

## Consumer Focus Group Notes

Focus groups were held with people living with HIV/AIDS throughout the state. Local case managers and AIDS service providers assisted with organizing the focus groups. A total of 28 people participated in five focus groups. Summaries of those focus groups are included in this section.

### HIV Alliance, Eugene, Oregon: March 19, 2001

8 participants

#### Please describe your current living situation and its stability.

- Male 1:** Lives in a recovery house, but not sure what will do after.
- Male 2:** In a converted motel/apartment. Pretty stable but better if rent lower. Doesn't want to live in Springfield although rent is cheaper there.
- Male 3:** Owns a house—stable.
- Male 4:** Lives with mom – “rents the couch.” Stable, but not ideal, better than the street. Uncertain about length of stay there and future possibilities.
- Male 5:** Has Section 8. Pays \$135 for a \$475 apartment in Springfield. Took 2 1/2 years to get.
- Female 6:** Lives with family member in Springfield, area is dangerous. There since 1998, can stay as long as needed.
- Male 7:** Lives alone in studio near campus. Pretty stable but “pricey for what I get.” Some flexibility with landlord.
- Male 8:** Lives in house that family owns “2 bedroom shack that’s sinking into the mud.”

#### How many have been homeless in the past?

All but one (male)

#### Issues that affect rental ability with landlord?

- Criminal history, income
- Biggest problem with housing: cost
- Mostly landlords just don't care.
- Told by landlord: “We prefer you not make your health status known to your neighbors.”
- “I live in a recovery house, but I don't tell people I have HIV—it is none of their business”.
- Many report having to “jump though the hoops with the management company.”
- Mostly management companies manage apartments here: they have a more technical screening process. They look for 2-3 times rent for income, which is almost impossible.
- Direct relationship with owner very good—OK with Section 8
- Landlords want to deal with Section 8.
- Eugene is more expensive than other areas.
- Case Manager added: Springfield has more drug activity, not a safe environment.

**What about transportation?**

- Some people have cars
- Expecting changes in bus routes
- Bus system is fair in most areas of Eugene and Springfield.
- Eugene is talking about getting light rail
- Some disabled services for bus — have to be unable to ride bus.

**How do you get information about the services you need?**

- “I go to my case manager. If I didn’t know my case manager I’d be screwed.”
- “This is the only agency that does HIV services here. If you are not in this agency you’re out of luck.”
- “White Bird Clinic is good. They have a self-help guide and also a phone line for information and referral.”

**What kinds of things have been issues in the past? What are the things that are needed?**

- Legal issues are a problem. Credit problems are hard to overcome to get housing.
- Prejudice; e.g., when homeless couldn’t get into housing because didn’t have rental history
- Paying more than 50% of income for rent seems not worth it: “It also makes more sense to be homeless and not spend all that money”. Another participant agreed, “Yeah, I did that too, until I came down with cryptococcal meningitis.”
- Screening criteria of management companies. Wide agreement to statement “I could never rent a place with a management company”.
- Most service agencies put an emphasis on families and it is easy for people with HIV to fall through the cracks of populations served. “We are not their target population.”
- HIV/AIDS is not really considered among other disabilities. Person has to have AIDS and be disabled by it to qualify for reduced rate bus pass.

**How is living in Eugene?**

- To live in Eugene with a low income, you have to be creative about everything.
- It seems like for every extra dollar you get, your benefits are reduced by \$2.

**Who has moved?**

Two report moving to Eugene from out of state for family or other personal connection.

**Tell us about your health care.**

- Most people on Oregon Health Plan, which provides low-cost to no-cost health care.
- Public health benefits are only this extensive in Minnesota and Hawaii in addition to Oregon.
- Good access to medications “delivered to my door”
- One person reports issue with over the counter meds recently. Not covered by OHP but Ryan White can’t help.

