

**2003 NEEDS ASSESSMENT**  
**for the Minnesota HIV Services Planning Council**  
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## SUMMARY OF BASIC DATA

**PURPOSE** The purpose of this needs assessment was to (uniquely) gather information from people infected/affected by HIV/AIDS, to understand their experiences and circumstances, to gather information about HIV status and health care, to learn about mental health, emotional support and behavioral issues, and to determine service gaps and priorities. This information should inform planning and priority setting concerning services.

**METHOD** This needs assessment is based on face-to-face interviews with a diverse, representative sample of 242 HIV+ Minnesotans. As it is not possible to enumerate this population and so draw a random sample of them, interview participants were recruited through a snowball referral process.

There were six interviewers; one did interviews in Spanish as well as English; one did interviews in Amharric as well as English. Several additional interviews were done using interpreters.

Most interviews took about 1 ½ hours; the shortest time was about 45 minutes while the longest interview was 2 hours and 45 minutes. Participants were given a \$30 cash stipend at the conclusion of the interview and offered a copy of the newest HIV Resource Guide for Minnesota.

**LIMITS** It is important to keep several things in mind reading this report.

- 1) **The findings from this report cannot be generalized to the entire HIV+ population in Minnesota.**
- 2) It is important to remember that **this survey is based on self report information.**

## DEMOGRAPHICS

**GENDER** Of the 242 people surveyed for this report, 63.6% identified themselves as male, and 33.1% identified themselves as female. Eight persons, or 3.3% identified themselves as transgender.

**SEXUAL ORIENTATION** Of the 242 people interviewed for this survey, 33.1% reported they are gay/homosexual/or lesbian, while 47.5% identify as heterosexual. Thirty-six people, or about 15% of those interviewed identify themselves as bisexual, and 9 chose “other” as a category. [The “other” category was most often chosen by a transgender person who could identify whom they preferred as sexual partners, but for whom the existing labels are confusing or don’t apply.]

Of the total 154 males, 74 or 48% identified themselves as gay; 29 or 19% bisexual; and 3 or 2% other. Among the 80 females, 3 or 3.4% identify as lesbian, 68 or 85% as heterosexual, and 7 or 9% as bisexual.

**RACE AND ETHNICITY.** People who were interviewed were asked to describe their race and ethnicity. A total of 18 indicated American Indian/Native American, 4 Asian Pacific, 82 African American or Black, 15 as African-born; 88 European American, 22 Latino/Hispanic, and 12 Biracial/Multiracial or Other.

In addition, each person was asked if they considered themselves to be Latino/Hispanic. While 18 people identified as Latino/Hispanic for “race,” an additional 8 persons identified answered “Yes” to this question, including 2 who identified as African American, 2 who identified as white/European American, and 4 who identified as biracial.

**ZIP CODE** Of the 242 people interviewed, 146 or 60% were from Hennepin County, and 49 or 20% were from Ramsey County. Of the 195 people from these two counties, 53 or 21.5% were from suburban areas. Twelve people, or about 5% were from additional counties in the metro area and 34 or 14% were from Greater Minnesota.

**AGE** The people we interviewed ranged in age from 18 to 64 years of age, with the average age being 39.2 years and the median age being 40 years. Approximately 16% were 29 years or less, while about 10.3% were 50 years or over.

**DISABILITIES** When asked “Do you have a disability other than HIV?” 47.5% of those interviewed reported no disabilities, while the remainder identified at least one, and 39 or 16% identified more than one disability. The largest number 60, or about 25% total identified a psychiatric disability. The next largest number, 36 or 15%, identified “other” disabilities. An additional 30 or 12% said they believed they may have an undiagnosed disability – examples include psychiatric disabilities, learning disabilities or concerns about increasing cognitive and memory impairment.

**EDUCATION** About 16% of those interviewed did not finish high school; 31% report high school as their highest formal education. An additional 31% have had some college, while 15% have a college or technical degree and 7% have graduate work or a graduate degree.

**COMMUNICATION ACCESS** Of those interviewed, 16% do not have a telephone and 19% have no way of getting messages. Seventy-seven percent do use voicemail or answering machine for messages. Of those interviewed, 55% have access to e-mail and 56% use the Internet; 26% report access to a computer at public places including HIV/AIDS serving organizations and the public library.

**INCOME LEVELS** In response to a question “How much money did you have in the last month to live on?” the mean (average) response was \$956; the median (midpoint) response was \$800. About 4% of those interviewed reported no cash income, while

23% had \$500 a month or less. Sixty-three percent of those interviewed report \$1000 or less per month to live on, 29% have between \$1001 and \$2000 a month to live on, while only 7% have more than \$2000 a month..

To manage on low incomes, sixty-two percent of those interviewed report using a food shelf in the previous six months; 56% report using free meals. Nearly 30% reported using free clothing in the previous six months and 16% used free places to stay.

