

We listened...2005

2005 Survey for People Living with HIV and AIDS in Oregon

Executive Summary
June 2006

Prepared by:

Kathy Pickle, MPH

Susan Van't Hof, MPH, MIA

Ronda Bard, PhD

Dena Wilson

Doris Cordova



Program Design and Evaluation Services
Oregon Department of Human Services
800 NE Oregon Street, Suite 550
Portland, OR 97232
971-673-0589

Full report will be available July 2006 on the web at
<http://www.oregon.gov/DHS/ph/hiv/services/needs/reports.shtml>

EXECUTIVE SUMMARY

Background

The Oregon HIV Care Services Program contracted with Program Design and Evaluation Services (PDES) to assess the needs of PLWH/A in Oregon and evaluate how well the current HIV care system is addressing their needs. For 2005, PDES designed a short version of the 2002 needs assessment survey to answer the following questions:

- What are the key service needs, gaps, and barriers to care for PLWH/A served by Oregon's Ryan White CARE Act programs?
- What do health care access and unmet need for regular medical care indicators look like for this group of PLWH/A?
- What do housing adequacy and stability indicators look like for this group of PLWH/A?
- How do these service needs and gaps, healthcare use and housing indicators vary by geography, race/ethnicity, gender, age, and diagnosis-related characteristics?

Methods

PDES developed a survey based on the 2002 "We're Listening" Needs Assessment survey, asking about demographic characteristics; service needs, gaps, and barriers; health care access; and housing-related issues. Eight of the 12 services included ones for which 40% or more of the 2002 survey participants had reported a need. The 2005 survey also included questions about potentially emerging needs and selected services prioritized by HRSA or Oregon's planning groups, such as help in purchasing Over-the-Counter Medicines, Substance Abuse Treatment, and Acupuncture or Naturopathic Treatment. The survey was administered in English and Spanish.

The sample was taken from all PLWH/A receiving case management services through Oregon's Ryan White Title I and Title II programs as of Fall 2005. Ryan White services are administered through the Title I HIV Client Services Program in the Portland Eligible Metropolitan Area (EMA), which includes Clackamas, Columbia, Multnomah, Washington and Yamhill Counties in Oregon and Clark County in Washington. The Title II HIV Client Services Program administers services in the Balance of State, or the 31 other counties in Oregon. To ensure that we collected an adequate amount of information from three sub-populations with smaller numbers of people (women, people of color, and rural PLWH/A), we asked every person in these populations to complete the survey. However, it was possible to ask fewer White non-Hispanic men in the EMA to complete the survey. For the largest provider of case management in the EMA, therefore, only one-in-every three White non-Hispanic males were included in the sample.

Surveys were distributed to clients through their Ryan White case managers. Clients returned the survey in a confidential self-addressed, stamped envelope to PDES or their case manager, who in turn mailed it to PDES. A \$2 thank-you was included with the survey.

Survey distribution began in mid-October 2005 and continued through mid-February 2006. A total of 1,164 surveys were sent to PLWH/A who received Ryan White case management services – 525 were distributed in the EMA and 639 in the Balance of State. Forty-three of those sent were determined "undeliverable". PDES received a total of 644 surveys back, for an overall

response rate of 57%. The Balance of State returned 377 surveys (61% response rate), and 269 were received from EMA clients (53% response rate).

The data were weighted to make up for discrepancies between the group who responded to the survey and the target group (i.e., people living with HIV/AIDS who were receiving Oregon Ryan White Title I or Title II case management services). The primary subgroup difference of interest was region (EMA versus Balance of State). For key service outcomes, five additional characteristics were examined: age, gender, race/ethnicity, months since initial HIV diagnosis, and AIDS diagnosis.

Key Results

Results of this study suggest that Oregon's Ryan White Care Act system is doing well in ensuring health care and key support services for many people living with HIV/AIDS (PLWH/A) in Oregon and in Clark County, Washington, particularly in regards to assistance in getting HIV medications, health insurance, regular medical visits and lab tests, dental care and housing. However, substantial numbers of PLWH/A experienced difficulties in getting critical support services, and some PLWH/A may be experiencing disruptions in getting the HIV care they need to stay healthy.

