

Consumer Input: Survey and Focus Groups

The needs assessment process sought input from consumers through a survey and through focus groups. This section presents data from 173 surveys of people living with HIV/AIDS in the balance of state and findings from focus groups conducted with 28 people living with HIV/AIDS in Eugene, Roseburg, Coos Bay, Bend, and Malheur County.

The survey and focus groups were intended to assess the housing needs and preferences of respondents. Individuals were asked questions pertaining to personal demographics, income and benefits, living situation, history of homelessness, housing preferences, etc. Survey results were analyzed and are presented below. A copy of the survey tool can be found in Appendix III. Transcripts from the focus groups are in Appendix II.

Overview of Consumer Input

A vital component of the needs assessment process is soliciting consumer input. This needs assessment and planning process utilized three methods of consumer input: participation in the Steering Committee, including oversight of the needs assessment, setting priorities, and developing recommendations; group meetings of consumers to discuss housing issues; and a housing survey, the results of which are presented here.

People living with HIV/AIDS throughout Oregon were surveyed regarding their current and previous living situations, housing needs, and housing preferences. The survey was available in English and Spanish. Many service agencies worked to distribute the survey to people living with HIV/AIDS.

The other main strategy for consumer input was consumer focus groups—small group discussions of related housing and service issues. Focus groups were conducted in Eugene, Roseburg, Coos Bay, and Bend. Due to the small numbers and large distances involved, one-on-one telephone interviews were employed in Malheur County. Service providers worked to recruit participants in each area.

The topics addressed in both the focus groups and the survey were similar. The range of issues addressed in the survey was more comprehensive, and the input more specific. The focus groups gathered more qualitative information and gave more open-ended opportunities for consumers to give their input.

Findings

One hundred seventy-three people living with HIV/AIDS in Oregon completed the housing survey. The survey was conducted through outreach by agencies serving people living with HIV/AIDS. For this reason, people who are already receiving services are likely to be over-represented in this survey. However, in basic demographic characteristics, including age, race, gender, and region of residence, survey respondents are very similar to people known to be living with HIV/AIDS in

general. For this reason, survey results may be considered reasonably representative of people living with HIV/AIDS in the Oregon.

In general, survey respondents had very low incomes, with a median income of \$650 per month, equivalent to \$7,800 per year. The median housing cost (including rent or mortgage and utilities) paid by respondents was \$367 per month. Thirty-six percent of survey respondents were paying 50 percent or more of their monthly income on housing costs, meeting HUD's definition of "severely rent burdened." The close balance between income and housing costs, a major component of a household budget, put people at an increase risk of homelessness. Thirty-five percent of respondents indicated that they would need to move if their housing costs went up by \$50 a month.

Living alone was the most common household arrangement reported by survey respondents, at 31 percent of the total. Another 30 percent reported living with a spouse or partner, and 19 percent reported living with children. More than half of women who responded to the survey lived with children compared to only 6 percent of men.

The issues faced by many people living with HIV/AIDS are not limited to economic concerns. More than half of respondents indicated that they had been homeless in the past, while 40 percent had been incarcerated at some point. Sixteen percent of respondents indicated that they were disabled by their mental illness, 6 percent reported they were disabled by their drug use, and 3 percent by their alcohol use.

Many people living with HIV/AIDS utilize support services. Fifty-seven percent of survey respondents had participated in mental health services in the 3 months prior to the survey, and 15 percent had participated in a drug or alcohol treatment or recovery program. Seventy-one percent reported having a case manager. Many focus group participants mentioned the importance of having a case manager.

Survey respondents indicated a preference for an apartment or home of their own, even if it were to cost more than shared living. The large majority would prefer to live in an apartment building where a variety of people live, rather than in a building dedicated for people living with HIV/AIDS. Survey respondents and focus group participants indicated that a range of assistance to access and maintain housing would be helpful, including lists of affordable and appropriate rental housing and transportation to look at housing.

Method of Obtaining Consumer Input

Consumer Survey

People living with HIV/AIDS in 21 counties completed a total of 173 HIV/AIDS housing consumer surveys. The Steering Committee worked with drafts provided by AIDS Housing of Washington to develop the survey tool that was used. A copy of the tool is provided in Appendix III.

Multiple service providers worked to distribute the survey using strategies developed at the local level. Agencies distributing surveys included:

- Clatsop County Health Department
- Clatsop County AIDS Coalition
- Coos County Health Department
- Curry County Health Department
- Deschutes County Health Department
- HIV Resource Center (Douglas County)
- Hood River County Health
- Jackson County Department of Health and Human Services
- Josephine County Health Department
- Klamath County Health Department
- HIV Alliance (Lane County)
- Lincoln County Health and Human Services
- Marion County Health Department
- New Hope Clinic (Walla Walla, WA)
- Umatilla County Public Health Division
- Eastern Oregon Center for Independent Living
- Women's Intercommunity AIDS Resource
- Oregon Department of Corrections

Agencies used strategies developed at the local level to reach consumers. In most instances, case managers gave surveys to consumers in person and either collected completed surveys in person or provided envelopes for the surveys to be mailed to AIDS Housing of Washington. A few providers mailed surveys directly to consumers with a return envelope. HIV Alliance in Lane County had a high response rate from surveys included in the agency's regular newsletter mailing.

Consumer Focus Groups

Focus groups were the other strategy for soliciting consumer input into the needs assessment and planning process. Focus groups involved gathering small groups of people living with HIV/AIDS to discuss housing histories, housing and services needs, and housing preferences. Each participant received a \$10 stipend for participating in a one-hour meeting, and some refreshments were provided.

A total of 28 people participated in focus groups held in Bend, Coos Bay, Eugene, and Roseburg. Because of the numbers of people and distances involved, one-on-one telephone interviews took the place of a group meeting in Malheur County. In addition, a focus group was scheduled for Salem, but no participants attended.

Presentation of Data and Findings

Findings from the survey and focus groups are presented by issue or theme. Each section begins with a presentation of survey data. Summaries of issues identified and discussed in the focus group follow. Quotes from the focus group and comments provided by survey respondents are given as anecdotal illustration of many of these issues.