**WORK** Of the 242 people interviewed, 36% indicated they are currently working for pay and another 18% described themselves as currently unemployed but looking – a total of 54% either working or seeking work. Nearly 60% of those working report working 31 to 40 hours or more a week, while 20% work less than 20 hours a week.

Twenty-six percent of those interviewed described themselves as currently disabled, while 2% are currently in school and just over 1% are retired. Approximately 33% of those not working had last worked for pay in 2003; 21% had last worked for pay between January 2000 and December 2002. About 10% had stopped working before January 1995.

**HIV AFFECTS ABILITY TO WORK** The majority of those interviewed (57.4%), including people currently working, indicated that their HIV status/disease has affected their ability to work. Just over 18% have had to decrease hours although continuing to work. Nearly 20% quit work because of illness, and another 4% quit because of job stress. Forty percent said that HIV has not affected their ability to work.

**HIV STATUS KNOWN ON THE JOB** Seventy four people, or about 30% of all interviewed, reported that their HIV status was known on the job. Of those, 35 people, or 47%, had requested job accommodations due to HIV. Of those, 32 reported a positive reaction, 12 reported a negative reaction from employers, and 3 reported a mixed reaction.

**HARASSMENT OR DISCRIMINATION ON THE JOB** Twenty-six people or 11% of all interviewed (36% of those whose status was known on the job) felt they were subjected to discrimination or harassment due to their HIV status. 10 people or 4.1% of all interviewed (14% of those whose status was known on the job) took or tried to take action in response to the discrimination or harassment.

**LIVING SITUATION** Of the 242 people interviewed, 15.3% reported currently living in a house/condo or apartment which they owned; 54.5% indicated they currently rent a house/condo or apartment; 30% reported they have a housing subsidy. Eighteen percent reported living with someone else temporarily or permanently, and approximately 7% reported living in some form of housing program (including adult foster care, group homes, treatment facilities and HIV specific housing).

Of those interviewed, 3.3% reported at the time of the interview living either in shelters or on the street. Over half, 55% report they have been homeless at some point in their lives.

**HOUSING CONDITION** Nineteen percent of those interviewed reported they are not satisfied with the physical condition of the place where they are living; 16% do not feel their neighborhood is a safe place; and 5% feel they have been turned down for housing due to their HIV status. Over 80% report one or more barriers to affordable housing.

**HIV AFFECTS HOUSING** Nearly 30% reported that their HIV status has affected their housing. Twenty-five percent have had an unlawful detainer – 15% of those with unlawful detainers felt their detainer was related to their HIV status. Nearly half, 46% -- indicated that paying for housing has been a problem constantly, often or sometimes in the past year.

**HOUSING NEEDS MET** Overall, 22% of those interviewed rated their housing needs completely met; 81% rated their housing needs as adequately, well or completely met. Fifteen percent said their housing needs were poorly met and 4% said their housing needs were not at all met.

**TRANSPORTATION** Forty-six percent of those interviewed reported it was very easy to get to their doctor or medical services, while 5% reported it was very hard. Forty percent of those interviewed report most often taking a bus to their medical appointments; 39.7% go by car, using either their own car, a ride from a friend or family member, or borrowing a car. Forty-four percent of those interviewed report some kind of financial support for transportation; 55% do not receive any transportation assistance.

We asked each person interviewed about the time and/or miles traveled to see their HIV doctor. The following table summarizes this information for all and by geographic area.

LOCATION	TIME	MILES
<b>ALL</b> [N=242]	The mean (average) MILES to see a doctor was 5; the median (midpoint) was 5 miles.	The mean (average) TIME to see an HIV doctor was 45 minutes; the median (midpoint) time was 45 minutes.
<b>METRO</b> [N=155]	In the metro area, the mean MILES to see a doctor was 7.07; the median was 5 miles..	In the metro area, the mean TIME to see a doctor was 25.75minutes; the median was 20 minutes.
<b>SUBURBAN</b> [N=53]	In suburban areas, the mean MILES to see a doctor was 18.65; the median was 20 miles.	In suburban areas, the mean TIME to see a doctor was 42.86 minutes; the median was 32.5 minutes.
<b>GREATER MN</b> [N=33]	In Greater MN, the mean MILES to see a doctor was 54.47; the median was 25 miles.	In Greater Minnesota, the mean TIME to see a doctor was 62.13 minutes; the median was 34 minutes.

**TRANSPORTATION NEEDS MET** Nearly 28% of those interviewed said their transportation needs were completely met; an additional 28% said they were well met. About 34% people said their transportation needs were adequate met, and 10% said they were met poorly or not at all.

**CURRENT RELATIONSHIP STATUS** More than half (55%) of those interviewed identify themselves as single, and another 16% indicate they are separated, divorced, or widowed. This compares to 17% who report a partner in a committed relationship and 12% who report they are currently married. Just over 40% indicate they have been legally married at some point in their lives.

