been reported. In less than ten years since the Centers for Disease Control's classification of AIDS, AIDS has been reclassified as a pandemic - affecting millions of women, men and children the world over. In October, 1994, the WHO's Strategic Meeting on Prevention of HIV/AIDS announced that a conservative estimate of the cumulative HIV infections exceeded 17 million and approximately one fifth (1/5) of the cases have been reclassified as "individuals with AIDS".

The National Research Council (1993) reports that the AIDS pandemic is like none other in that, once an individual becomes infected, the debilitating aspect of the disease may rest dormant for many years (eight years, on average). Because the infected, who have been diagnosed as HIV positive, rarely experience sudden onset of symptoms, only rough estimates

of HIV positive individuals can be used to predict those persons who will eventually succumb to AIDS (National Research Council, 1993:3). Administrators of public policy need to be able to forecast demographic changes within their client communities in order to implement strategic initiatives that will stabilize fluctuations in service needs. It is for this reason that agencies and institutions that currently provide health, social and economic services for individuals with HIV disease and individuals with AIDS, must closely examine the efficiency and effectiveness of current services to meet the growing and changing needs of clients.

AIDS and the General Population: Current Knowledge and Awareness

In 1991 the National Center for Health Statistics (NCHS) published the results of a continuing AIDS awareness survey. The objective of the National Health Intervention survey is to measure adults' knowledge of AIDS and HIV. The collection of these data is instrumental for the strategic planning of prevention and education programs. Findings from their most recent survey indicated that general awareness regarding the transmission of HIV remained high when compared to 1990 results. Knowledge did, however, vary across age, socioeconomic and education levels (NCHS, 1991:1).

From 1990 to 1991 the most notable changes in response patterns were associated with the respondents' self-identified knowledge level. In 1990, 19% of those surveyed indicated that they knew "a lot" about AIDS. By 1991, this percentage increased to 29%. Individuals over the age of 50, and those who had less than a high school education were less likely to indicate that they knew "a lot about AIDS." Blacks and respondents over the age of fifty were more likely to say that they knew "nothing" about AIDS (NCHS, 1991:2-3).

The 1991 results show an increase from 79% to 86% in the proportion of individuals who recognized that the AIDS virus was referred to as HIV (NCHS, 1991:1). Although respondents'

self-reported knowledge about AIDS was high in 1991, misconceptions regarding the transmission of the HIV virus persisted. Approximately 50% of those surveyed indicated that HIV transmission through casual contact with a health care worker was either "very likely" or "somewhat likely." Additionally, 18% of the respondents believed that it was "somewhat likely" for the virus to be transmitted through shared dining utensils. When race/ethnicity and education were controlled, Blacks and individuals with less than a high school education were more likely to believe that a person donating blood could be exposed to the virus. However, the NCHS suggests that this particular question may have a low reliability. A positive response does not clearly distinguish between individuals who are misinformed regarding HIV transmission and those who believe that this type of transmission is theoretically possible if certain (unspecified) procedures are not followed (NCHS, 1991:3).

The NCHS also collects supplemental attitudinal data regarding perceptions of condom effectiveness and drug therapy. Data from 1991 revealed that a substantial proportion of males still believe that both latex and natural membrane condoms both provide equally good HIV virus barrier prevention (21% in 1990 and 14% in 1991). On the positive side, in 1991 males were more likely to express correct awareness of the hazards associated with combining oil-based lubricants with latex condoms than they had been in 1990. Even when controlling for age, sex, race/ethnicity and education, the majority of all subsets responded "don't know" to both condom awareness questions (NCHS, 1991 :13).

The more formal education the individual had the more closely his or her factual knowledge matched their self-reported awareness. Individuals with more education were more likely to respond correctly to questions about HIV transmission and the risk factors associated with the virus. Respondents who had a high school education or less were more likely to

respond incorrectly to HIV-related question, and to respond "don't know" to all survey questions (NCHS, 1991:2).

Approximately 60% of the respondents did not know that there is a difference between natural membrane and latex condoms with respect to protection from the HIV virus. Eighty percent believed that they had no chance of ever becoming infected. Approximately 30% believed that it was "somewhat likely" for them to become exposed to the virus if someone who was HIV-positive coughed on them (NCHS, 1991:2-4). Even though 80% of those surveyed recalled having seen a TV service announcement about AIDS, only 70% reported using information acquired from TV programs. About 45% had heard a service announcement on the radio, 10% had read information in a magazine, and 67% had read a newspaper article about AIDS. However, only 30% had ever discussed AIDS with any of their 10-17 year old children (NCHS, 1991:9). Apparently, adults in general, and parents in particular, had not been able to bridge the communication gap about the virus with young people. Undoubtedly children will inherit similar social misconceptions about the virus if they are not encouraged to speak publicly and candidly with their parents, family, teachers and peers.

Awareness is impacted by education and is facilitated by exposure to educational tools. Beliefs and opinions are shaped by a multitude of institutions and organizations. It is for this reasons that the CDC enlisted the efforts of businesses, media, religious and social organizations across the country in order to bring about a comprehensive HIV prevention network. Not only does this partnership ensure that accurate information is disseminated, but it also creates a multiplier effect on public awareness, because the same information is communicated from a variety of sources. "Messages addressing often strongly held beliefs and values relating to the

HIV epidemic needs to be delivered to the American public from a variety of sources that they admire, trust and respect” (Moore, et al., 1991:679).

Administrators of the CDC determined that the "specific scope and content of HIV education should be locally determined and should be consistent with parental and community values (Moore, et al., 1991:679)." In order to effectively institutionalize HIV education, the CDC employed an array of institutions including State and local agencies, as well as high schools and colleges.

As young adults comprise the fastest growing HIV population, they must be furnished with accurate easily available information; education is necessary for preventing infection. Schools and universities have the responsibility and the means to effectively promote awareness of HIV-associated risk behaviors. The CDC's Division of Adolescent School Health (DASH) oversees health information that is disseminated to educational institutions and participating agencies. It is this collaborative effort that enables the CDC to increase awareness on a multitude of fronts (Moore, et al., 1991:679).

Trends in Heterosexually Transmitted HIV

In the U.S., from 1991 through 1992, heterosexual transmission of HIV accounted for the largest proportionate increase of all AIDS cases. Again, in 1993, the number of AIDS cases attributed to heterosexual contact more than doubled (AIDS Intervention Newsletter, 6/17/94:1).

In 1994, AIDS was the #4 killer of U.S. females between the ages of 25-44. The HIV positive rate of incidence in females is four times that of males in the U.S. Although women are more likely to be exposed to the virus through contaminated needles, sexual transmission has risen dramatically in the last three years (AIDS Information Newsletter, 6/17/94:1). Within eight years (from 1985 to 1993) the proportion of males who were documented as HIV positive and

were exposed to the virus through un-protected sex with a male partner decreased from 63.5% to 46.6%. During this same period the proportion of intravenous drug-using females and females exposed to this virus through sexual contact increased by 10% (from 17.4% to 27.7%) (AIDS INFORMATION NEWSLETTER, 6/17/94:2). According to the National Center for Disease Control and Prevention, for cases diagnosed in 1992 for the first time since the start of the epidemic more women were infected through sex (50%) than through drug use (44%) (AIDS INFORMATION NEWSLETTER, 6/17/94:2).

By 1993, the majority of Heterosexually acquired AIDS cases were through sexual contact with an IDU partner (up 79% from 1992), or through sexual contact with a partner whose HIV infection was not reported or diagnosed (up 195% from 1992). In 1993 local and state health departments reported 6056 female cases of heterosexually acquired HIV infection. Of these infected women, the median age was 38, 50% were non-Hispanic Black, and 24% were Hispanic. When examining the geographical location of cases reported in 1993, the highest proportion of documented cases were found in Southern and Northeastern regions. Additionally, both of these regions accounted for 77% of reported heterosexual IDUs (AIDS INFORMATION NEWSLETTER, 6/17/94:1-2).

Although individuals who have been classified as "at risk" are more likely to be male, CDC findings continue to indicate a greater proportionate increase among females within specific populations and geographical regions. "For example, among disadvantaged young women who enter the Job Corps and among childbearing women in the South, HIV positive rates were higher during 1991-1992 than during earlier years" (AIDS INFORMATION NEWSLETTER, 6/17/94:3). Furthermore, there is a disproportionate HIV positive prevalence rate among non-whites, especially women and children.

The threat of contracting HIV is far reaching. As of 1988, the fastest growing population of new cases occurred among young people between the ages of 15-24. In 1988, 15-24 year olds accounted for 2% of reported AIDS cases. By 1991, 20% of all reported cases occurred within individuals between 20-29. Because the average HIV incubation period is 10 years, the probability that this age cohort were infected by the virus during their teens is high (Moore, et al., 1991:678).

Data reveal that individuals who received HIV-related counseling and testing at a publicly funded clinic and who do not have access to health insurance are significantly more likely to be male, a racial/ethnic minority, adolescent, and to test positive (Valdiserri, et al., 1995: 51). These findings support the fact that most publicly funded programs are reaching individuals who may not have alternative means of receiving HIV testing and service needs. “Although the implementation of the Ryan White CARE Act has provided additional opportunities for HIV infected persons to receive early intervention services, health service researchers continue to demonstrate that lack of health insurance can result in inadequate preventative care and may present a major barrier to accessing ambulatory medical care” (Valdiserri, et al., 1995: 51).

Persons at risk for heterosexually transmitted HIV infection include individuals with:

- any sexual contact with any partner where there is not consistent condom use
- any sexual contact with a partner with HIV infection, AIDS virus or risk factors for HIV infection (including IDUs and recipients of contaminated blood/blood products)
- living in an area with prevalent HIV infections among intravenous drug users

For women, having sexual contact with a partner who has risk factors for HIV infection, include a partner who has had:

- any unprotected sexual contact

- male to male sexual contact, intravenous drug use, received blood or blood products contaminated with the virus
- other diagnosed or un-diagnosed sexually transmitted diseases (STDs)

It is noteworthy to add that in the past there has been a tendency to misclassify individuals at risk (there are no published estimates on the number of cases that were originally classified as “not at risk”). In 1993, of the 86,961 individuals who were originally classified as IDU cases, approximately 15% of those individuals were found to have had heterosexual contact with a partner who was later classified as at risk for the virus. Currently, the CDC is working with six local and state health departments on their reporting process for heterosexually acquired HIV infection (AIDS INFORMATION NEWSLETTER, 6/17/93:3). Uniformity in reporting must take place for the monitoring of such cases in the wake of heterosexually transmitted HIV.

Cumulative Texas AIDS Surveillance Data: San Antonio EMA

Of the 2,642 cumulative AIDS cases reported to the San Antonio Metropolitan Health District (SAMHD) from 1981 through December, 1995, 45% are currently living with AIDS. Through 1995, adults accounted for 98% of the cases reported for Bexar County. Forty-six percent of the cumulative cases reported are for individuals between 30-39 years of age. Heterosexuals and young adults represent two of the fastest growing HIV-infected groups (Moore, et al., 1991: 678). Twenty-four percent of all Bexar County AIDS cases reported through 1995 were for individuals 20-29 years of age. Demographically, case surveillance data for Bexar County indicate there have been a disproportionate number of Hispanics living with AIDS: 45% were Hispanic, 44% White, non-Hispanic, and 11% Black. Fifty percent of all adolescent AIDS cases were Hispanic, 27% White, non-Hispanic and 23% Black (SAMHD AIDS Surveillance Report, 1995: 1).

Approximately 70% of the cumulative AIDS cases were for self-identified homosexual or bisexual males, 9% homosexual/bisexual intravenous drug users, and 8% reported intravenous drug use (IDU) only. Among females, 40% of the cases acquired HIV through heterosexual contact, 26% through IDU, and 9% through a blood transfusion. Among adolescents, about 37% identified themselves as homosexual or bisexual, and 47% were hemophiliacs. Fifty percent of the female adolescent cases were IDUs (SAMHD AIDS Surveillance Report, 1995: 1).

Cumulative Texas Aids Surveillance Data: State of Texas

By September 1995, 35,000 HIV cases in Texas had been reported to the CDC. Of these cases, 42% are currently living with AIDS. Forty seven percent of cumulative Texas cases were between the ages of 30-39, 24% between 20-29, and 20% between 40-49. Since 1981, Texas has reported 212 pediatric AIDS cases (1% of total cumulative cases). Among adult cases, 60% are White, non-Hispanic, 23% are Black and 16% Hispanic. Approximately 50% of all pediatric cases in Texas are Black. Homosexual and bisexual adults and adolescents represented 70% of all cases reported, and 10% were homosexual or bisexual drug users, and 10% reported IV drug use only. Females were more likely than males to report contracting HIV through IV drug use (39%) or unprotected heterosexual sex (39%). Seven percent of females with HIV in Texas reported they were infected through a contaminated blood transfusion.

Needs Assessment: Quality Improvement Evaluations

Quality improvement evaluations within the human service arena can occur at either the case or program-levels. Evaluations occurring at the case-level aim to increase the knowledge base of client needs, assist in policy making decisions affecting clients, help demonstrate accountability and insure that the program is meeting the needs of clients at the individual level.

Program-level evaluations can occur by aggregating case-level data. Hence, an advantage of collecting case-level evaluations is that not only are the individual needs of clients being assessed, but descriptive information about the program's clients can also be reviewed (Gabor and Grinnell, 1994:8). In Evaluation and Quality Improvement in the Human Services, Gabor and Grinnell (1994) suggest that theory testing be included in the quality improvement process. Simply put, knowledge-based evaluations should be gathered from in-line health service providers in order to derive testable hypotheses regarding client needs. Knowledge-based evaluations should also strive to test hypotheses within the actual client-server environments.

Above all, evaluations in the human services attempt to assess the needs of clients (Gabor and Grinnell, 1994: 9). Practitioners are interested in knowing the degree of efficiency that they have in processing their caseloads and effectiveness of their interventions on individual cases. Comparably, clients must be included in the information sharing process. Often, clients may draw their own conclusions about the program's effectiveness based on their individual experiences. The research and evaluation process should be integrated in order to fully maximize the scope of the impact of the program's intervention. A combination of research approaches is necessary, including quantitative assessments based on scientifically selected samples and more qualitative research focusing on in-depth interviews and focus groups to explore particular issues.

Needs Assessment Processes

Needs assessment evaluations investigate the specific needs of a targeted population, not the needs of the supporting program (Gabor and Grinnell, 1994: 20). Typically, needs assessment occurs before a program is initiated. However, this evaluation process should be re-introduced after the program is implemented in order to determine the changing needs of clients.

Ideally, assessment research is an ongoing process, gathering data over time both on the same clients and on the general population of clients. Following the same people over time allows an assessment of the changing circumstances of particular clients, while sampling the general population of clients provides an overall perspective from both continuing and new clients. Client-service needs should, of course, remain congruent with changes in client demographics.

Needs assessments seek to collect such information as:

- socioeconomic profile of the community
- particular needs of the community, with respect to the type of program offered (including general and mental health, education, transportation, family support and economic support)
- kinds of services that would be most attractive and beneficial to the target community (Posavac and Carey, 1992; Gabor and Grinnell, 1994: 20).

When data are available regarding the past needs of clients, follow up evaluations provide an important means of assessing the changing needs of the community over time. Re-assessing client needs is instrumental in determining how the program is progressing or regressing. Measuring program objectives is fundamental to the quality improvement process. Thus, standardized measurements and precision should be part of the evaluation process.

Practitioner objectivity is strongly enhanced when the evaluations are driven by an external source (Gabor and Grinnell, 1994:14, 100). Evaluations that are performed by external individuals are often thought of as being more credible; certain biases in the measurement instrument and data collection process are less likely to occur when non-affiliated individuals are involved in the quality improvement process. Because relationships between the client and the health service worker is often informal and personal, practitioners run the risk of assuming client

needs or influencing how the client may respond. Clients may feel obligated to share feelings and concerns that they perceive to be expected by their service provider. External evaluations offer some security of guarding against practitioner bias, and the effect of personal bias on measuring program objectives (Gabor and Grinnell, 1994:100).

Relatedly, measurement precision is important to the quality improvement process: whoever records or collects the data must not use vague or general descriptions. Measurements should have discrete attributes so that there is no confusion regarding the conclusions drawn from the evaluated data. Clients, health service providers and those individuals responsible for the needs assessment must have a common awareness of the measurement, as well as, the program objectives. Standardizing the measurements not only increases the precision of the evaluation, but also allows the data to be compared over time.

The 1993 USCM Technical Report

In 1993, the United States Conference of Mayors (USCM) issued a technical assistance report for community-based organizations (CBOs) and local health departments (LHDs) that were attempting to assess the needs of their HIV/AIDS prevention and service programs. The report was intended to offer general guidance for CBOs and LHDs that gather client information in order to measure program objectives.

Needs assessment evaluations can range from assessing the needs of a particular target population to assessing the comprehensive needs of the entire community. Large-scale evaluations place demands on program budgets and constraints on the time of cases workers. In an era where funding sources have become scarce, and services reduced, administrators must be able to clearly:

DEFINE the target population and/or community

DESCRIBE the services and programs provided by organizations/agencies

IDENTIFY client needs and concerns

EVALUATE the problems/needs consistently against criteria specific to the population or community

FORMULATE and prioritize ways to address discover problems

COMMUNICATE the results to all audiences: decision makers, health service workers, the population and community (USCM, September, 1993:2).

Once the research question(s) is/are explicitly known to decision makers and information gathers, the methodology of the needs assessment can be customized to model the target population and their setting (USCM, September, 1993:1-2). Clearly stated research objectives are an efficient means of gathering information using available resources in order to ascertain emerging program needs from the target population or community.

The USCM suggest that HIV/AIDS programs incorporate the community in all strategic measures. Planning and implementation processes should aim to address the specific concerns and needs of service users. If community involvement and collaboration is overlooked, the integrity of the research results might be in jeopardy. The USCM strongly encourages community involvement in order to bring about awareness of culturally relevant and community-sensitive areas when collecting data (USCM, September, 1993:4). This was accomplished in this study through the input of the Ryan White Needs Assessment Committee.

Community involvement instills trust. When clients are excluded from the information-sharing process, client participation and collaboration efforts can be greatly diminished. Serving on advisory committees, participation in public hearings and serving as temporary consults are ways in which the USCM suggests clients be utilized in order to foster trust and secure working relationships (USCM, September, 1993:4).

Once the data are collected and the needs assessment process complete, it is important to evaluate the efforts utilized in implementing the project and reaching desired goals (USCM, September, 1993:11). The USCM (1993) suggests that the evaluation process garner information regarding the scope and location of client need, the inclusiveness of the study, indicators of increased awareness among the community and indication of community involvement (USCM, September, 1993:11).

Thus, any needs assessment associated with HIV/AIDS service programs can be greatly enhanced when administrators, in-line service providers and clients are working in collaboration. Determining program boundaries facilitates the assessment process by forcing evaluations to focus on current objectives and the targeted community. The HIV/AIDS community is not demographically static - intervention programs and needs assessment evaluations are sure to fail when contingent upon a non-collaborative efforts (USCM, September, 1993:1-8).

OTHER NEEDS ASSESSMENT FINDINGS WITHIN TEXAS

TDH Region 8 Health Services Delivery Area (HSDA)

During May, 1993, the San Antonio EMA HIV/AIDS Consortium members decided to reactivate the 1992 Needs Assessment Committee. Using earlier assessments conducted in 1990-91 and in 1992 as examples, the Committee planned to construct and distribute a survey instrument that would measure the needs of the community in order to educate agencies reporting to the Consortium. Surveys were non-randomly distributed through out the community in areas where HIV infected individuals were most likely to be found. A Spanish survey was not made available, however, bilingual volunteers assisted with data collection (Bexar County HIV/AIDS Needs Assessment, 1993:1).

Demographics: About 85% of the sample were male, 15% female and 1% described themselves as transgendered. Thirty nine percent identified their race/ethnicity as white, non-Hispanic, 45% as Hispanic, and 11% were Black. Most respondents (72%) were diagnosed with HIV within Bexar County; 87% of the respondents were diagnosed with HIV while living within Bexar County or the surrounding area. When asked to disclose all risk factors that may have contributed to their HIV infection, over 40% indicated (unprotected) male-to-male sexual contact, 18% from multiple sex partners, 15% from heterosexual contact, 11% from IDU and 11% were not sure of the mode of their HIV transmission.

Income: Twenty three percent of the respondents depend on Social Security as a source of income, 21% on food stamps and 16% on Supplemental Security Income (SSI). Only 14% are currently employed. Approximately 62% of the 1993 Needs Assessment respondents receive \$600/month or less from all income sources. It is not surprising that most respondents (70%) were worried about their financial situation. Survey results indicate that 50% of the clients required financial assistance with food, utilities, household items and rent. In order to ensure that the budgeted dollars remain where they were allocated, the Program makes use of existing agencies to defer need away from primary service agencies. Housing Opportunities for People Living with AIDS (HOPWA) provides assistance to clients for their rent and utility bills. Although there are food programs that currently exist, many clients indicated that they were in need of food aid. Survey results did not allow for the assessment of whether the need stemmed from lack of awareness, or if the need persisted because it was directly related to other needs. For example, lack of transportation may impact food bank and clinic accessibility (Bexar County Needs Assessment, 1993:5).

Health Insurance: Forty eight percent of the sample did not have health insurance. Of these individuals, 51% did have health insurance in the past. Individuals who had insurance in the past indicated that the reason that they had lost their coverage was related to losing their paid employment (35% report that losing their job was not related to their HIV infection, while 17% indicate that it was). Roughly 8% were covered by private insurance. Of the individuals who currently have health care coverage, 88% indicated that their current coverage does not sufficiently cover all of their health care costs. Respondents were in need of dental care; 93% of those surveyed do not have sufficient access to a dentist. Analysis of the top three health care related needs ranked by 40% of the sample revealed that clients did not have adequate access to a dentist, did not currently require home health care and are waiting, on average, two hours to be seen by their physician. Over 70% of the sample is receiving medical service from Medical Center Hospital/Brady Green CHC (Bexar County Needs Assessment, 1993:10).

Transportation and Housing: Respondents indicated that there was not enough available transportation to meet their schedules (19%) or that they did not have adequate funds to satisfy their transportation needs. Seventy seven percent did not receive any assistance with their transportation needs, and 46% desired such aid. Most respondents relied on public transit (VIA) (27%) or their own vehicle (25%) for transit needs. Of the individuals who indicated that they were in need of assistance, 58% say that their greatest need was with financial aid. Although most respondents lived alone (78%), either in an apartment (43%) or a home (40%), over 50% disclosed that they were in need of some financial assistance in order to support their housing arrangements (Bexar County Needs Assessment, 1993:15).

Medication and Eye Care: Generally, individuals who required medication for their HIV infection (or related symptoms) were not experiencing problems in receiving medications

(65%). Of the individuals who were experiencing problems, most of their dilemmas came from long waiting lines at the pharmacy (34%) or from searching for supplemental funds to subsidize medications (35%). Over 90% of those surveyed were not involved in a pharmaceutical reimbursement program. Approximately 10% of the sample has participated in a clinical trial at some time. Fifty percent of the respondents were currently enrolled in the Texas HIV Medication Program. Clients indicated a need for assistance with their eye care needs; 80% indicated that they required financial assistance for the purchase of their eye care products.

Mental Health: Since becoming aware of their HIV infection, 15% had experienced depression, 12% said they experienced exaggerated mood swings, 11% reported excessive anxiety and 12% claimed to have had communication problems with others. Only 34% of the respondents who expressed such feelings had pursued mental health care from a professional. Less than 10% sought counseling from their case manager, a psychiatrist or significant other. The greatest difficulties associated with not obtaining mental health services were tied to cost (20%) and lack of knowledge concerning preexisting services (44%) (Bexar County Needs Assessment, 1993:12).

Most clients were in need of bereavement assistance. Over 90% had not made funeral arrangements. Sixty percent of the sample indicated that family members or significant others were in need of bereavement counseling. Most clients were in need of legal information regarding their Directive to Physicians (70%) and Durable Power of Attorney (71%). Approximately half of the clients surveyed were in need of legal guidance in order to prepare their will, Power of Attorney and bill collection matters (Bexar County Needs Assessment, 1993:14).

Education/Information: Over half of those surveyed disclosed that they require additional information regarding how to identify and manage HIV related symptoms, infection control, nutritional supplements and information on how to obtain community services. Sixty percent indicated a need for legal information (Bexar County Needs Assessment, 1993: 5).

This survey also evaluated client need for supplemental income, general and mental health care, personal and home care support, transportation, bereavement and education services. Each question was designed to measure the client's present need. Attempting to capture changes in service needs within client populations facilitates the Consortium's objectives that aim to identify the range of needs of client using the various agencies' services. Community profiles help determine the amount of assistance the average individual may require at various stages of their illness. Additionally, by capturing the client's present use patterns, administrators are better able to direct funds towards agencies that support the services that are in great demand.

The 1993 Bexar County HIV/AIDS Consortium's assessment survey identified client need for services that would provide assistance with income, information sharing, medical and mental health. Unfortunately, the results generated by the survey were obtained through non-random means and did not include any references to the client's primary agency. Therefore, it

becomes impossible to examine whether client need is driven by absolute need (the service is not available) or if the need is not being fulfilled because of a lack of client awareness. Further, the assessment committee did not provide any demographic information tied to need. Demographic information may indicate that there are specific populations within the community that have a greater need tied to their socio-economic and educational backgrounds. The Program's summary report acknowledges this issue by indicating that the current assessment instrument does not address case management as a source for disseminating agency and program service information. "Though case management is not a direct need, most needs are dependent on case managers to administrate services in order the need of individuals can be meet" (Bexar County Needs Assessment Report, 1993:10).

Greater Houston EMA

In 1994, the Houston Community Needs Assessment Committee approached the Office of Community Projects' Graduate School of Social Work in order to collect measures of client service need and use within the Greater Houston EMA. The information gathered would assist with funding and project coordination. The sample was stratified by agency site. Each site was given a specified number of participants that were needed for a representative sample [selection process qualifiers for participation included: sex, race/ethnicity and mode of transmission (Greater Houston EMA, 1994: 2)]. The sample was matched with case surveillance data on age, sex and race/ethnicity.

Methodology: Face to face interviews were conducted at participating agency sites. The survey instrument included questions, in both English and Spanish, that measured client's self-reported use patterns. The Committee's final report acknowledges biases that were inadvertently built into the survey. Because individuals were interviewed at their participating agency site,

client reported need may not be captured fully if they have not been exposed to all program services. Additionally, the report indicates that clients may have expressed unsubstantiated need for services available because of the attention that they are receiving from their participation in the survey; the survey may produce a “Hawthorne” or “captured audience” effect (Greater Houston EMA, 1994: 2-3).

Demographics: Approximately 92% of the sample were 26 years of age or older. Eighty seven percent of the sample was male. Fifty five percent of the Greater Houston EMA sample identified themselves as Caucasian, 33% Black and 13% Hispanic. Less than 4% of the sample was interviewed in Spanish. Approximately 64% of the individuals interviewed indicated that the mode of their HIV transmission was the result of un-protected sex between two males, 24% through heterosexual sex (no indication of the respondent’s sex was reported) and 15% of the sample reported that they became exposed to the virus through IDU (Greater Houston EMA, 1994: 3-5).

Housing: If given the choice, clients preferred to live by themselves then in a group home (89%). Eighty one percent of all respondents preferred to live in a group home setting with services provided within the home, then live in a group home with out such services. When asked to rank their preference in housing, most respondents rated living near their doctor, hospital, counselor, family and friends and near a bus stop as being 'very important'. Most of the sample considered living in a home without rules regarding drugs and alcohol (78%) and living near childcare center or school (87.3%) as 'not applicable' to them (Greater Houston EMA, 1994:7).

Health Care: The majority of respondents depend on a medical coverage card, Medicaid or Medicare for health care coverage. Sixty percent of those surveyed received their medical

coverage through a medical clinic card. Only 5% have private insurance. Over 83% of the sample was not employed. The primary source of income for 65% of the respondents was supplemented by Social Security.(Greater Houston EMA, 1994: 8).

Education: The Committee's 1994 needs assessment uncovered interesting findings regarding the sources that client's most desire for obtaining information about HIV and social services. The Committee's final report included percentages for clients' ranking of current source(s) of information and rankings for the sources of information that they most prefer. At the time of data collection, 97.5% of the sample received program service information from the place that they were tested (and only 4.8% prefer this place as a source of information). Approximately 91% receive information from their case manager or social worker, with 33.2% favoring these individuals as sources of information. Surprisingly, 88.4% prefer “radio” as a source for HIV and service materials (with 11.6% currently receiving such information from radio). Sixty percent of the sample wanted information to be provided at their place of employment and 50% report that they currently received such information at work. Sources of information that were matched on current client use patterns and preference include school, church, newspaper and telephone hot lines (Greater Houston EMA, 1994: 9).

Respondents indicated that they prefer to access program services the most during weekday mornings, afternoons and evenings. Client problems most often associated with accessing their services, include long waiting lists, location was difficult to access, transportation problems, staff were rude or not helpful, could not receive a service without a referral from a case manager, and the quality of the service was poor (Greater Houston EMA, 1994: 10).

Usage and Need: Self-reported need rates exceeded usage rates in all service areas except for peer counseling. Approximately 22% reported that they had access to a peer

counseling group within the last 12 months and anticipate that they will utilize this service again within the next 12 months. Less than 1% indicated that they have a need for this type of service. Service areas where client need exceeded client use the greatest were for adult day care, counseling (pastoral, Buddy and crisis), vocational training/placement, dental and eye care, financial assistance, food supplies, housing, transportation and legal assistance (Greater Houston EMA, 1994: 11-13).

Unfortunately, the construction of the survey instrument did not permit evaluators to partition reported need away from awareness of services provided by the program. Further, the survey did not measure client's awareness of services provided outside of their primary agency. If the data were available, researchers would be better able to predict which services are in need of additional funding and support, as well as uncovering unnecessary duplications of services and directing efforts toward expanding client awareness of services dispensed by the Consortium. Results from the needs assessment seem to suggest that efforts should be directed at increasing client awareness concerning the scope of services offered by the program. It is not clear whether clients were unable to access certain services because they were unaware that they exist, were unable to access them because of lack of transportation, or because of administrative barriers tied to case manager referrals.

NEEDS ASSESSMENTS OUTSIDE OF TEXAS

St. Petersburg/Tampa

In 1993, the Tampa/St. Petersburg Eligible Metropolitan Area HIV/AIDS Continuum of Care collaborated with four surrounding counties in order to gather instrumental data that would measure where service need is the greatest within the HIV/AIDS community. The sample was stratified by participating agencies. Self-administered survey instruments were distributed to

providers, and, in turn, providers distributed surveys to clients. Not only did this assessment attempt to capture current client need, but also attempted to solicit much-needed information regarding the opinions and needs of providers. Because case managers distributed surveys to clients non-randomly, the results may show effects of experimenter bias (Tampa/St. Petersburg Needs Assessment, 1993: 1).

Respondents ranked twelve service areas for need. The top six areas, in ascending order were: financial help (81%), transportation (37%), pharmaceuticals (32%), health care (30%), legal assistance (25%), and mental health care (22%). Regardless of sex, race/ethnicity or county, financial assistance was ranked consistency as the most important need. The top six needs perceived by the providers, were: housing (housing was not included in the client's list as a category), financial help, transportation, dental care, emotional support and medical care (both tied), legal assistance, case management and home health care (all tied) and HIV/AIDS education (Tampa/St. Petersburg Needs Assessment, 1993: 1-2).