The majority of survey data is presented as “frequencies” or the number of times that respondents gave a response. In presenting subsections of information, the percentage of the actual number of responses to the question was used. Where possible, comparisons between cohorts of respondents are presented. Most comparisons are between genders or based on whether or not a respondent reported a history of incarceration. The number of responses did not allow for comparisons between racial/ethnic groups or across counties.

A total of 173 completed surveys were returned for analysis. Some individuals did not respond to one or more question(s). Because the number of non-responses varies from question to question, unless otherwise noted, all percentages listed in the “Consumer Input” section of the *Oregon Balance of State HIV/AIDS Housing Plan* represent percentages of the entire sample of survey respondents or cohort of respondents. This presentation of the analysis is a more stable basis for comparison of responses to survey questions. In tables in this section, a dash (—) is used to indicate no respondents, in lieu of 0 percent.

Reliability of Data

The survey pool represents approximately 17 percent of the 1,031 individuals estimated to be living with HIV/AIDS in the counties of Oregon outside of the Portland metropolitan area. Compared to Oregon’s living AIDS case profile, the survey sample proportionately included:

- More women—women were 26 percent of survey respondents versus 9 percent of those living with AIDS.
- Fewer people aged 20 to 39 years old—younger adults were 39 percent of respondents versus 65 percent of living AIDS cases.
- More people aged 40 years and more—older adults were 57 percent of respondents versus 35 percent of reported AIDS cases.⁵⁴

These demographic differences are not the result of targeted outreach; the differences merely reflect the demographics of those who returned completed surveys. Because the data available is for AIDS cases, while the survey included people living with HIV or AIDS, differences may reflect, in part, the differences between the population with HIV and the population with AIDS. In addition, differences between the survey respondent population and the reported population with AIDS may reflect the different rates at which segments of the population access HIV/AIDS services, since service providers were the primary agents for survey distribution.

⁵⁴ Because statistics for age are the person’s age at diagnosis, and not age as of September 30, 2001, these numbers may overstate the differences. For example, a person diagnosed at age 35 ten years ago would be represented in the 30 to 39 age group in epidemiology data rather than the 40 to 49 age group of the survey.

Respondent Demographics

HIV Status

Respondents were asked if they were infected with HIV, the virus that causes AIDS, and, if so, to specify their current HIV status. Respondents indicated the following about their HIV status: Forty-one percent had received an AIDS diagnosis from their doctor; 28 percent were HIV-positive, without symptoms (asymptomatic); and 28 percent were HIV-positive and experiencing symptoms (symptomatic).

HIV/AIDS Disability

Respondents were asked if their doctor had told them that they were disabled by HIV/AIDS. Sixty percent (103) of respondents indicated that their doctor had told them they were disabled by HIV/AIDS, while 39 percent had not been told they were disabled.

Gender and Sexual Orientation

Respondents were asked to indicate their gender. Seventy-four percent (128) of respondents were male and 26 percent (45) were female. Although respondents had the option of indicating they were transgender (male to female) or transgender (female to male), no respondents selected these options.

Respondents were asked to choose a statement which best described them in terms of sexual behavior. Respondents indicated these responses in the following proportions.

- 46%: "I am a man who only has sex with men."
- 28%: "I am a woman who only has sex with men."
- 15%: "I am a man who only has sex with women."
- 8%: "I am a man who has sex with men and women."
- 1%: "I am a woman who has sex with women and men."
- 0%: "I am a woman who only has sex with women."
- 3%: "I am not described by any of the above."

Race/Ethnicity

Respondents were also asked to indicate their race/ethnicity. Seventy-eight percent (135) of respondents identified as White/Caucasian; 8 percent (14) as Hispanic/Latino, 8 percent (14) as multiracial; 3 percent (5) as American Indian/Alaska Native; 2 percent (4) as African American/Black; and 1 percent (1) as Asian/Pacific Islander.

Of the 14 respondents indicating that they were multiracial, 9 wrote that they were White/Caucasian and American Indian/Alaska Native, 4 wrote that they were White/Caucasian and Hispanic/Latino, and 1 indicated White/Caucasian, American Indian/Alaska Native, and Hispanic/Latino.

Because epidemiology statistics do not include a category for multiracial, it is difficult to compare the race/ethnicity of survey respondents directly to reported AIDS cases. However, the race/ethnicity profile of respondents appears to be very similar to reported cases. The most significant difference was in African American respondents; although 7 percent of people living with AIDS in Oregon are African American, just 2 percent of survey respondents were. However, because the majority of the state's African American population lives in the Portland metropolitan area, survey respondents may be more reflective of the balance of state population.

Age

Respondents were asked to indicate the year that they were born. From this information, their age was calculated. The average age of respondents was 42 years old, and the median age was 41. Respondents ranged in age from 12 to 80 years old. Respondents included:

- 1% aged 13 and under
- 0% aged 13 to 19
- 8% between the ages of 20 and 29
- 31% between the ages of 30 and 39
- 37% between the ages of 40 and 49
- 17% between the ages of 50 and 59
- 3% aged 60 and over

Four percent (6) of respondents did not respond to this question.

City and County of Residence

Respondents were asked to identify the city and county in which they resided. Persons living with HIV/AIDS from 50 cities and 21 counties responded to this survey. **Table 17** shows the number of respondents and percentage of all survey respondents from each county.

There is AIDS outside of
the Portland (area).
Don't forget us.

– focus group
participant

Table 17
County of Residence of Respondents

County	Number of Consumer Survey Respondents	Percentage of Consumer Survey Respondents
Baker	1	1%
Clatsop	2	1%
Coos	7	4%
Coos Curry	1	1%
Crook	1	1%
Deschutes	9	5%
Douglas	18	10%
Hood River	1	1%
Jackson	18	10%
Josephine	7	4%
Klamath	3	2%
Lane	44	25%
Lincoln	6	4%
Linn	2	1%
Malheur	7	4%
Marion	33	19%
Polk	5	3%
Umatilla	1	1%
Total Surveys	173	100%

Note: 4 respondents (2 percent) did not answer this question. Total also includes one survey each from three counties in the Portland-Vancouver OR-WA EMA: Multnomah, Washington, and Yamhill.

Income and Benefits

Work

Respondents were asked to indicate whether they were paid for doing any work. Thirty-two percent (55) of respondents worked for pay, while 68 percent (117) did not.

Men and women were paid for work in similar proportions. People who had been incarcerated at some point were much less likely to be paid for work than those who had not; 21 percent of people with a history of incarceration were paid for work, while 39 percent of people without such a history were.