**What is most important consideration in deciding where to live?**

- Cost
- Transportation (get to where you need to go)
- Half of participants would move to Springfield to save money and half wouldn’t.
- If you needed assistance in the home where would you want to live?
- I spent 6 months in nursing home, 3 in hospice, and I am not leaving home again.

- “It is nice to have your place, but I’ve been sick enough where services are critical.”—worth it to move.

**If your rent went up by \$50 or your income went down by \$50 would you have to move?**

- 4 yes: “I’d have to get a roommate.”
- Case manager added: pride issues prevent others from accessing services outside of AIDS service organization.
- Reports of frustration with the Housing Authority “they treat you like a criminal to find out if you are a criminal.” Upset about being fingerprinted for housing application.

**What is the most important to think about with housing and people living with HIV/AIDS in Eugene?**

- Not that bad. Being gay is most difficult in a small town.
- For housing and jobs, HIV/AIDS not accepted in small town. People with HIV/AIDS not recognized like elderly as having housing needs. No awareness about the difficulties of living with HIV/AIDS.
- If you are eligible for something, go for it, but have your paper work in order and be on time.
- Don’t want to disclose; you shouldn’t need to.
- Important to let people know what resources are available ahead of time, so they don’t get into a crisis.
- Frustration that property owners/managers have much power and a renter doesn’t have recourse.
- Biggest problem is money—not enough income to clear screening for housing.
- There should be tax breaks for renters, a renters’ rebate.
- Section 8 should be automatic for people with disability.

**Roseburg, Oregon: May 3, 2001**

12 participants

**Male 1:** Lives alone in garage. Can pay with general assistance.  
Agency helps by providing payee services and paying rent directly.  
No indoor plumbing in unit. Seems stable, but not technically a living space.

**Male/female couple:** One bedroom rent for \$380  
\$425 in income  
No rental assistance  
Feel stable, but “don’t like it”

**Male 2:** \$315/month for a one bedroom with a lingering cat smell  
Some neighbors have mental health issues; noisy  
Heat turned off because cannot pay bill  
80% of income to rent  
Told neighbors about HIV, important to him

**Male 3:** Lives at Mission  
Recently returned to Oregon (3 weeks)  
Doesn’t qualify for assistance  
Wants to find employment, but difficult while at the mission

- Male 4:** Has roommate since 2 months ago  
Mom leases unit, but complicated relationship with mother (tenuous)  
Harassed by neighbors, some police involvement
- Male 5:** Lives in another town with mom and sister  
Difficult relationship with mom, who is very religious  
Came to help mom with sick dad 3 years ago  
Living there can be difficult—can't be open  
Not eligible for assistance  
Laid off but not eligible for unemployment
- Male 6:** Full blown AIDS since 1983 though he had 2 stable situations  
Landlords “lunatic” and housing fell through  
CM found him an apartment  
Gets SSDI—pretty good  
Gets pneumonia regularly so can't work; doesn't want to lose benefits  
Stable now with rental assistance  
One wish: government break on rent  
Likes central location  
Hard to find a place that takes pets  
Dog is your best friend, “No way I am moving into a place without him.”  
Doctor qualified as assistance animal
- Female 1:** Lives with husband and teenage sons  
Full blown AIDS  
SSD goes entirely to rent every month  
Needs utility assistance
- Male 8:** Now in nice apartment, previously trailer in drug neighborhood  
He and wife bought house in another town, been there 8 years  
Has been shot and harassed there  
Probably 15 people in this town with HIV/AIDS; doesn't want to leave because it will affect everybody  
Gets \$650 and pays \$550 in housing costs  
Wife works, they get regular utility assistance  
Many expenses, barely cover rent  
Food is the first thing to go—St. Vincent de Paul, food stamps  
Also bipolar  
Communities vary quite a bit in attitude

#### **Why are you in Roseburg?**

- Support I get from the HIV Resource Center, I was through here before and liked it, but the love people at the center have for me is it
- VA center and HIV Resource Center, both important resources (1 person receiving VA services)
- Like the area—the city has more resources but it's crazy.
- I have always liked Southern Oregon.