Demographic Information: Of the respondents who completed and returned the assessment, 62% identified their race as White, 27% as Black, 7% as Hispanic and 4% as American Indian/Alaskan Native. Over 75% of the sample was male. The majority of the respondents (52%) identified themselves as homosexual and 12% as bisexual. The sample was relatively young, with most respondents reporting their age under 40; 17% of the sample were between the ages of 20 and 29. Male clients appeared to have slightly more formal education, although 47% of the females and 30% of the males had less than a high school education (Tampa/St. Petersburg Needs Assessment, 1993: 7-8).

The majority of the sample was identified as of AIDS-symptomatic. Fifty five percent of the sample described their everyday abilities as being moderately or completely impaired due to

their illness. Less than 10% reported feeling healthy all of the time. Between 52% and 66% of the sample had been diagnosed with AIDS. Case surveillance data were obtained to ensure that a representative sample was drawn. Unfortunately, the surveillance data was comprised exclusively of people with AIDS, while the needs assessment sample contains both individuals with AIDS and individuals who have not been diagnosed with AIDS. However, when comparing both samples, analysis reveals that clients who have not developed AIDS are over-represented in the assessment sample by only 3% in 3 of the 4 counties (Tampa/St. Petersburg Needs Assessment, 1993: 12).

Financial Assistance: Assistance with food, housing, and medicines and for a vacation were the top four areas of financial need ranked by clients. Females out ranked males in all areas of financial need. Seventy percent of females indicated a need for assistance with food, 76% for clothing and 58% for the care of a child (compared with 60% of the males who expressed need for assistance with food, 10% for clothing and 11% for the care of child). Seventy percent of Hispanics, who comprised only 7% of total respondents, reported they needed food assistance. This compares to slightly over 50% of members of other race/ethnic groups indicating a need for food services. Over 70% of Blacks sampled indicated a need for financial help with their clothing. Implications related to financial need become great, considering only 15% of all respondents were currently employed and almost half of those employed at the time indicated that they were experiencing difficulty in maintaining enough strength to keep their employment (Tampa/St. Petersburg Needs Assessment, 1993: 19-20).

Perhaps reflecting that the majority of the sample was symptomatic, over half of the respondents expressed a need for assistance with daily household activities. Not only did clients communicate a general need for transportation but also for someone who would do the driving

(46%). Other areas of need that required paying for assistance included help with legal matters (45%), emotional matters, and with shopping and laundry (40% each) (Tampa/St. Petersburg Needs Assessment, 1993: 21).

Service Providers: There was a lot of overlap in the services provided by participating agencies, many of which were not identified by clients as service areas most needed. Approximately two thirds of the service providers sampled indicated that they provide counseling services (not including mental health), 52% provided educational and risk reduction services, 48% offered case management and 44% client advocacy. Of the services that clients prioritized by need, only 21% of the providers reported offering housing-related assistance, 31% transportation, 17% financial assistance and 38% primary medical care. For practical purposes, providers were not presented with a list of services that encompass the scope of all services offered by all agencies. Therefore, there was no adequate way of assessing the proportion of providers that offered pharmaceutical assistance, since this option was not made available in the provider survey. As between 52%-66% of the sample have been diagnosed with AIDS, services related to medicine and acute care should have been included in the provider survey (Tampa/St. Petersburg Needs Assessment, 1992: 35).

Of the three providers that responded to the survey, two had outreach programs. These outreach programs tended to target ethnic minorities, women and homeless individuals. Relatedly, providers were asked to indicate (from a provided list) the top three service barriers that prevent low income and minority individuals from receiving services. Awareness of services (67%), transportation (42%), trust (42%) and awareness of organizations (40%) were consistently mentioned as barriers to services (Tampa/St. Petersburg Needs Assessment, 1993: 36).

Effective communication is key for building trust and maintaining rapport with clients. Although the Tampa/St. Petersburg area has a considerable Spanish-speaking only population, 73% of the providers reveal that they have difficulty communicating with their Spanish-speaking clients. Providers also indicated that their staff members are not sufficiently trained to communicate with hearing or language impaired individuals.

The assessment committee that supported both client needs and funding requirements made recommendations to the planning council. Providers indicted that awareness of the types of services available was a major barrier preventing low income and minority individuals from accessing services. Survey results show that African American and female clients tended to have less formal education and express more difficulty with reading and writing than Whites and males. Because the survey was self-administered, illiterate and non-English reading individuals were not represented in the study. The Tampa/St. Petersburg EMA made recommendations that would attempt to impact both of these barriers. For example, out-reach programs should emphasize non-written strategies, using techniques that are culturally sensitive to non-English speakers (Tampa/St. Petersburg Needs Assessment, 1993: 42).

Recommendations were also made for creating strategies that exclusively target Hispanic needs. Results indicted that in one community Hispanics are experiencing more difficulty receiving primary medical care and medicines than non-Hispanics. Combined with the rising incidence of HIV among Hispanics, a directive was issued for the implementation of an Hispanic-only HIV service organization. Further, the final assessment report also suggested that the newly created organization should not become a splinter of an already-existing, primarily white, non-Hispanic organization (Tampa/St. Petersburg Needs Assessment, 1993: 43). Finally, the assessment committee recommended that further research be initiated in order to gather

much-needed data on the scope of community transportation and legal assistance needs (Tampa/St. Petersburg Needs Assessment, 1993: 49).

Seattle EMA

The 1992 Suncoast AIDS Network (SCAN) Needs Assessment entailed a three step research process. The first step attempted to estimate current population need. The second estimated provider capacity, with the third comparing capacity and need in order to produce quantified results.

Demographics: The prevalence of reported cases remains within the homosexual and bisexual communities. Ninety percent of Seattle's EMA clients were self-identified homosexual and bisexual males. Since 1987, reported cases acquired through heterosexual (either male or female) contact, IDU and through prenatal exposure have not risen above 1-2%. The greatest use of service remained within the homosexual and bisexual communities (SCAN, 1992: 38).

Within the Seattle EMA, in 1992, the estimated total population with HIV virus was 11,915. Of these cases, 96% were male, 4% female and less 1% pediatric. The greatest proportion of total cases has been identified as being HIV positive and non-symptomatic (75%). Approximately 10% of individuals were symptomatic (non-AIDS) and 15% were alive with AIDS (SCAN, 1992: 47).

Health: Findings related to current capacity indicated that all providers did not support primary care needs, that there was a provider shortage to support all of the needs of the entire population. The EMA program supported only 55% of male primary care needs and 50% of female needs. The current program only supported two-third of the entire population. Additionally, the program could only support 34% of the mental health need (SCAN, 1992: 39).

Case Management: Traditionally, case management services were delivered to Class IV HIV (AIDS) clients only. Incidentally, the program could only support 44% of the combined need of Level II and III males, and 50% of Level II and III females. According to the CDC's definition of Level I clients, there is a significant deficiency in the units of service that can be delivered within the EMA. SCAN'S concluding notes do, however, mention that there were other programs that had developed within select communities to exclusively support the specific and growing needs of Level I clients

Housing: In the past, the Foundation had been able to assist clients with emergency, traditional and permanent subsidized housing. Research revealed that the need for housing within the EMA had exceeded availability. Current capacity could only support 38% of reported need. Related to housing needs were nutritional and transportation assistance. Many of the individuals who need access to food banks/home meals and transportation the most were also unable to independently finance their housing. There was only one organization with SCAN's EMA (Chicken Soup Brigade) that supports food bank and housing needs. This organization could only support 28% of the estimated need. This same organization solely, fulfilled 41% of the transportation needs within the Seattle EMA (SCAN, 1992: 41).

The Seattle EMA Continuum of Care receives funding from local, state and federal agencies. Program coordinators regulate agency services by mandating that providers explicitly state the services they offer so that lead agencies can ensure that their services are not duplicated, when not needed. The Foundation's current objectives were based on a large scale needs assessment, planning and prioritization process that took place in 1992 (SCAN, 1992: 42).

In part, the success of the Seattle Continuum of Care is due to the mainstreaming of existing agencies/organizations and the establishment of lead agencies that coordinate, develop and implement community and home-based AIDS-related services. Additionally, the Foundation

closely monitors the eligibility of the ill for case management and provides creative approaches to care and culturally sensitive services to disenfranchised populations (SCAN, 1992: 44).

Collaboration and awareness of the services coordinated through the lead agencies has enabled Seattle's Continuum of Care to respond successfully to changing clients' needs.

SUMMARY OF NEEDS ASSESSMENT REPORTS

The following list highlights those areas of common need reported by the various reports reviewed:

- **FINANCIAL AID**
 - **Living Expenses**
 - **Medical Expenses**
 - **Pharmaceutical Expenses**
- **HOUSING/SHELTER**
- **FOOD**
- **TRANSPORTATION**
- **COUNSELING**
- **LEGAL AID**
 - **Power of Attorney**
 - **Wills**

Most clients are in need of financial assistance to help defer expenses tied to every day living (housing, food, utilities), medical and pharmaceutical costs. The majority of clients in these needs assessments reported preferring to live alone and in close proximity to their health caretakers and agencies. Clients used food services, in particular on-site meals and food banks, extensively. Transportation to and from service agencies as well as medical facilities was also widely utilized. Many clients reported that they desired more peer and buddy counseling assistance programs, and that they need guidance in making power of attorney and funeral

arrangements. Preferred hours of operation for service agencies included weekday mornings, afternoons and evenings.

NEEDS ASSESSMENT RESEARCH METHODOLOGY

This project was designed to provide an assessment of the use of services and the levels of satisfaction with services provided currently by community based organizations in San Antonio, as well as an evaluation of services clients would like to have available. This needs assessment is based on a survey of clients using a modified version of the questionnaire developed in 1994 by the Ryan White Needs Assessment Committee. The questionnaire ranged from a little over 30 minutes to complete when self-administered by relatively unimpaired clients to well over an hour in personal interviews with expressive clients or those with more extensive physical/medical challenges.

The sampling strategy was originally planned to be based on interviews with randomly selected clients drawn from a compilation of unique identification numbers provided by Community Based Organizations. The randomly selected clients were to be contacted by their case managers, who would obtain signed consent forms and make arrangements for the interview. Most of the interviews were to be completed by telephone, with a subset to be interviewed personally. Unfortunately, there were a lot of problems with the accuracy of the original list of unique identification numbers. Case managers had difficulty contacting the clients. Many clients had no phone numbers or their phones were disconnected and reconnected periodically, probably associated with ability to pay monthly bills. Often clients on the list were deceased by the time the attempt was made to contact them. Clients actually contacted for telephone interviews were often too ill to be interviewed at the time of the call and appointments were repeatedly rescheduled. After struggling with these difficulties through October and November of 1995, the sampling approach was reconceptualized in consultation with members of the Ryan White Needs Assessment Committee.

The new sampling strategy was designed in two main parts:

1. Each agency was asked to provide a "convenience" sample of at least five on-site clients, paying attention to representing the diversity of their clients in terms of age, gender, race and ethnicity, and stage of illness. Agency representatives attended a training session on November 29, 1995, focusing on procedures for obtaining consent forms and conducting the on-site interviews. Additionally, interviewers from UTSA conducted group interviews on-site at the larger agencies, interviewing all consenting clients on a variety of days and evenings. Refusals were rare and in most cases all on-site clients were given the opportunity to participate. Therefore, this non-random convenience subset can be expected to represent the population of on-site users of services from December of 1995 through June of 1996.

2. An updated file of unique identifiers provided by the various service providers, based on data from January 1, 1995 through December 15, 1996, was compiled in the COMPIS Program and became the new source of a stratified random sample of all known HIV positive and AIDS patients. Agencies were provided with the new randomly drawn unique identification numbers in January of 1996. Again, the agencies were to make the first contact with potential respondents and make arrangements for the interviews. Once consent was obtained, arrangements were made for personal telephone interviews when possible, or for personal interviews at the agency or at the home of the client when necessary. The desired completed sample size was set at 285 completed surveys, to produce a plus or minus 5% probability of error based on the estimated size of the client population. This randomly drawn sample was designed to represent all **known** HIV positive and AIDS cases whether or not they are current on-site users of services, and the total sample is large enough to allow meaningful analysis of different subgroups within the overall sample. Omitted from this assessment, of course, are all of the HIV/AIDS infected individuals in the community who have

never been in contact with any of the service providers that contributed to compiling the list of clients.

Interviewers from the Gay and Lesbian Student Association at UTSA were identified and trained for this project. Some of the interviewers were gay, some were lesbian, and some were heterosexual, but all have a sustained involvement in protecting and promoting the rights of gays, lesbians and bisexuals. Additionally, two interviewers were fluent in Spanish. Two of the interviewers were Hispanic and one was African American. Therefore, these interviewers had both the sensitivity and empathy required to create rapport with the respondents. They were trained in effective telephone as well as personal interviewing techniques, and in data entry procedures, and they met as a group periodically to discuss their experiences. They also displayed enormous patience, since problems with scheduling and rescheduling appointments continued throughout the data collection process. Nevertheless, 290 interviews were finally completed.

SAMPLE PROFILE

As shown below, agency personnel completed 85 interviews and UTSA interviewers completed 205. Of the total of 290 interviews, only 35 ended up being completed on the telephone. Thirteen interviews were conducted in Spanish, all of them completed by UTSA interviewers. The distribution of respondents by source agency is also provided.

Sources of Interviews

ORIGIN OF COMPLETED INTERVIEWS

	TOTAL	%
1) UTSA Interviewers	205	70.7
2) Agency Personnel	85	29.3
TOTAL USABLE RESPONSES	290	100.0

TYPE OF INTERVIEW

1) In person interview	255	87.9
2) Telephone interview	35	12.1
TOTAL USABLE RESPONSES	290	100.0

LANGUAGE OF INTERVIEW

1) ENGLISH	277	95.5
2) SPANISH	13	4.5
TOTAL USABLE RESPONSES	290	100.0

SOURCE AGENCY FOR INTERVIEW

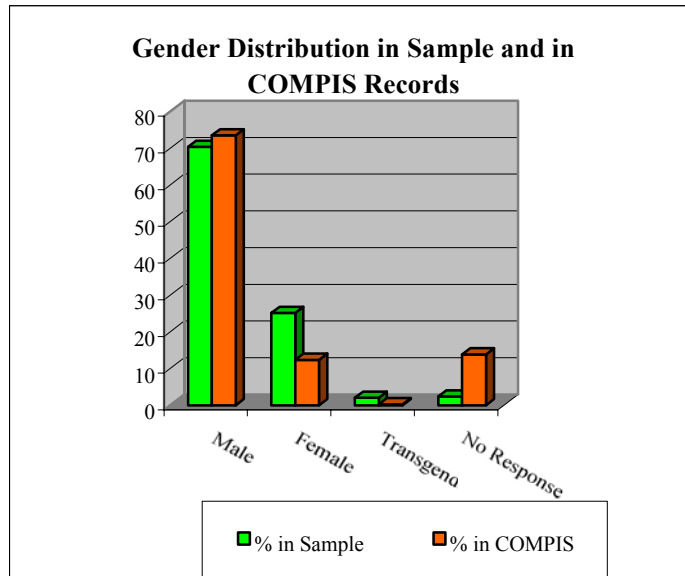
1) AARC	53	18.3
2) BEAT AIDS	28	9.7
5) HISP AIDS COMMITTEE	40	13.8
6) INTERIM HEALTH CARE	2	0.7
7) SAAF	17	5.9
8) SAMHD	29	10.0
9) WELLNESS CONNECTION	20	6.9
10) UTHSC PEDIATRICS	35	12.1
11) FFACTS	34	11.7
12) LOS MUJERES PROJECT	3	1.0
13) PROVIDENCE HOME	21	7.2
14) RYAN WHITE DENTAL	8	2.8
TOTAL USABLE RESPONSES	290	100.0

Demographic Characteristics

The following pages provide a profile of demographic characteristics of the sample respondents, with selected comparisons to the client base as recorded in the COMPIS Program. An active effort was made to oversample women in the on-site convenience interviews to assure sufficient numbers of female respondents for analysis. Therefore, 25.17% of the sample respondents are women compared to 12.37% in the COMPIS client base. The interviews completed by Agency personnel produced 38.1% female respondents, and of the convenience sample respondents as a whole, 36.1% were female. All 6 of the transgender respondents were obtained from the random sample process and were interviewed by UTSA interviewers.

How do you classify your gender or sex?

	<u>Sample Respondents</u>		<u>COMPIS Client Base</u>
	Frequency	%	%
Male	204	70.34	73.51
Female	73	25.17	12.37
Transgender	6	2.07	0.27
No Response	7	2.41	13.85

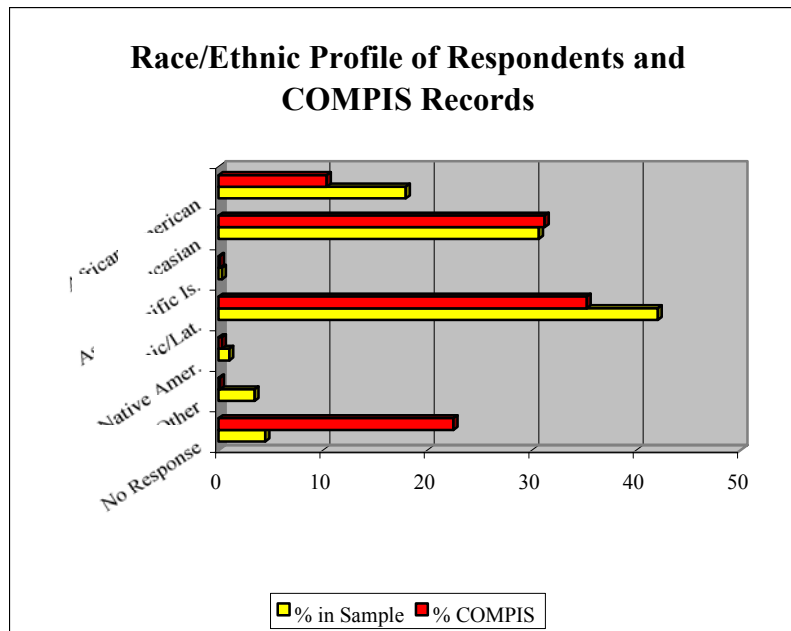


Race and Ethnicity

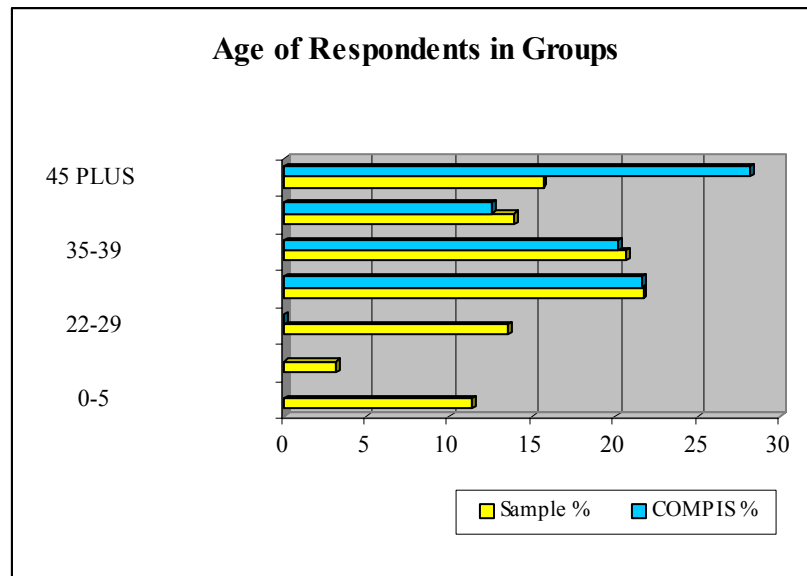
The racial and ethnic distribution of the respondents is shown below. Again, a deliberate attempt was made to oversample minority respondents, especially African Americans. This outcome is reflected in the sample percent of 17.83 compared to the COMPIS percent of 10.37 for African Americans. It is also reflected in the sample percent of 42.07 compared to the COMPIS percent of 35.27 for Hispanics. The large percent for No Response/Unknown in the COMPIS data file makes this comparison problematic. It is likely that a disproportionate share of the unknown respondents in the COMPIS file is comprised of minority clients. If this is the case then the sample respondents represent the racial and ethnic distribution of the client base very well.

What is your race/ethnicity?

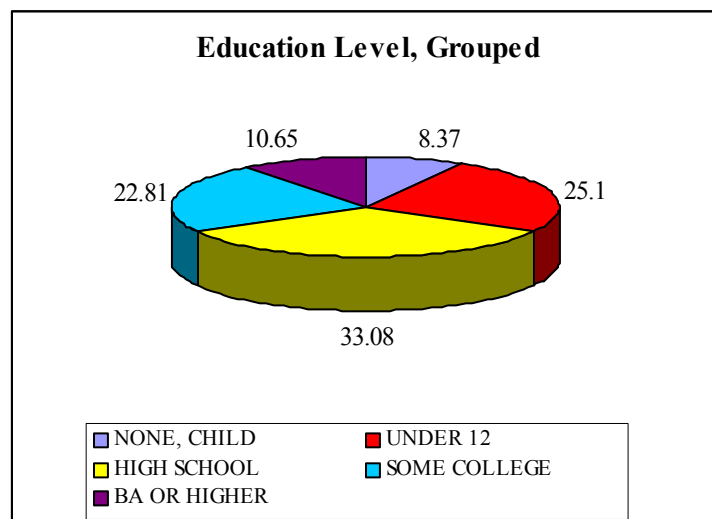
	<u>Sample Respondents</u>		<u>COMPIS Client Base</u>
	Frequency	%	%
African American	52	17.93	10.37
Caucasian	89	30.69	31.24
Asian/Pacific Is.	1	0.33	0.15
Hispanic/Lat.	122	42.07	35.27
Native Amer.	3	1.03	0.32
Other	10	3.45	0.15
No Response	13	4.48	22.50



The following pages also provide information on respondent characteristics based on their reported ages, living arrangements, education levels, total monthly incomes, CD4 levels and sources of infection. **These results illustrate that the sample represents the diversity of the client base quite well.**

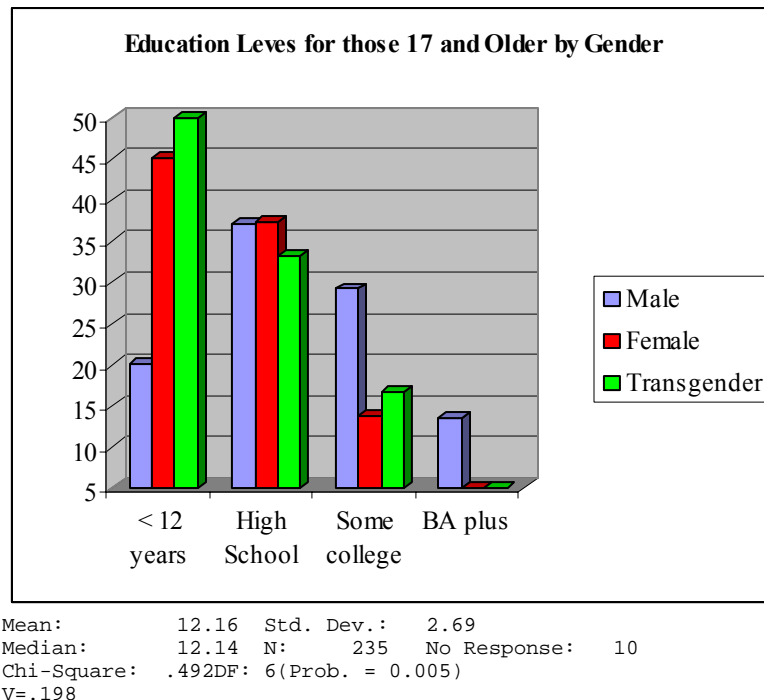


COMPIS data are for ages 0 through 29
Mean Age = 32.58 Median Age = 34.56
Std.Dev. 13.80



Mean Years Education, 11.11 Median Years Education, 12.01
Std.Dev. 4.28

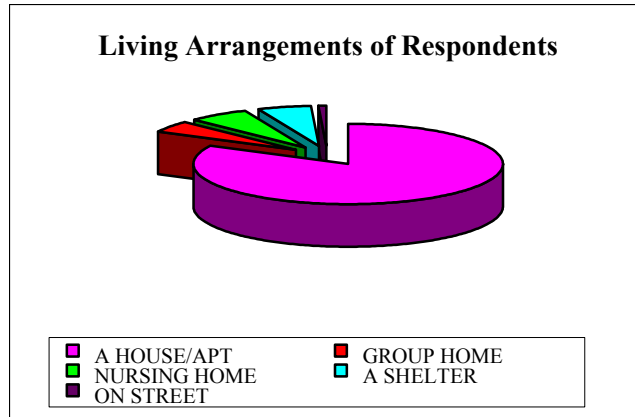
The following data are subset to include only those age 17 or over, which omits the impact of the pediatric cases on the overall educational level.



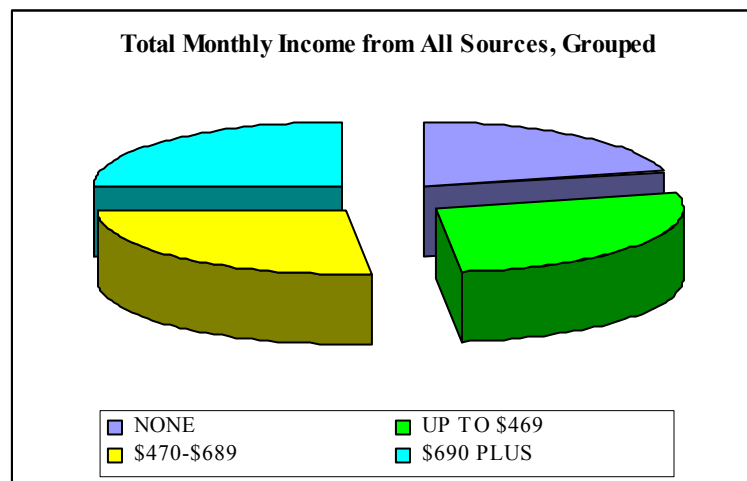
One important observation is that there is a substantial difference in educational attainment between the men and the women. Note the much higher proportion of women with less than a high school degree. The transgender respondents also tend to have very low levels of education.

Living Arrangements

The vast majority of respondents report themselves to be living in a house or apartment, at 82.56%. Only two of the respondents indicated that they are homeless and living on the street, with



another sixteen indicating that they are presently living in a shelter or at a temporary residence.



Mean \$493.70 Median \$467.89
Std.Dev. \$430.79

There is a close association between income level and age, as shown below.

AVERAGE INCOME LEVELS BY AGE GROUP

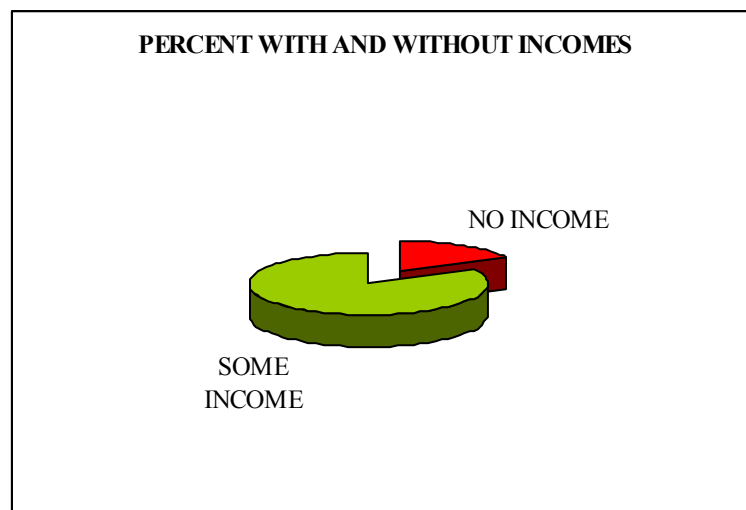
N: 275	No Response: 15		
	N	Mean	Std. Dev.
0-5	32	176.813	209.548
10-19	9	237.889	197.991
22-29	38	439.132	275.332
30-34	61	574.262	519.194
35-39	54	496.444	394.947
40-44	38	518.263	401.509
45 plus	43	677.605	494.454

N: 275 No Response: 15
F = 5.725 Prob. = 0.000 ETA SQ. = 0.114

Since the pediatric cases affect the income information, we have subset to include only those aged 17 and over. As shown below, the mean for this group is \$538 per month -- which is well below the monthly income level of \$645 (\$7740 per year) that defines poverty for a one-person household. Note that 42 of these respondents (nearly 18%) reported no income at all.

INCOME LEVELS FOR THOSE AGED 17 AND OVER

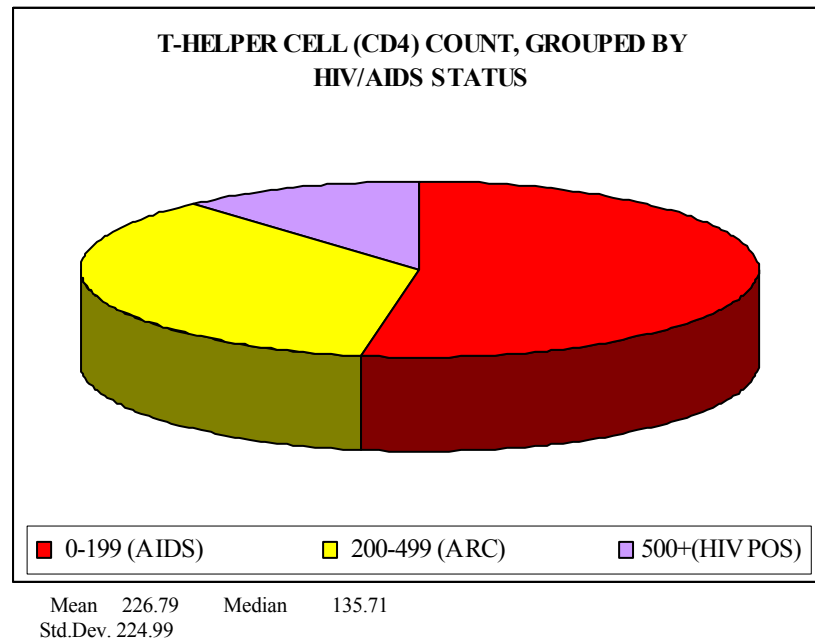
Mean: \$538.24 Std. Dev.: \$436.72
N: 239 No Response: 6



HIV STATUS

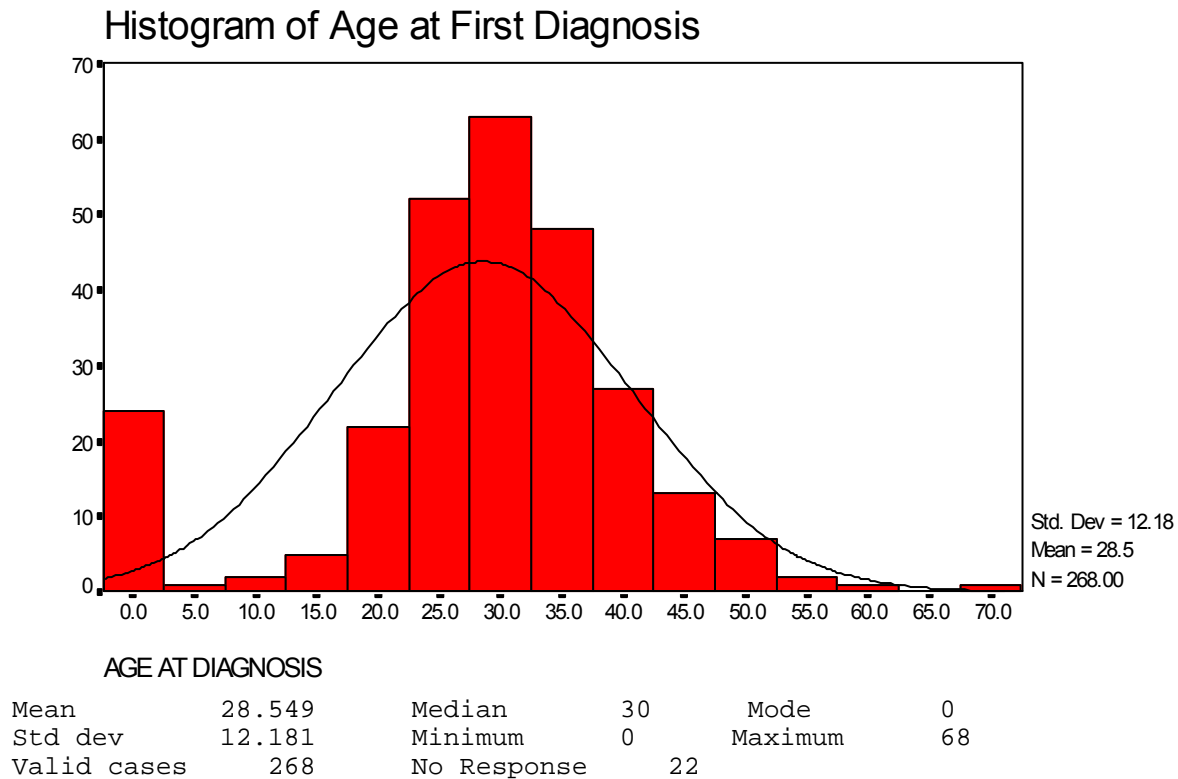
Data for our analysis were collected prior to the release of the new HIV/AIDS drug “cocktails” and the use of viral load measures as indications of how far along the disease had progresses. Therefore, we rely on T-helper cell counts (CD 4 cells) to create categories, which relate to disease progression. The 57 respondents with no response to this question were examined to determine their impact on later analyses. Nearly 50% of them (28) were among the pediatric patients. Excluding the children, the missing respondents were generally spread across the main

demographic groups, indicating that their exclusion will not seriously bias analyses based on this variable.