**PARENTAL STATUS** Nearly half of those responding (48%) indicate that they do have children. About 27% indicated they would like to have children (either more children or to have children).

Overall, the parents in this survey reported they had (collectively) 292 children. The average among parents was 2.6 children. The majority of parents have one or two children (58%), while about 27% have three or four children, and 15 parents have five or more children (6% of those with children, or 3% of the total 220 people interviewed).

Approximately 20% of parents have children 10 years of age or younger; while about 44% have adult children, aged 20 or older. Eighteen percent of all interviewed have children living with them on a full-time basis. Eleven, or 4.5% of those interviewed report they have children who are HIV+.

## HIV STATUS

**HIV STATUS** Of the 242 people interviewed, 25.2% report they are HIV+ with no symptoms, 27.7% reported they are HIV+ with some symptoms, and 45.5% of those interviewed have had an AIDS diagnosis. Of the 110 people who have had an AIDS diagnosis, 73 (66.4% of those who have had an AIDS diagnosis) report they are now stable. Thirty people, or 12.4% report their health situation is worsening – symptoms becoming less management, becoming worse, nearing end of effective treatments or nearing the end of life.

**YEAR OF DIAGNOSIS** Nearly 18% of those reported they received their first positive test results in the previous two years (2003 and 2002); 14% were first diagnosed between 2000 and 2001; 11.6% between 1998 and 1999; 23.6% between 1995 and 1997; and 33% received their first positive diagnosis prior to 1995.

**TRANSMISSION ROUTE** Those interviewed were also asked to identify the likely transmission route, by which they became HIV+. Forty-four percent indicated male/male sex, 33% indicated male/female sex, 9% indicated injecting drug use, 3% indicated blood transfusion and 12% indicated unknown or other (multiple factors).

**STATE OF DIAGNOSIS** 67% of those interviewed were living in Minnesota when they tested positive; 11% in other midwestern states, 21% elsewhere in the U.S. and 1% outside of the U.S. 83 people, or 76% had received an AIDS diagnosis in Minnesota, and 25% received an AIDS diagnosis outside of Minnesota.

**FACTORS WHICH MAY HAVE PLAYED A ROLE** When asked about factors that may have played a role in becoming HIV+, 17% indicated that sexual abuse may have played a role, while 57% indicated that substance use (drugs or alcohol) have may played a role.

**CD4/T CELL COUNTS AND VIRAL LOAD** All 242 people interviewed were asked about CD4/T cell counts and viral loads. Ninety-four reported they have had CD4/T-cell counts and 92% reported viral load tests. Around 87% report that they had had these tests quite recently, the vast majority within the last six months.

Of those interviewed, nearly 20% reported a current CD4/T cell count of 200 or less, while 24% reported a count between 201 and 400. Just over 27% reported CD4/Tcell counts of more than 400, while 23% indicated either they didn't know or couldn't remember the number.

Nearly 40% reported their viral load was currently undetectable, while 38% reported a detectable level of viral load. Nearly 20% indicated they didn't know, couldn't remember or had not had a recent count. Of those reporting a specific viral load, nearly 13% had viral loads between 50 and 5000; 17% had viral loads between 5001 and 50,000 and 8.3% had viral loads of 50,0001 or higher.

## HEALTH CARE

**ACCESS TO MEDICAL CARE** Of the 242 people interviewed, 94% report they have a primary physician for HIV treatment. Of all interviewed, 3.3% indicate that at some point in the previous year they had been denied medical care because they could not pay or were not insured. Nearly 13% indicated they did not seek care at some point because of concerns about paying for it.

**HOSPITAL EXPERIENCES** Essentially, the majority of those interviewed had no hospital contact in the previous 12 months – 46% had not gone to the emergency room, more than 71% had not been admitted to the hospital, and 71% spent no time in a hospital in the past year.

Of those who did spend time in hospitals in the past 12 months, 62 or 26% visited the emergency room once; 14% twice, and 14% visited between 3 and 14 times.

47 persons, or nearly 20% of all interviewed were admitted once to the hospital in the past 12 months; 14 or 6% were admitted twice, and 5 were admitted between 3 and 4 times. .

Of those admitted to the hospital, 36 spent one week or less in the hospital, while 24 spent between 1 and 4 weeks. Only 11 persons, or 4.5%, spent more than 4 weeks in the hospital in the past 12 months.

**INSURANCE** The majority of those interviewed (87.2%) currently had health insurance at the time of the interview. About 15% reported some form of private insurance (4% through COBRA); 73% reported they have some type of public insurance, including Medicare. About 26% of those interviewed have at some point since their diagnosis lost their health insurance. Sixty-one or 25.2% reported having had difficulty becoming eligible for a public health insurance program.

Of all interviewed, 8% report they have a deductible for their health insurance coverage; 17% report a copay for medical care, and 8% have a spend-down. Nearly 9% of all interviewed said that their copay, deductible or spend-down has prevented them from going to or seeking health care.