While working is not an option for everyone, some of the practical considerations involved with choosing to work were outlined in the following comment, written by a survey respondent:

“Working is necessary for my mental health. However, I am penalized for working: cut in SSI, cut in food stamps, increased cost of transportation and car upkeep, I would be better off financially by staying home, plus Housing Authority raises my rent.”

Income

Respondents were asked to provide an estimate of monthly income and expenses. No restrictions were given on the source of income, so respondents made individual choices on whether to include wages, benefits, under-the-table work, and income from other sources, such as assistance from friends or family.

The average income of respondents was \$863 per month. The median income, the amount which divides the income distribution for all respondents into two equal groups, half having incomes above that amount, half having incomes below that amount, was \$650 per month. Incomes varied considerably; some variation can be seen between groups.

Table 18 shows the median income for respondents, not including contributions from others in the household, by employment status, gender, and history of incarceration.

Table 18
**Median Monthly Income Reported, by Employment Status,
Gender, and Previous Incarceration**

Demographic Category	Median Income of Respondents
<u>Employment Status</u>	
Not paid for work	\$560
Paid for work	\$1,000
<u>Gender</u>	
Female	\$628
Male	\$670
<u>Previously Incarcerated</u>	
Had been incarcerated	\$555
Had not been incarcerated	\$792

Table 19 shows the monthly income reported by respondents.

Table 19
Monthly Income Reported by Respondents*

Monthly Income	Number of Respondents	Percent of All Respondents
No income	19	11%
\$1–250	8	5%
\$251–500	11	6%
\$501–750	57	33%
\$751–1000	32	19%
\$1,000 or more	37	21%

*Note: 9 respondents (5 percent) did not respond to this question.

Benefits and Assistance

Respondents were asked if they received financial or medical benefits. Seventy-three percent (126) of respondents indicated that they received some form of *financial benefits*, while 24 percent (41) indicated that they did not receive financial benefits. Four percent (6) of respondents did not answer this question. **Table 20** reflects the financial benefits received by respondents.

Table 20
Financial Benefits Received by Respondents

Benefit Received	Respondents Receive	
	Number	Percent
Food Stamps	67	39%
Social Security Disability Insurance (SSDI)	64	37%
Social Security Income (SSI)	32	19%
Social Security	15	9%
General Assistance	10	6%
TANF (Temporary Assistance for Needy Families)	7	4%
Veteran's benefits	4	2%
Retirement income	2	1%
Other benefit	11	6%

Note: 4 percent (6) of respondents did not answer the financial benefits question.

A few focus group participants discussed applying for SSI. One had been rejected at least once, and had given up for the time being, relying on a partner for support and a Section 8 voucher. Another was living with his mother while recovering from surgery and unable to return to his job that

required heavy lifting. He anticipated being turned down three times before receiving SSI. One challenge mentioned by a few people was obtaining copies of all the paperwork and records required, and getting them transferred to the appropriate locations.

Ninety-one percent (158) of respondents indicated that they received some form of *medical benefits*, while 8 percent (13) indicated that they did not receive benefits. One percent (2) of respondents did not answer this question. **Table 21** reflects the medical benefits received by respondents.

Table 21
Medical Benefits Received by Respondents

Benefit Received	Respondents Receive	
	Number	Percent
Oregon Health Plan	92	53%
Medicare	54	31%
CareAssist (state AIDS Drug Assistance Program)	46	27%
Private health insurance	30	17%
Veteran's medical benefits	8	5%
Private disability insurance	4	2%
Other insurance	14	8%

Note: One percent (2) of respondents did not answer the medical benefits question.

At least one focus group participant mentioned needing to limit work hours in order to remain eligible for the Oregon Health Plan. Although working more hours would provide a slightly higher income, it would not be enough to cover necessary medical expenses.

The median monthly health care cost⁵⁵ for both people with and without health insurance was \$0. One possible explanation for this is that people without health insurance are not accessing health care in a typical month. A recent study in Multnomah County estimated that 9 to 11 percent of people living with HIV/AIDS are not in HIV medical care, and found a lack of health insurance to be the most common barrier cited by people out-of-care. Other barriers cited were avoidance and medication non-adherence, health care system barriers, and social and legal barriers.⁵⁶

Expenses

Respondents were asked to indicate the amount of money they paid each month for various categories of expenses. **Table 22** summarizes the median monthly expenses for respondents.

A lot of things I'd like to do with
my life but I just don't have the
money.

– focus group participant in
Roseburg

⁵⁵ The survey question was “How much do you spend on medications and other health care costs (including co-payments and insurance premiums) in an average month?”

⁵⁶ Lindstrom, Sia H., MA, MPH, David Dowler, PhD, and Michael J. Stark. Program Design and Evaluation Services. Multnomah County Health Department and Department of Human Services, Health Services. *Barriers to Care: HIV-Positive People Not Receiving Health Care For Their HIV Disease*. Page 12. May 2001.

Table 22
Median Monthly Expenses Reported in Selected Categories

Expense	Median Monthly Expense for Respondent
Rent/mortgage	\$300
Utilities, including gas, electric, water, and phone	\$95
Transportation, including bus pass, car repairs, car insurance, taxi fare	\$64
Food	\$150
Medications and other health care costs, including co-payments and insurance premiums	\$0

The median monthly total housing cost (rent or mortgage and utilities) was \$367. Monthly health care costs reported by respondents ranged from \$0 to \$1,200, with an average of \$60. The median of \$0 indicates that half of respondents were paying that amount in monthly health care costs, and half were paying more.

One focus group participant mentioned the interrelationship of these expenses in the overall budget, and that a shortfall in one area may lead to seeking assistance for another. For example, if a person who depends on a car for transportation needs to make a car repair, but no assistance is available for car repairs, that person will seek assistance in other areas of the budget where assistance may be available—food, utilities, or rent.

Housing Cost Burdens

A household is considered to be experiencing a “housing cost burden” when it is paying more than 30 percent of its monthly income on housing expenses, which include rent/mortgage and utilities. A household is considered to be experiencing a “severe housing cost burden” when it is paying more than 50 percent of its monthly income on housing expenses. Respondents were not asked to indicate the percent of their household income spent on housing expenses; rather, they were asked for monthly household income, monthly rent, and monthly utility expenses. Using these figures, respondents’ housing cost burden was calculated. Nineteen percent (32) of respondents did not provide enough information to allow for the calculation of this statistic.