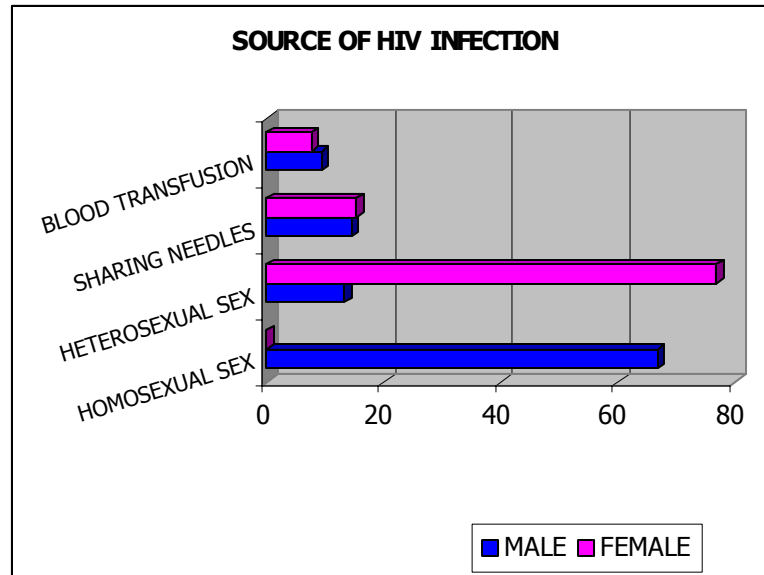
Age of Diagnosis

The age at which sample respondents reported that they were first diagnosed with HIV is shown below. The mean is 28.5, which is somewhat influenced by the 23 respondents diagnosed at birth. The median is 30, which is a more realistic average.



Source of infection

The Figure on the next page provides information on how the respondents age 17 and over think that they got HIV. Focusing on the males first, nearly 67% identify sex between two males as the probable source of infection. This is followed by 14.4% who think it is from injecting drugs with needles, 13.3% who think it is from heterosexual behavior, and 9.4% who indicated blood or blood products transfusion. Nearly 77% of the females identify heterosexual behavior as the probable source of infection, followed by 15.4% who think it is from injecting drugs with needles and 9.7% who indicated blood or blood products transfusion.



Multiple Sources of Infection

The issue of multiple at risk behaviors is explored briefly with the data on the next page, focusing on male and female respondents aged 17 and over. Note that the percentages presented are “total” percentages, showing the joint occurrence of two behaviors. For example, out of the total of 181 males providing responses, 11 or 6.1% identified **both** homosexual behavior and injecting drugs with needles as probable sources of the infection. Only 8 or 4.4% answered yes both to heterosexual behavior and needles as likely sources of the infection. Shifting to the women, again only 4 (7.7%) identified both needles and heterosexual behavior as probable sources. The clearest conclusion that can be drawn from this information is that even though many of the respondents report having engaged in a variety of high-risk behaviors, based on other questions on the survey, they tend to identify only one probable source of HIV infection.

REPORTS OF MULTIPLE SOURCES OF HIV INFECTION AMONG MALES 17-75 YEARS OLD

Homosexual Sex and Shared Needles

	No	Yes	No Response	TOTAL
No	45	15	0	60
	24.9	8.3		33.1
Yes	110	11	0	121
	60.8	6.1		66.9
No Response	0	0	10	10
TOTAL	155	26	10	181
	85.6	14.4		100.0

Chi-Square= 8.253 df=1(Prob. = 0.000) V=.214

Heterosexual Sex and Shared Needles

	No	Yes	No Response	TOTAL
No	139	18	0	157
	76.8	9.9		86.7
Yes	16	8	0	24
	8.8	4.4		13.3
No Response	0	0	10	10
TOTAL	155	26	10	181
	85.6	14.4		100.0

Chi-Square=8.093 DF= 1(Prob. = 0.000)
V: 0.211

FEMALES 17-75 YEARS OLD

Homosexual Sex and Shared Needles

	No	Yes	No Response	TOTAL
No	8	4	0	12
	15.4	7.7		23.1
Yes	36	4	0	40
	69.2	7.7		76.9
No Response	0	0	2	2
TOTAL	44	8	2	52
	84.6	15.4		100.0

Chi-Square=3.861 DF= 1(Prob. = 0.049)
V=0.272

ASSESSING THE IMPACT OF THE TWO PART SAMPLE DESIGN

With the complex final sampling process, it is important to assess whether sampling design issues affected the distribution of the respondents. Several tests are presented below, with cross-tabular results and Chi-Square tests for the likelihood that differences are systematic or likely to be due to chance. Each table gives the number of respondents for each category first and then the percentage below. The direction of the percentages, row or column, is always indicated by a total of 100% in the respective location. All of the following cross-tabular data presentations are interpreted in the same manner. For example, of the total of 52 African Americans, 32 were interviewed by UTSA and 20 by Agency personnel, representing 16.4% and 24.4% respectively. Overall these results show the diversity of respondents for both sources of interviews, and the Chi-Square significance level (Prob. = 0.371) indicates the differences between the UTSA and Agency percentages could be due to chance. The “Prob.” number is the significance level or the probability that the observed differences in a table are due to chance or sampling error. With samples of this size, researchers often use a significance level of 0.10 or smaller to establish “**statistical significance**” -- which means that they conclude that there probably is a real difference shown in a particular table. The most conventional approach is to use 0.05 or smaller as the basis for deciding that the differences in the table are statistically significant. The actual probability (significance level) is reported throughout this document, allowing the readers to exercise their own judgments on this issue.

[Please note that when there are many categories with few respondents, the Chi-Square statistic tends to be biased and should be used only with caution. If only African American, Hispanic and Caucasian respondents are included in the UTSA/Agency comparison, the Chi-

Square is 2.922, with 2 degrees of freedom and a significance level of 0.232 -- leading us to the same conclusion of no significant difference.]

Major focus should be given to any differences between respondents selected through the convenience sampling approach compared to those identified by the random selection process. This is explored below with several different comparisons. First we continue to focus on race and ethnicity. Again, based on the Chi-Square statistic, there is no statistically significant difference between the convenience and random sample respondents (Prob. = 0.101). Confining the analysis to the three largest groups produces a Chi-Square of 2.770, with 2 degrees of freedom and a significance level of 0.250. Therefore, there is no evidence of systematic difference in racial and ethnic composition for the two different groups.

RACE/ETHNICITY OF RESPONDENTS BY SOURCE OF INTERVIEW

	UTSA	AGENCY	TOTAL
African Amer.	32	20	52
	16.4	24.4	18.8
Caucasian	66	23	89
	33.8	28.0	32.1
Asian/Pacific Is.	1	0	1
	0.5	0.0	0.4
Hispanic/Lat.	89	33	122
	45.6	40.2	44.0
Native Amer.	2	1	3
	1.0	1.2	1.1
Other	5	5	10
	2.6	6.1	3.6
No Response	10	3	13
TOTAL	195	82	277
	100.0	100.0	100.0

Chi-Square=5.381 DF=5 (Prob=.371)
V=0.139

RACE/ETHNICITY OF RESPONDENTS BY RANDOM/CONVENIENCE SELECTION

	Random	Convenience	Total
African Amer.	31	21	52
	16.9	22.3	18.8
Caucasian	65	24	89
	35.5	25.5	32.1

Asian/Pacific Is.	1	0	1
	0.5	0.0	0.4
Hispanic/Lat.	81	41	122
	44.3	43.6	44.0
Native Amer.	2	1	3
	1.1	1.1	1.1
Other	3	7	10
	1.6	7.4	3.6
No Response	9	4	13
TOTAL	183	94	277
	100.0	100.0	100.0

Chi-Square=9.214 DF= 5 (Prob.=.101)

V=0.182

As shown below, there is no systematic difference in the self-reported HIV status of the respondents between those selected between the convenience and random processes. In fact, the distributions are virtually identical, reinforcing our conclusion that no bias emerged from the two different sampling approaches.

SELF REPORTED HIV STATUS BY RANDOM/CONVENIENCE SELECTION

	Random	Convenience	Total
POS. ASYMPTOMATIC	49	25	74
	27.1	26.9	27.0
POS. SYMPTOMATIC	69	39	108
	38.1	41.9	39.4
AIDS	53	25	78
	29.3	26.9	28.5
DON'T KNOW	10	4	14
	5.5	4.3	5.1
No Response	11	5	16
TOTAL	181	93	274
	100.0	100.0	100.0

Chi-Square=0.532 DF=3 (Prob.=.912))

V=0.044

The income distributions for the convenience and random respondents are not significantly different from each other.

TOTAL MONTHLY INCOME BY RANDOM/CONVENIENCE SELECTION

	Random	Convenience	Total
None	33	26	59
	17.9	27.1	21.1
Up to 469	51	25	76
	27.7	26.0	27.1
470-689	49	25	74
	26.6	26.0	26.4
690 Plus	51	20	71
	27.7	20.8	25.4
No Response	8	2	10
TOTAL	184	96	280
	100.0	100.0	100.0

Chi-Square=3.758 DF= 3 (Prob. = 0.289)
V=0.116

We also explored whether or not there were systematic differences in the overall level of satisfaction with services provided by the community agencies. As is very clear below, there is no meaningful pattern of differences, providing a solid basis for combining the convenience and randomly selected respondents for further analyses.

OVERALL SATISFACTION BY RANDOM/CONVENIENCE SELECTION

	Random	Convenience	Total
Very Satisfied	70	40	110
	37.8	42.1	39.3
Satisfied	75	41	116
	40.5	43.2	41.4
Neutral	30	12	42
	16.2	12.6	15.0
Dissatisfied	6	1	7
	3.2	1.1	2.5
Very Dissatisfied	4	1	5
	2.2	1.1	1.8
No Response	7	3	10
TOTAL	185	95	280
	100.0	100.0	100.0

Chi-Square=2.570 DF= 4 (Prob. = 0.632)
V=0.096

Type of interview sometimes can also have an effect on responses. Below we examine in person versus telephone and English versus Spanish interviews. Interestingly, the percent very satisfied was higher among those interviewed by telephone, though this is not statistically significant. If a bias existed, we would expect those at home, away from the agencies, being interviewed by “strangers” not affiliated with the agencies, would be more likely to express dissatisfaction. This is clearly not the case here.

OVERALL SATISFACTION BY TYPE OF INTERVIEW

	In Person	Telephone	TOTAL
VERY SATISFIED	92	18	110
	37.6	51.4	39.3
SATISFIED	103	13	116
	42.0	37.1	41.4
NEUTRAL	40	2	42
	16.9	5.7	15.0
DISSAT.	6	1	7
	2.4	2.9	2.5
VERY DISSATISFIED	4	1	5
	1.6	2.9	1.8
No Response	10	0	10
TOTAL	245	35	280
	100.0	100.0	100.0

Chi-Square=4.256 DF= 4 (Prob. = 0.372)
V=0.123

We also explored the possibility that language of interview might have a bearing on levels of satisfaction. In theory, this could happen if the Spanish speakers encountered greater difficulties in obtaining assistance and services, or based on imperfect translation of the questionnaire, or some other factor, or a combination of possibilities. The results do not show any systematic or statistically significant difference between those respondents interviewed in English or Spanish.

OVERALL SATISFACTION BY LANGUAGE OF INTERVIEW

English	Spanish	TOTAL
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VERY SATISFIED	105	5	110
	39.2	41.7	39.3
SATISFIED	112	4	116
	41.8	33.3	41.4
NEUTRAL	40	2	42
	14.9	16.7	15.0
DISSAT.	7	0	7
	2.6	0.0	2.5
VERY DISSATISFIED	4	1	5
	1.5	8.3	1.8
No Response	9	1	10
TOTAL	268	12	280
	100.0	100.0	100.0

Chi-Square=3.563 DF= 4 (Prob. = 0.468)
V=0.113

ECONOMIC STATUS OF RESPONDENTS

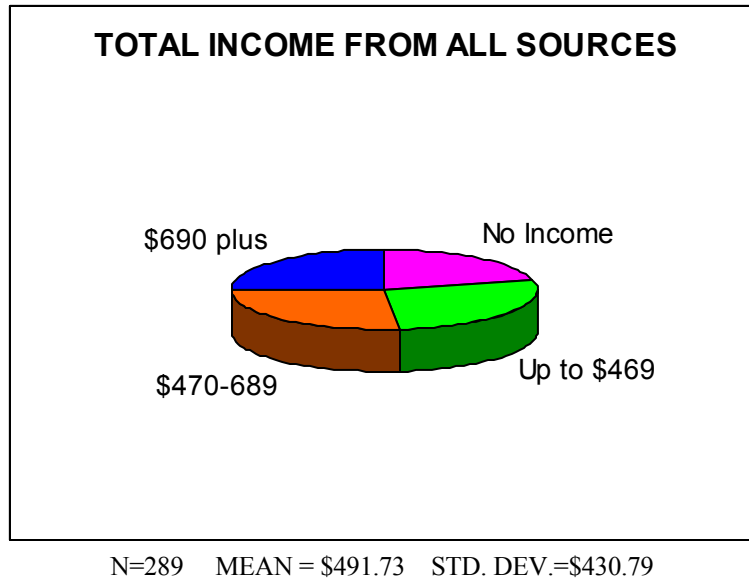
It will come as no surprise that the respondents collectively represent a group of people in dire economic circumstances. Respondents were asked to report their monthly income from each of twelve different sources. Based on the sum of the incomes from all of these sources, 200 out of the 280 responding to the income questions, or 74.1%, are at or below the official poverty line. The official poverty line for a one-person household is \$7,740, based on the 1996 poverty guidelines from the U.S. Department of Health and Human Services. This official figure translates into a monthly income of \$645.00. The mean monthly income for these respondents is \$492. Of course, the extent of poverty is underestimated by these figures because a substantial number of these respondents have more than one person being supported by the income.

Fewer than 15 percent of the respondents are employed and provide information on income levels (see data on next page). The average monthly income for these employed respondents is just over \$718, translating into an annual employment income of just over \$8,600. The two most frequent sources of income are Social Security and Disability Income (SSDI) and Supplemental Security Income (SSI). Combining all income from all sources, the average monthly income is just under \$492, translating into an annual income of barely over \$5900. Furthermore, over twenty

percent of the respondents report that they have **no source** of income at all. Very few of the respondents are receiving assistance from family or friends (7.47%), and those few receive on average only about \$263. Assuming that the information reported is reasonably accurate, this information provides clear evidence of the extensive need for support services. These individuals are not able to afford the basic necessities of life, much less the expensive medical treatments and necessary medications.

INCOME AVAILABILITY AND LEVEL BY SOURCE

	<u>Yes - Have Income From:</u>		<u>Mean</u>	<u>Std.Dev.</u>
	<u>Number</u>	<u>Percent</u>		
Employment Income	42	14.89	718.45	513.37
Private Disability Insurance	6	2.13	326.00	72.43
Social Security (SSDI)	106	37.59	552.40	198.84
SSI	60	21.28	380.07	132.28
VA Benefits	2	0.71	1283.50	843.58
Unemployment Compensation	2	0.71	608.50	270.82
Retirement Income	6	2.14	1044.33	752.51
AFDC	27	9.57	153.00	81.45
Worker's Compensation	0	0.00	---	---
Child Support	5	1.77	222.60	134.89
Income from Family/Friends	22	7.83	262.82	238.10
Other Income Sources	20	7.09	167.00	129.17



Below is a series of analyses of variance demonstrating the variations in total monthly income among sub-categories of the respondents. Based on the means, these results confirm the pervasive economic problems across all of the different categories.

- With the exception of those aged 30-34, there is a consistent pattern of increasing income as the age group increases. The low incomes for the pediatric cases (age 0-5), may bias the overall average. However, the mean monthly income for only those aged 17 and over is only \$538, or \$6,456 per year -- still well below the poverty line. There are still 42 or 17.6% of these older respondents who report NO income. This zero income group is further explored in the service utilization section.
- Minority respondents have significantly lower incomes here, just as they do in the larger population.
- Interestingly, clients classified with AIDS, whether by their self-designation or by their reported CD4 levels, have higher incomes -- undoubtedly related to their greater eligibility for disability assistance. As shown later in a special section on those with CD4 counts below 200, these

respondents are more likely to receive assistance for rent, utility bills and telephone bills. For this group, 55.4% receive Social Security and Disability Income compared to 25.5% with CD4 levels of 200 or above.

- Both those reported being tested and diagnosed with HIV prior to 1988 and in 1995/96 report significantly lower incomes -- the latter due in part to the fact that the youngest children comprise a large portion of the recently diagnosed group. Those filling out the questionnaires reported very low incomes for the 0-5 (\$177/month) and 10-19 (\$238/month) respondents.
- Just as in the population at large, education plays a very important role in the economic levels of the respondents. Those with higher levels of education also report higher levels of economic support.

INCOME INFORMATION BY AGE

	N	Mean	Std. Dev.
0-5	32	176.813	209.548
10-19	9	237.889	197.991
22-29	38	439.132	275.332
30-34	61	574.262	519.194
35-39	54	496.444	394.947
40-44	38	518.263	401.509
45 plus	43	677.605	494.454

N: 275 No Response: 15

F = 5.725 Prob.= 0.000

ETA SQ. = 0.114

INCOME INFORMATION BY RACE AND ETHNICITY

	N	Mean	Std.Dev.
Black	50	403.500	309.812
Hispanic	121	459.686	438.469
White	87	591.391	432.904
Other	13	393.538	335.201
N:	271	Missing:	19

F=2.951 Prob.= 0.033
ETA SQ. = 0.032

INCOME INFORMATION BY CD4 LEVEL

	N	Mean	Std. Dev.
AIDS	121	577.851	420.447
ARC	79	517.304	459.181
HIV-POS	26	421.615	512.108
N:	226	Missing:	64

F=1.458 Prob.= 0.235
ETA SQ. = 0.013

INCOME INFORMATION BY SELF-REPORTED HIV STATUS

	N	Mean	Std.Dev.
POS ASYMPTOMATIC	69	559.464	504.209
POS SYMPTOMATIC	106	446.708	381.301
AIDS	77	568.688	432.418
DON'T KNOW	13	194.846	225.109
N:	265	Missing:	25

F=3.891 Prob.= 0.010
ETA SQ. = 0.043

INCOME INFORMATION BY YEAR TESTED

	N	Mean	Std. Dev.
Pre-88	46	477.370	405.768
88-91	77	639.078	513.650
92-94	98	489.857	398.646
95-96	43	319.163	309.760
N:	264	Missing:	26

F=5.407 Prob.= 0.001
ETA SQ. = 0.059

INCOME INFORMATION BY EDUCATION

	N	Mean	Std. Dev.
None-Children	22	216.455	221.885
Under 12 years	66	371.333	311.918
High School Degree	86	522.547	371.992
Some College	59	672.949	509.237
BA plus	24	760.958	589.843

N: 257 Missing: 33

F=9.341 Prob.= 0.000

ETA SQ. = 0.129

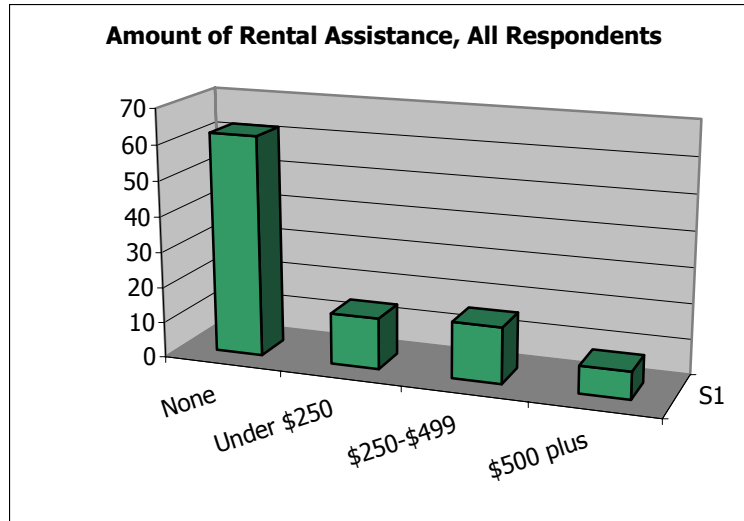
RENTAL ASSISTANCE

Beyond the basic sources of income, about 38 percent of the respondents indicated that they receive some financial assistance for rent. Across all of the clients responding, this averages to about \$125 **per year**, or just over \$10 per month. Considering only those 108 clients actually receiving assistance, the average annual support is just under \$330 annually (or close to \$28 per month).

Have you received financial assistance for rent in the last 12 months?
If so, how much financial assistance have you received?
(If no assistance received, enter 0).

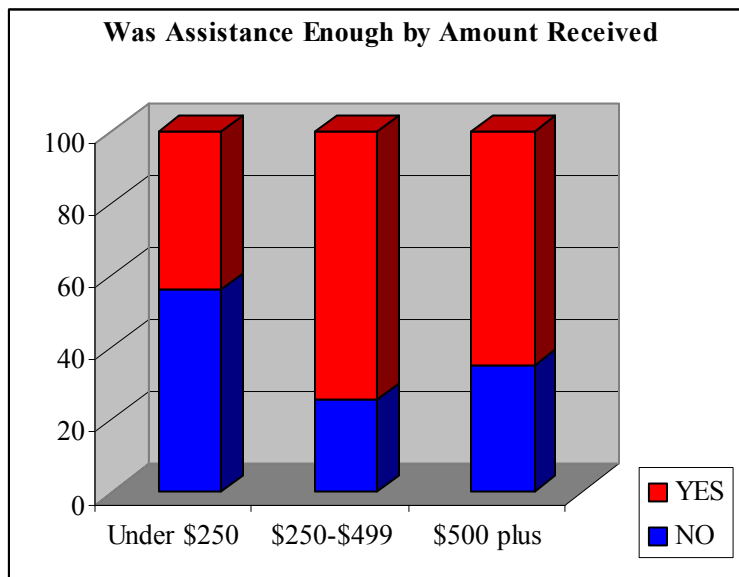
ALL RESPONDENTS

Mean=	\$125.01	Std. Dev.=	\$235.93
N:	285	No Response:	5



MEAN AMOUNT FOR RESPONDENTS RECEIVING ASSISTANCE

Mean= \$329.90 Std. Dev.= \$281.98
 N: 108 Missing: 0

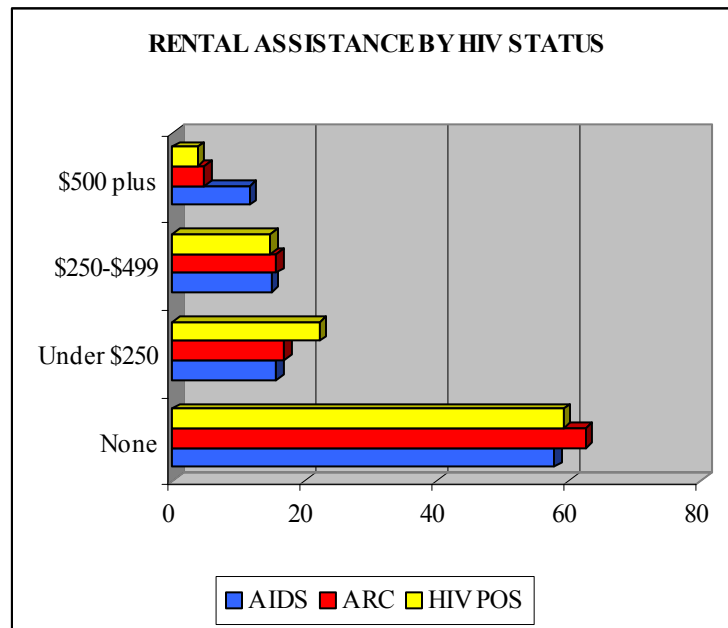


Chi-Square=7.494 DF=2 (Prob.=.024)
 V=.278

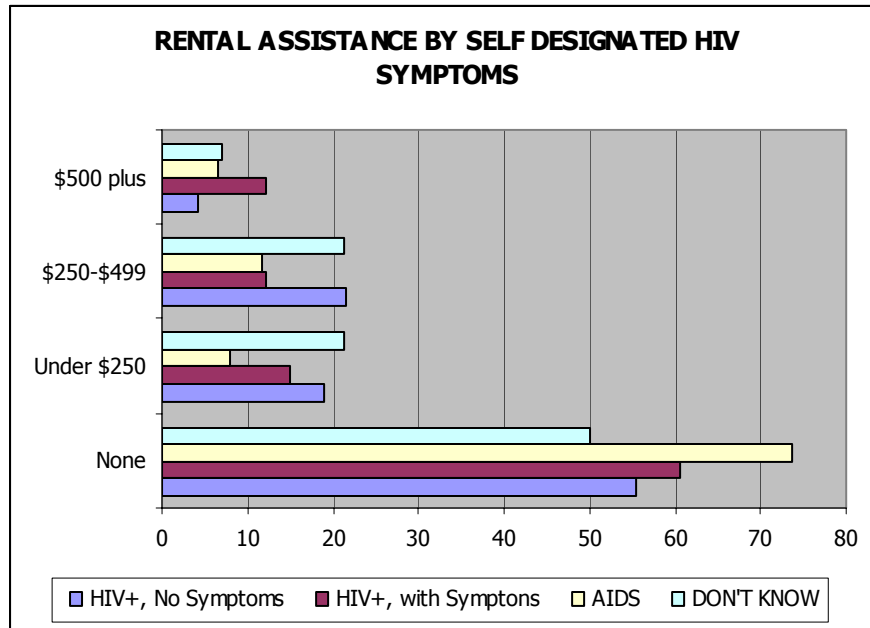
Of course, as level of support increases, the percent of respondents believing that the support is enough increases. Of those receiving less than \$250 per year, nearly 56% indicate that this is not enough. Of those receiving \$500 or more, 65% thought it was enough.

The data below show that the proportion receiving rental assistance is about the same for the clients classified as AIDS (CD4 level under 200), ARC (200-499) or HIV Positive. This

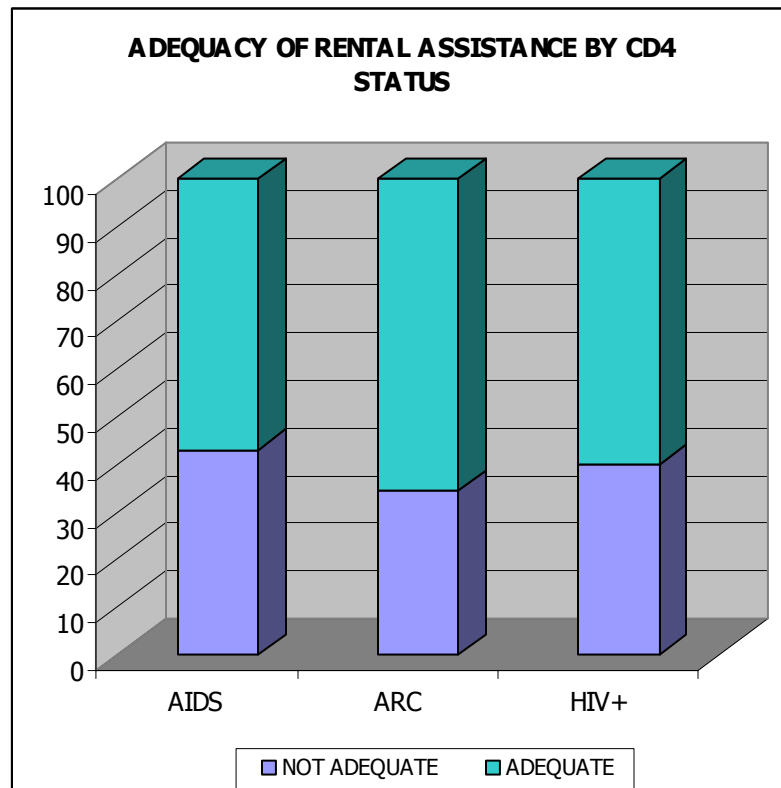
pattern does not hold up, however, based on self-designated HIV status, where those labeling themselves as having AIDS are the **least** likely to report receiving assistance (73.7% indicate no rental assistance). Perceptions of whether the assistance is enough also do not vary much by status based on CD4 levels, those labeling themselves as having AIDS are more likely to say that the assistance is not enough.