Forty-three of those interviewed reported their need to pay for medical care was completely met. Of all, 88.4% reported their need to pay for medical care was completely, well or adequately met. Only 9% said their need to pay for medical care was fairly, poorly or not at all met.

**SOURCES OF INFORMATION** We asked what sources of information people found useful for learning about medical care and treatments for HIV/AIDS. Responses included 84% who felt doctors were very useful; 54% who said nurse/clinic staff were useful, 46% who cited case managers as useful, and 39% identified health educators. Forty-five percent of people found written materials to be useful and 43% identified other HIV+ people as a useful source of information about medical care. Twenty percent indicated they found the Internet to be a useful source of information.

**MOST USEFUL SOURCE OF INFORMATION** When asked to identify the most useful source of information when first diagnosed with HIV, 60% cited their doctor as the most useful source of information. Doctors were also cited as the most useful source of information currently for 52% of those interviewed.

**PHYSICIANS** Of the 242 people interviewed, 92% report they have a primary physician for HIV treatment. 88% report they feel their physician is very knowledgeable about HIV/AIDS. The majority of people interviewed report seeing their physician on some interval of three months or less. About 9% see their physician less often and 8% did not report seeing a physician on a regular basis.

**HEALTH CARE BARRIERS** Survey participants were asked about barriers to getting or maintaining health care for HIV. The largest percentage of survey participants identified the following as barriers:

- 34.3% Transportation to appointments
- 20.7% Finances
- 19.8% Distance/access
- 10.7% The way I was treated by people at the office/clinic

**HEALTH CARE FACILITATORS** Survey participants were asked a number of questions about factors which facilitated their getting or maintaining medical care for HIV. The highest ratings were given to:

- 75.6% Having an excellent doctor knowledge about HIV
- 62.0% Good relationship with the doctor
- 56.6% People at the office/clinic seem to care about me
- 52.5% People explain things in terms I can understand

**MEDICAL ADHERENCE** Of all interviewed, 134 or 55.4% reported they had kept all of their HIV medical appointments in the prior six months. Another 29% said they had kept most of them – about 75%. Top reasons for missing appointments include transportation (cited by 21.1% of those interviewed), not remembering (16.1%) and feeling ill (15.3%).

**ANTIRETROVIRAL MEDICATIONS** Of those interviewed, 89% have talked with their doctor about antiretroviral medications, 78% have had their doctor recommend medications, and 62% are currently taking antiretroviral medications.

Of the 242 people interviewed, 72% indicated they felt very comfortable talking with their physician about medications, and nearly 90% indicated they feel their physician respects their right to make decisions about taking the medications.

**TAKING PILLS** Of the 150 people surveyed who were taking antiretroviral medications, 61 or 41% of them ( 27% of all 242 surveyed) take less than five pills a day; 69 or 46% (28% of all interviewed) take 5 to 10 pills a day; 48 or 32% (20% of all interviewed) take 11 to 15 pills a day, and 33 or 22% (14% of all interviewed) take more – up to 6 people who take 30 or more pills a day.

**SIDE EFFECTS** One hundred nineteen people reported having side effects from medications – this is 49.2% of all interviewed, and 80% of those on antiretroviral medications. The average number of side effects was 3.01. The most frequently reported side effects were fatigue and diarrhea, each reported by 71 persons, 47% of those taking medications and 29% of all interviewed.

Eight-five people, 35% of all interviewed (57% of those taking medications) report their side effects are mild or only sometimes interfere with daily activities. Thirty-five people, 23% of those on medications, (15% of all interviewed) indicate their side effects regularly interfere with daily activity or are severely incapacitating.

**MEDICATION ADHERENCE** Of the 242 people interviewed, 46% indicated they have talked with a doctor, pharmacist or another health care professional about medication adherence (taking medications on time and not missing doses). Thirty percent indicated they have participated in a medication adherence counseling program, and 31 people or 12.8% of all interviewed participate in a Ryan White funded medication adherence program at their clinic or hospital.

Of those interviewed, 37 people or 15.3% of all interviewed, said they had missed a dose of their medications in the prior three days. Sixty-one persons, or about 41% of those taking medications (25% of all interviewed) have had a drug holiday, for a variety of reasons. Sixty-five people, 43% of those taking medications (27% of all interviewed) reported they had stopped medications on their own (not at their doctor's direction) at some point.

**PHARMACISTS** Of the 242 people interviewed, over half (51%) indicated they are very comfortable or comfortable talking with their pharmacist about HIV medications. Only 6% indicated they were uncomfortable or very uncomfortable. Forty-eight percent felt their pharmacist has been a helpful resource, 62% felt their pharmacy staff respect their confidentiality, while 12% indicated they had any complaints or problems with their pharmacy.