Among survey respondents, the median monthly housing cost burden was 45 percent. Thirty-six percent (62) of respondents paid more than 50 percent of their monthly household income on housing costs, 28 percent (49) paid 31–50 percent, and 17 percent (30) paid less than 30 percent.

Women were more likely to be rent burdened than men were, with 61 percent of women paying more than 50 percent of their income to housing costs, as compared to 38 percent of men. Similarly, just 8 percent of women were spending less than 30 percent of their income on housing costs, compared to 26 percent of men.

Effect of Rent Increase or Income Decrease

Respondents were asked to indicate if they would have to move if their housing costs (rent and/or utilities) went up by about \$50. Thirty-five percent (61) of respondents indicated that they *would* have to move, while 61 percent (105) of respondents indicated that they would not have to move.

Current Housing Situation

Household Composition

Respondents were asked with whom they lived. Some respondents checked more than one answer. *Table 23* details the current household composition of respondents.

Table 23
Current Household Composition

Current Household Composition	Number of Respondents	Percent of All Respondents
Alone	54	31%
Husband/wife/partner	52	30%
Child or children	32	19%
Friend(s)/roommate(s)	27	16%
Mother/father/other family	19	11%
Other residents of a group home, shelter, or hospital	7	4%
Live with other	2	1%

Note: 1 respondent (1 percent) did not respond to this question.

Just 4 percent of women (2) were living alone, compared to 41 percent (52) of men. Women were more likely to live with a partner than men (44 percent versus 25 percent) were. More than half of women surveyed (53 percent) lived with children, compared with just 6 percent of men.

Several women wrote comments on their surveys regarding the challenges of living with HIV/AIDS and supporting children at the same time. One wrote, “HIV+ women sometimes have children. We care more about the needs of our children than ourselves. We are concerned about food, clothing, furniture, warm beds, washing machines & dryers, yards to play in, and the neighbors.”

The majority of focus group participants said that they live either alone, with a partner, or with a partner and children. A number of people also reported living with their parents. For some, parents were an important source of support and sharing housing had many benefits. Others were in the arrangement out of necessity and there were tensions.

Respondents were asked whether any of the adults or children in their household were also living with HIV/AIDS. Eighteen percent (31) responded affirmatively, and 76 percent (131) responded negatively. Six percent (10) were unsure, and 1 percent (1) did not answer this question.

Current Housing Situation

Respondents were asked what kind of place they lived in. **Table 24** presents all of the types of housing indicated as current residence by respondents. Respondents were allowed to select just one type of housing situation.

Table 24
Current Housing Situation of Respondents

Current Housing Situation	Number of Respondents	Percent of All Respondents
Rent an apartment, house, condo, or mobile home	79	46%
Own a house, condo, or mobile home	38	22%
With friends or relatives, can stay as long as needed	16	9%
With friends or relatives, can stay only a short while*	13	8%
Jail/prison	6	4%
Rent a room	4	2%
Hotel/motel rented by the month or week*	4	2%
House, apartment, condo, or other home with services for people with disabilities	3	2%
Group home	2	1%
Homeless (streets, park, car, under bridge)*	1	1%
Staying in a shelter*	1	1%
House, apartment, condo, or other home where I get help for alcohol or drug problems	—	—
Other	6	4%

*People living in these situations are considered homeless or at risk of homelessness.

Eleven percent of all respondents were on the streets, in shelters, in residential hotel/motels, or staying with friends or family temporarily when they completed the survey—each of these individuals are considered homeless or at risk of becoming homeless.

Women were more likely to be renting an apartment, house, condominium, or mobile home than any other housing situation, with 62 percent reporting this option. Although renting was also the most common response for men, at 40 percent of the total, men's responses were more distributed across the other options.

Focus group participants reported living in a variety of housing situations, ranging from staying in a motel to living with family to owning a home. When describing their current housing situation and stability, focus group participants who were satisfied with or confident about their housing

frequently mentioned having a friendly landlord. Presumably because it is not always the case, participants were likely to mention the possibility of being open about their HIV-status to their landlord and/or neighbors as a plus.

Housing Quality

Respondents were asked to indicate whether or not their current home had a range of qualities or deficits. This question required respondents to make an assessment that may differ from the assessment that a HUD-certified Housing Quality Standards inspector might make. For instance, a person who lives in a home with substandard weatherizing may not label it that way. **Table 25** presents the result of this question.

Table 25
Respondents Whose Homes Have Selected Characteristics

	Number	Percentage
Indoor bathroom	165	95%
Hot and cold running water	164	95%
Access to a complete kitchen	160	93%
Adequate heating	157	91%
Enough living and sleeping space for everyone in household	149	86%
Adequate insulation or weatherization	130	75%
Bugs, mice, or rats	38	22%
Water leaks	24	14%
Unsafe or inadequate wiring or electricity	23	13%

Forty-six percent (80) of respondents indicated their current housing had at least one quality problem, meaning that they either responded negatively to the first 6 attributes listed above or positively to one of the last 3 problems.

One survey respondent wrote the following comment related to housing quality concerns: “We have lived for 12 years in totally inadequate housing, 5 years of that HIV+. We cannot afford to live anywhere else. The quality of our lives is directly affected by lack of running water and an indoor toilet. . . . It is only a matter of time until our health forces us to find other housing but currently we could never afford new housing or to even move from where we are now unless we had assistance. For us this is a daily, ongoing problem with no end in sight.”

Housing quality was also an issue of concern identified by focus group participants. A few focus group participants mentioned not having indoor plumbing, while others had less specific quality concerns (“I live in a two bedroom shack that is sinking into the mud.”)

Another aspect of quality identified by focus group participants was the quality of the neighborhood. Some areas that are more affordable to people living with HIV/AIDS have problems

with criminal activities, particularly drug-related activities. Lane County participants particularly noted this.

Resident Satisfaction

Respondents were asked to rate their satisfaction with their current apartment or house on a scale of 1 to 5, with 5 being very satisfied. The average rating was 3.7, and the rating receiving the largest share of responses was “very satisfied.” **Table 26** presents the satisfaction ratings participants gave their homes.