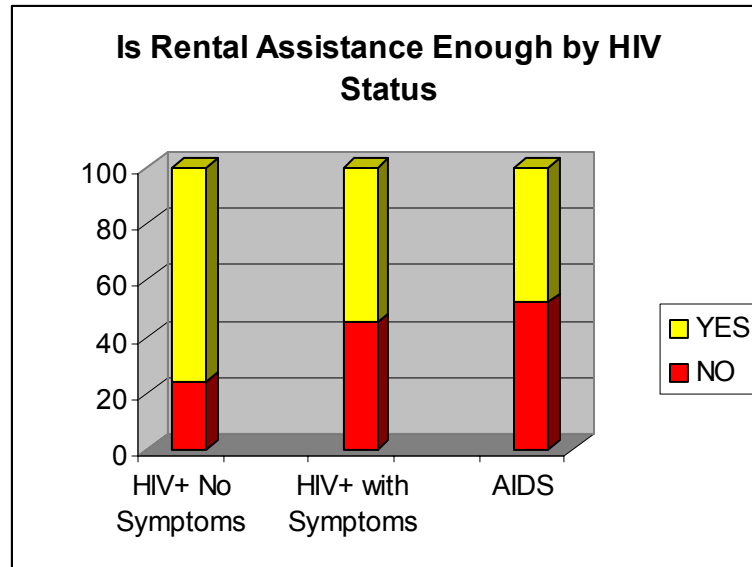
Chi-Square=4.257 DF=6 (rob.=.642)
V=0.096



Chi-Square=13.798 DF= 9 (Prob. = 0.130)
V=0.130



Chi-Square=0.577 DF= 2 (Prob. = 0.749)
V=0.080

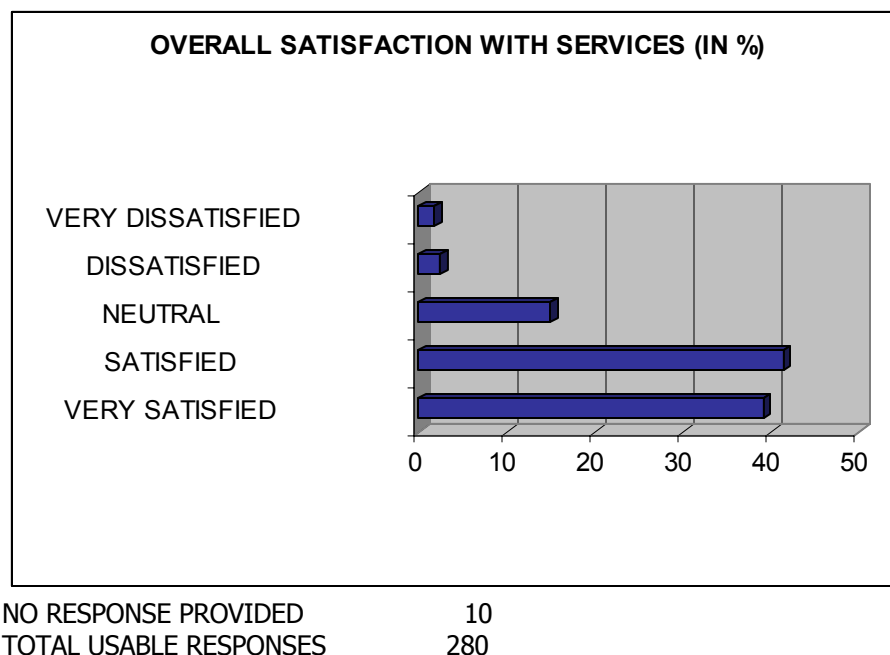


Chi-Square=4.995
V=0.226

DF= 3 (Prob. = 0.172)

OVERALL SATISFACTION WITH SERVICE AGENCIES

Respondents were asked, “Overall, how satisfied are you with the agencies from which you received services during the last 12 months? Would you say you are very satisfied, satisfied, dissatisfied or very dissatisfied?” While many respondents could report specific instances of problems or frustrating and difficult situations, when the services were placed in this overall context they reported a high level of satisfaction. Respondents were asked: “OVERALL, HOW SATISFIED ARE YOU WITH THE AGENCIES FROM WHICH YOU RECEIVED SERVICES DURING THE LAST 12 MONTHS? WOULD YOU SAY THAT YOU WERE VERY SATISFIED, SATISFIED, DISSATISFIED OR VERY DISSATISFIED?”



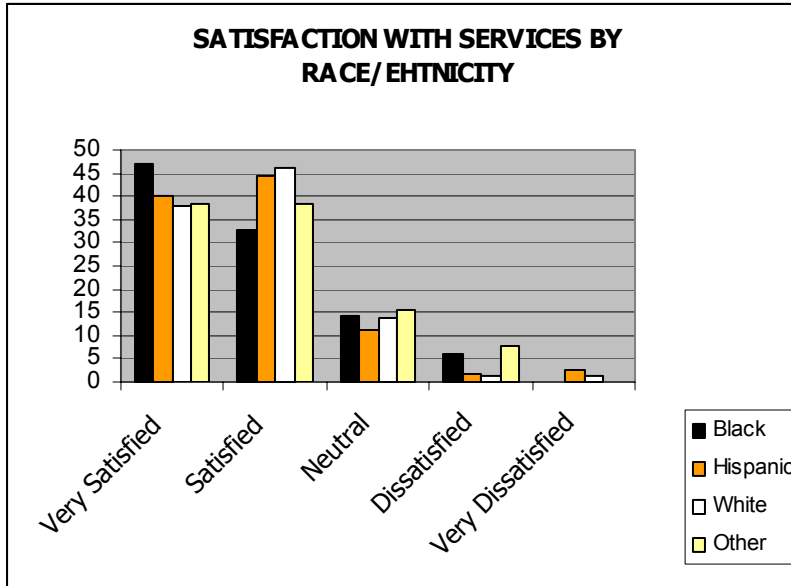
As depicted in the previous figure, most respondents reported they were “very satisfied” (39.3%) or “satisfied” (41.4%) with the services received by San Antonio agencies during the last 12 months. While very small proportions report being “dissatisfied” (2.5%) or “very dissatisfied” (1.8%), a notable percentage reported they were “neutral” (15%). Given the intensity of need associated with many of the services provided, it may be that the “neutral” category captures those clients who do not want to criticize a service for fear of losing it. As reported earlier in the methodology discussion, there were no statistically significant differences between interviews from the random or convenience samples, between those conducted by Agency or UTSA personnel, between interviews conducted in person or by telephone, or between interviews conducted in English or Spanish. As shown below, high levels of satisfaction prevail among all race and ethnic groups, and among males, females and the transgendered. HIV status does not appear to systematically influence overall satisfaction, whether it is based on the self classification of the respondents or on the CD4 level classification.

The year the respondents were tested and first diagnosed as HIV positive appears to make some difference, with those diagnosed prior to 1988 being less likely to indicate they are very satisfied. This same group is the source of four out of the five respondents who indicated that they are very dissatisfied. One agency representative suggested that this might be the “grumpy old man” syndrome -- linked to the idea that grumpy people tend to live longer. An alternative interpretation might be that those who have struggled with the disease and getting assistance for the longest time cumulatively have had more frustrating experiences, contributing to a greater likelihood of expressing overall dissatisfaction.

There are also differences shown by education. Those with a bachelor’s degree or higher are more likely to indicate that they are very satisfied. Interestingly, those responding for the pediatric cases (those with zero years of schooling and also among those in the age group of 0-5) were those most likely to indicate that they are very satisfied.

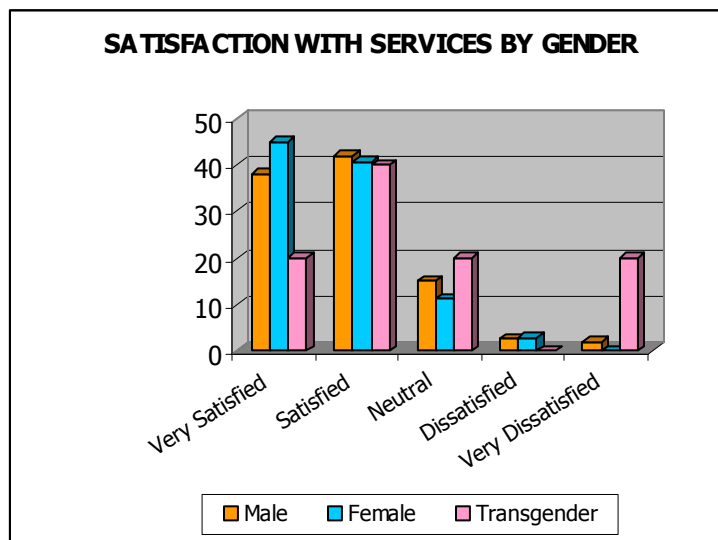
There is no clear pattern by income level. Those reporting no monthly income are just as satisfied as those with income. Only those with \$690 per month or more are a little different -- they are somewhat more likely to choose the satisfied category and somewhat less likely to indicate that they are very satisfied. Overall, the differences by income level are not statistically significant.

Finally, data are reported by the primary or source agency for the particular interviews. Some words of caution are in order here. It is our observation that most of the clients used services from several different agencies. Therefore, the satisfaction levels reported here cannot be assumed to reflect the perceived quality of the services delivered by any particular agency.

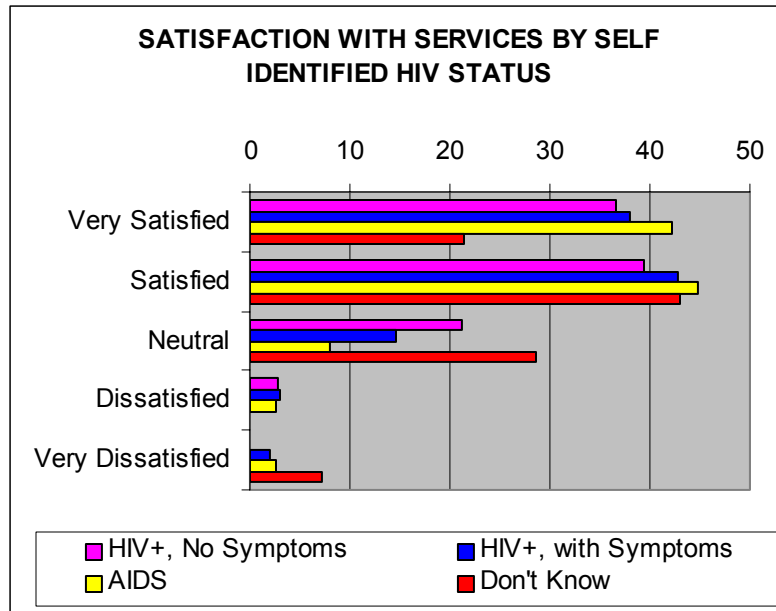


Chi-Square=9.177
V=0.107

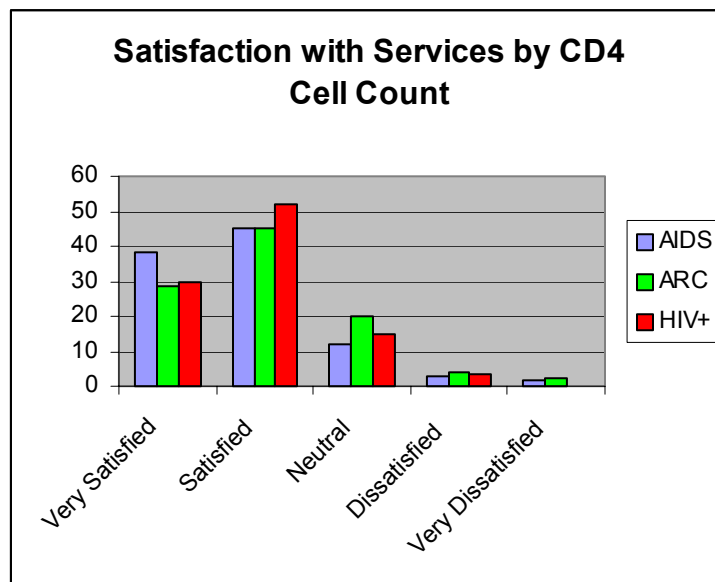
DF= 12 (Prob. = 0.688)



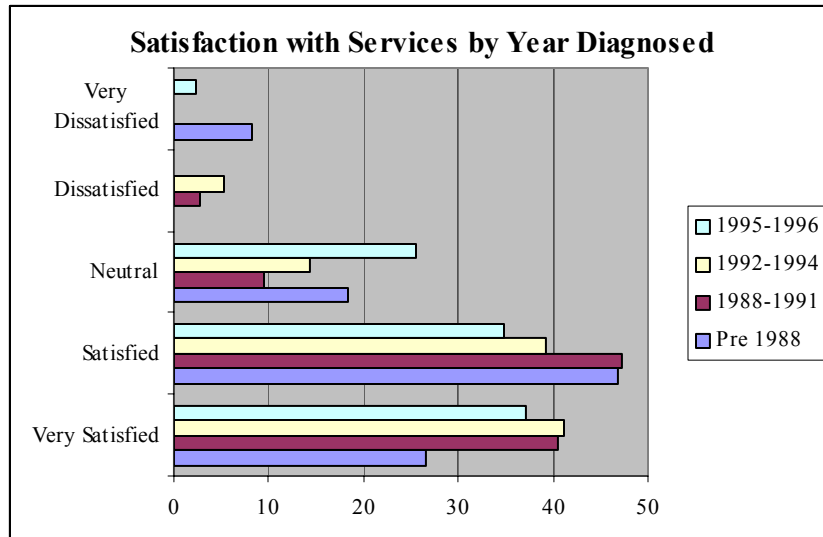
Chi-Square=12.354 DF= 8 (Prob. = 0.136)
V=0.150



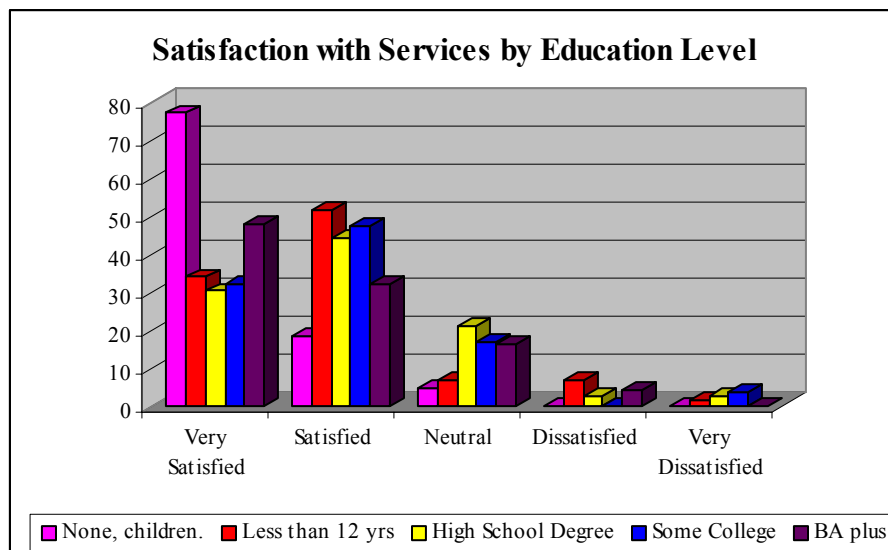
Chi-Square= 11.644 DF= 12 (Prob. = 0.475)
 V=0.121



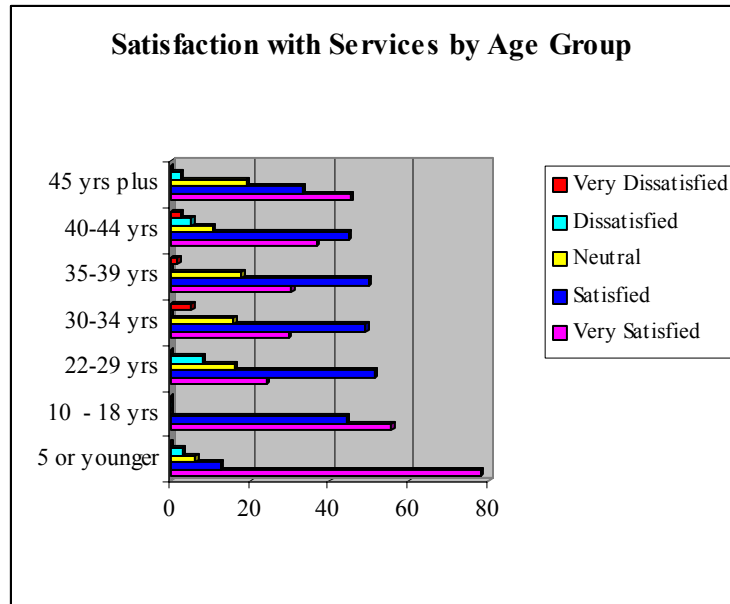
Chi-Square=4.703 DF= 8 (Prob. = 0.789)
 V=0.102



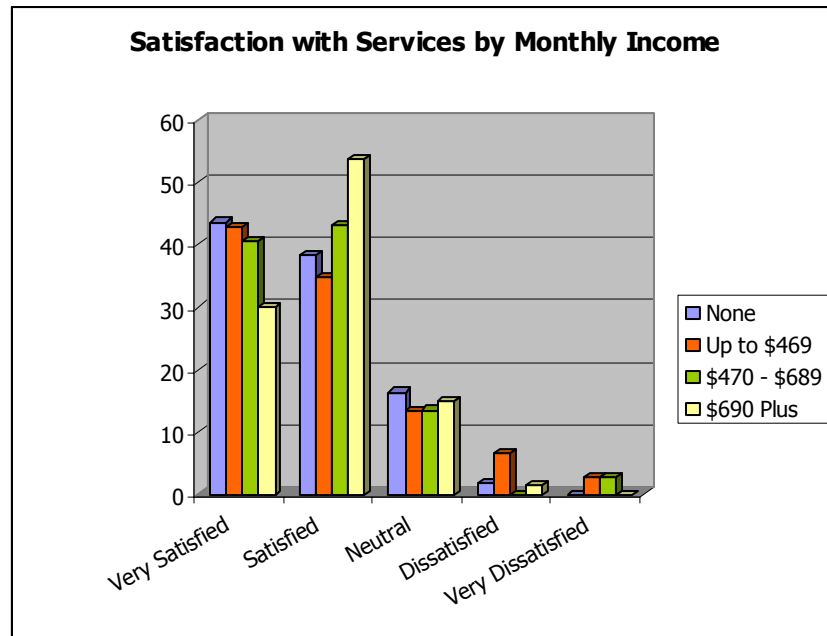
Chi-Square=26.556 DF= 12 (Prob. = 0.009)
V=0.183



Chi-Square= 31.204 DF= 16 (Prob. = 0.013)
V=0.175



Chi-Square=6.711 DF= 24 (Prob. = 0.004)
V=0.208



Chi-Square=16.087 DF= 12 (Prob. = 0.187)
V=0.141

OVERALL SATISFACTION BY PRIMARY (SOURCE) SERVICE AGENCY

	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied	Total
AARC	26.0	52.0	20.0	0.0	2.0	100.0

B.E.A.T.	24.0	48.0	20.0	8.0	0.0	100.0
HAC	35.0	32.5	25.0	2.5	5.0	100.0
OHC	0.0	100.0	0.0	0.0	0.0	100.0
SAAF	35.3	52.9	11.8	0.0	0.0	100.0
SAMHD	17.9	57.1	17.9	7.1	0.0	100.0
WC	61.1	27.8	0.0	5.6	5.6	100.0
STAC	58.8	35.3	5.9	0.0	0.0	100.0
FFACTS	32.4	47.1	17.6	2.9	0.0	100.0
MUJERES	0.0	66.7	33.3	0.0	0.0	100.0
PROV HOUSE	90.5	4.8	4.8	0.0	0.0	100.0
RWD	62.5	25.0	0.0	0.0	12.5	100.0
TOTAL (n)	110	116	42	7	52	80
TOTAL (%)	39.3	41.4	15.0	2.5	1.8	100.0

Chi-Square= 79.572 DF=44 (Prob. = .001)
V=0.267

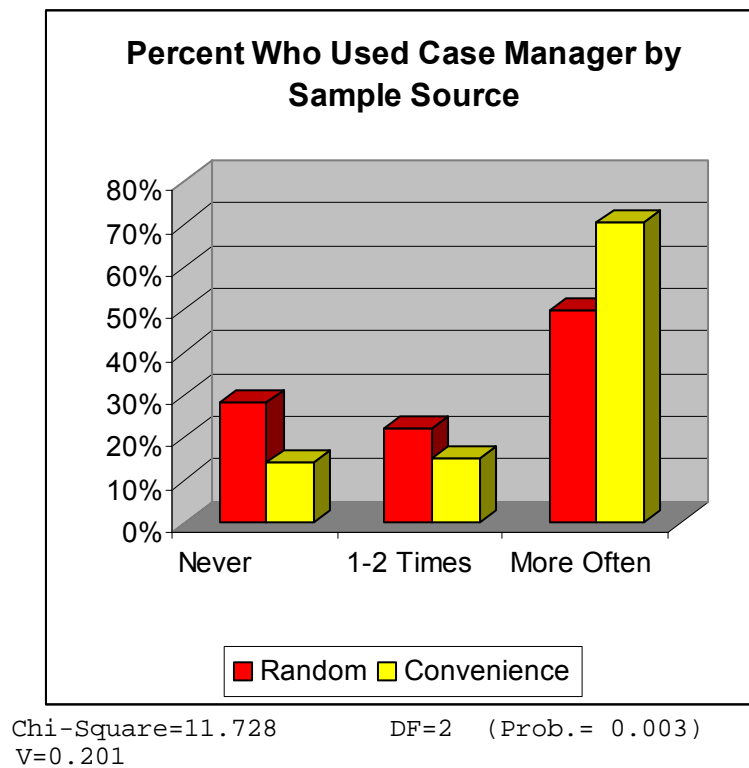
SERVICE UTILIZATION AND SATISFACTION

The following section discusses and displays a summary of service utilization by the clients included in the sample. Additionally, clients' levels of satisfaction with the various services provided are presented (the frequencies for satisfaction levels with specific services can be found in Appendix A). In almost all cases, the proportion saying "dissatisfied" or "very dissatisfied" was quite small. This is due in part to the small proportion of clients reporting using these services. While for the most part we report satisfaction levels, if the proportion satisfied is lower than the proportion using a service this indicates some level of dissatisfaction.

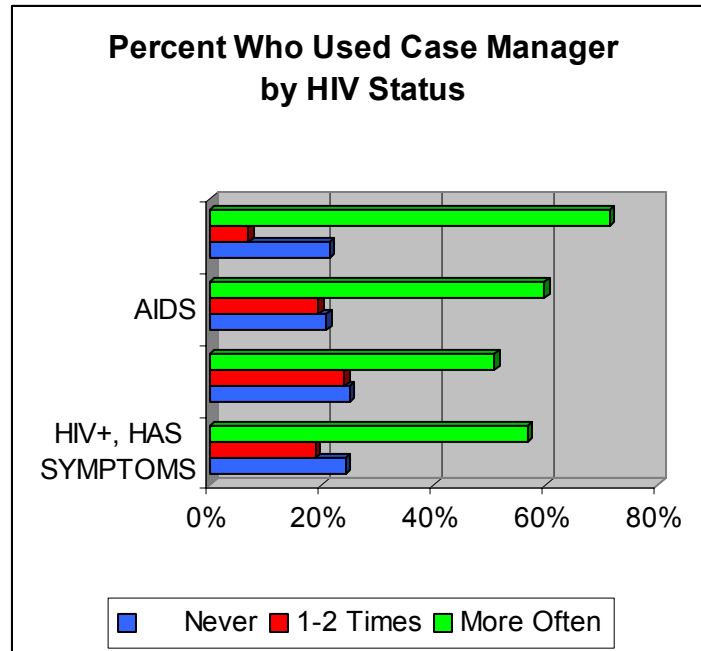
Case Management

Interestingly about one fourth of the respondents reported that they had not used a caseworker in the last year, although all the clients in our sampling frame are assumed to have been assigned an identification number and a caseworker. This finding held up both for those with and those without medical insurance. As shown below, the proportion that says they have never visited a case manager in the last year is even greater among those from the randomly

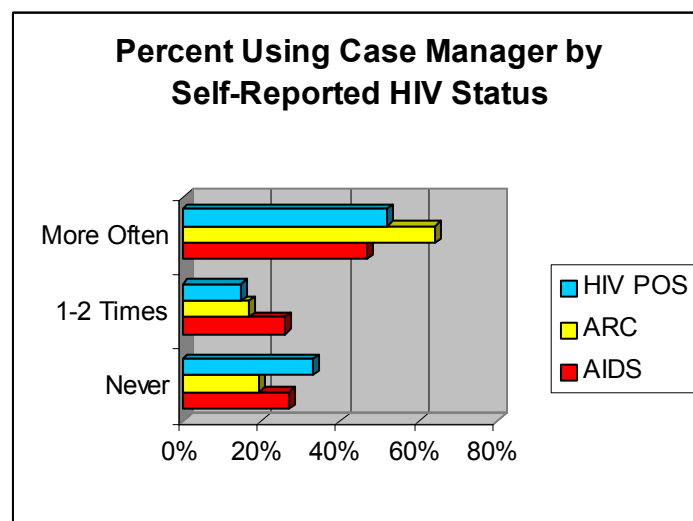
selected respondents (28.3%) than among those in the on-site convenience sample (14.3%). This suggests that a large proportion of clients are not benefiting from case management services.



Strikingly, there is no relationship between AIDS/HIV status and the likelihood of using case management services, whether we use the self-designated HIV status variable or the status based on reported CD4 levels. Close to twenty percent or more of respondents report never having visited a case manager in the last year in all categories. This percent is up to 27% for those with CD4 levels below 200 (AIDS) and about one in three (33.3%) for those reporting CD4 levels of 500 or more.



Chi-Square=3.703 DF= 6 (Prob. = 0.717)
V=0.082

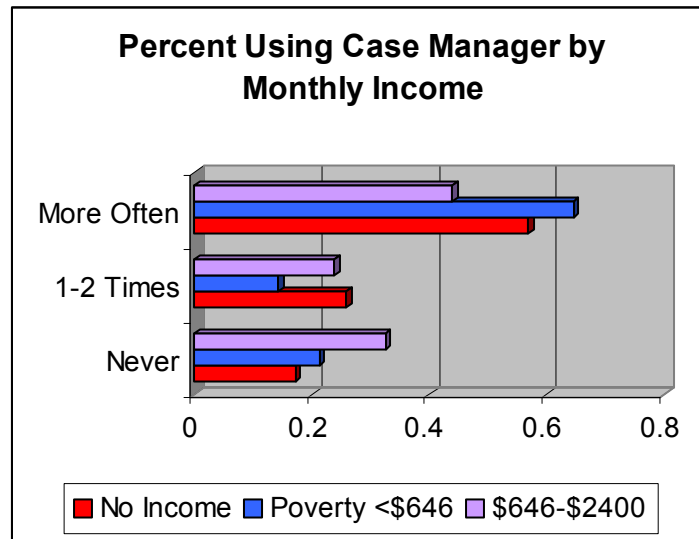


Chi-Square=7.422 DF= 4 (Prob. = 0.115)
V=0.126

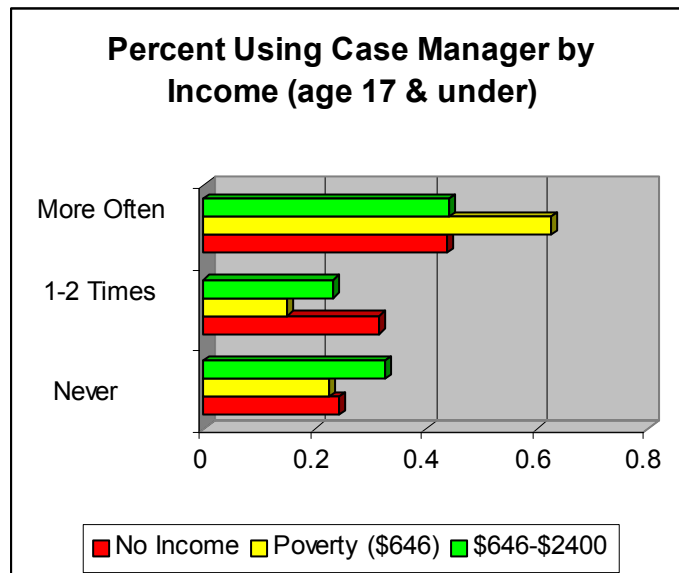
As shown below, there is a small but statistically significant relationship between income level and use of case management services. Those reporting no monthly income or income below the poverty level are more likely to report frequent use of case management, at 56.9% and 64.5% respectively, than those with higher incomes. Looking at only those age 17 and over, part

of the usage of those with no income is accounted for by pediatric case management.

Nonetheless, the overall pattern holds, and it is positive that those with the lowest incomes and, hence, the greatest need are the most likely to be taking advantage of case management assistance.

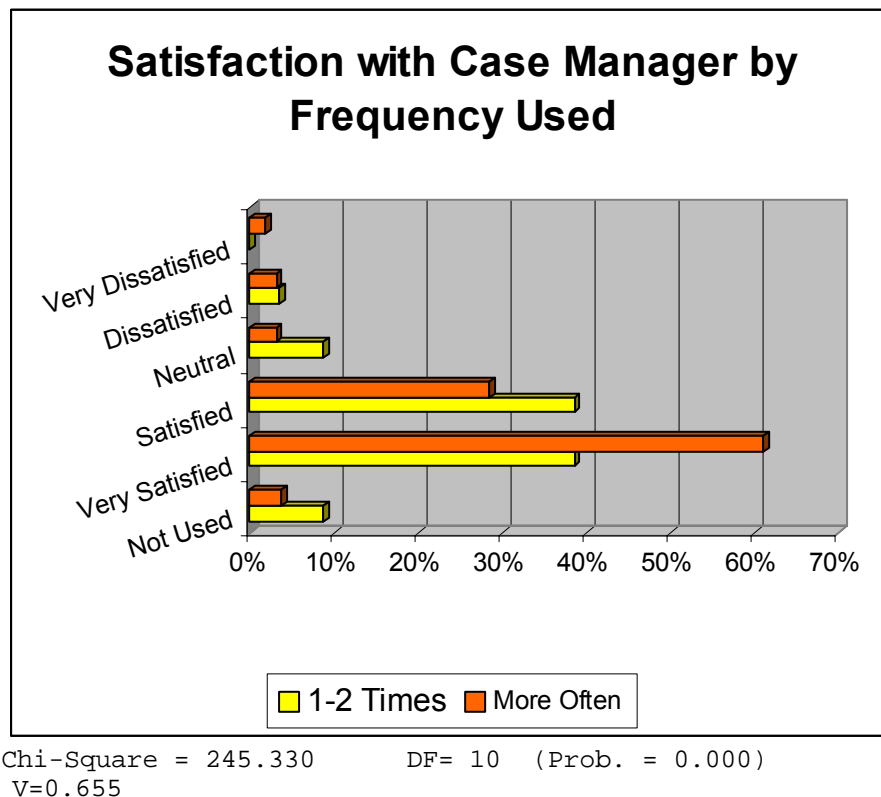


Chi-Square=11.877 DF= 4 (Prob. = 0.018)
V=0.146



Chi-Square=10.203 DF= 4 (Prob. = 0.037)
V=0.146

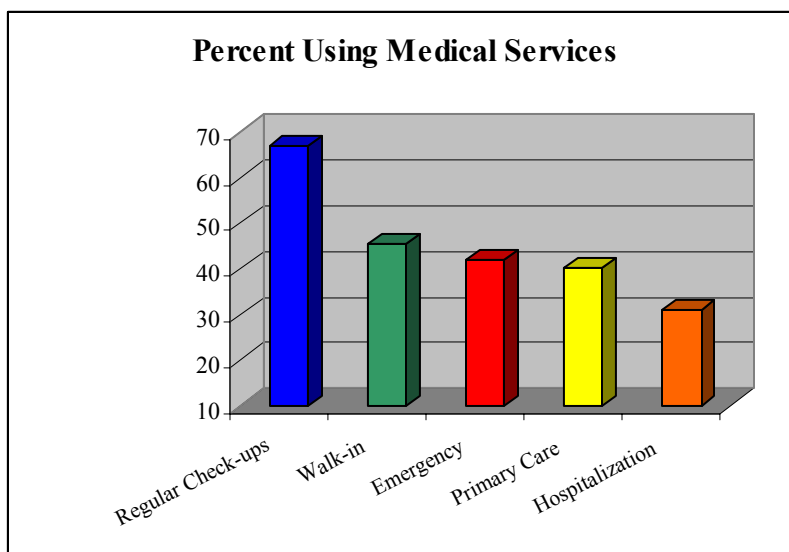
About 42% reported being “very satisfied” and close to 24% reported being satisfied with case management services. About 3.5% reported being “neutral,” slightly over 2.4% reported they were “dissatisfied,” and less than 1% reported they were “very dissatisfied.” The satisfaction levels are substantially higher among the more frequent users -- 61.1% “very satisfied” and 28.4% satisfied, for a total of 89.5%.