**DENTAL CARE** Fifty-seven percent of those interviewed report they currently have a dentist while 72% report some form of insurance coverage for dental care. Six percent of those interviewed felt that they have, at some point, been denied dental care due to their HIV positive status. Seventy percent of those interviewed indicated they have a need for some kind of dental work, 40% for some work beyond routine maintenance of cleaning.

**COMPLEMENTARY CARE** About 44% of those interviewed reported using complementary care or alternative medicine in the prior year to manage disease symptoms or medication side effects. Of these, 23% report using acupuncture, 36% used massage, 18% chiropractic care, 6% herbal medicines, and 3% reported other.

**CLINICAL TRIALS** Nearly half of those interviewed indicated that they have thought about or tried to get involved in an HIV clinical trial. Twenty-three percent of those interviewed indicated they have participated in a clinical trial – 10% for testing a new drug, 2% for an observation study.

Twenty-five percent of those interviewed said they would be willing to consider a clinical trial “to help improve medical care for people who are HIV+.” Those not willing to consider a trial cited “hadn't heard of them” (13%), “not wanting to be someone's guinea pig” (11%) and “distrust of the medical professional (10%) as their reasons.

Fifty-one percent of those interviewed said their doctor's opinion would be very important in making a decision about a clinical trial. Twenty one percent said their case manager's opinion would be very important in making such a decision.

**SELF RATING OF PHYSICAL HEALTH** We asked the 242 people interviewed to self rate their physical health. Eighteen percent rated their physical health as “excellent,” 35% said “very good,” and 28% said “good.” Fifteen percent of those interviewed rated their health “fair” and 4% rated it “poor.”

**MEDICAL NEEDS MET** Of the 242 people interviewed, 50% said their medical needs were met completely; 27% said they were well met, and 16% said their needs were adequately met. Five percent of those interviewed said the medical needs were met poorly and 1% said they were not at all met.

## **MENTAL AND EMOTIONAL WELL BEING**

**MENTAL HEALTH/EMOTIONAL SUPPORT** Nearly half (47%) of those interviewed have sought mental health or emotional support services since testing positive. Fifty-five percent reported seeing an individual therapist, while 34% participated in group therapy, 55% participated in an emotional support group. And 20% reported counseling from a clergy member. Fifty percent of those interviewed felt their mental health therapist was knowledgeable about HIV.

Twenty-five percent of those interviewed said that HIV was the primary reason for seeing a mental health therapist, while 37% said it was one of the reasons for seeing a therapist. Sixty-five percent of those interviewed had insurance coverage or accessed mental health/emotional support services without charge.

**SOURCES OF EMOTIONAL SUPPORT** People were also asked a number of questions about sources of emotional support, not limited to formal support groups. Forty-two percent of those interviewed reported support from a church or spiritual community; 82% report supportive friends, 74% supportive family, and 70% report support from a network of other HIV+ people.

**LOSS OF SUPPORT DUE TO HIV STATUS** We asked several questions about loss of support, which is an issue for many HIV+ people. Forty percent of those interviewed reported there were people who were no longer supportive of them once they learned they were HIV+. One third [74] reported loss of support from family members. Ten percent of those interviewed have lost the support of ALL family members.

**LIVING WITH OTHERS** Of the 242 people we interviewed, the majority (62%) live with some else, while more than one third – 36% -- live alone. About 15% report living with friends, 13% report living with a lover or partner, 12% with children or grandchildren, 9% with a husband or wife, and 5% with parents.

**OPENNESS/INTEGRATION WITH HIV+ COMMUNITIES** We also asked a series of questions about openness or integration with the HIV+ communities within Minnesota. We asked people to estimate how many people (excluding health professionals) know that they are HIV+ and about numbers of people they know who are living with HIV. We also asked how many people they know who have died from AIDS.

About 28% of those interviewed indicated that few people (no one, hardly anyone or less than 10) knew of their HIV status. About 33% believed that about 25 people knew of their status, while another 37% indicated 50 or more people knew of their HIV status – some indicating “I would tell anyone.”

Thirty-two percent of the people interviewed knew less than 10 persons living with HIV, 22% knew 20 to 25 persons. About 44% of those interviewed indicated they knew more than 25 persons – including about 8% who said they knew “too many to count.”

About 20% of those interviewed did not know anyone who has died from AIDS, and approximately another 18% know only 1 or 2 people. About 23% reported they know 5 to 10 people who have died from AIDS, while nearly 20% reporting knowing more than 16 people – including 14 people who said they knew 100 or more people who have died from AIDS.

**OVERALL SELF RATING OF MENTAL HEALTH** Just over 35% of those interviewed indicate that they see their mental health as “excellent” or “very good,” with 38% indicating a midpoint rating of “good,” and about 22% rating it as “fair” or “poor.”

**OVERALL MENTAL HEALTH NEEDS MET** The results indicate that 52% of those interviewed feel their mental health needs are met well or completely, while 6% feel they are met poorly or not at all.