Table 26
Resident Satisfaction with Home at Time of Survey

	Number	Percentage
1-Not satisfied at all	14	8%
2-Not satisfied	20	12%
3-Housing is OK	42	24%
4-Satisfied	32	19%
5-Very satisfied	64	37%

Note: One respondent did not answer this question.

Women were more likely than men to be “very satisfied” with their current housing; nearly half—48 percent—indicated this option, compared to about a third—34 percent—of male respondents.

Rental Assistance

Respondents were asked if they were currently receiving housing or rental assistance from the government or another organization. Sixty-seven percent (116) said they were receiving no housing assistance, and 4 percent (6) were not sure. Twenty-eight percent of respondents (48) were currently receiving some sort of housing or rental assistance. The proportions of men and women receiving assistance did not differ significantly. The types of assistance indicated were as follows:

- 16% (28) were using a Section 8 certificate or voucher.
- 8% (13) received rental assistance from another source.
- 5% (8) lived in subsidized or public housing.
- 2% (3) lived in a home for people living with HIV/AIDS.
- 1% (1) received assistance through Shelter Plus Care.

Housing assistance appeared to have a significant impact on housing costs. The median monthly rent or mortgage cost for respondents with assistance was \$180, compared to \$325 for those without assistance. The median monthly utility cost for people with assistance was \$80, compared to \$100 for those without. Finally, the median total monthly housing cost was \$276 for people with assistance and \$415 for those without.

Respondents were also asked if they were on any waiting lists for housing or rental assistance. Eight percent (14) of respondents were on waiting lists for rental assistance, while 86 percent (148) were not. Five percent (8) were not sure if they were on a waiting list for rental assistance and 2 percent (3) did not answer this question.

Some focus group participants indicated that they had Section 8 vouchers, and that these were very helpful in making housing affordable and increasing stability. Several mentioned living with parents who received their own Section 8. Most participants had some ideas about where to access housing assistance and how long it might take. In most areas, there was a perception that it would take a long time to access any assistance, and that the process was difficult. In one group, a participant with Section 8 advised others to be persistent, saying, “If you are eligible for something, go for it. But have your paperwork in order and be on time.”

Complexity of Lives

Homelessness

Respondents were asked if they had ever been homeless. Homelessness was further defined as “without a regular place to stay the night.” More than half of respondents (53 percent or 92) indicated that they had been homeless at some point in the past. Similarly, many focus group participants reported having had periods of homelessness.

Respondents were asked follow-up questions about their history of homelessness. One question addresses the length of the respondent’s longest period of homelessness in the three years prior to completing the survey. Ten percent of respondents indicated that their longest period of homelessness in the past 3 years had been between 5 weeks and a year, while 10 percent indicated they had been homeless one to four weeks, 9 percent had been homeless for more than a year, and 5 percent had been homeless a few days up to a week.

Respondents were asked to choose from a list of possible reasons why they had last become homeless. Responses were as follows:

- 20% of respondents indicated that the reason they became homeless the last time was due to inadequate income from a job or benefit checks.
- 15% had been evicted.
- 13% indicated that their family, partner, or roommate made them move out.
- 10% became homeless due to reasons related to their use of alcohol or drugs.
- 9% had moved to a new area and had no money, friends, or family.
- 5% became homeless after their release from jail, county lock-up, or prison.
- 14% became homeless the last time for another reason.

Women were slightly more likely to report previous homelessness than men were. Sixty-one percent of female respondents had been homeless while 51 percent of male respondents had been

homeless.⁵⁷ Respondents who had been incarcerated in the past were much more likely to report a history of homelessness as well. Eighty-three percent of those who had been incarcerated also reported prior homelessness, compared to 35 percent of those who had never been incarcerated.

Respondents were asked if they had ever slept outdoors, in a car, in a shelter, or traded sex for a place to sleep or for rent money since they had learned of being HIV-positive. The majority (62 percent) of respondents indicated they had not done any of these things. **Table 27** summarizes the percentage of respondents who have engaged in these activities for a place to sleep.

Table 27
**Activities Respondents Engaged in to Find a Place to Sleep
Since Being Diagnosed HIV-positive**

Activities	Percentage of Respondents
Slept in the street, park, or another place outside	23%
Slept in a car	23%
Slept at a shelter	13%
Traded sex for a place to spend the night or for rent money	6%

Note: 108 respondents (62 percent) had not done any of these things, and 6 respondents (4 percent) did not respond to this question.

Incarceration

Respondents were asked if they had ever been in jail or prison, and, if so, when they had most recently been released. Forty percent (69) of respondents had been incarcerated at some point, while 59 percent had not. Of respondents who had been incarcerated, 25 percent had been released within the past year, and 75 percent had been released more than a year ago.

In addition, respondents were asked if they had ever been convicted of a felony. Twenty-one percent (37) of respondents had been convicted of a felony, while 77 percent (133) had not. Two percent (3) of respondents did not respond to this question.

⁵⁷ Rates differ slightly from summary statistic because only respondents for whom both gender and prior homelessness were available were included.

Disabilities Other Than HIV/AIDS

Respondents were asked if they had any disabilities affecting their daily life⁵⁸, and, if so, to indicate their disability. Seventy-four percent (128) of respondents indicated they had a disability affecting their daily life, while 24 percent (41) did not.

Fifty-nine percent (102) of respondents indicated that their HIV/AIDS-related disability complicated their daily life, while 60 percent (103) indicated previously that their doctor had told them they were disabled by HIV/AIDS. The question was asked both ways because an individual's perception of their disability may differ from a medical definition. Respondents who indicated one or more disabilities are presented in **Table 28**.

Table 28
Disabilities of Respondents

Disability	Number of Respondents	Percent of All Respondents
HIV/AIDS	102	59%
Physical disability	53	31%
Mental illness	28	16%
Drug abuse	11	6%
Developmental disability	7	4%
Alcohol abuse	5	3%
Deaf	4	2%
Blind	2	1%
Other	16	9%

Note: 4 respondents (2 percent) did not respond to this question.

Forty-one respondents (24 percent) indicated that they were not disabled. Four percent (6) of respondents indicated both a disability related to mental illness and to drug or alcohol abuse. National studies and the practical experience of Oregon's HIV/AIDS service providers indicate that the prevalence of mental illness and substance use issues among people living with HIV/AIDS are probably much higher in actuality. In general, people tend to underreport these issues in surveys. The following section, "Support Services," contains additional information about participation in related services, which is another indication of the extent of these issues.