Clients were asked about health care access, housing stability and adequacy, and service needs, gaps and barriers. For twelve specific services, clients were asked if they needed the service in the past 12 months, and whether they always received the service when they needed it. Findings indicate some gaps in both Core and Support Services, some of which had increased since the 2002 survey.

For two Core Services, Dental Care and Mental Health Counseling, roughly half of those who needed them continued to have gaps and barriers to care. A significant proportion of clients also lacked help in meeting basic needs. The gap remained high for Emergency Assistance with Rent or Utilities, Assistance with Groceries or Meals, Transportation, and Ongoing Help with Housing. The gap for Outpatient Medical Care (i.e., visits with medical care professionals) was smaller but appeared to have increased since 2002, as had gaps in Mental Health Counseling, Substance Abuse Treatment, Emergency Assistance with Rent or Utilities, and Assistance with Groceries or Meals. Although the proportion of clients who identified the need for Outpatient and Residential Substance Abuse Treatment remained relatively small, gaps for these services appeared to have doubled between 2002 and 2005.

- **Healthcare System:** Clients generally reported good access to medical care and HIV medications, but most were heavily dependent on public systems (Oregon Health Plan, Medicare, and Oregon's Medical Insurance Pool), and one in four (25%) had experienced a gap in health coverage in the past 12 months.

The proportion of clients that reported receiving help from CAREAssist increased from 43% in 2002 to 68% in 2005. In addition, the percentage of those who knew whether or not they received help from this program appears to have increased.

Almost all participants (97%) reported having had at least one CD4 or viral load lab test in the past 12 months. However, African Americans were more likely than White non-Hispanics to report no lab tests in the past year, and those with no lab tests were also likely to be more recently diagnosed with HIV.

- **Housing Issues:** Housing-related help continued to be a priority need for PLWH/A, with roughly two in five clients identifying a need for Ongoing Housing Help and two in five reporting a need for Emergency Assistance with Rent or Utilities. A significant proportion of clients (26%) reported having been in unstable housing situations in the past year, and one in seven (15%) had been homeless at some point in the past 2 years. However, the gap in getting Ongoing Help with Housing appears to have decreased since the 2002 survey (52% in 2002 vs. 38% in 2005).
- **Service Needs and Gaps:** Clients were asked if they *needed* 12 specific services in the past 12 months, and whether they always received the services when they needed them. “*Service gaps*” were defined by clients who reported needing a service but reported receiving it only “some” or “none” of the time.