**QUALITY OF LIFE.** We asked people a series of questions about their quality of life. We asked people to indicate, on a scale of 1 to 7 (with 1 for the most positive rating and 7 for the worst], their rating for a series of statements about life. The following table summarizes these responses – rank ordered by mean (average response).

<b>Question. How do you feel about...</b>	<b>Mean</b>	<b>Rank</b>
The support available to you for managing HIV/AIDS.	<b>2.51</b>	<b>1</b>
The way you’re managing to live with HIV/AIDS?	<b>2.93</b>	<b>2</b>
The way you handle problems that come up in life?	<b>3.03</b>	<b>6</b>
The way other people treat you?	<b>3.06</b>	<b>4</b>
The amount of love and friendship in your life?	<b>3.07</b>	<b>3</b>
Your spiritual life?	<b>3.08</b>	<b>5</b>
What you are accomplishing in life?	<b>3.27</b>	<b>8</b>
Your own family life (however you define family – partner/spouse, children)	<b>3.47</b>	<b>7</b>
The way others respond to your HIV+ status?	<b>3.56</b>	<b>9</b>
Your sex life?	<b>4.15</b>	<b>10</b>

*Note: Smaller numbers are more positive. The highest average rating is for support available for managing HIV/AIDS; the most negative rating is for sex life.*

## BEHAVIORAL ISSUES

**DIET AND NUTRITION.** Sixty-three percent of those interviewed indicate that they eat at about the same time from day to day, while 72% reporting eating the same types of food from week to week, and 70% report eating the same amount of food from week to week. Sixty-one percent report eating the same amount of food from day to day.

**REGULAR MEALS** Ninety-two percent of those interviewed report they regularly eat dinner, while 79% regularly eat lunch and 57% regularly eat breakfast. Eight-seven percent indicate they regularly eat snacks. Eighty-nine percent of those interviewed report usually shopping for their own groceries, and 86% report usually doing their own cooking.

**FOOD AND MONEY** Seventy-six percent agreed that they have to budget money pretty carefully in order to have enough money for food, while 39% indicate they have trouble getting food at the end of the month. Nineteen percent said that in the prior 30 days, there were two or more days when they didn't have anything (or barely anything) to eat.

**DIET CONCERNS** About 40% of those interviewed report they have concerns or worries about their diet and 44% try to follow a special diet to include/exclude certain foods in order to stay healthier. About 68% report taking vitamins, minerals, herbs or other nutritional supplements. About 39% report some foods or beverages they cannot tolerate due to allergic reactions or trouble digesting them. Forty-seven percent of those interviewed have talked to a dietitian or nutritionist about their diet, while 32% have participated in an education program or workshop on diet and nutrition – 23% attended an HIV-specific program.

**USING FOOD SERVICES** Fifty-six percent of those interviewed indicated that they have eaten at a congregate meal program. Thirty-two percent report that they eat at least once a week at such a program; about 8% report eating every day. About 15% of those interviewed indicated they have had meals delivered. Seven percent indicate they currently receive daily meals; in total 13% receive meals at least once a week.

**SELF RATING OF DIET AND NUTRITION** Participants were also asked to rate their diet and nutritional needs. Six percent said "excellent," while 28% said "very good" and 38% said "good." About 19% rated their diet and nutrition as "fair" and 8% said "poor."

**OVERALL DIET AND NUTRITIONAL NEEDS BEING MET** About 16% of those interviewed said their diet and nutritional needs were completely met; 34% said they were well met, and 39% said adequately met. About 11% said their needs were fairly, poorly met or not at all met.

**SEXUAL ACTIVITY AND PREVENTION** We asked a number of questions about sexual activity and about safe sex and prevention. Forty-five, or 20% of those interviewed reported not having sex in the past year with either men or women. Another 2% did not answer these questions. When asked about how many partners in the previous year, the range of responses for those who reported having sex with men was

1 to 200, with an average of 4.54 men and a median of one man. Of those who reported having sex with women in the previous year, the range of responses was 1 to 9, with an average of less than one and a median of zero women.

Of all interviewed, 65% reported having had another sexually transmitted disease in the past, 39 or 18% reported having had an STD in the past year. Of all those interviewed, 62 or 26% reported they have ever exchanged sex for something they needed, including housing/place to stay (6%); drugs (12%); money (6%) and food (2%). Of those interviewed, 99 people or 41% reported their most recent sexual partner was HIV+; 45 or 19% reported they did not know.

When asked about sources of information about safe sex, 54% identified their physician as very useful, 41% identified written materials, 41% identified other HIV+ people, and 38% identified case managers. More than half of those interviewed (152 or 63%) indicated they would be interested in participating in a program (such as a workshop, seminar or conference) about HIV prevention designed for people who are HIV+.

**TOBACCO USE** Nearly 78% of those interviewed reported they have ever smoked 100 cigarettes in their life; 65% report they are currently smoke cigarettes every day. The average number of cigarettes a day smoked was 12.28; the median was 10 and the mode 10 cigarettes a day. Nearly 60 have tried to quit smoking, and 33% indicated they would be interested in a smoking cessation program. Nearly 60% indicated someone smokes tobacco regularly inside their home.