⁵⁸ This question was phrased "Do you have any disabilities that make your day-to-day life difficult?"

Housing Discrimination

Respondents were asked whether they had been discriminated against when trying to obtain housing. Thirty-five percent (61) of respondents indicated that they had been discriminated against when trying to obtain housing, while 62 percent (107) indicated they had not. Those respondents who said they had been discriminated against were asked to check all of the reasons they had been discriminated against in a list of factors. **Table 29** presents the reasons listed.

Table 29
Respondents Reporting Housing Discrimination, by Type of Discrimination

	Number	Percentage
Health: HIV infection or AIDS	29	17%
Sexuality: gay, lesbian, bisexual, or transgender	21	12%
Criminal history or prison record	16	9%
Source of income	15	9%
Source of rent (Section 8 certificate or voucher)	12	7%
Disability or handicap	10	6%
Race or ethnic background	8	5%
Live with someone not married to	7	4%
Number of children or people in family	6	4%

Note: Respondents could check more than one type.

Many focus group participants mentioned having concerns around telling landlords or neighbors about their HIV-status, or having experienced discrimination related to HIV-status. Some described HIV/AIDS as being associated closely with being gay in public perception, and stereotypes and biases related to both being applied by property managers and neighbors.

Barriers to Housing

Respondents were asked if they had experienced trouble in getting or keeping housing. Slightly more than half (51 percent) of respondents had had trouble in getting or keeping housing, while 49 percent had not. Respondents were given a list of reasons and asked to check all the reasons that related to their housing trouble. *Table 30* presents the reasons respondents gave.

Table 30
Respondents Barriers to Getting or Keeping Housing, by Reason

Type of Barrier	Number of Respondents	Percent of All Respondents
Not enough money for security deposit, and first and last months' rent	67	39%
Credit problems	59	34%
Could not afford rent and utilities	57	33%
Pets were not allowed in the housing that was available	29	17%
No transportation to search for housing	27	16%
Smoking was not allowed in the housing that was available	18	10%
Alcohol or drug use	11	6%
Domestic violence in household	10	6%
Mental illness	7	4%
Immigration status	5	3%
Participation in a methadone maintenance program	1	1%
Another reason	12	7%

Note: Respondents could check more than one type.

Many focus group participants identified barriers to obtaining housing in the applicant screening process, particularly the screenings conducted by larger property management companies. Commonly mentioned obstacles were: a need for multiple references, prior credit problems, multiple fees, including application fees and non-refundable move-in fees, and background screening that examined even an applicant's driving record.

A few focus group participants also mentioned pets as a concern, because many apartment buildings will not accept pets. One described his dog as his best friend, and said, "(there is) no way I am moving into a place without him." Medical providers can often qualify pets as assistance animals, allowing the animals into housing, but pet deposits and fees can still be unaffordable.

Another barrier identified by focus group participants and not included in the survey was medical marijuana. Oregon law allows certain people to qualify to have marijuana legally for medical purposes. However, people who qualify must grow their own marijuana. A few focus group participants identified this as a housing concern, since property managers, particularly those in housing funded by the federal government, often do not allow marijuana possession on site.

Support Services

A number of focus group participants mentioned the importance of support services, and case managers who can help access them. Services addressed explicitly in the survey were HIV/AIDS services, alcohol and drug treatment and recovery, mental health services, transportation, and case management.

Alcohol/Drug Treatment

Respondents were asked whether they had help from specific types of alcohol or drug recovery or treatment programs in the three months prior to completing the survey. In total, 15 percent of respondents had participated in at least one type of alcohol or drug recovery or treatment program in the 3 months prior to the survey. There was some variation by gender; 16 percent of men had participated in such a program, compared to 9 percent of women.

Percentages participating in each type were as follows:

- 12% (20) of respondents were in a 12-step program: Alcoholics Anonymous, Narcotics Anonymous, Cocaine Anonymous, or other.
- 4% (6) were in an inpatient treatment or recovery program.
- 3% (5) were in an outpatient program, excluding methadone.
- 1% (1) were involved in drug court.
- 1% (1) were in a methadone maintenance program.
- 1% (2) were in some other drug treatment or recovery program.

By comparison, a review of client records from CareAssist, the state AIDS drug assistance program, found that 31 percent of the clients had documentation of drug use, and half of these had been referred to treatment.⁵⁹

Mental Health Services

Respondents were asked whether they had help from specific types of mental health staff and programs in the three months prior to completing the survey. A total of 57 percent (98) of respondents had participated in at least one type of program. There was a slight difference in participation rates between genders—47 percent of women versus 60 percent of men. Thirty-six percent (63) had participated in a mental health program other than a support group.

Participation by type was as follows:

- 28% (49) of respondents had been in an HIV/AIDS support group.
- 27% (47) had seen a mental health counselor or therapist.
- 16% (27) had seen a psychiatrist for medication to help with a mental illness.
- 15% (25) had been in another kind of support group.

⁵⁹ Oregon Department of Human Services, Health Services. Quality of Care Study: Medical Record Review for Care Assist. Unpublished data. November 14, 2001. Records reviewed were from October 21, 1999 through October 21, 2000.

- 3% (5) had received crisis intervention.
- 1% (2) had been in a psychiatric hospital.
- 0% had been in a group home or apartment for people with mental illness.
- 8% (14) had been in some other program.

By comparison, 24 percent of clients included in the CareAssist medical record review had a mental illness diagnosed by the HIV provider, and two-thirds of these were referred to a mental health specialist.⁶⁰

Eight percent (13) of respondents reported participation in both a mental health and a drug or alcohol treatment or recovery program in the 3 months prior to the survey. Several survey respondents wrote comments related to the importance of, or their desire for, HIV/AIDS support groups.

Many of the focus group attendees participated regularly in HIV/AIDS support groups, in part because people in a support group are more likely to attend a focus group. One person interviewed in eastern Oregon mentioned not knowing anyone else who was HIV-positive, thinking that it might be helpful to connect with others, but also not wanting to acknowledge her HIV-status publicly.