The importance of case management services is illustrated well by the following quote: “I don’t want someone to do it for me. I must have independence and be able to help myself.” This Hispanic bisexual male, with an AIDS diagnosis and self-reported depression, was making the argument that the best form of assistance is that which enables the clients to help themselves.

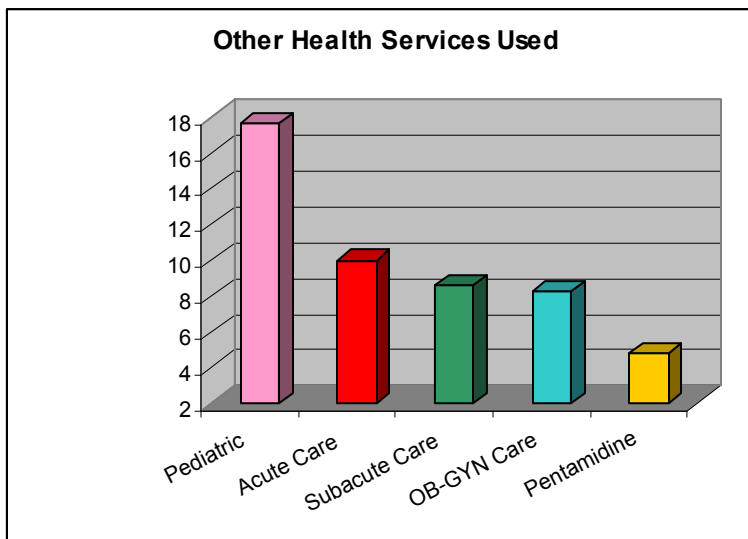
Medical and Dental Services/Needs

As depicted in the next Figure, close to 67% of those interviewed stated that they receive regular checkups through the various San Antonio based agencies. Over 58% of respondents reported being “very satisfied” (37.55%) or “satisfied” (20.58%) with those services. More than 45% have utilized walk-in clinic services, while more than 40% receive primary care. About 24% of respondents said they were either “very satisfied” or “satisfied” with walk-in clinic experiences, and 34.6% were either “very satisfied” or “satisfied” with primary care services. Thirty-nine percent report needing hospitalization, and slightly more than 42% needed emergency room care. Close to 29% report satisfaction with hospital services, and about half of those were “very satisfied.” About one fourth responded that they were either “very satisfied” (13.5%) or “satisfied” (11.7%) with emergency room treatment.

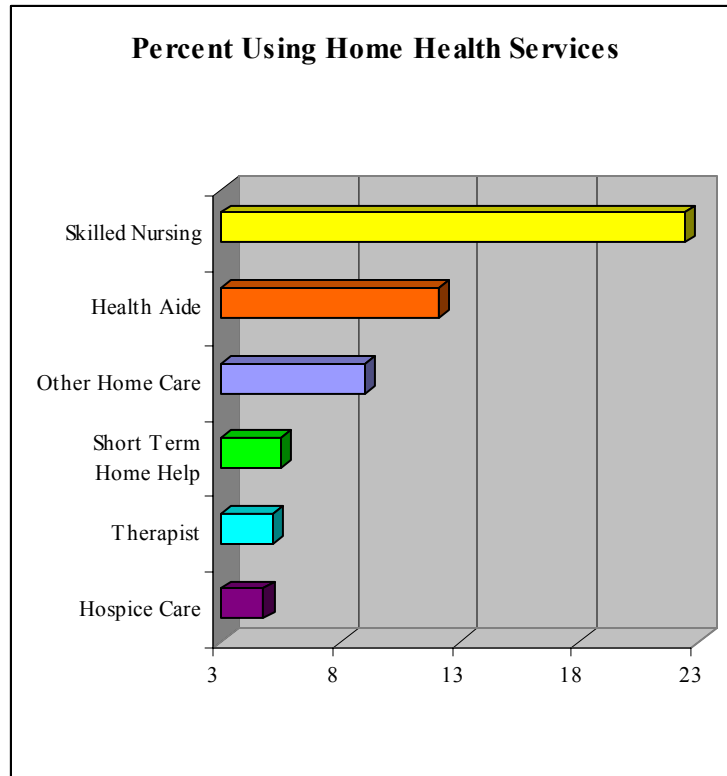


The next figure shows that among those surveyed, almost 17% used pediatric care, 10% used acute care, close to 9% used subacute care, about 8% used obstetric and/or gynecological care, and almost 5% received pentamidine treatments. While the majority of respondents reported

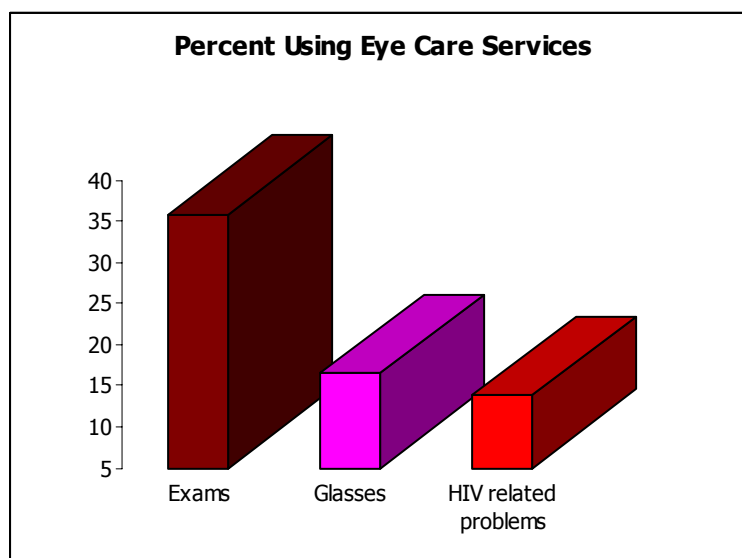
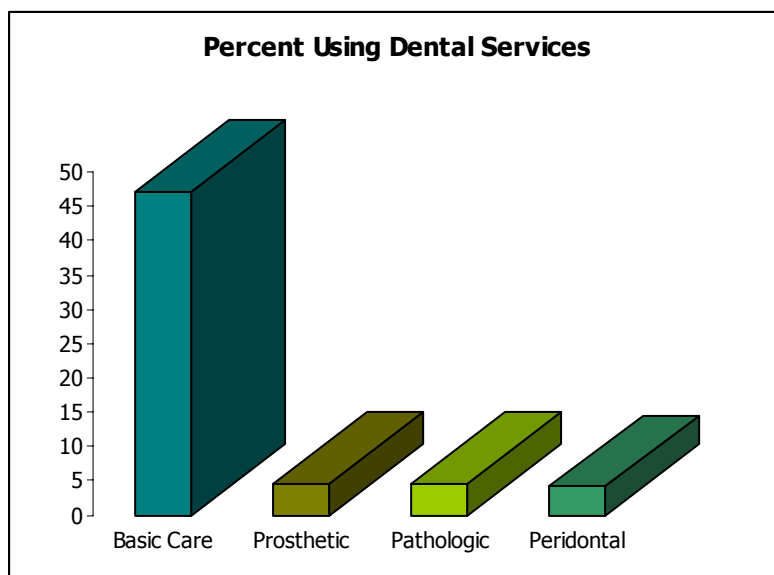
never using these services, about 15% report satisfaction with pediatric care, 9% were satisfied with acute care, about 7% were satisfied with subacute care, slightly over 6% reported satisfaction with obstetric or gynecological care, and about 3%, were satisfied (most of whom were “very satisfied”, 2.5%) with pentamidine treatments.



In addition, some clients used home health care services (see following Figure). About 22% used a skilled home nurse, about 12% used a professional health services aide, 5.2% used a licensed therapist, and 4.8% received hospice services. Once again, while most respondents reported never using these services, approximately 5% reported using short-term home services. Finally, 9% reported unspecified “other” home health related services. Well over 20% reported satisfaction with skilled home nurse services, close to 10% with home health aide services, about 3% with licensed therapist services, and over 3% with hospice care.

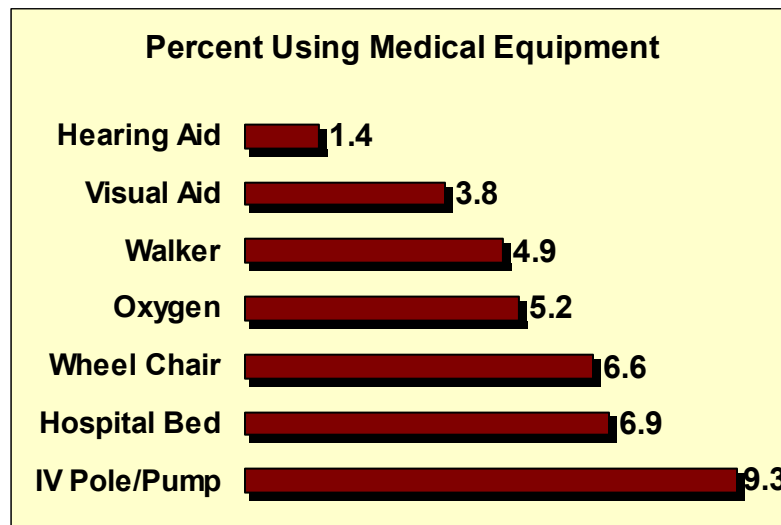


The next two Figures indicate the percent of clients using various dental and eye care services. Notice that over 47% of the clients surveyed reported receiving basic dental services, while over 4% received some type of dental prosthetic device, some type of treatment for a dental pathology, or received periodontal treatments. Close to 36% reported regular eye exams, over 16% said they received glasses, and well over 13% stated that they received some type of HIV-related eye treatment.



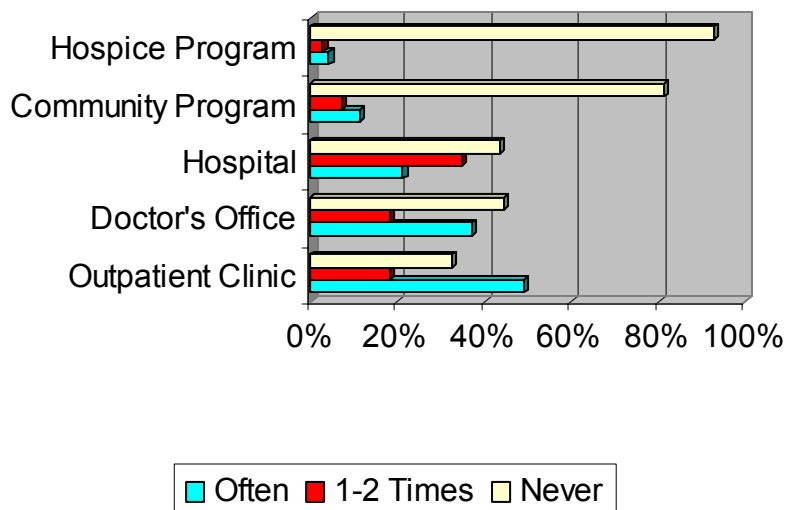
A small proportion of individuals specified that they used medical equipment provided by San Antonio services (see Figure on next page). Over 9% used an IV pole or pump, close to 7% received a hospital bed, over 6% received a wheelchair, over 5% needed oxygen, and close to 5% received a walker. Additionally, 3.8% said they required services for visually impairment,

and 1.4% for hearing impairment. Only about 1% reported dissatisfaction with any of the equipment specified.

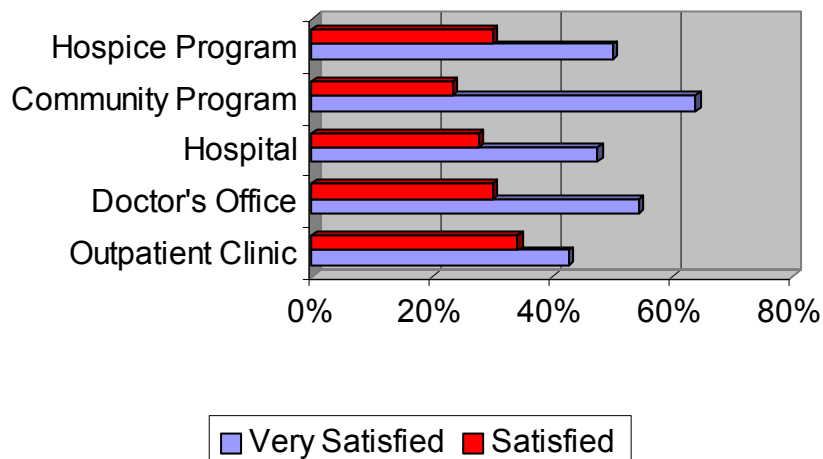


The next two Figures show frequency of use of various medical facilities, as well as the proportion reporting they are “very satisfied” or “satisfied” with the services at those facilities. Almost fifty percent report using an Outpatient Clinic “often,” with well over 50% reporting they were “very satisfied” with the services. Close to 40% visited a doctor’s office “often,” and over 50% reported being “very satisfied.” Slightly over 20% reported using a hospital “often,” and close to 50% reported being “very satisfied.” Less than 20% reported using community based health services treatment “often,” although over 60% reported being “very satisfied.” Only about 5% report they used hospice services, but about 50% report being “very satisfied” with hospice services.

Frequency Seek Care/Follow-up

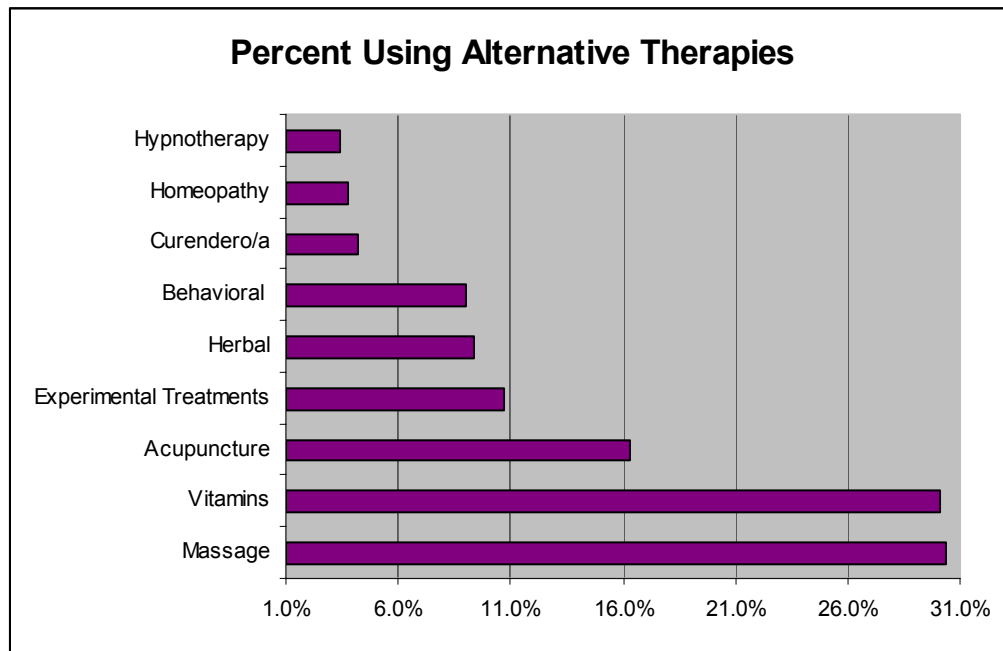


Satisfaction with Medical Services Used



Alternative Health Treatments

As seen in the next Figure, of the various alternative health care treatments available, the largest proportion of respondents use massage therapy (31.4%) and vitamins or vitamin supplements (30.1%). Over 16% said they used acupuncture. Close to 22% were “very satisfied,” and over 6% were “satisfied” with message therapy; over 17% reported being “very satisfied” and almost 11% reported being “satisfied” with vitamin therapy. Close to 11% had received unspecified experimental treatments, and 8.3% reported either being “very satisfied” or “satisfied” with those treatments.



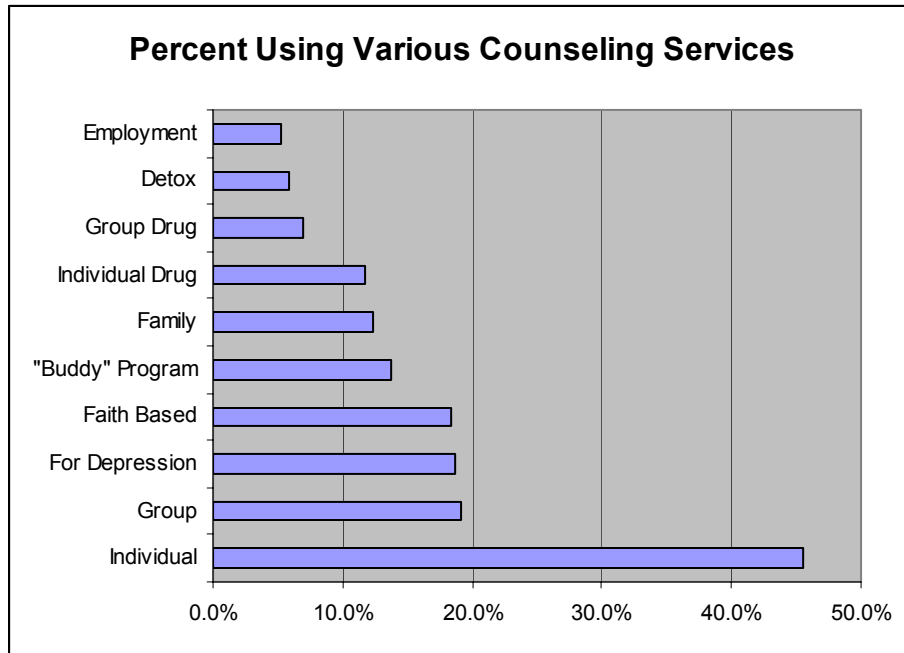
Over 9% used herbal therapies, and over 8% were satisfied with them. Nine percent used behavioral therapy, with close to 7% reporting satisfaction. Over 4% said they had used a curendero(a), while 3.8% said they used homeopathy treatments and 3.4% used hypnotherapy. Well over ninety percent reported never using these latter services, however, 4% reported satisfaction with a curendero(a), about 4% with homeopathy treatments, and less than 2% with hypnotherapy.

Counseling Services

Looking at the Figure on the next page, we find that over 45% of respondents reported receiving individual counseling. Less than half of that proportion reported using other types of counseling services: about 19% reported using group counseling, over 18% used depression or pastoral counseling, about 14% used a “buddy” counselor, a little over 14% used family counseling, and slightly over 5% used employment counseling. Almost 23% reported being “very satisfied” and almost 16% being “satisfied” with individual counseling. Those reporting either being “very satisfied” or “satisfied” with the other forms of counseling were about proportionate to use.

Close to 12% of those surveyed reported receiving individual drug related counseling, almost 7% group drug related counseling, and almost 6% reported using detoxification services.

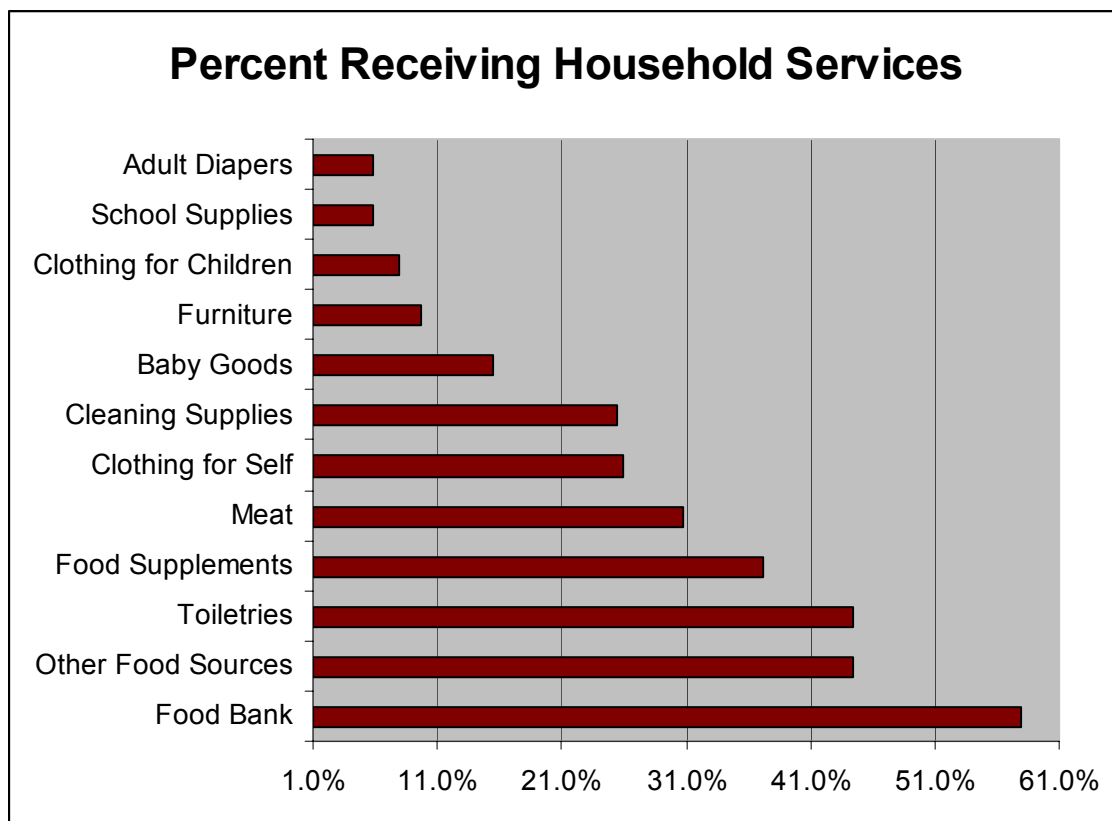
Dissatisfaction levels were higher for drug related counseling than for other types. Seven percent reported satisfaction with individual drug counseling and almost 3% classified themselves as neutral or dissatisfied. Almost 4% were satisfied with group drug counseling, while 2% reported being either neutral or dissatisfied. Finally, about 2% reported satisfaction with detox treatments, while another 2% were dissatisfied.



Household Necessities

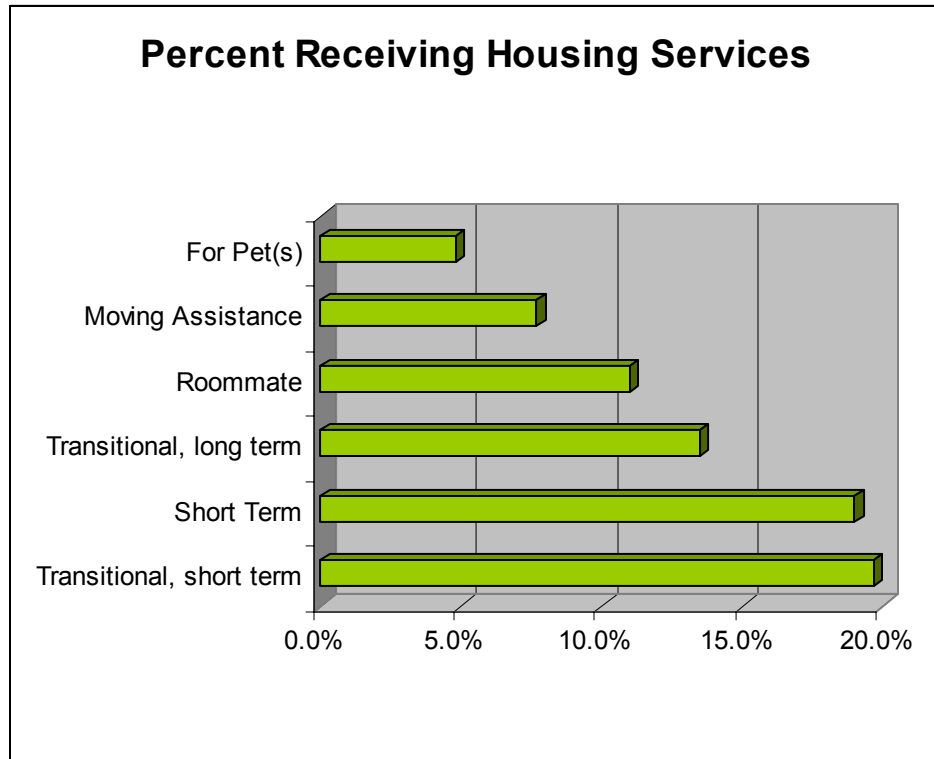
A majority of respondents (almost 60%) reported using a food bank to obtain food, while almost 45% report receiving other basic food and toiletries from community based organizations (see Figure on next page). Over 72% report satisfaction with food provided by the food bank, 39% with basic food and about 36% with toiletries from community based organizations. Close to 40% reported receiving meat and about 30% receiving food supplements, with 22% expressing satisfaction with the meat received and about 22% with the food supplements. Over 25% used cleaning and other household supplies; while almost 19% expressed satisfaction with those supplies. Over 15% used baby supplies, and close to 10% furniture. Almost 14% were satisfied with the baby supplies received, and about 7% with the furniture. Close to 6% reported using either school supplies or adult diapers. About 5% were satisfied with the school supplies, and about 4% with the adult diapers.

About one fourth of the respondents said they received clothing assistance for themselves, and about 8% said they received clothing for their child(ren). A little over 21% reported satisfaction with the clothing received for themselves, and 6.5% with the clothing received for their child(ren).



Housing Services

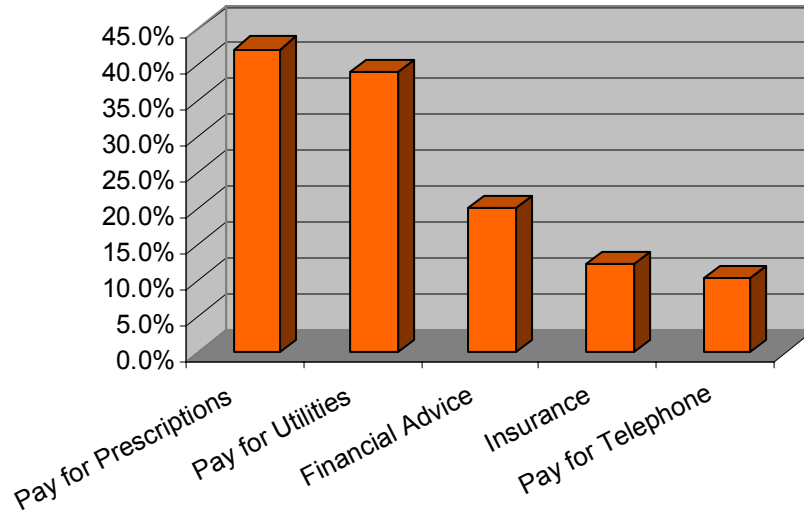
Over 19% of the respondents reported using transitional short-term housing, while 19% reported using short term housing and about 14% reported using transitional long-term housing (see Figure on next page). Eleven percent reported help with finding a roommate, almost 8 percent reported receiving assistance with a move to a different residence and about 5% reported assistance with finding a home for a pet. While usage of these services was not high, clients who used them were, for the most part, either “very satisfied” or “satisfied.”



Financial Assistance

As shown in the next Figure, the largest proportion of clients who said they received financial assistance did so for medical prescriptions (42.1%). The next largest group received help making utility payments (39%). About 12% reported assistance in paying insurance co-payments, and a little over 10% in paying their telephone bills. Approximately 12% reported receiving some unspecified financial advice. About 37% reported satisfaction with prescription assistance, 32% with assistance with utilities, about 9% with insurance co-payment assistance, a little over 8% with assistance with their telephone bills. Six percent reported satisfaction with the financial advice received.

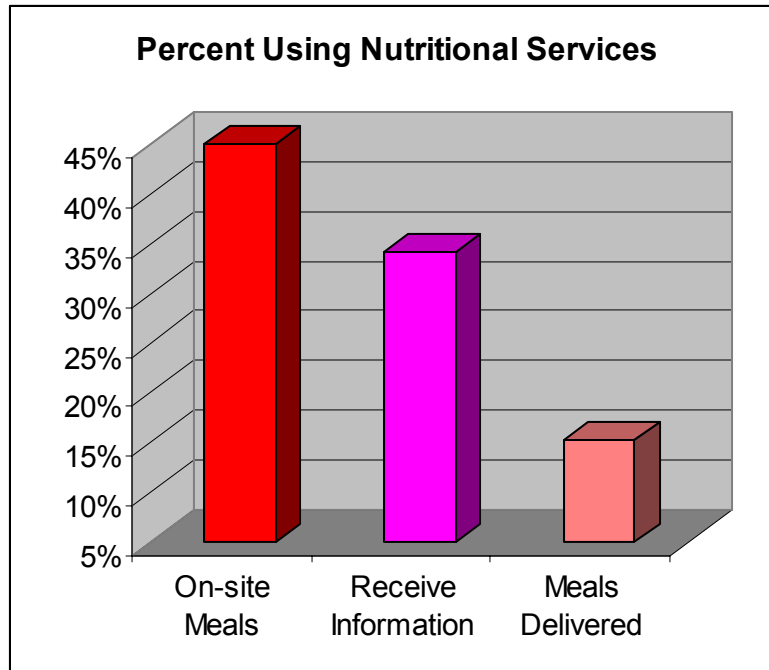
Percent Receiving Various forms of Financial Assistance



Nutritional Assistance

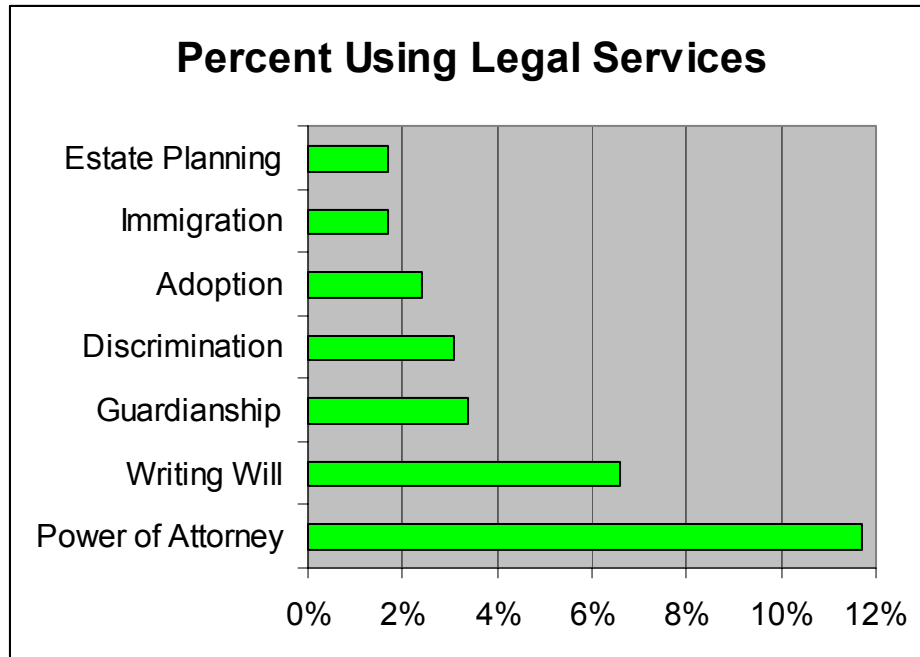
A substantial proportion (45.2%) of respondents said they ate the on-site meals provided primarily by AARC and SAAF (see next figure). About 26% reported being “very satisfied” with on-site meals, and about 12% report being “satisfied.” Over 34% reported receiving information about nutrition, and 27% were satisfied with the information received.

Approximately 15% reported having meals delivered to them ready to eat; and virtually all using this service reported being either “very satisfied” or “satisfied.”