**ALCOHOL USE** Nearly 30% of those interviewed report they never use alcohol, while 8% report daily use in the prior 6 months, 33% use alcohol once or twice a week, and 19% use alcohol one or twice a month.

**DRUG USE** While 56% of those interviewed report never using marijuana, 15% report daily use, 13% weekly use, and 9% report monthly use in the previous six months. Six percent of those interviewed indicate marijuana use once in the prior six months. Eighteen people reported use of meth/speed/crystal – 2 people indicated daily use, 2 weekly use, 7 or 3% using it about once a month, and 7 or 3% indicated they have used it in the prior six months.

Nine people, or 4% of those interviewed, reported daily crack use, 5 or 2% weekly crack use, and 12 or 5% reported monthly crack use, and 8 or 3% report using crack once in the previous six months. Seventeen people reported cocaine use in the previous six months – 9 people or 4% report use once a month, 7 or 3% report using it once in the previous six months. Eight people reported heroin use – 3 or 1% daily, 4 or 2% monthly, and 1 reporting using heroin once in the previous six months.

No one reported daily use of poppers or inhalants, but 4 people reported daily use, 4 monthly use and 7 use once in the previous six months. Two people

reported monthly use of designed or party drugs, like Ecstasy or Special K, and 7 reported use in the prior six months.

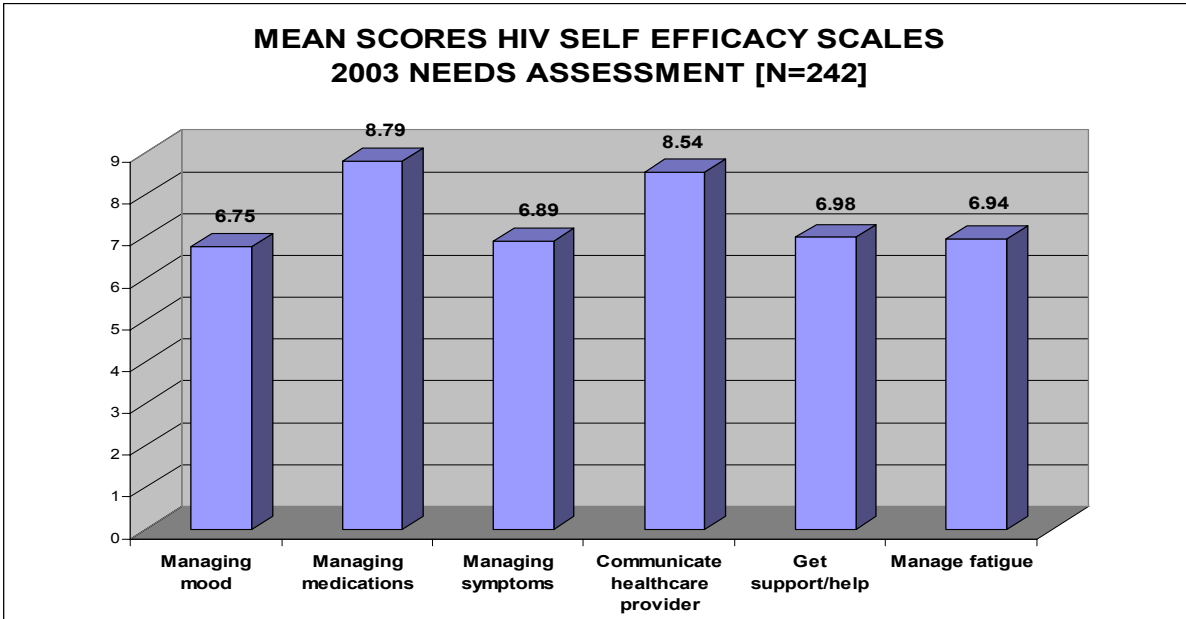
Twenty-three percent of those interviewed report ever injecting drugs, 7% have participated in needle exchange, while 5 or 2.1% report currently injecting drugs.

**SUBSTANCE ABUSE/CHEMICAL DEPENDENCY TREATMENT** Twenty-four percent of those interviewed reporting that they think their drug and alcohol use is a problem, while 31% acknowledge that others have told them their use is a problem. Thirty-seven percent have had a Rule 25 assessment, and 31% have been enrolled in a drug or alcohol treatment program in the prior five years. Nearly 42% enrolled in such a program only once, while 22% went into treatment twice, 16% three times and 17% went into treatment four times or more – up to 14 times.

The majority (107 or 74) of those who enrolled in drug or alcohol treatment in the previous five years were HIV+ while they were enrolled in the program. Only 33 or 14% felt that the program adequately addressed HIV/AIDS. Nearly 20% report that they have a partner who uses alcohol or drugs, 11% feel their partner's use is a problem. Twenty-one percent of those interviewed report attending AA/NA or another support group and 50% of all interviewed acknowledge their drug and alcohol use affects their safe sex practices.