Transportation

Respondents were asked whether they use the following types of transportation to get to appointments or to look for housing:

- 71% (122) of respondents drove their own car.
- 60% (103) relied on the car of a friend or family member.
- 53% (92) walked.
- 41% (71) used public transit.
- 28% (48) used a bicycle.
- 19% (33) used taxis.
- 12% (20) used a van service (for example, for people with disabilities or a social service agency van).
- 8% (14) used another type of transportation.

Focus group participants described a variety of means of transportation. Generally, participants using van services were satisfied with them. Some people living with HIV/AIDS who need transportation assistance may not fit into the disability criteria established for non-HIV/AIDS-specific transportation services. Taxis were another common means of transportation. For people with cars, paying for insurance was a particular concern.

⁶⁰ Ibid. CareAssist is Oregon's state AIDS drug assistance program.

Respondents were also asked about the distance they usually have to travel to get to both their HIV/AIDS medical care, in particular, and to their other medical and service appointments. Respondents were slightly more likely to travel further for HIV/AIDS medical care than for other types of medical and service appointments. Twenty percent of respondents reported traveling further than 50 miles for HIV/AIDS medical care, compared to 12 percent traveling that distance for other types of appointments. **Table 31** compares the distances traveled for both.

Table 31
Distance Traveled to HIV/AIDS Medical Appointments and to Other Medical and Service Appointments, by Percentage of Respondents

Distance Traveled	To HIV/AIDS medical appointments	To other medical and service appointments
1 to 10 miles	54%	57%
11 to 50 miles	24%	30%
51 to 100 miles	9%	4%
101 to 200 miles	8%	6%
More than 200 miles	4%	2%

Note: 3 respondents did not reply to the question about HIV/AIDS services, and 2 did not respond to the question about medical and service appointments.

Several focus group participants mentioned balancing concerns about housing costs and local transportation when considering where to live. For example, focus group participants in Eugene indicated that although housing was cheaper in Springfield, it would be harder to get around there, and therefore it was not worth moving. Similarly, focus group participants in Bend and Roseburg mentioned the higher cost of living in the central city but thought these costs were worth the improved accessibility in these areas.

For people living in the balance of state, transportation to and from specialty medical care can be a very different issue than accessing local transportation. For example, one person living in eastern Oregon described using a partner's car while in the county, but taking a bus 18 hours each way to Eugene twice a year for specialty medical care. Another mentioned that she was "supposed to" be seeing a doctor in another community but had not been going, in part because of the distance.

Case Management Services

Respondents were asked if they were currently receiving case management services. Seventy-one percent (122) of respondents had a case manager, and 28 percent (49) did not. Because service agencies and case managers worked to distribute the survey, the proportion with case managers is likely larger than that in the entire population of people living with HIV/AIDS.

Those respondents who said they have a case manager were asked how often they see their case manager. The frequencies were as follows:

- 6% (11) of respondents see their case manager more than once a week.
- 17% (29) see him/her once a week to a few times a month.
- 17% (29) see him/her once a month.
- 30% (52) see him/her less than once a month.

Those respondents who did not have a case manager were asked whether or not they would like to have a case manager. Thirteen percent (49) of all respondents replied that they did not have a case manager but would like one. Fifteen percent did not have one but did not want to have one at the time of the survey.

Many focus group participants indicated that they would not be aware of resources available to them without a case manager's assistance. As one participant put it, when asked where he went for help, "I go to (case manager). If I didn't know (case manager), I'd be screwed."

Use of and Need for Other Support Services

The last page of the survey was a question labeled optional that asked about support services. Specifically, given a list of services, respondents were asked which services they were currently receiving enough of, services currently received but not enough, services they needed but were not able to access, and which services they did not need. Seventy-seven percent (133) of respondents chose to respond to this question, although they may not have responded to every service listed.

Table 32 shows the results for all respondents. The percentage indicates the portion of respondents who gave a particular answer. Responses are given as a percentage of the responses received for each question, and not as a percentage of all survey respondents, as the results for most previous questions have been. It is important to look at all four responses for each type of service, since a service may be both available to many and needed by many. The need for a service by only a small proportion of the respondents does not necessarily indicate that the service is unimportant. For example, although 97 percent of respondents said they do not need interpreter services, it is easy to imagine the critical difference interpreter services can make to an individual who is monolingual in a language other than English.

Table 32
Support Services Received and Needed by Respondents (n=133)

Type of Service	Currently Receiving Enough	Currently Receive, but Not Enough	Need, but Not Able to Access	Don't Need
Assistance with daily activities	14%	5%	2%	80%
Assisted transportation	12%	5%	8%	75%
Benefits counseling	22%	14%	18%	47%
Case manager	41%	17%	19%	23%
Child care	1%	—	4%	95%
Day treatment	2%	2%	2%	94%
Dental care	25%	27%	27%	20%
Education/literacy program services	3%	4%	17%	76%
Food bank, food vouchers, and/or groceries	13%	30%	21%	36%
Home-delivered meals	2%	2%	9%	87%
Homemaker services	9%	4%	8%	79%
Interpreter services	2%	—	1%	97%
Legal services	4%	5%	24%	67%
Life skills training	5%	5%	8%	82%
Nutritional counseling	5%	4%	20%	72%
Primary medical care	47%	11%	5%	38%
Professional home health care	4%	2%	2%	92%
Respite care	2%	—	4%	95%
Vocational rehab and employment services	4%	5%	15%	76%
Other services	—	—	14%	86%

Moving In and Out of Metropolitan Areas

Focus group participants were asked whether they had moved from another area, whether they had thought about moving to another area, and what some of their considerations for moving were. This question was not addressed in the survey tool but was identified as an issue of interest.

The majority of focus group participants had lived in their area for a considerable length of time, if not their entire life. Some people had moved in from other states, or other areas of Oregon. Most mentioned having friends or family in the area as their reason for moving there, although the Oregon Health Plan was mentioned by one person as an additional factor.

Focus group participants responding to these questions mostly indicated that they felt they have everything they need where they are living, so there is no reason to move. Generally, people were not interested in leaving home. Cultural differences between rural and urban areas seem to be a factor—as one person put it: “the city has more resources but it’s crazy.”

Housing Preferences

The information included in this section represents only those who responded to each housing preference question, not the entire survey sample, unless otherwise indicated. In each table, the number (n) of respondents to each question is indicated.