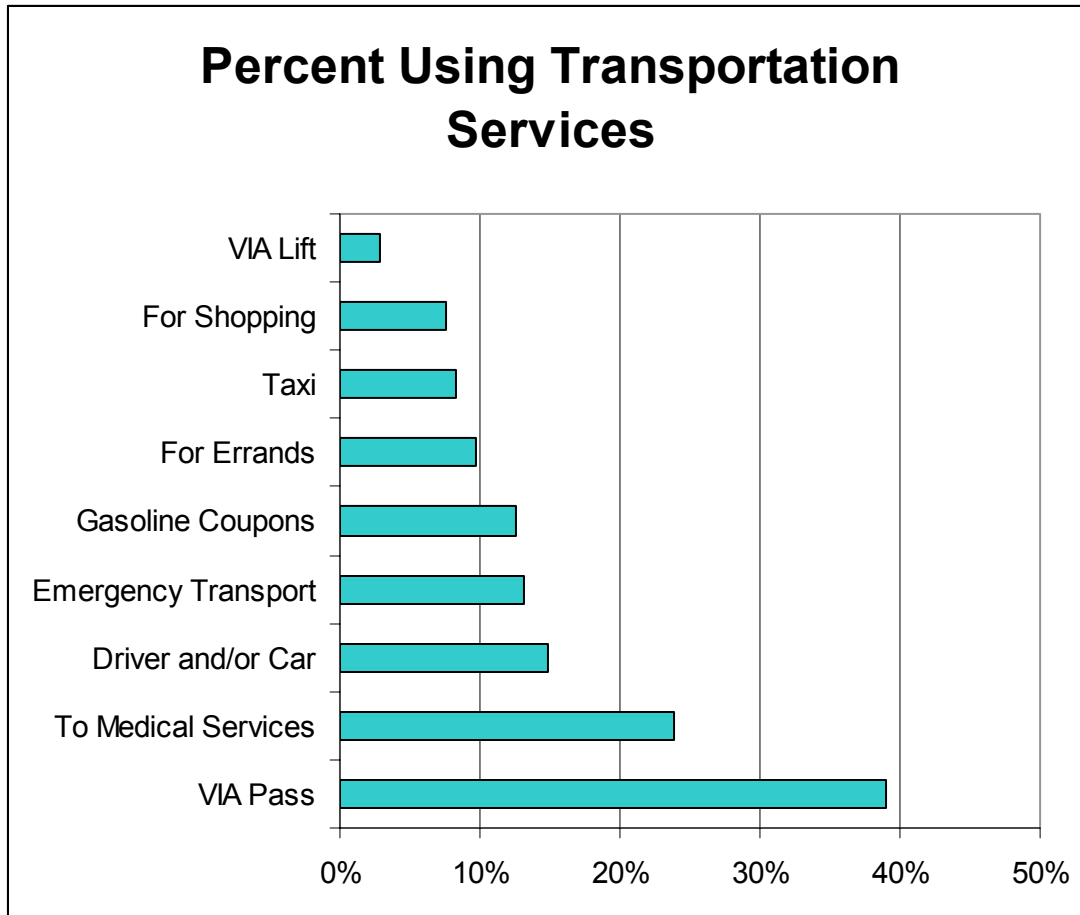
Legal Services

Less than 12% of respondents reported receiving any type of legal assistance. The largest proportion (11.7% -- see next Figure) said they received help with a power of attorney. Just under 7% received assistance writing a will, though it is worth noting that a number of respondents requested additional information about establishing wills in their open-ended comments. About 3% said they received help creating guardianships or handling problems with discrimination. Only 2.5% reported adoption or child custody assistance, and 1.7% reported help with immigration or in estate planning. Clients reporting use of these services were satisfied for the most part, although close to 1% report being "neutral" or "dissatisfied" with help with immigration, and almost 2% reported being "neutral," "dissatisfied" or "very dissatisfied" with the help received for discrimination.



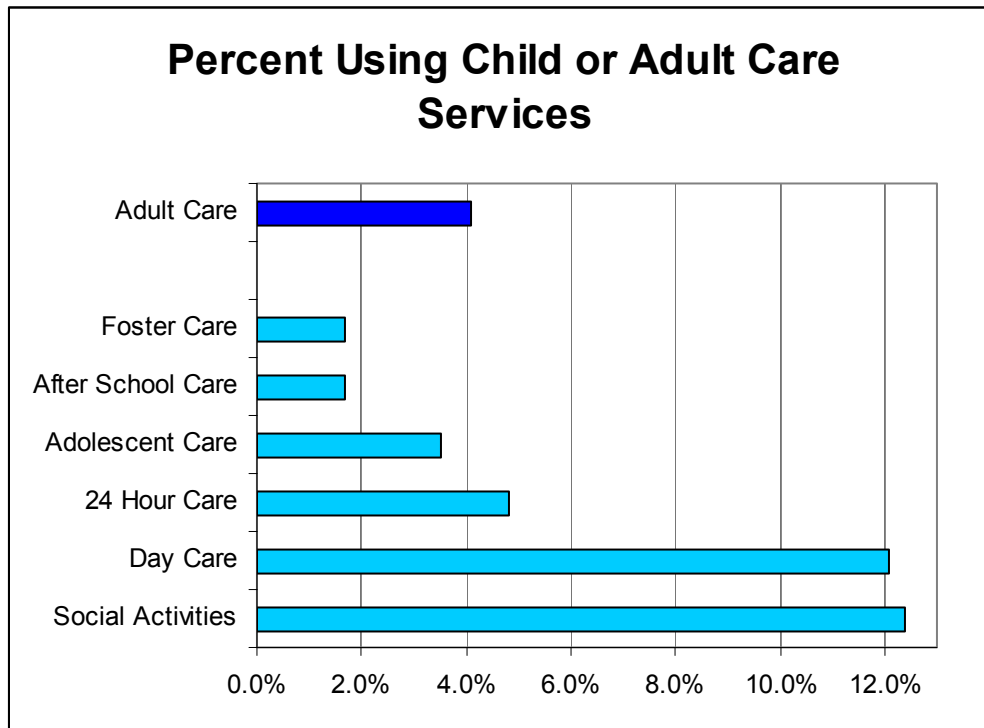
Transportation Services

As shown on the next page, 39% of respondents said they received VIA bus passes, which constituted the largest proportion of transportation assistance used. Over 30% report satisfaction with VIA service. Almost 24% reported using transportation to medical services, and 15% reported being “very satisfied,” and about 6% reported being “satisfied.” About 15% used a car or driver, slightly over 13% used emergency transportation, and over 12% received gasoline. For the most part, those using these services were either “very satisfied” or “satisfied” with them, although about 4% expressed less than satisfaction with the amount of gasoline received. Almost 10% used transportation assistance in order to complete errands, a little over 8% used taxis, and less than 8% used assistance in order to complete shopping. Once again those few using these services appear satisfied with them. Less than 3% of respondents reported using the VIA Lift service, about 1.5% report being satisfied while another 1.5% report being dissatisfied with this mode of transportation.



Child and Adult Care

Only a small proportion of clients reported using any type of childcare service (see Figure on next page). The largest proportion reported using social activity programs (12.4%), with 12.1% reporting they used day care services. A substantial proportion of those using these services report they are either “very satisfied” or “satisfied” with them. About 5% of respondents reported using 24 hour extended child care services, and less than 4% reported using adolescent day care services. Users were satisfied with those types of care. Less than 2% of those surveyed reported using after school care for children or foster care. Those few using these services were satisfied with them.



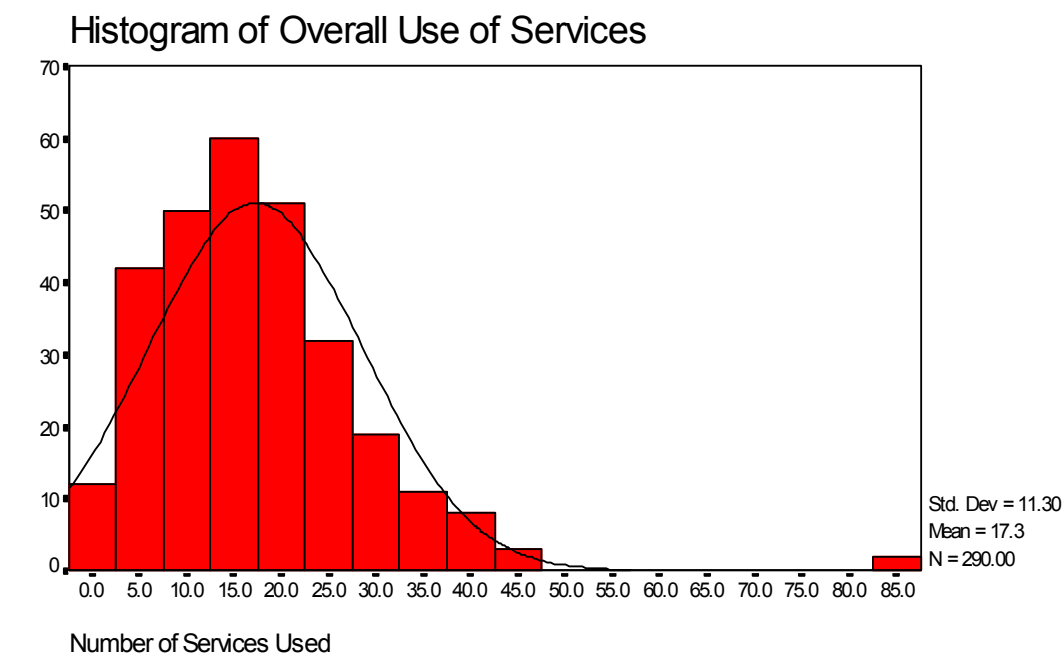
Finally, only about 4% of those responding to this survey reported using adult care services. Almost all, 3.5% were either “very satisfied” or “satisfied” with this service.

EXTENT OF SERVICE UTILIZATION

The questionnaire identifies 104 different services that the respondents might have used in the last 12 months, plus whether or not they received any money to help with rent payments. One of the values of this project may have been to make clients more aware of the broad array of support services available, since they frequently commented that they had no idea that so many services or some of the particular services were available. When this happened, we encouraged the respondents to talk to their case managers for more information.

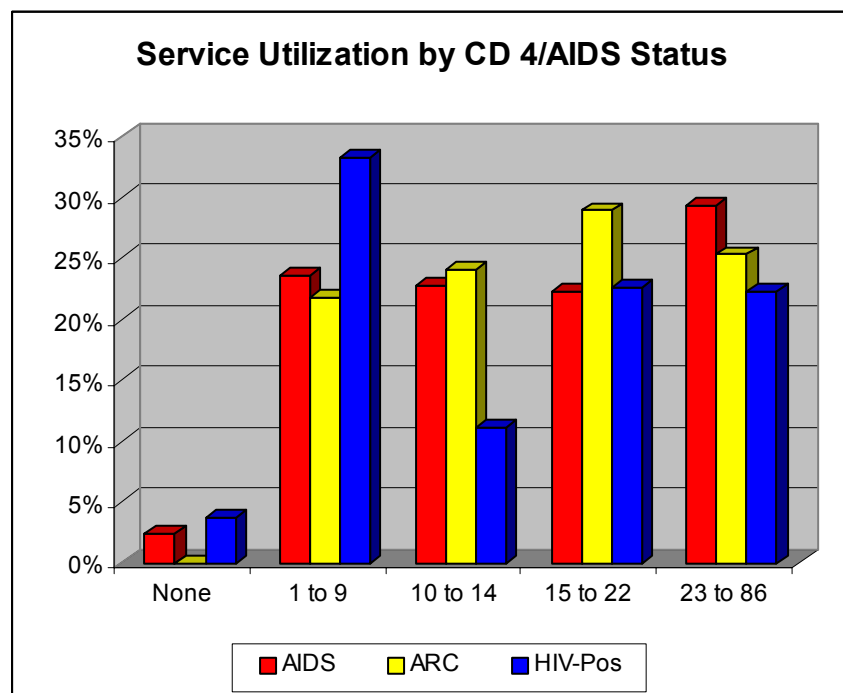
OVERALL UTILIZATION

With so many services available, how many different services do the clients tend to use? Based on whether or not they indicated that they had ever used particular services, we computed the total number of services that they claim to have used in the last 12 months. To illustrate the range, five respondents indicated that they had used none of the services and two respondents indicated that they had used 85 and 86 services respectively. (The last two are quite unusual, since the next largest number reported is 46.) The histogram on the next page illustrates the overall distribution of service use. The modal and median number of services used is 14 and 15, respectively, and the mean is 17.3. About 23% of the respondents reported using fewer than 10 different services, with another 23% indicating 10 to 14. Nearly 28% reported 15 to 22 different services and another 27% reported 23 or more different services used (see data following histogram.)



Mean	17.283	Median	15.000	Mode	14.000
Std dev	11.303	Minimum	.000	Maximum	86.000

We speculated that service usage would vary by disease stage. This idea proves to have little support. As shown below, just over 29% of the respondents reporting a CD4 count below 200 were in the highest usage category. This compares to about 25% of the ARC respondents and 22% of the HIV positive respondents. Three out of four of those claiming to use no services are in the AIDS group. However, they are somewhat less likely to be in the low (1-9) service category than the HIV positive patients. The basic findings in the crosstabular analysis are reinforced by the following analysis of variance, which shows that there is no consistent pattern of variation in the mean CD4 level by extent of service use.



Chi-Square = 6.97628 DF = 8 prob. = .539
Cramer's V = .122

AVERAGE CD4 LEVELS BY EXTENT OF SERVICES USED

	Mean CD4 Level	Std. Dev.	Frequency
No Services Used	187.2500	256.2100	4
1 - 9 used	246.9107	212.6218	56
10 - 14 used	188.7059	181.6476	51
15 - 22 used	280.2712	298.3112	59
23 to 86 used	192.1429	175.1368	63

F = 2.23, d.f. = 3, Prob. = .085 Eta-Sq = .03; Eta = .17

Another possibility explored is that those in contact with case managers would be more likely to be aware of and use more of the available services. This is clearly supported by the data on the next page. Those indicating that they have never used case management services in the last 12 months on average used just under 11 different services. This compares to nearly 18 different services for those seeing a case manager one or two times and to nearly 20 different services for those seeing a case manager more often. These results are statistically significant and indicate that case managers play an important role in assuring that their clients take advantage of available services.

Income level does not appear to have much bearing on service use, as shown in the following crosstabulation and analysis of variance. Interestingly, those reporting no monthly income have almost the same level of service use (mean of 16.3) as those with a monthly income that exceeds the poverty level for a one-person household (mean of 16.6). Those with some income, but below the poverty level were the most likely to use many services (see the crosstabulation) and had a mean of 18.3.

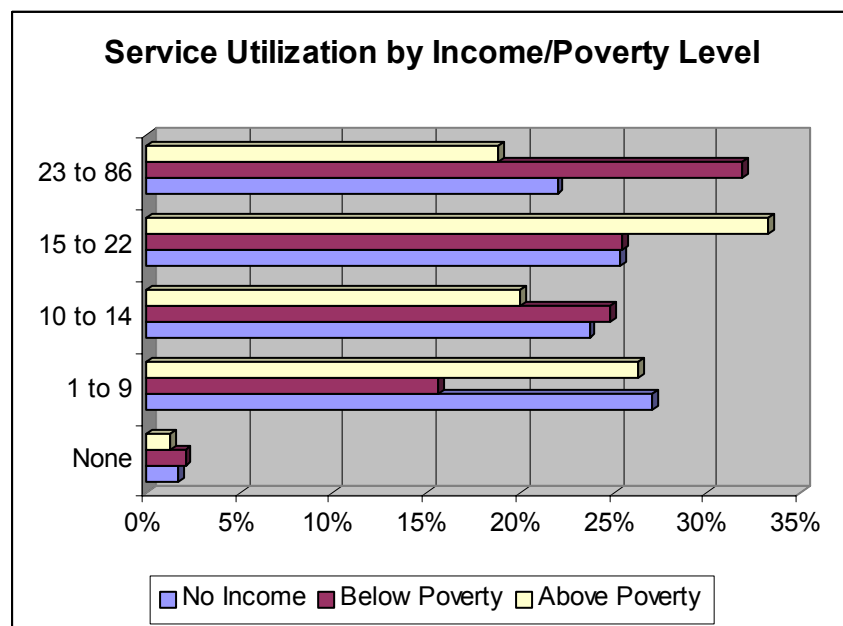
Also explored is whether there is any difference in overall satisfaction with services based on extent of service usage. The crosstabulation that follows indicates that there is little relation between extent of service usage and overall level of satisfaction. Over 40% of those in the two highest usage

categories indicated they were very satisfied overall, compared to about 36% for those using between 1 and 14 services.

AVERAGE SERVICE USAGE BY USE OF CASE MANAGEMENT

	Mean	Std Dev	Frequency
Never	10.6618	8.5442	68
1-2 Times	17.9825	15.6142	57
3 or More	19.8537	9.3193	164

F = 17.89, df = 2, Eta-sq = .11 Eta = .33

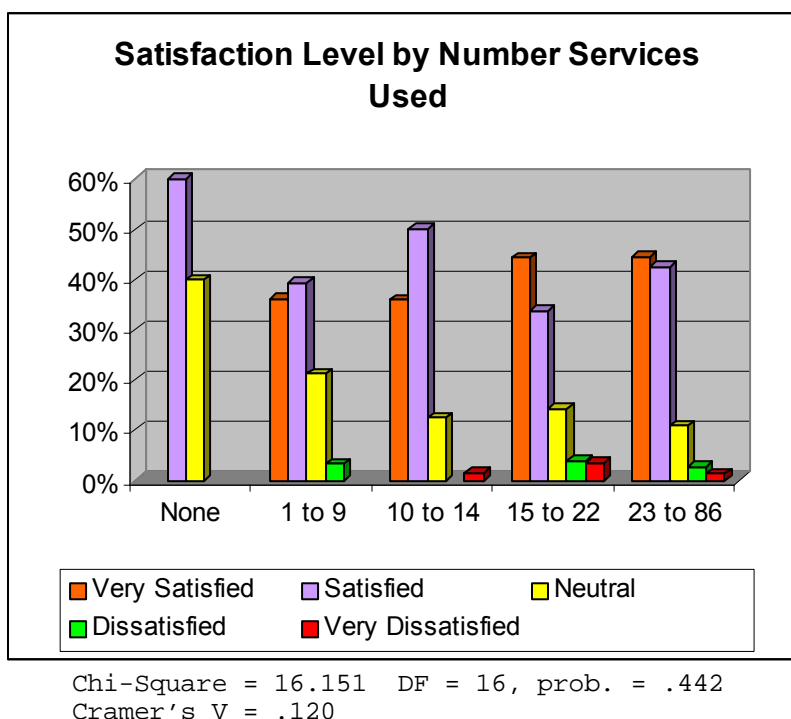


Chi-Square = 10.043 DF= 9 prob. = .262
Cramer's V = .13392

AVERAGE NUMBER OF SERVICES USED BY MONTHLY INCOME LEVEL

	Mean	Std. Dev.	Frequency
No Income	16.3390	13.1564	59
Below Poverty	18.3050	9.7453	141
Above Poverty	16.5750	12.4105	80

F = .922, Prob. = .398, Eta-Sq = .0066, Eta = .081

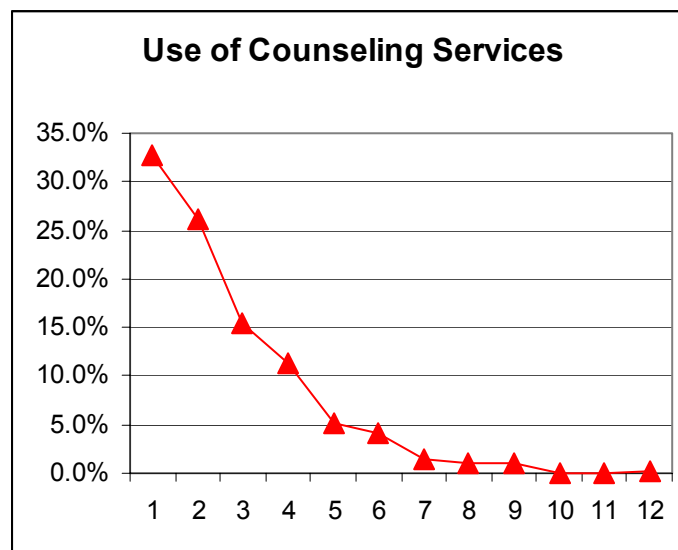
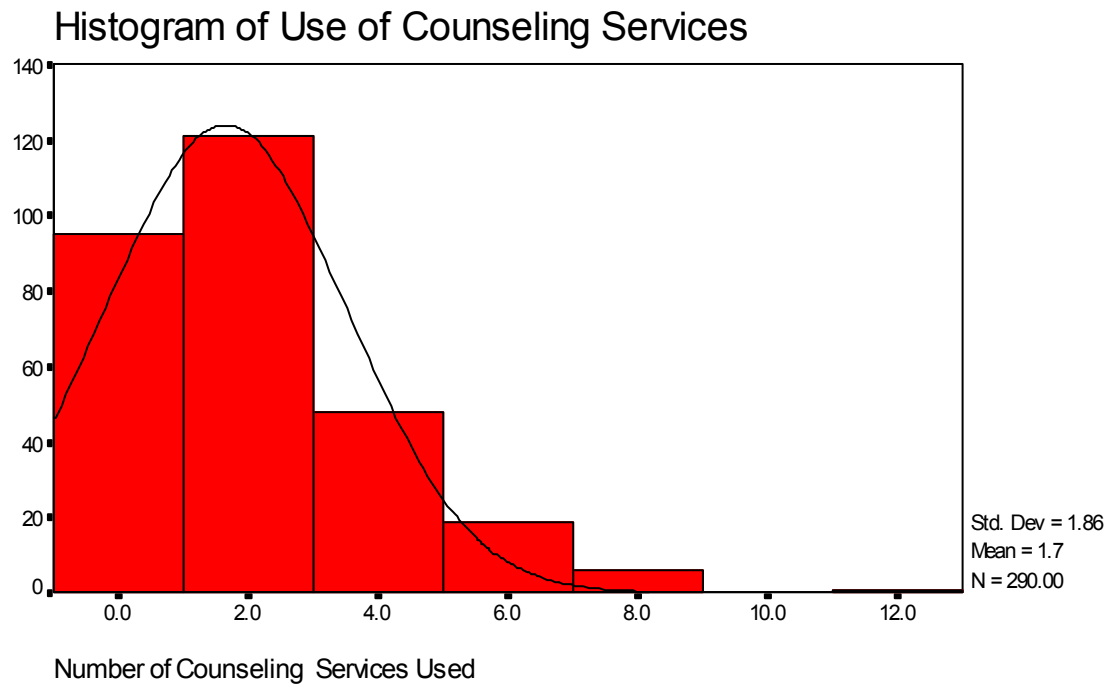


Use of Counseling Services

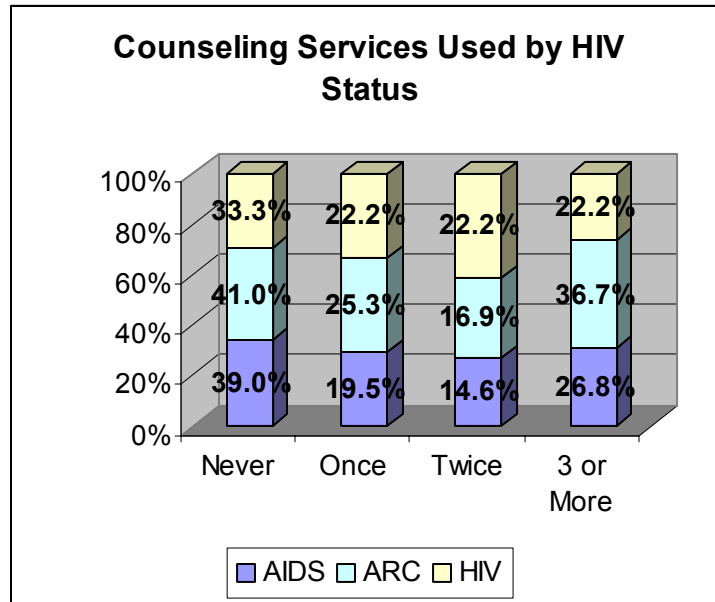
One important subset of services available is in the area of counseling to provide psychological, emotional and spiritual support for the respondents as they attempt to deal with the reality of their disease. Eleven different types of counseling services are included on the questionnaire. As is illustrated in the following histogram and display of frequency of use of counseling services, approximately one third indicate that they use no counseling. One person indicated taking advantage of all 11 types of counseling. The mean of 1.67 illustrates that the largest cluster of respondents used counseling once or twice in the last 12 months.

Strikingly, there is no consistent relationship between CD4 level and use of counseling services. Nearly 40% of those with CD4 levels below 200 indicate no use of counseling services, compared to 33% of the HIV positive and 24% those with CD4 levels between 200 and 499. The

largest percentage reporting frequent use of counseling services (3 or more times) were those classified as Aids Related Complex (ARC) AT 33.7%.



Mean 1.666, Std dev 1.861 Median 1.000 Minimum .000 Maximum 11.000



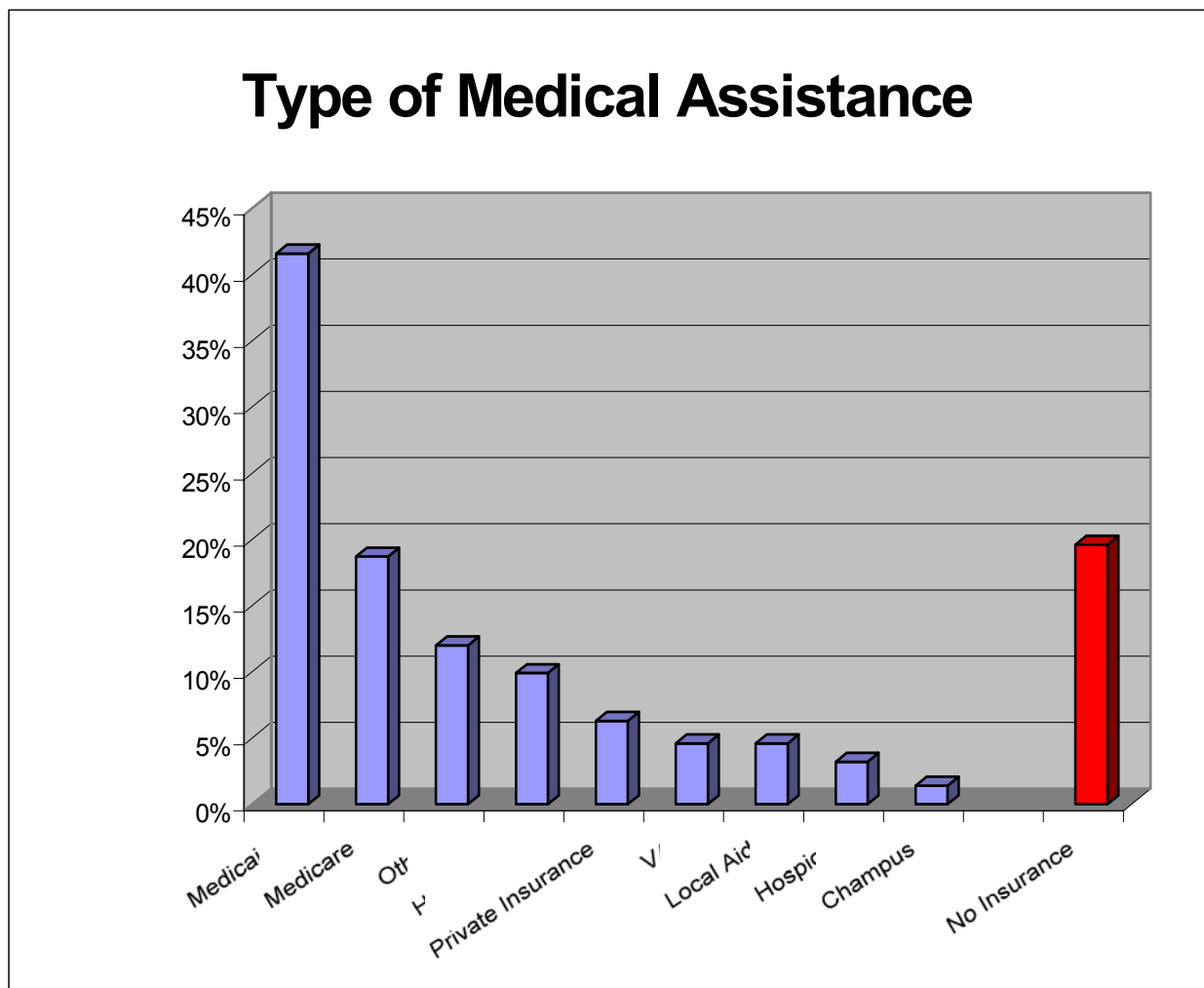
Chi-Square = 6.184, DF = 6, prob. = .402
Cramer's V = .115

CLIENT NEEDS

The diversity of client needs was well illustrated by comments from the respondents. One Hispanic female client who found out about her HIV status in 1994 said, "I would like a buddy or friend to talk to. I am rejected by my family. I really need child care ... parenting tires me out." An Hispanic male with nine years of education commented, "Sometimes the pharmacy runs out of medications or doesn't have the right amount that I need." An Anglo male who found out about his status in 1993 said, "Please let the Dental Clinic have money for updated equipment. Without good teeth, I don't want to smile and I lose self esteem." Another Anglo male stated, "I will need help to plan a budget I can live on as I will be making a lot less money than ever before. Where can I volunteer to do office work. I would like to feel useful with my life." A 35 year old Hispanic gay man reported wanting help "... with providing Christmas gifts." An extensive review of actual service use and satisfaction with those service follows.

MEDICAL ASSISTANCE/NEEDS

The Figure on the next page displays the limited financial assistance available to support the medical needs of the respondents. Fewer than 42% indicate that they receive Medicaid, with Medicare a distant second source at 18.7%. It seems noteworthy that the percent with **no assistance** for medical costs (19.6%) exceeds the second most frequently used source. Under



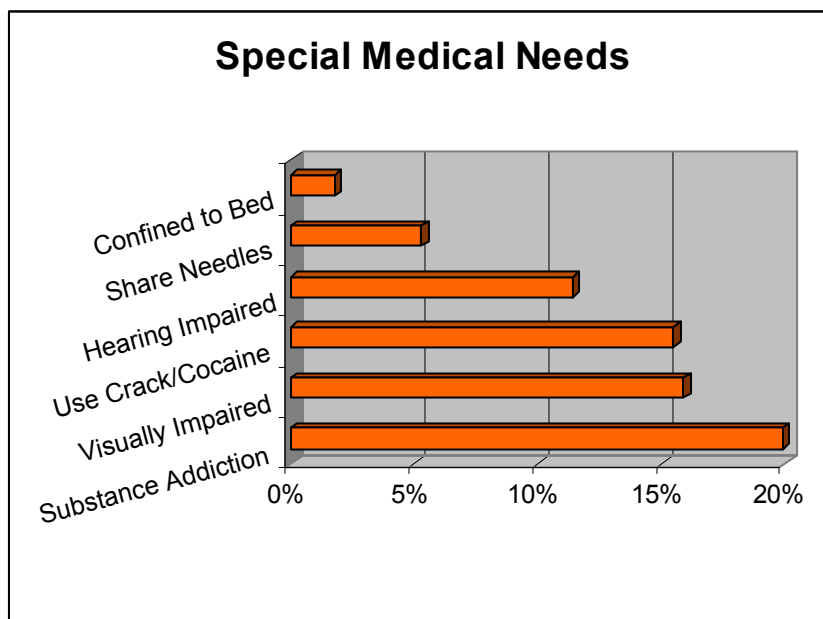
10% have HMO/PPO access and only 6.3% report other private health insurance. Fewer than five percent have other forms of medical assistance. Overall, 73 respondents (25.9%) indicated that they did not have Medicaid, Medicare, HMO/PPO, private insurance, Champus, veteran's

benefits or Community Based Organization assistance for medical care needs. This figure, however, is substantially lower than comparable information from previous needs assessments.