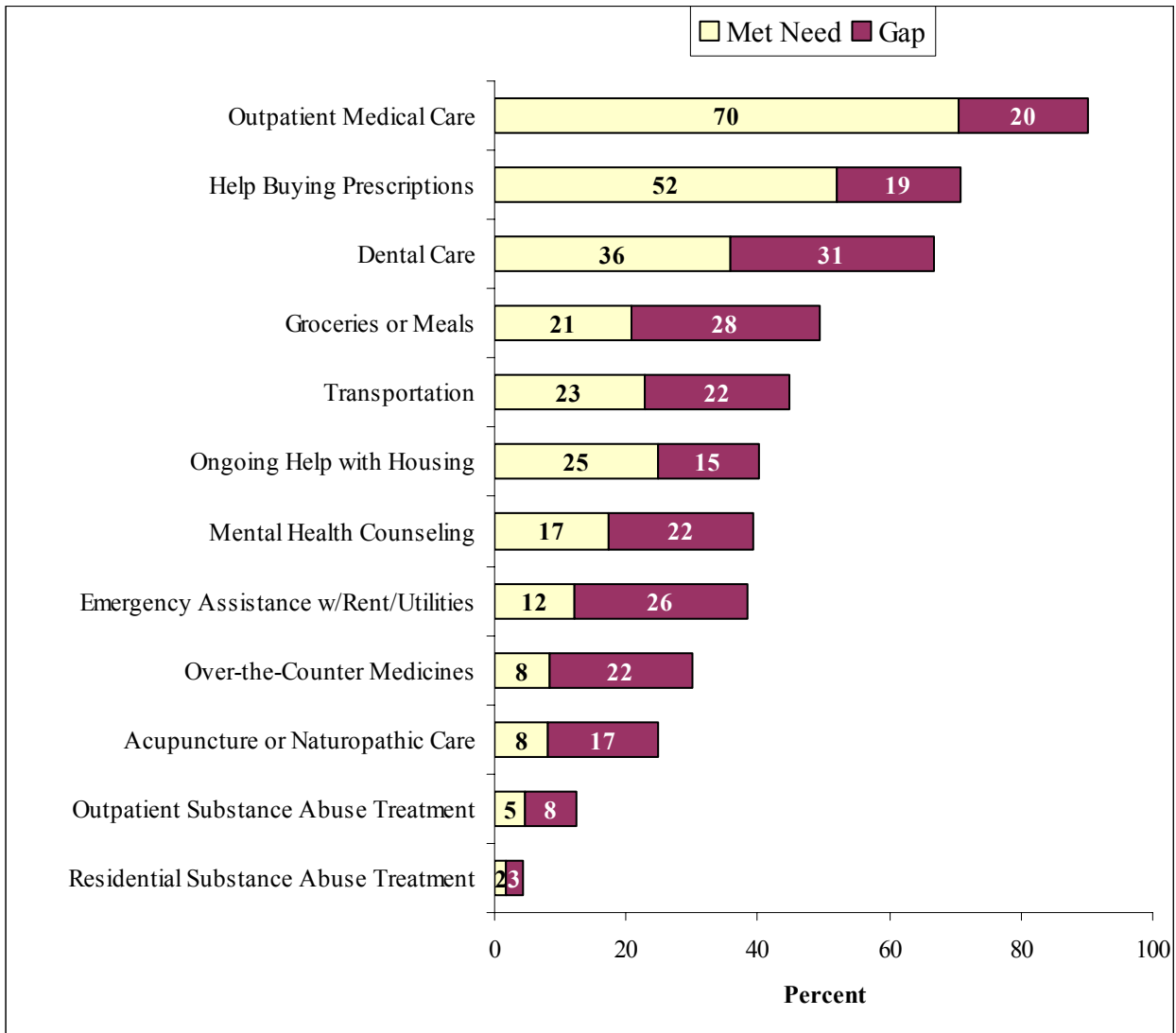
The five services with the highest reported need:

- o Outpatient Medical Care (90%)
- o Help Buying Prescriptions (71%)
- o Dental Care (67%)
- o Groceries or Meals (49%)
- o Transportation (to and from appointments) (45%)

The five most *needed* services included three of the Core Services identified by both HRSA and the Oregon HIV Care Coalition (OHCC)—Outpatient Medical Care, Help Buying Prescriptions, and Dental Care. (Other Core Services include health insurance and case management.) The fact that almost half of the Ryan White clients reported needing Transportation to and from appointments and Assistance with Groceries or Meals indicates a continuing challenge to provide some assistance with basic needs.

The Figure below shows those who reported need, broken out into two groups: 1) those who needed the service and reported no trouble receiving it (met need), and 2) those who needed the service and reported receiving it “some” or “none” of the time (gap). The darker portion at the right of each bar represents the percentage of all clients who needed the service, but reported a service gap.

Percent of Total Clients with Met Need and Service Gap



Note that percentages in this figure do not always add up to the total percentages for total need, because of rounding.

In the Table below, *gaps* are presented by “population perspective”—showing those with a gap as a proportion of all PLWH/A receiving Ryan White case management services in Oregon and Clark County, and by “service perspective”—showing those with a gap as a proportion of those who reported needing the service. The population perspective looks at gaps in relation to how many in the total population are affected. The service perspective indicates the relative difficulty in receiving a service among those who need it.