Comparing Housing Options

Respondents were presented with a series of choices and asked to indicate their preferred option in each set. Making choices about a large budget item such as housing often involves choosing between what is possible. Without practical constraints, consumers might make other choices; the intent of the paired choices is to get closer to the kinds of compromises that consumers often make.

The first question asked respondents to indicate, given their situation “right now,” if they would rather stay where they are or move to another place. This question is asked to get a sense of consumer satisfaction with their housing, or a sense that it is appropriate to their needs.

The majority of respondents indicated that they would rather move than stay where they are. Women were slightly more likely to indicate that they would prefer to stay where they are. Responses are given in **Table 33**.

Table 33
**Responses to Staying or Moving Housing Options Pair,
for All Respondents and by Gender**

Option	Total Respondents	Male	Female
Right now, would you rather:	<i>N=169</i>	<i>N=126</i>	<i>N=43</i>
Stay where you are, or	59%	56%	67%
Move to another place?	41%	44%	33%

The remaining housing preference questions presented pairs of options and asked respondents for their preference “if (they) had to move next month.” The intent of framing the question this way was to have respondents base their decision on current health and income, and but also imagine having some time to plan ahead. The responses to these pairs are given in **Tables 34 through 37**.

The first pair which asked the respondent to imagine if they had to move next month focused on living alone versus sharing with other people. In most housing markets, living alone means paying more rent than sharing housing, so the issue of paying more rent was included in the question.

Eighty-six percent (143) of respondents would have preferred living in a place of their own to sharing a place with other people, even if it meant paying more rent. Women preferred living in a place of their own more strongly than men did, with 95 percent of women indicating this preference. **Table 34** presents the results of this pair.

Table 34
**Responses to Living Independently or Sharing Housing Options Pair,
for All Respondents and by Gender**

Option	Total Respondents	Male	Female
If you had to move next month, would you rather:	<i>N=166</i>	<i>N=124</i>	<i>N=42</i>
Have a place of your own <i>even if it means paying more rent,</i> or	86%	83%	95%
Share a place with other people?	14%	17%	5%

Next, respondents were asked to compare moving in with family or friends versus moving into a shared HIV/AIDS housing facility. Fifty-eight percent of respondents indicated that they would rather live with family or friends than to share an HIV/AIDS housing facility. However, 42 percent indicated they would move into an HIV/AIDS housing facility. Responses from men and women were very similar. Respondents who do not have friends or family with whom they can live may have selected this option more as a default than because they are interested in HIV/AIDS housing; this issue is addressed in the following question as well. **Table 35** presents responses to this survey question.

Table 35
Responses to Shared Housing Options Pair, for All Respondents and by Gender

Option	Total Respondents	Male	Female
If you had to move next month, would you rather:	<i>N=160</i>	<i>N=122</i>	<i>N=38</i>
Move in with family or friends, or	58%	57%	61%
Move into shared housing with other people who are living with HIV in a building that was specifically designed for people living with HIV?	42%	43%	40%

The next question asked survey respondents to compare apartment living situations based on the mix of other residents in the building. Generally, survey respondents preferred to be in a building with all kinds of residents than a building dedicated for people living with HIV/AIDS. Men were more likely than women were to prefer living in housing dedicated solely to people living with HIV/AIDS. **Table 36** presents the preferences expressed between living in an apartment building where only people with HIV/AIDS live, versus an apartment where people of any HIV status could live.

Table 36
**Responses to HIV/AIDS Housing Options Pair,
for All Respondents and by Gender**

Option	Total Respondents	Male	Female
If you had to move next month, would you rather:	<i>N=163</i>	<i>N=124</i>	<i>N=39</i>
Live in an apartment building where <i>only</i> people with HIV/AIDS live, or	23%	27%	10%
Live in an apartment building where different kinds of people live together, whether they have HIV or not?	77%	73%	90%

The final pair of preference questions asked respondents to indicate whether they would prefer living in housing where people are required to be clean and sober, or in housing where they would not be evicted for using drugs or alcohol. In AIDS Housing of Washington's national work, people living with HIV/AIDS have commonly indicated that they prefer not to live with people with substance use issues, yet many people living with HIV/AIDS have had difficulties maintaining housing that includes sobriety as an eligibility requirement. **Table 37** presents responses related to drug and alcohol policies in housing.

Table 37
**Responses to Drug and Alcohol Housing Options Pair,
for All Respondents and by Gender**

Option	Total Respondents	Male	Female
If you had to move next month, would you rather:	<i>N=161</i>	<i>N=123</i>	<i>N=38</i>
Live in a place where you won't be evicted if you use drugs or alcohol, or	44%	46%	40%
Live in a place where people are required to be clean and sober?	56%	55%	61%

Respondents were asked whether they would be willing to move to a different neighborhood/city if it would mean paying less for rent, if they had to move in the next month. This question was intended to gauge in a general way the relative importance of location versus cost in housing selection. Sixty-seven percent (110) indicated they would be willing to move, while 33 percent (54) indicated they would not. Men and women indicated a willingness to move in similar proportions.

Housing Services

Respondents were asked if they would use various housing services. The number and percentage of respondents indicating they would use each of the housing services are given in *Table 38*.

Table 38
Respondents Indicate They Would Use These Housing Services, by Number and Percent

Potential Services	Number	Percent
Lists of affordable apartments or houses	146	88%
A person to help you in case of a housing problem	138	83%
A person to take you around to look at available housing	107	65%
A person to help you fill out housing applications and other forms	89	54%
Other kind of housing service	40	47%

Note: 7 respondents (4%) did not respond to this question. Respondents were given a space to write in the "other" service they had in mind, but most did not.

Focus group participants in Bend mentioned a number of these services as being of potential benefit, including assistance finding a unit where a Section 8 voucher could be used and transportation around to available housing. Consumers expressed an interest in a list of "bad landlords," or those who were known not to accept Section 8 vouchers or to discriminate against people living with HIV/AIDS. At the minimum, consumers felt that these properties should not appear on lists put out by housing agencies as potential places to rent.

Focus group participants also mentioned additional sources of utility assistance as something that would be helpful. For people who are already paying a large proportion of their income toward housing costs, unexpected increases and periods of higher monthly bills can be unmanageable. Most sources limit how much assistance or the number of times assistance can be accessed per year. Participants expressed concern about future utility costs.