- Why go anywhere else after 9 years?
- “I feel like I am part of this community, easy to get that sense of ‘I live here and I am part of this community.’”
- Another reason to live here is that the rent is cheap. About 3 people paying a comfortable proportion of income to rent.

**Have you ever been homeless?**

10 of 12 had been homeless

**Where do you get medical care?**

2 people get care outside of the county. One woman is suppose to, but she isn’t going. Doctors in Roseburg are close together.

**Douglas County is geographically large, how do you manage that?**

- HIV specialists: none here, only in Eugene and Portland
- Dental care on OHP: hard to get appointments
- OHP: everything has to be pre-approved
- SSI difficult to deal with, hard to get copies of own medical records

**Transportation**

- Get help from the HIV Resource Center, to medical appointments and grocery store
- For HIV Resource Center: 100 miles round trip to give someone in Glendale a ride
- Hard to find out information about services available
- Health Department has disability services van
- HIV Resource Center is critical to working people with other resources.
- A multi-service center would be a good idea.

**In the future, ideal housing/housing services**

- Vouchers, more choices
- Too many rules in veterans’ housing, not desirable. Like more independence.
- Pets would be allowed.
- Nice, clean, functional unit (e.g., 2 days with a broken toilet)
- Safe
- Centrally located (access to store)
- Women with kids: sometimes kids don’t know about HIV, so wouldn’t want housing that requires identifying as HIV-positive. Important to keep family safe and together

**What is important to know about living with HIV/AIDS in Roseburg?**

- Single disabled woman: HUD waiting list is a joke for families. (too long)
- Unemployment rate is high, lots of people in need
- “It is very redneck oriented” “County is backward”
- HIV and gay are always identified together
- Wants badly to go back to work but can’t because of health. As a result, people see him as a loser or free loader, which makes him uncomfortable/frustrated. “If anyone thinks this is a fun way to live, collecting your check and trying to make ends meet, they have got another think coming.”

- “A lot of things I’d like to do with my life, but I just don’t have the money.”
- “Working at all means losing your check.”
- Cannot afford to earn so much that would lose eligibility for OHP
- Working in sales with fluctuating income means changing eligibility, going on and off benefits.
- “It’s just like wading through a bucket of crap.”
- Question of changing T-cell count and SSI eligibility
- “There is AIDS outside the Portland EMA—don’t forget us”
- HIV Resource Center goes toward supporting people directly.

### **Bend, Oregon: July 22, 2000**

5 participants

**Male 1:** Need sewer and water  
Got help from COCAAN with weatherization: doors windows, sunlight, utilities  
Costs more than house is worth  
“Our housing is great except there is no sewer or water.”

**Male 2:** Has 7 cats; hard to find landlord that will take 7 cats  
Finding something affordable  
Cleans bathrooms at trailer court, gets paid under the table to pay rent  
First and last months, and deposit is a big barrier to housing

**Male 3:** Good housing situation  
Moved from Seattle with relative, and lives with her now

**Male 4:** BendAid at COCAAN pays first and last months rent just for HUD Housing  
On waiting list for BendAid

**Male 5:** Living in motel since November  
Costs about ½ of disability payment, which works out OK  
Has no transportation expenses because of convenient central location  
Doesn’t need more space  
Has family that wants to help, does help with emergencies, extra expenses

#### **General discussion of lengthy HUD waiting list.**

**Male 1 and Male 2:** In housing for more than 10 years, very established there, owners protective of them

**Male 3:** In place with relative more than 5 years

#### **Have utilities prices gone up?**

- \$120-130/month, propane heat. Approx. 30% more than last year
- Would like larger tank, but too expensive to upgrade
- Hotel not upgrading as previously planned, mainly due to increased utility costs

**Male 2:** Did guide to resources, few options open  
Would turn to friends if needed help

### **Transportation**

- Keep car running – Males 1, 2, and 3 have cars
- Dial-a-Ride, used since November. 50 cents each way. Today was the first time they were late.
- Insurance is a concern because of cost.
- Just getting services in Bend and don't travel
- San Francisco – has flown down and driven twice to specialist for special health issue.