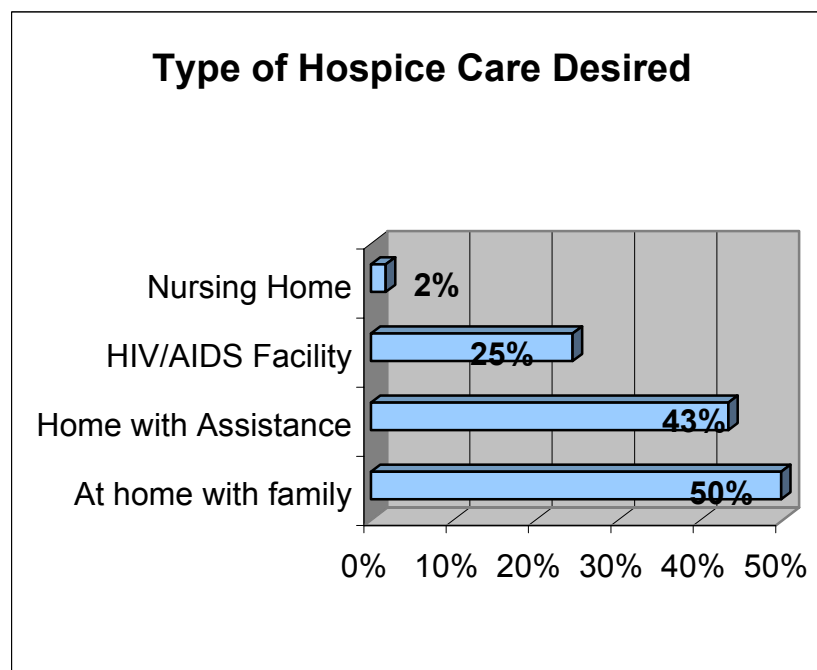
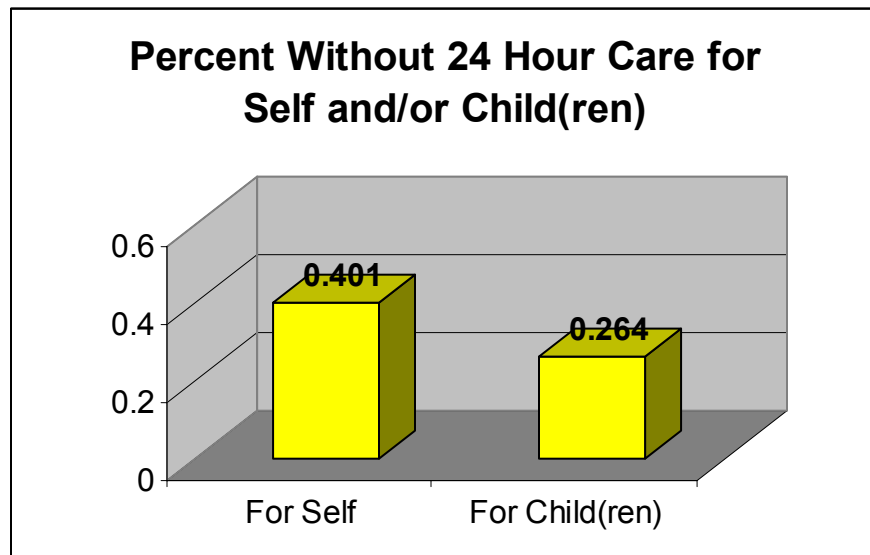
SPECIAL MEDICAL NEEDS

Nearly one in five of the respondents report substance addiction as a special medical need and closely associated with this is the use of crack and/or cocaine at 15.5% (see Figure on next page). Furthermore, 5.3% indicate that they still regularly share needles with others. Visual impairment affects nearly 16%, hearing impairments affect 11.4% and just fewer than 2% report being confined to bed.

In the second Figure following this page, just over 40% indicate that they have no one to care for them 24 hours a day if they become ill. Over one in four report that they have no one to care for children. In terms of type of care desired, almost exactly half indicate that they prefer to receive hospice care services “...at home just with my friends and/or family who care for me 24

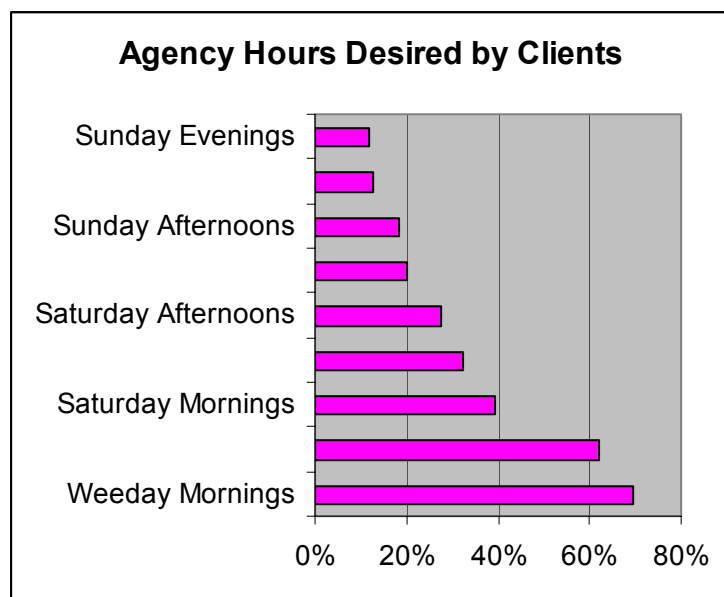


hours a day.” This is closely followed, at 43.4%, by “...at home with emotional and spiritual support and assistance in addition to family who cares for me 24 hours a day.” About one in four chose “...in a special HIV/AIDS facility” and only 1.8% selected “...in a nursing home.”



DESIRED HOURS FOR CLIENT SERVICES

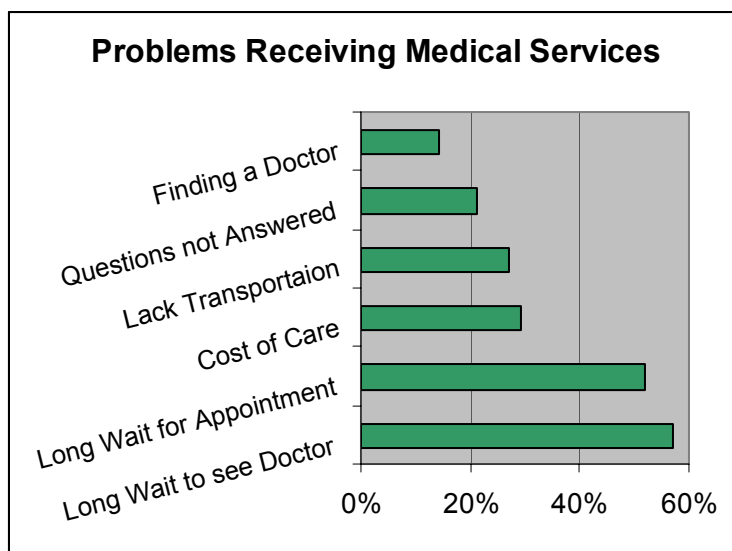
Respondents were asked, “If you could tell agencies what times you need them to be open, what times of the day and days of the week would that be? (Check all that apply).” The Figure on the next page summarizes the results. Weekday mornings and afternoons predominate, with nearly 70% and 62% respectively. Nearly 40% identified Saturday mornings, with another 27.7% selecting Saturday afternoons. Nearly one in three chose weekday evenings. Sunday was less frequently chosen, but still close to one in five chose Sunday mornings and afternoons.



MEDICAL SERVICES PROBLEMS

The figure on the next page identifies the problems most frequently reported related to seeking or receiving medical services during the last twelve months. Long waits top the list, with well over fifty percent citing long waits to get appointments and long waits to see the doctor. Costs of medical care and location/transportation issues related to obtaining medical treatments were next at 29.1% and 27.2% respectively. Over one in five report problems with

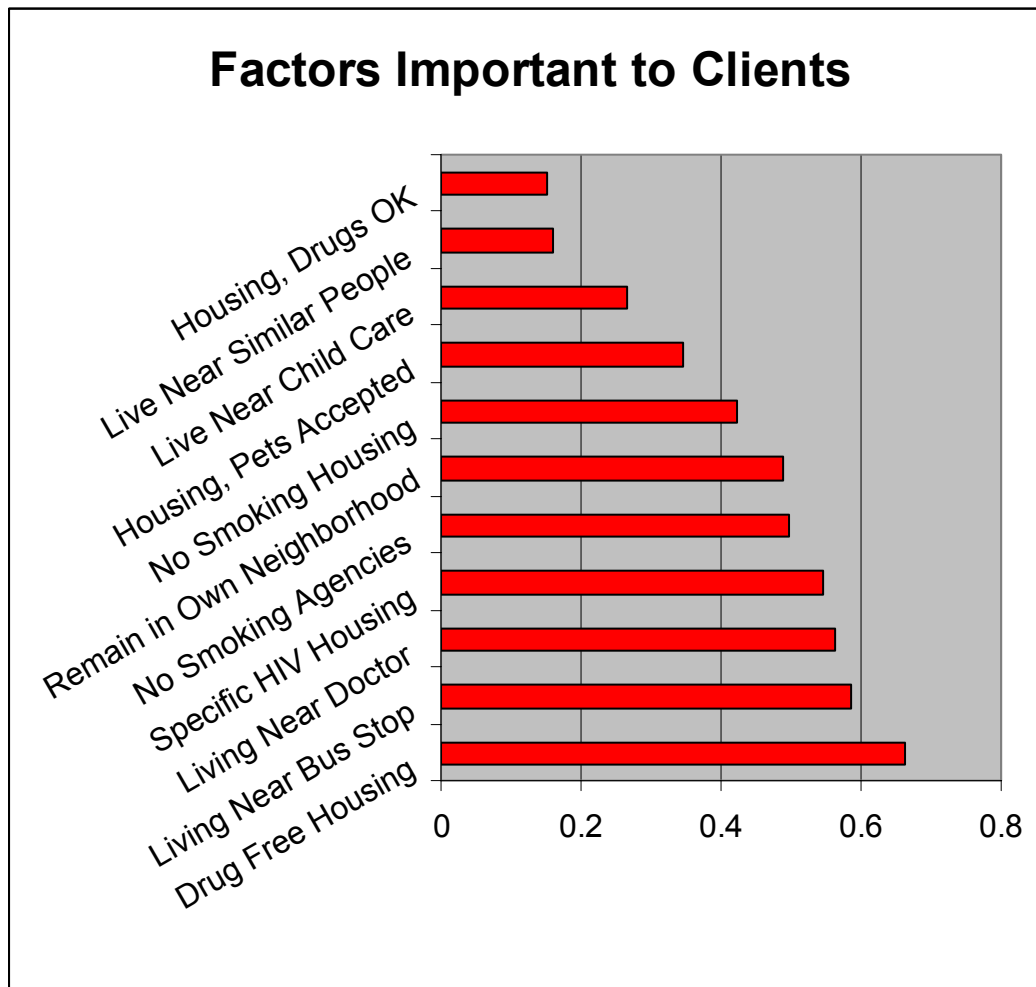
their questions not being answered by doctors or nurses. Just over 14% indicate problems in finding a doctor at all.



FACTORS IMPORTANT TO CLIENTS

The questionnaire contains the following statement: “The following list of questions asks how important to you some things are about your services. Please tell me whether the item is very important, somewhat important or not important at all.” The Figure on the next page provides a rank order based on the “very important” category. Alcohol and drug free housing is at the top of the list, with 66.2% indicating this is very important to them. Access to public transportation (bus stop) and living near their doctor or hospital are priorities for 58.5% and 56.2% respectively. “Housing for people with HIV infection” (54.5%) is fourth on the list. Smoke free environments at the agencies and in housing are very important to 49.6% and 42.4% of the respondents. Nearly half (48.8%) indicate that remaining in their favorite neighborhoods is very important. Housing that allows pets is very important to over one in three of the respondents. Childcare is next, at 26.5%. “Living with people who are my same race, sexual

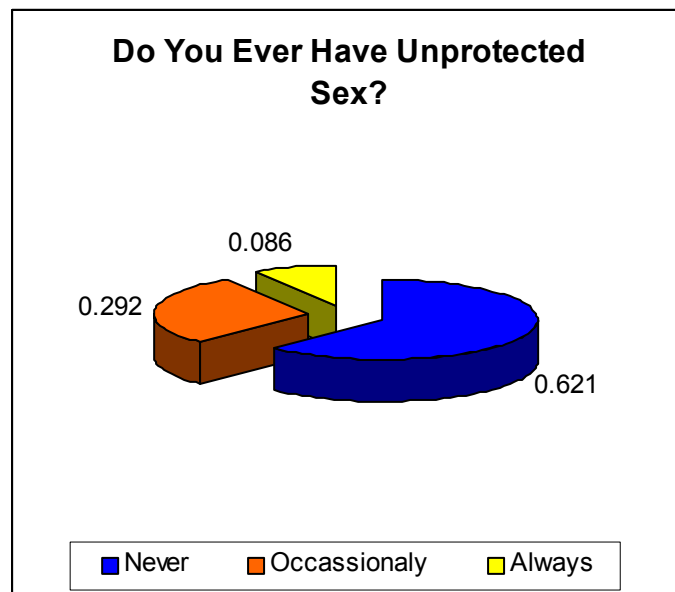
orientation, gender” is very important to only 16.1% and living in housing where alcohol and drug use are acceptable is very important to 15%.



HIGH RISK SEXUAL BEHAVIOR

According to information released from the 11th International Conference on Aids (San Antonio Express-News, July 9, 1996), “A generation of young gay men across the industrialized world, tragically ignoring the lessons of the AIDS epidemic, risk a new wave of HIV infection by engaging in dangerous sex ...” The behavior of our sample respondents appears to reflect this

type of world-wide concern. Almost 38% of the respondents indicated that they continue to have unprotected sexual relations occasionally or always. This seems like a high percentage among this already infected population and warrants further exploration.



The following tables provide data by gender, race/ethnicity, age, education and HIV status. The most striking observation is that unprotected sexual activity is prevalent for all groups. Females are less likely than the males or the transgendered to report **never** having unprotected sex (52.9%) -- and, as is shown in Appendix B, over 88% of the females report themselves to be heterosexual. There is very little difference by race or ethnicity. The percent reporting never increases with age (except for the children aged 0-5, of course). Close to half report at least occasional unprotected sex for respondents in their twenties and thirties, and this drops to just over one in four for those aged 40 and over. Research reported in the Express-News article suggest that, "...about one third of young gay men in their twenties engage in anal sex without condoms, the riskiest form of homosexual behavior." The article suggests that the young feel invincible and believe that they won't get sick from anything. However, one man in

his late twenties with AIDS indicated that this type of behavior may “... be an attempt to feel normal.” The stigma of focusing on safe sex might intrude on attempts to form close relationships.

HAVE UNPROTECTED SEX BY LEVEL OF GENDER, AGE, EDUCATION AND SELF-DESIGNATED HIV STATUS

<u>GENDER</u>	Never	Occasionally	Always	TOTAL
Male	64.5	29.6	5.9	100.0
Female	52.9	29.4	17.6	100.0
Transgender	66.7	16.7	16.7	100.0
N	151	71	21	243
Chi-Square= 8.050 DF= 4 Prob. = 0.089 V= 0.129				

<u>RACE/ETHNICITY</u>	Never	Occasionally	Always	TOTAL
Black	66.7	23.1	10.3	100.0
Hispanic	59.6	30.8	9.6	100.0
White	61.4	31.3	7.2	100.0
Other	72.7	18.2	9.1	100.0
N	147	69	21	237
Chi-Square= 2.020 DF= 6 Prob. = 0.918 V= 0.065				

<u>AGE GROUP</u>	Never	Occasionally	Always	TOTAL
10-19	40.0	20.0	40.0	100.0
20-29	51.4	34.3	14.3	100.0
30-34	53.3	41.7	5.0	100.0
35-39	58.9	33.9	7.1	100.0
40-44	74.4	20.5	5.1	100.0
45 and older	73.8	14.3	11.9	100.0
N	145	71	21	242
Chi-Square= 24.114 DF= 12 Prob. = 0.020 V= 0.223				

<u>EDUCATION</u>	Never	Occasionally	Always	TOTAL
Under 12 years	54.0	31.7	14.3	100.0
High School Degree	63.5	31.8	4.7	100.0
Some College	67.8	20.3	11.9	100.0
BA or Higher	61.5	34.6	3.8	100.0
N	148	68	21	233
Chi-Square= 10.745 DF= 8 Prob. = 0.217 V= 0.151				

<u>HIV STATUS</u>	Never	Occasionally	Always	TOTAL
HIV+, Asymptomatic	50.0	42.4	7.6	100.0
HIV+, Symptomatic	63.6	24.2	12.1	100.0
AIDS	76.9	21.5	1.5	100.0
Don't Know	33.3	33.3	33.3	100.0
N	149	69	21	239
Chi-Square= 22.698 DF= 6 Prob. = 0.001 V= 0.218				

Education level appears to have only a little impact, with nearly 40% of those with college degrees engaging in high risk sexual activity. Assuming that those with higher levels of education are more informed about the negative consequences of high risk sexual behavior, this finding is very surprising -- but consistent with the idea of avoiding stigma and striving to appear “normal.”

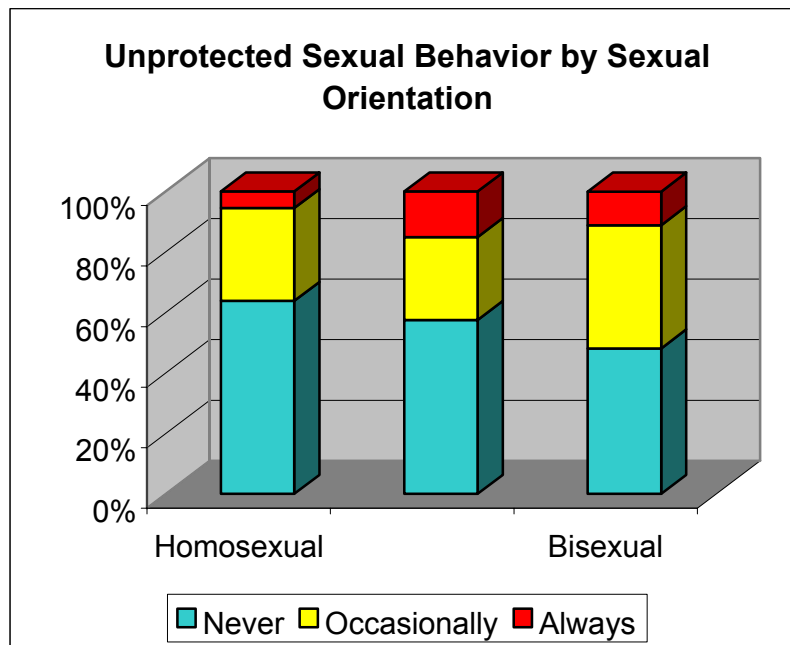
HIV status makes some difference -- only about one in four of those who designate themselves as AIDS practice unprotected sex compared to half of those who classify themselves as HIV Positive, but asymptomatic. Even so, the level of high risk behavior for all categories is extensive.

As shown below, the place where respondents usually got information for services for persons with HIV/AIDS during the last 12 months had no clear relevance for whether or not they engaged in unprotected sexual activity. Even those whose primary source of information is case managers or social workers (the Soc Work category) have close to 30% who occasionally or always have unprotected sex. Looking at the other two large categories (Doctor’s Office and Others with HIV/AIDS), the findings remain the same -- 38% or more report engaging in high risk sexual behavior.

UNPROTECTED SEX BY USUAL SOURCE OF HIV SERVICES INFORMATION

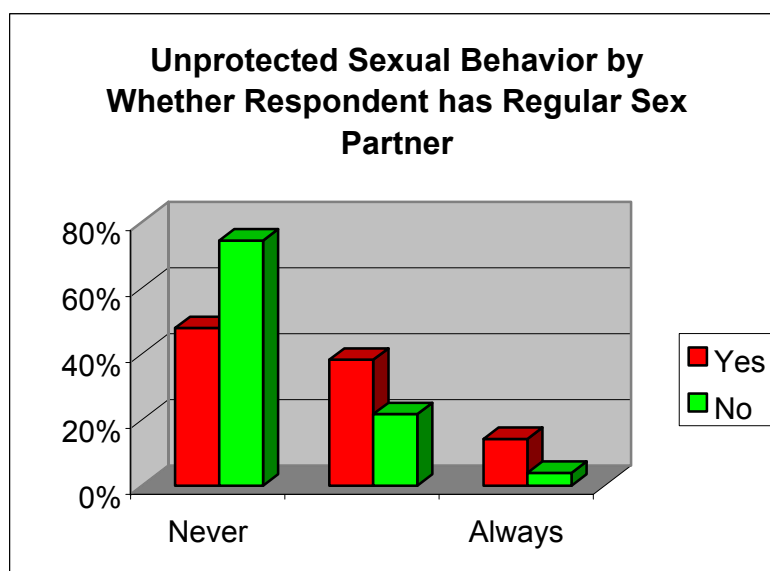
	Never	occasionally	always	TOTAL
Place Tested	52.9	35.3	11.8	100.0
Local Hangout	57.1	28.6	14.3	100.0
Church	100.0	0.0	0.0	100.0
On Job	37.5	50.0	12.5	100.0
Doctor’s Office	62.1	26.3	11.6	100.0
My Family	0.0	100.0	0.0	100.0
Others-HIV/AIDS	60.5	34.9	4.7	100.0
Outreach Center	60.0	20.0	20.0	100.0
Social Worker	70.9	23.6	5.5	100.0
Brochure	80.0	20.0	0.0	100.0
HIV Hotline	100.0	0.0	0.0	100.0
Counselor	50.0	50.0	0.0	100.0
N	150	69	21	240

The results below show that large percentages of respondents report that they have unprotected sex occasionally or always regardless of their sexual orientation.



Chi-Square= 6.840 DF= 4 Prob. = 0.144 V= 0.123

Those with a regular sex partner are even more likely to engage in high risk behavior, with 38.1% saying occasionally and 14.2% saying always. The reference to “occasionally” may illustrate the type of denial that would go along with the desire to “behave normally,” simply

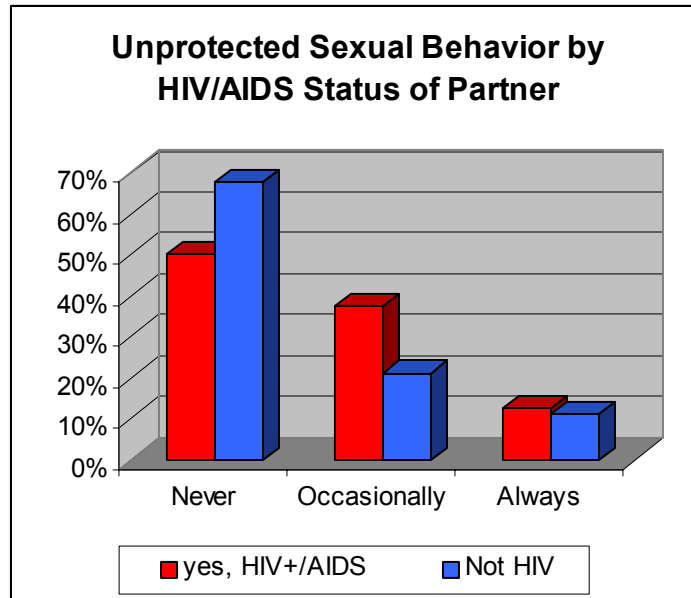


Chi-Square= 19.719 DF= 2 Prob. = 0.000 V= 0.285

ignoring the fact that “it only takes once.” The large category indicating that they have no regular sex partner and never engage in unprotected sex may be misleading. Many of these people are not having unprotected sex because they are not having any sex. If partners were to become available, their future responses might change to reflect the same level of high risk behavior.

The data on the following page focus on the type of caregiver reported to be available for 24 hour care and the HIV/AIDS status of that person. We can reasonably assume that a “partner” as a primary caregiver is likely to be a sexual partner for those engaging in sexual activity. Over 47% of those with HIV/AIDS infected partners report engaging in unprotected sex at least occasionally. This is occurring even in the face of current information that indicates that partners can re-infect each other with different forms of the virus. Even more astonishingly, 44% of those stating that their partners are not infected still indicate that they at least occasionally engage in unprotected sex. These partners are obviously at very high risk.

The potential impact of drug use is also explored based on reports of regularly sharing needles with others, being addicted to substances and whether or not they report using cocaine or crack in the last twelve months. Sharing of needles is not strongly related to the likelihood of engaging in unprotected sex. This same pattern of finding prevails for whether or not they report substance addiction. Cocaine or crack use, however, appears to make a difference. Those using cocaine or crack are substantially more likely to engage in unprotected sexual activity. In particular, they are more than twice as likely to say that they occasionally engage in unprotected sex.



Chi-Square= 4.794 DF= 2 Prob. = 0.091 V= 0.186

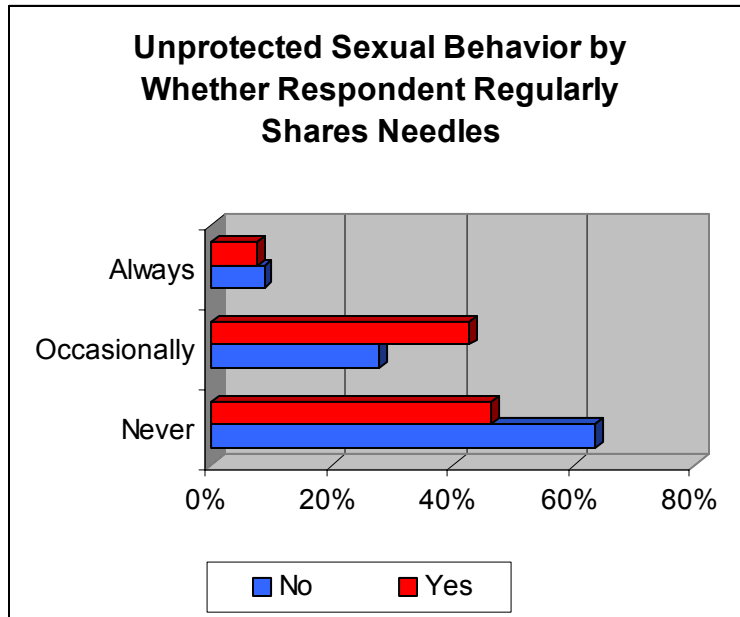
UNPROTECTED SEX BY TYPE OF CAREGIVER

A. Caregiver has HIV+/AIDS

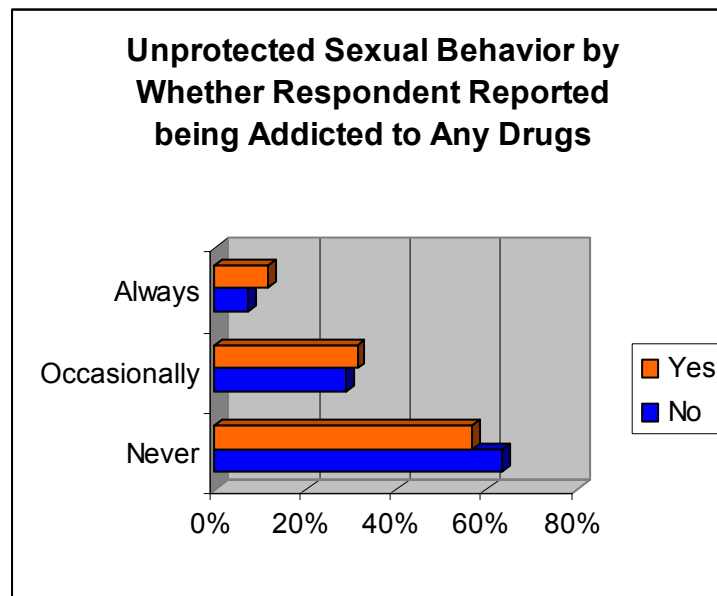
	Never	Occasionally	Always	TOTAL
Partner	52.6	36.8	10.5	100.0
Family	50.0	25.0	25.0	100.0
Roommate	20.0	60.0	20.0	100.0
Friend	100.0	0.0	0.0	100.0
Parent/s	20.0	60.0	20.0	100.0
N	18	15	6	39
	46.2	38.5	15.4	100.0

B. Caregiver does not have HIV+/AIDS

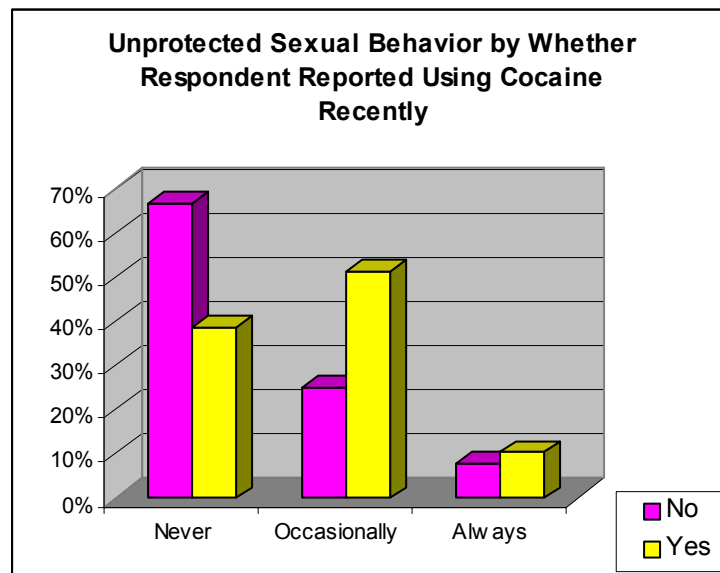
	Never	Occasionally	Always	TOTAL
Partner	56.0	32.0	12.0	100.0
Family	67.9	17.9	14.3	100.0
Roommate	100.0	0.0	0.0	100.0
Friend	33.3	66.7	0.0	100.0
Parent/s	81.8	9.1	9.1	100.0
Other	60.0	40.0	0.0	100.0
N	48	18	8	74



Chi-Square= 2.004 DF= 2 Prob. = 0.367 V= 0.094

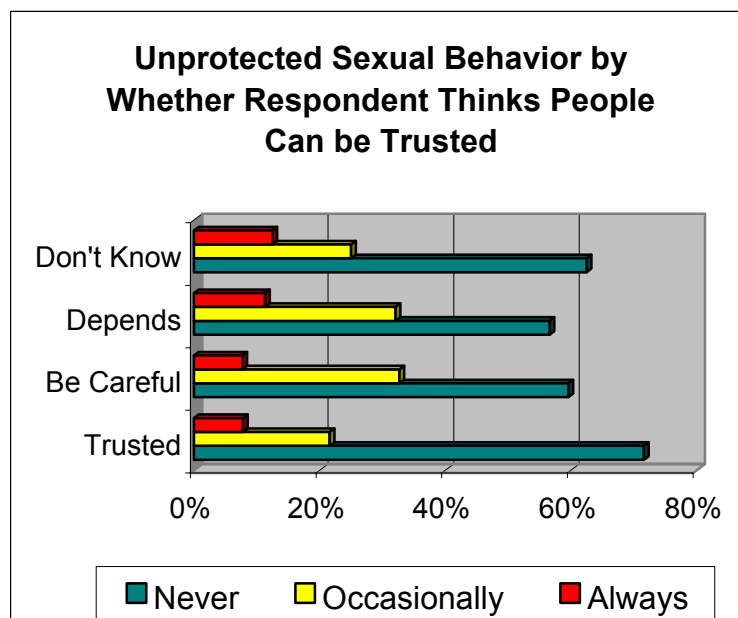


Chi-Square= 1.269 DF= 2 Prob. = 0.530 V= 0.073



Chi-Square= 11.963 DF= 2 Prob. = 0.003 V= 0.223

Finally, we explored responses to the question, “Generally speaking, would you say that most people can be trusted or that you can’t be too careful in dealing with people?” While not statistically significant, it is noteworthy that those believing people can be trusted have the largest percentage in the Never category on having unprotected sex.