**INCARCERATION** Of the 242 people interviewed, 24% indicated they have spent more than 30 days in either prison, jail or the workhouse. 16% of all interviewed, and 67% of those who have been incarcerated, were HIV+ while incarcerated. Following release, 56% (of those incarcerated) saw an HIV physician within one month of release while 13% did not see an HIV doctor for more than one year. After release, 51% saw a service provider within one month but 18% did not see a service provider for more than one year.

**SELF EFFICACY** In order to gather information about factors related to managing HIV as a chronic disease, we used a set of scales developed by Shively, Gifford, Bormann and Smith in 1998 for the VA San Diego Health Care System. Respondents were asked indicate their level of confidence (on a 1-10 pt. scale with 10 indicating complete confidence) in response to a series of questions. Mean (average) scores for each scale were: **I. Managing Mood**, 6.75; **II. Managing Medications**, 8.79; **III. Managing Symptoms**, 6.89; **IV. Communicating with Health Care Provider**, 8.54; **V. Getting Support/Help**, 6.98; and **VI. Managing Fatigue**, 6.94.



## SERVICES

**SOURCES OF INFORMATION ABOUT SERVICES** The largest number of people interviewed (43%) cited their case manager as the best source of information about HIV services, followed by 20% who indicated medical or health care professionals are the best source. Word of mouth was identified as the best method/channel by 55% of those interviewed, followed by 28% who said printed materials. Of the 242 people interviewed, 29 or 12% said they had difficulty getting information from printed materials, like brochures or information guides.

**BARRIERS** Approximately 76% of those interviewed identified barriers to obtaining HIV services. The range of barriers was between 0 (reported by 41 people or 17% of all interviewed) to 25. The average number of barriers was 5.44; the median 4.

The largest number of people -- 55% of those interviewed -- identified attitude barriers, followed by 52% who said knowledge of and about services was a barrier. Forty-eight percent cited access or cost barriers, while 32% indicated system issues, 26% indicated provider issues and 15% cited cultural barriers.

**KNOWLEDGE OF SERVICES** When asked about **knowledge of services**, the top ratings went to case management (99%), emergency financial assistance (91%), food shelf (86%), transportation (84%) and primary medical care (81%). Services cited **least often** in terms of **knowledge** were: benefits counseling (31%); care advocacy (37%); interpretation/translation (38%), Pharmacy/ADAP (45%), and outreach (46%).

**USE OF SERVICES** For **services used in the prior year**, the **top five** services cited were: emergency financial assistance (79%); case management (74%); primary medical care (69%); food shelf (59%), and information and referral (55%). Ratings for services **used in the prior year** were **lowest** for: home health (5%), chemical

dependency treatment (7%), interpretation/translation (8%), benefits counseling (9%), and outreach (15%).

**MET AND UNMET NEED** The **highest** ratings for **needs being currently met** complete, well or adequately were for the following services: Emergency Financial Assistance (80%); case management (76%); on-site meals (72%); primary medical care (70%); and information and referral (68%).

The highest ratings for **unmet needs**, or **needs being currently met poorly or not at all** were for: Assistance finding shelter or housing (13%); Legal services (9%); complementary care (8%); dental care (8%); and transportation (7%).

**TOP RANKED SERVICES** After answering questions about knowledge, use, need and future estimates for 25 services areas, those interviewed were asked to rank services by choosing the top five most important, and the bottom five among the 25 services.

<b>RANKING OF TOP SERVICES</b>	<b># of Top 5 Votes</b>	<b>% of Top 5 Votes</b>	<b>Rank</b>
Emergency Financial Assistance	135	12%	<b>1</b>
Case Management	127	11%	<b>2</b>
Primary Medical Care	117	10%	<b>3</b>
Pharmacy/ADAP	95	8%	<b>4</b>
Transportation	86	8%	<b>5</b>

**BOTTOM RANKED SERVICES** The bottom 5 ranked services (of 25 services) included: Interpretation/translation (25); complementary care (24); outreach (23); care advocacy (22), and chemical dependency treatment (21).

**GAPS OR LOOPHOLES IN SERVICES** People were also asked, “Do you think there are gaps or loopholes among these services – are there times when you have tried to use one or more service and it hasn’t worked for you?” Over 80% answered no, while 45 or 19% identified some gap or missing services which particularly affected them.

A number of comments were made about the need or additional or different help from services which currently exist. For example, several called for increases in the available emergency financial assistance. Additional areas for comment included housing, transportation, complementary care and emotional support. A particular theme under emotional support concerned a desire for programs, activities and support for children of HIV+ parents, and for family activities. Missing services included programs for the deaf, arts programs, burial assistance, loan programs and veterinarians for pets.