### **Housing**

- In Oregon you have to grow your own medical marijuana, which can be a housing issue.
- Been here long time, Central Oregon has everything you need.
- One participant came from LA because he had family here.

### **Difficult to use Section 8 Vouchers**

- While you are looking, you need to live somewhere—maybe 10 or more months to wait
- Tighter screening requirements: Criminal history, 3 references, credit check, \$25-50 application fee, even \$200 non-refundable application fee. Have to do for all apartments, even with Section 8.
- How do you get around to look for housing with out transportation?
- HUD does inspections

Growth: rents going up. More apartments here now, more people live in Redmond. People who are working in services need housing, too. Just getting a list of apartments that might be available isn't that helpful. So much demand for housing that it is often full, or landlords won't rent to you.

### **What kinds of housing assistance do you think would help people living with HIV/AIDS in Bend?**

- Someone to help find housing for use with HUD voucher
- Transportation to view housing
- Active, accurate lists of available housing
- Utilities assistance, concern that they will double next year. Assistance is now available only once a year.
- Connection with friendly landlords and/or a list of the bad landlords
- Homeless services/shelters. Salvation Army closes in the winter

### **Other Issues**

- Importance of neighbors/owners, managers
- Felony background or even driving record can be a barrier
- Maintaining quality for HUD
- Disability utility would be helpful special rate

**Coos Bay, Oregon, August 7, 2001**

2 participants

- Participant 1:** Was living in Portland, had low-income housing through HUD. Hospitalized in Portland, but needed to be discharged to someone, so moved to Coos Bay to live with family. Upset that HUD did visits twice a year to check on unit. Lots of HIV-positive people on the streets.
- Participant 2:** No housing problems. But it is very important. How can people be expected to get proper nutrition, go the doctor? “If I didn’t have a (spouse) who works I’d have trouble.” People on disability need to spend all their income to get housing, pay utilities, etc. Originally people feel real good about getting help, but after months of getting food, gas, utility vouchers it impacts them negatively emotionally. Emergencies come up and if you make too much to qualify for help, those emergencies can be problematic. Can become a real strain on relationships. Average “Joe” living with HIV needs that stable base—but can’t possibly afford that stable base if you are living on disability and paying unsubsidized rent.
- Participant 1:** After doing all the running around to get paper work complete you get so tired. A lot of people interrogate you.
- Participant 2:** Sometimes people step up to help. One woman took care of the paper work for me; I couldn’t have done it. Big difference between a “gatekeeper” and other workers who are just easier.
- Participant 1:** Needed to use agency and family support to pay deposits, first and last months rent, etc. It costs money now even to fill out an application.
- Participant 2:** People need a house no doubt. When you hear from people about their experience, it gives you a perspective. People in transition from jail, substance use treatment, etc.
- Participant 1:** It is important to have housing; it builds your self-esteem. A lot of people coming off the street with HIV/AIDS and have histories that get in the way of getting housing. Need clothing and food resources. Good case management is really good. Buddy programs are important. Transportation is a real bitch sometimes.
- Participant 2:** People who have car repair problems have to supplement with food, gas, power, rent assistance, rather than just getting the direct assistance with the car repair. Very limited public transportation available in the city/county, doesn’t go everywhere and is infrequent. The rural transportation gap is certainly there, but strategies always seem to fall short. Cabs are pretty affordable here, you can get anywhere for \$5. Companionship is the thing. If you’re not doing well, it is hard to do anything by yourself: food shopping, medical care, etc. People need buddies. Local nutrition group is pretty cool, variety of people, 4 to 12 at a time, educational, people cook and clean up together.

**Note: Malheur County interviews were conducted with one man and one woman. For reasons of confidentiality, interviews are not transcribed here.**