Chi-Square= 4.515 DF= 6 Prob. = 0.607 V= 0.097

CONFIDENCE IN INSTITUTIONS AND TRUST IN PEOPLE

Local, State and National Institutions

When confronted with a life threatening disease, one possible response is to lose confidence or trust in support institutions. The Figure on the next page provides an assessment of the level of confidence or trust that the respondents express toward various institutions. Ranking at the top are the Community Service Agencies, with 45.1% indicating a great deal of confidence and 41.0% indicating only some. Medicine is a close second. Both the scientific community and organized religion are accorded a great deal of confidence by only about one in four of the respondents, and state and federal government produce the lowest levels of confidence.

Comparing Sample and National Responses

Hostility toward lesbian and gay people has increased since the AIDS epidemic (Herek, 1991; Herek & Glunt, 1990; Pleck et al., 1989), although this may be mitigated as the community becomes better educated about AIDS (Colasanto, 1989). Nonetheless, it is clear that there is still a negative stigma attached to individuals with HIV disease and AIDS, and as a result they may have become further marginalized compared to the larger gay and lesbian community. Because of their marginalized status, it would seem likely that individuals with HIV disease or with AIDS would express less confidence in those institutions designed to support American society. It is also likely, given the stigma attached to their disease, that they would have less trust in people in general. In order to test this hypothesis, we compared responses from this sample to responses from the 1994 General Social Survey (GSS) on questions related to institutional confidence and levels of trust in people. The GSS provides responses to a variety of

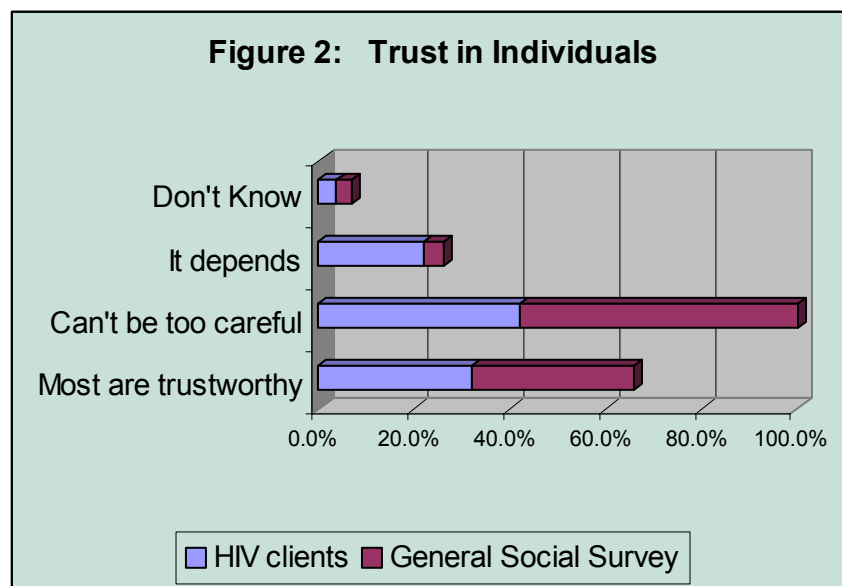
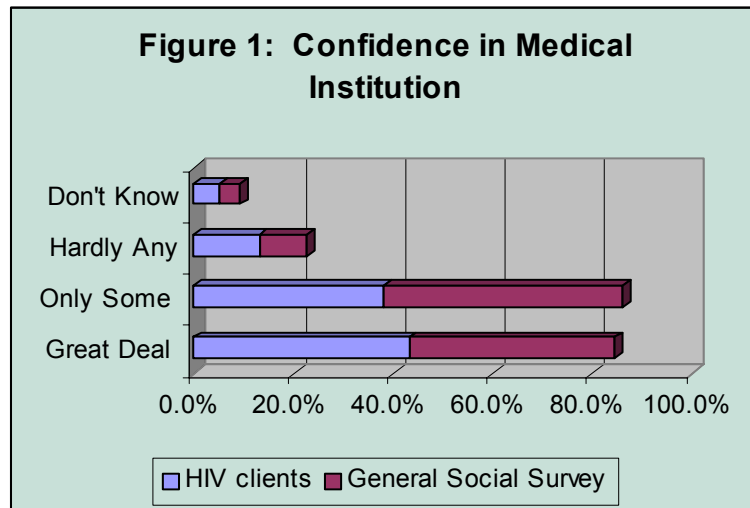
issues related to public attitudes and concerns from a stratified random probability sample of individuals 18 years or older, who are English-speaking and non-institutionalized. Eight questions, five related to trust in institutions, and three to trust in people from the 1994 GSS were also asked of all respondents to the San Antonio Needs Assessment and Client Survey.

Confidence in Institutions

Responses from the San Antonio clients and from the national sample are included in the following table. There is very little difference in the level of confidence in organized religion and in the federal government between the two groups, although the respondents to this survey are somewhat more likely to say they “don’t know” (9.5%, 9.0% respectively) compared to the national sample (2.2%, 2.1% respectively). Confidence in the scientific community, medicine and Congress are distinctly lower among this group than the national sample. Only 27.9% of clients said they have a “great deal” of trust in the scientific community, compared to 38.2% of the respondents to the GSS, and only 37.9% of this group compared to 49% of national group said they had “only some” trust. Most telling perhaps, 21.2% of the San Antonio respondents compared to 7% of the national respondents said they had “hardly any” trust in the scientific community.

The proportions of those expressing a “great deal” of confidence in medicine were about the same for each group, and slightly higher for the San Antonio respondents (43.2% compared to 41.3%). However 38.3% of the clients compared to 47.8% of the national group said they had “only some” confidence in medicine. And 13.2% of those with HIV disease or AIDS compared 9.7% of the GSS respondents said they had “hardly any” confidence in medicine. Once again these respondents were a little more likely to say they had a “great deal” of confidence in Congress --- 9.1%), compared to 7.7% nationally. Once again the responses were dramatically

lower among those who said they had “only some” (25.6%) and dramatically higher for those saying “hardly any” trust in Congress among the group with HIV disease or AIDS compared to those in the national sample (50%, and 39.2% respectively).



Trust in People

Respondents to the San Antonio survey were almost equally likely (32.1%) as the national sample (33.9%) to say that “most people can be trusted,” and less likely to say that “you can’t be too careful” in dealing with people (41.2%, compared to 61.1%). This group was a lot less likely than the national sample to say that most people would “try to take advantage of you if they got a chance” (20.6% compared to 39.1%) , and slightly less likely to say that most people “would try to be fair” (48.9% compared to 53%). The respondents with HIV disease or AIDS were far more likely to say that “most of the time people try to be helpful” (60.6%) than the respondents to the GSS (46.3%), and dramatically less likely to say that people are “mostly just looking out for themselves (11.7% compared to 46.5%). In all cases, the San Antonio respondents were far more likely to choose the qualifying response of “it depends” to each of these three questions than the respondents from the national sample (see following table).

Summary

These results lend some support to the hypothesis that individuals with HIV disease or AIDS are somewhat more likely than the general public to lack confidence in major government, scientific or medical institutions. This does not seem unusual given the combinations of the stigma attached to their illness, their dependence on government support for services to keep them alive and as healthy as possible, and the great difficulty in finding and adequate treatments and in making those treatments available to those who need them.

Interestingly, these respondents are more likely than the general public to say they trust other people, although they are also more likely to respond with a qualified trust (i.e. “it depends”). Perhaps this level of trust emanates from the fact that the service providers in the San Antonio community have worked at meeting the needs of those clients using their services.

Because they are dependent on those agencies for their daily lives, they deal with the service providers on a regular basis. If their experience is positive, they should develop a sense of trust in the agencies and the individuals who work within them. It seems likely that the same trust they have developed in agency personnel would carry over into their views of the general public.

CONFIDENCE/TRUST: RESPONDENTS COMPARED TO NATIONAL SAMPLE

I'M GOING TO NAME SOME INSTITUTIONS IN THIS COUNTRY. AS FAR AS THE PEOPLE RUNNING THEM ARE CONCERNED, WOULD YOU SAY YOU HAVE A GREAT DEAL OF CONFIDENCE, ONLY SOME CONFIDENCE, OR HARDLY ANY CONFIDENCE AT ALL IN THEM?

ORGANIZED RELIGION?

	TOTAL	%	NATIONAL %
1) GREAT DEAL	67	27.57	24.2
2) ONLY SOME	94	38.68	51.5
3) HARDLY ANY	59	24.28	21.7
4) DON'T KNOW	23	9.47	2.2
NO RESPONSE PROVIDED	47		0.4
TOTAL USABLE RESPONSES	243	100.00	

FEDERAL GOVERNMENT

	TOTAL	%	NATIONAL %
1) GREAT DEAL	38	15.51	11.2
2) ONLY SOME	107	43.67	51.4
3) HARDLY ANY	78	31.84	34.9
4) DON'T KNOW	22	8.98	2.1
NO RESPONSE PROVIDED	45		0.4
TOTAL USABLE RESPONSES	245	100.00	

SCIENTIFIC COMMUNITY

	TOTAL	%	NATIONAL %
1) GREAT DEAL	67	27.92	38.2
2) ONLY SOME	91	37.92	49.0
3) HARDLY ANY	51	21.25	7.0
4) DON'T KNOW	31	12.92	5.2
NO RESPONSE PROVIDED	50		0.5
TOTAL USABLE RESPONSES	240	100.00	

MEDICINE

	TOTAL	%	NATIONAL %
1) GREAT DEAL	105	43.21	41.3
2) ONLY SOME	93	38.27	47.8
3) HARDLY ANY	32	13.17	9.7
4) DON'T KNOW	13	5.35	0.7
NO RESPONSE PROVIDED	47		0.4
TOTAL USABLE RESPONSES	243	100.00	

CONGRESS

	TOTAL	%	NATIONAL %
1) GREAT DEAL	22	9.09	7.7
2) ONLY SOME	62	25.62	50.0
3) HARDLY ANY	127	52.48	39.2
4) DON'T KNOW	31	12.81	2.4
NO RESPONSE PROVIDED	48		0.6
TOTAL USABLE RESPONSES	242	100.00	

WOULD YOU SAY THAT MOST OF THE TIME PEOPLE TRY TO BE HELPFUL, OR THAT THEY ARE MOSTLY JUST LOOKING OUT FOR THEMSELVES?

	TOTAL	%	NATIONAL %
1) TRY TO BE HELPFUL	160	60.61	46.3
2) JUST LOOK OUT FOR THEMSELVES	31	11.74	46.5
3) IT DEPENDS	58	21.97	6.4
4) DON'T KNOW	15	5.68	0.4
NO RESPONSE PROVIDED	26		0.3
TOTAL USABLE RESPONSES	264	100.00	

DO YOU THINK MOST PEOPLE WOULD TRY TO TAKE ADVANTAGE OF YOU IF THEY GOT A CHANCE, OR WOULD THEY TRY TO BE FAIR?

	TOTAL	%	NATIONAL %
1) WOULD TAKE ADVANTAGE OF YOU	54	20.61	39.1
2) WOULD TRY TO BE FAIR	128	48.85	53.0
3) IT DEPENDS	63	24.05	6.7
4) DON'T KNOW	17	6.49	0.8
NO RESPONSE PROVIDED	28		0.4
TOTAL USABLE RESPONSES	262	100.00	

GENERALLY SPEAKING, WOULD YOU SAY THAT MOST PEOPLE CAN BE TRUSTED OR THAT YOU CAN'T BE TOO CAREFUL IN DEALING WITH THEM?

	TOTAL	%	NATIONAL %
1) MOST PEOPLE CAN BE TRUSTED	84	32.06	33.9
2) CAN'T BE TOO CAREFUL	110	41.98	61.1
3) IT DEPENDS	58	22.14	4.2
4) DON'T KNOW	10	3.82	0.3
NO RESPONSE PROVIDED	28		0.4
TOTAL USABLE RESPONSES	262	100.00	

WOMEN'S NEEDS

Demographic Profile

The adult women who completed interviews were, on average, slightly younger than the men (35.5 years old for women, 37.4 years old for men), and had substantially lower average levels of education (10.7 years for women, 12.5 years for men). The data for the female respondents are contained in Appendix B. Over 88% said their sexual partners were exclusively heterosexual, compared to about 6% each reporting exclusively homosexual or bisexual partners. More than 55% reported having a regular sexual partner. The largest proportion reported that they believe they got the HIV virus through heterosexual sex (42.86%), while 12.9% say they were infected by IV drug use. About 21% reported getting HIV at birth, and about 6% through a blood or blood products transfusion. Almost 34% self-described their HIV status as “positive, assymptomatic,” about 44% as “positive, symptomatic,” close to 18% as “AIDS,” and a little over 4% said that they did not know their HIV status. Their average CD4 count was 312.5, and the standard deviation is quite large (255.4) indicating considerable disparity.

Economic Profile

The majority of those interviewed received income from AFDC, SSI or SSDI. Of the 74 women in the sample, 20 reported receiving AFDC income with an average of \$145.17 per month; 20 reported SSI income with an average of \$402.95; 18 reported receiving SSDI with an average amount of \$460.39. Seven women said they received income from other, unspecified sources with an average monthly amount of \$236.43. Six reported income from a job, and the average for these few was considerably higher at \$813.50. The seven reporting they received funds from family or friends had an average monthly amount of \$408.25. Four women reported receiving income supplements for children at an average of \$163.75 per month. One individual

reported private disability income at \$300 per month, and one reported retirement income at \$600.00 per month. Over 42% of the women responding said they had children who needed care if they entered long term treatment. Clearly these women have considerable need for the assistance provided by the Community Based Service Agencies.

Overall Satisfaction

Compared to the overall sample, women are more likely to report being “very satisfied” with the agencies from which they received services during the last 12 months (45.1%, compared to 39.3% of all respondents), and report about the same levels of satisfaction, 40.8%, compared to 41.4%. While 2.8% said they were “dissatisfied,” compared to 2.5% in the overall sample, none of the women said they were “very dissatisfied” compared to 1.8% in the complete sample.

As was the case with the overall sample, the majority of the women reported receiving information about services from their doctor’s office (52.7%), and a little over 24% reported getting information from the case manager or social worker. A larger proportion of the women obtained information from their school (8.1%) than in the complete sample (4.5%). A much smaller proportion (5.4%) used other individuals with HIV or AIDS as their source of information (compared to 15.8% overall). None of the women reported getting information from “the place where they hang out,” the church, or their job.

Most usage and satisfaction patterns for the women differed very little from those of the complete sample. Although most women report not using these services, a larger proportion do report using clothing for their children (18.9%) and financial assistance with baby supplies (35%) than those in the larger sample. Among those using these services none were dissatisfied with the clothing, while 5.4% reported being either “dissatisfied” or “very dissatisfied” with the baby supplies.

As would be expected a large proportion of the women reported using obstetric and/or gynecological medical care (25.6% compared to 8.3% of all respondents), and almost 22% reported being “satisfied” or “very satisfied” with this care. Almost 42% of the women reported using pediatric health care, compared to about 16% over all. Of those using pediatric care all (39.1%) reported being “very satisfied,” and only 2.7% reported being “dissatisfied.”

A little over 12% of the women reported using transportation to day care compared to 6.8% of the whole sample. All of the women using this service reported being “satisfied” (1.4%) or “very satisfied” (10.8%).

Other Needs

Almost 42% of the women, compared to only about 14% of the complete sample say they have children who need care if they require long-term treatment. Of those 42%, close to 43% say they do not have a spouse or other family to care for them, and of those half say they would like for their service agency to make arrangement for the children’s care. Well over half of the women (56.5% compared to 26.5% of the complete sample) said that living near child care or a school was “very important” to them, and another 13% said that this was “important.”

Summary

While the primary needs of women with HIV disease or with AIDS are similar in many respects to the men, they do differ in that the women require more in the way of child care support. Furthermore, because the demographic profiles of the women differs importantly from that of the men it is likely that different measures will be required to meet their needs.

PEDIATRIC NEEDS

Demographic Profile

Adult caregivers, either a parent or someone appointed as guardian at a service agency, completed the surveys for the pediatric cases in the sample. The data for the Pediatric Cases are contained in Appendix C. The ages of the children ranged from under 1 year old to 5 years old: a little over 9% were under 1 year, about 28% were 1 year old, 25% were 2 years old, close to 19% were 3, and the same proportion (9.38%) were 4 and 5 years old. About 13% were diagnosed in 1991, a little over 65% between 1992 and 1994, and about 22% between 1995 and 1996.

Over 59% of these children were Hispanic, a little over 28% were Black, and 12.5% were White, non-Hispanic. They were almost equally divided among males (48.4%) and females (51.6%).

All of the cases for which there is a response said that HIV was contracted at birth (3 cases had no response). For about 17%, their HIV status was described as “positive, assymptomatic,” for about 30% it was “positive, symptomatic,” close to 35% were described as “AIDS,” and about 17% were categorized as “did not know” HIV status. Their average CD4 count was 451.8 with a large standard deviation indicating considerable disparity.

Economic Profile

The majority of those interviewed received income from AFDC, SSI or SSDI. Of the 32 pediatric cases in the sample, 9 were reported receiving AFDC income with an average of \$168.11 per month; and 5 were reported as receiving SSI income with an average of \$456.00. One child received income from family or friends for an average of \$666.00. Clearly almost all

of these children have considerable need for the financial assistance provided by the Community Based Service Agencies.

Overall Satisfaction

Individuals responding for the children, for the most part, reported being “very satisfied” (78.2%) or “satisfied” (12.5%) with the agencies from which services were received. Only about 6% responded “neutral” to this question, and about 3% responded “dissatisfied.”

Most usage and satisfaction patterns were similar to those of the complete sample. One difference was that well over half of the pediatric cases were described as using those services specifically designed for children such as daily child care (65.6%), social activities for children (68.8%), assistance with baby supplies (65.6%), and pediatric health care services (78.1%). The adults completing the survey were “satisfied” or “very satisfied” with services received, although one person said s/he was “dissatisfied” with the pediatric health care. These usage patterns are higher than those for the total sample for the various services. An additional 21.9% were reported using extended child care, 3.1% using after school day care, 6.3% using foster care, and 12.5% using clothing for children. Once again, those using the services expressed satisfaction with them.

A larger proportion of the children were said to use home health services than the respondents in the overall sample. Over 65% were categorized as having been visited by a skilled home health nurse during the past 12 months, and all were either “very satisfied” (62.5%) or “satisfied” (3.2%). A little over 28% were classified as using the services of a certified home health aide, and about 22% as using other unspecified home care. Respondents were all “very satisfied” with these services. About 44% of the children were said to use transportation to day care, and all were “very satisfied” with it.

Other Needs

All children were listed as receiving Medicaid to help defray medical costs, one was listed as having private medical insurance benefits, and three as receiving aid from other unspecified assistance programs. Almost 48% were listed as having no source of income at present. Without the benefits provided by the service agencies, it is clear that these children would not be able to survive.

Summary

The pediatric cases are clearly “special” in a variety of ways. First, they are not able to respond themselves to question related to usage patterns or satisfaction levels. As a result, they must rely on adult parents or other guardians/caretakers to interpret their needs to providers. Second they show higher usage patterns for programs designed for children than adults do for those designed for adults. Perhaps because their numbers are comparatively few, and their needs are somewhat different from adults these programs have been designed quite specifically to meet those needs. Third, it seems clear that home health services are an important part of the support structure for pediatric cases. As a distinct group among clients served by these agencies, their needs require a unique subset of assistance programs within the overall service system.

CLIENTS WITH CD4 COUNTS UNDER 200

Demographic Profile

The data for the respondents who stated that their CD4 cell count was less than 100 are contained in Appendix D. With CD4 cell counts of less than 200 individuals are officially classified as having full blown AIDS. About five percent of this group ranged in age from less than one year to 19 years old. A little over nine percent were in the 22-29 age group, Over 27%

were between 30-34, 21.5% between 35-39, over 22% between 40-44, and almost 15% were 45 years old or older. On average, respondents in this groups were a little older (36.1 years) than those in the complete sample (34.6 years). The largest proportion (38%) were diagnosed between 1992 and 1994, about 23% before 1988; close to 30% between 1988 and 1991, and about 9% between 1995-1996.

Over 42% of this group were Hispanic, over 12% were Black, more than 38% were White, non-Hispanic, and close to 7% were classified as “other” race or ethnicity. Most were males (86.8%, 13.2% females). Average education level was well below the total sample (10.7 years compared to 12.1 years).

Over 58% said they contracted HIV from sex between two males, 16.2% said heterosexual contact, 11.1% from IV drug use, 10.3% from blood or blood product transfusion, about 3% at birth, and 1 person said from lesbian sexual contact. Interestingly, of this group with CD4 cell counts of less than 200 only 49.2% self describe their HIV status as “AIDS.” About 37.7% describe their status as “positive, symptomatic,” about 11.5% claim they are positive, asymptomatic” and two respondents said they “did not know” HIV status. Their mean CD4 count was 71.7 with a standard deviation of 62.9, while the median was 26.5 indicating considerable disparity.

Economic Profile

A smaller proportion of this subset (15.7%) compared to the complete sample (21.1%) said they had no income. Of all 71 individuals who received \$690.00 or more per month, 39 were in this group of respondents. It is likely that these individuals receive more financial aid because they are most likely to have more severe and frequent medical problems. For example, over 42% receive some type of rent assistance, and close to 57% of those said the amount they

received was not enough. Over 45.5% received assistance with utility bills compared to 39% of total sample, and 12.1% received assistance with their telephone bills compared to 10.2% of the entire group. Unequivocally this group has considerable financial need. It is equally clear that the agencies are putting considerable effort into meeting their needs.

Overall Satisfaction

As with the other groups discussed, an overwhelming majority said they were either “satisfied” (38.5%) or “very satisfied” (45.3%) with the agencies from which they received services during the last 12 months. Twelve percent responded “neutral,” 2.6% said they were “dissatisfied,” and 1.7% said they were “very dissatisfied.” Interestingly, usage patterns, and satisfaction levels for the various services included in the survey were approximately the same for this group as for the complete sample.

Other Needs

Many of the needs of this group of respondents are medical, as they are the most susceptible to severe and frequent illnesses. For example over 8% are receiving pentamidine treatments compared to 4.8 % of the total respondents. About 47% compared to 42% of the complete sample said they had used an emergency room, and over 47% compared to 38% of all respondents had been admitted to a hospital during the last 12 months. Slightly larger percentages from this group said they experienced “long waits to see a doctor” (60.3%, compared to 57% of total), and that the cost of medical care was a problem (32.5%, compared to 29.1% of total). A much larger proportion (30%) reported that the doctor or nurse would not answer their questions than in the complete sample (21.4%).

Respondents in this subset (52.6%) were more likely than those in the general sample (49.6%) to say that no smoking in the various support agencies was “very important” to them.

They were also more likely than all respondents to say that living with people who are their same race, sexual orientation, or gender was “somewhat important” (23.7%, compared to 19% of total) to them, although no more likely to say this was “very important” (16.1%). They were far less likely than the overall respondents to say that living near child care or a school was either “very important” (11.3% compared to 34.7% of the total) or “somewhat important” (8.7%, compared to 18.4% of total).

Summary

The group of individuals who would be classified as full blown AIDS based on their last known CD4 count are both more likely to have high needs based on medical problems, and to receive somewhat higher levels of financial assistance based on those needs. The San Antonio service agencies seem to have done a good job in integrating the special needs of this group into the larger framework of providing services for individuals classified as HIV positive. Their needs may be further complicated by an inclination to deny the medical diagnosis of AIDS even when their CD4 count is below 200. See the data below, which show that over half of those that report their CD4 level to be below 200 label themselves as HIV positive asymptomatic or symptomatic.

SELF-REPORTED HIV STATUS BY LAST CD4 CELL CLASSIFICATION

	AIDS	ARC	HIV-POS	TOTAL
HIV+ Asymptomatic	11.5	37.3	72.0	7.4
HIV+ Symptomatic	37.7	51.8	24.0	1.3
AIDS	49.2	4.8	0.0	7.8
Don't Know	1.6	6.0	4.0	.5
	100.0	100.0	100.0	100.0
N	122	83	25	230
Chi-Square= 82.351 DF= 6 Prob. = 0.000 V= 0.423				

RECOMMENDATIONS FOR FUTURE DATA COLLECTION

The singular circumstances of the client base for this project establish unique challenges to standard data collection techniques. Our experience in completing this comprehensive survey provides the background for offering recommendations for future projects. Flexibility and patience are key to completing a designated number of surveys. The physical and mental states of individuals living with HIV disease and with AIDS vary dramatically, often over short periods of time. Furthermore, these individuals are subjected to numerous surveys in any given time frame. While standard data collection suggests a single method for collecting data, a combination of the various methods of gathering survey data seems to work best for this type of research, depending on the condition and desires of the respondent. Some individuals wish to be surveyed over the telephone, some want to self-administer the instrument, and others desire in-person interviews. Thus, the survey instrument itself should be designed with all three data collection techniques in mind.

- **In particular, self-administered instruments should never be unduly complicated or too long because respondents can simply give up and quit in frustration or fail to see and complete sections of the survey.**

The telephone interview process is equally challenging because respondents may agree to be interviewed, but no longer feel physically up to the survey when the call is made. Furthermore, because of severe economic problems, phones are frequently disconnected, some for short periods of time, others for longer periods. A typical survey process uses three call backs as the basis for no longer attempting to collect information from that respondent. This

would clearly be ineffective in this case. We frequently called the same respondent as many as 15 times in order to obtain a completed interview.

- **Thus, because numerous call backs may be required to complete one survey, no established number of calls should be used as a basis for excluding a respondent.**

There are large quantities of important data needed in order to effectively confront the complexity of problems associated with meeting the needs of individuals with HIV disease and those with AIDS. Trying to include all of the information in one instrument runs the risk of a survey that is too long and overly complicated.

- **One solution may be to divide the information into several modules (e.g. service satisfaction, economic needs, special clients needs) and collect data for one module at a time on an annual basis.**

Many of the services provided are used by very few clients. Thus, a survey designed around enumerating each and every service becomes unwieldy, too complicated and ineffectual. Three processes may be beneficial for gathering this information:

- **A suggestion box, which is easily accessible to clients, could be placed at each service provider.**
- **One day a month, each agency could collect information from clients using a short exit survey.**
- **Finally a well-designed focus group, conducted by objective (i.e. non-agency) facilitators could provide clients the opportunity to openly discuss services.**

A major problem encountered in this project related to the screening/safe-guarding of the clients from the research staff. The rationale for the approach was based on the very real need to

protect the confidentiality and even the identities of the clients. With this objective in mind, in the early phases of this project agency directors and case managers assumed an intermediary role, contacting clients and obtaining signed consent forms before the clients were contacted by the research staff. This well-intentioned plan proved to be a major obstacle for the timely completion of the data gathering part of this project. Making first contact with the randomly selected clients proved to be a major burden on agency personnel. Furthermore, the original lists of unique identification numbers were inadequate, perhaps because most records were maintained by hand. This meant that agency personnel were spending time attempting to contact deceased clients or clients who had moved or were otherwise unreachable.

- **The improved record keeping system should improve the ability to identify and locate clients in the future.**
- **A relationship of trust must be developed with research personnel in the future. It is not possible to perform the normal functions of agency personnel and also expect that they can take on the additional burden controlling client/researcher communication.**
- **Needs Assessment Committee members should develop methods for insuring that researchers are sensitive to the special concerns and confidentiality needs of the clients, and then give the researchers access to the information needed to complete the surveys.**

There are several issues which were not included in this survey which we believe would provide important information for assessing client needs. The following questions would contribute useful data for gaining a clearer insight into the needs of individuals living with HIV disease or with AIDS:

- **How do respondents get information about new therapies**
- **Do respondents believe disease maintenance is possible**
- **Do respondents believe a cure will be found in their lifetime**

- **Given the extent and severity of medical/physical problems, how do respondents prevent or limit inappropriate self diagnosing**
- **How many medications do clients take on a daily basis**
- **What impact do the medications s/he takes have on their lives (e.g. nausea, memory problems, disorientation, etc.)**
- **What type and level of support do respondents receive from their immediate family**
- **What has been most effective in providing the support needed on a daily basis**

CONCLUSIONS

Perhaps the most striking observation is that unprotected sexual activity is prevalent for all groups. Research reported in the Express-News article suggest that, "...about one third of young gay men in their twenties engage in anal sex without condoms, the riskiest form of homosexual behavior." The article suggests that the young feel invincible and believe that they won't get sick from anything. Clearly the use of cocaine and crack seemed to increase the likelihood of "occasionally" engaging in unprotected sex., which supports the "thrill of risk-taking with no worry about consequences" hypothesis. However, one man in his late twenties with AIDS indicated that this type of behavior may "... be an attempt to feel normal." The stigma of focusing on safe sex might intrude on attempts to form close relationships. Thus, individuals who experience anomie, may be less inclined to worry about infecting others. We used the question about trusting others as an indirect test of the negative feelings associated with anomie. Our findings did indicate that those individuals who say they believe that in general most people can be trusted had a smaller proportion who engaged in unprotected sex, although this relationship was not statistically significant.

As Mario Cooper, who was the first African American chair of the AIDS Action Counsel, stated in a recent editorial by William Raspberry (1996), which discusses unsafe sex practices among African-Americans:

There are an incredible number of factors that go beyond merely knowing how the disease is transmitted...It involves the search for affection and, no doubt, the thrill of risk-taking. But I think it also involves the devaluation of oneself because one is black and gay.

It is apparent from our data that current attempts to use education as the basis for preventing unsafe sex practices are not successful.

The complimentary issues of confidence in institutions and trust in individuals are important for insuring that San Antonio's community agencies are more effectively managing the needs of individuals with HIV disease and AIDS. The primary issue is one of communication. Members of an isolated group must trust gatekeepers of HIV services, or providers of services, before they can confidently communicate their needs and accept suggestions for managing their illness or lowering their risk of infecting others. Outreach and education strategies are needed to increase confidence and trust, and these strategies could, in the long term, improve survival rates and lower new infection rates in San Antonio.

Finally, the model of using empirical and evidence-based case studies as part of program evaluations is supported by our analyses. For example, because our results are based on a case study of San Antonio, Texas, which has a majority Hispanic population, we are able to effectively compare differences between Anglos and Hispanics with respect to their needs and use of community services. This information, in turn, can help to delineate the differential impacts of AIDS on minority populations, as well as help agencies structure programs to specifically meet the need of Hispanics living with HIV/AIDS. On the one hand socioeconomic

vulnerability is a strong predictor of perceived vulnerability to AIDS, and also of likelihood of engaging in risky behaviors (Neff and Crawford, 1998). On the other hand, cultural differences between groups may override such vulnerabilities. For example, more limited labor force participation among Hispanic along with cultural norms discouraging discussion of sexual behaviors may make Hispanic women in particular have more limited exposure to information about HIV/AIDS (Marin and Gomez, 1997). These factors could impact the groups' vulnerability to exposure to the virus as well as their proclivities to engage in risky sexual behaviors. Thus having empirical data with enough cases for valid comparisons becomes vital for understanding how minority groups such as Hispanics are coping with the reality HIV/AIDS in their community.

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