Service Gap Impact—Population Perspective and Service Perspective

Service Category	Service Gap from the Population Perspective <i>(percent of those in target population who faced a gap)</i>	Service Gap from the Service Perspective <i>(percent of those needing service who faced a gap)</i>
Dental Care	31%	46%
Groceries or Meals	28%	58%
Emergency Rent/Utilities Paid	26%	68%
Transportation	22%	49%
Mental Health Counseling	22%	56%
Over-the-counter Medicines	22%	72%
Medical Outpatient Care	20%	22%
Help buying Prescription Medications	19%	26%
Acupuncture or Naturopathic Care	17%	67%
On-going Help With Housing	15%	38%
Outpatient Substance Abuse Treatment	8%	62%
Residential Substance Abuse Treatment	3%	59%

- **Differences in Service Needs and Gaps between EMA and the Balance of State:**

While PLWH/A in the EMA reported a higher need for some services, they did not have higher gaps. Compared to those in the Balance of State, those living in the Eligible Metropolitan Area (EMA) reported a higher ***need*** for:

- o Outpatient Medical Care (94% in EMA vs. 86% in Balance of State),
- o Mental Health Counseling (44% vs. 33%)
- o Outpatient Substance Abuse Treatment (16% vs. 9%)

While PLWH/A in the Balance of State did not report a higher need for any services, they did have higher gaps for some services. Compared to those in the EMA, those living in the Balance of State reported a higher ***gap*** for:

- o Outpatient Medical Care (28% in Balance of State vs. 18% in EMA)
- o Help Buying Prescriptions (33% vs. 21%)

- **Barriers to Getting Needed Services:** Six *barriers* to accessing services were most frequently mentioned by respondents and these barriers impacted multiple service categories. These *barriers* included:
 - o Cost of service or other personal finance-related issues.
 - o Limited or no service availability.
 - o Lack of insurance or inadequate insurance.
 - o Transportation problems or the service is located too far away.
 - o Lack of knowledge about resources or the system of care.
 - o Cuts in funding or lack of public funding for the service.

- **Changes in Service Needs and Gaps since 2002**
 Among the services asked about in both 2002 and 2005, there appeared to be a change in reported *need* for four categories. Reported need for Dental Care, Emergency Assistance with Rent or Utilities, Mental Health Counseling and Ongoing Help with Housing appeared to have declined since the 2002 survey. Need for Outpatient Medical Care, Help Buying Prescriptions, Assistance with Groceries or Meals, Transportation, and both Outpatient and Residential Substance Abuse Treatment appeared to have stayed at roughly the same levels.

Although reported need for most services either stayed about the same or decreased somewhat, *gaps* in receiving most services either stayed level or increased. Among services asked about in both 2002 and 2005, the gap appeared to have increased for Outpatient Medical Care, Emergency Assistance with Rent or Utilities, Mental Health Counseling, and both Outpatient and Residential Substance Abuse Treatment. The notable exception is Ongoing Help with Housing, for which the gap decreased (52% in 2002 vs. 38% in 2005).

Limitations

It is important to keep in mind the following limitations:

- As is common in survey research, the data were self-reported and there was no ability to confirm the information reported.
- The sampling frame was PLWH/A *who had a Ryan White case manager at the time of data collection*. The findings are generalizable to PLWH/A in Ryan White case management, but not to the entire PLWH/A population of Oregon and Clark County.
- Because this survey was primarily mailed, case management clients who were homeless and those who asked that case managers not send them mail were less likely to receive the survey.
- The response rate was 57% and was somewhat lower for the EMA (53%) compared to the Balance of State (61%). Although it is not feasible to have a 100% response rate for a community survey, it is important to note that the survey sample represents the target population to the extent that the non-respondents would have reported similar information as the respondents. Since this is unknown, the information should be interpreted somewhat cautiously, and all efforts should be made to improve response rates in the future, particularly with respondents from the EMA.

Next Steps

Future needs assessments must expand the sampling frame to better represent all PLWH/A in Oregon, not just those in the Ryan White case management system. Future assessments should also employ methods that improve our ability to measure trends over time so that we can see how changes in external and internal systems may be influencing the needs of PLWH/A. One possibility to get stronger, more generalizable data is to recruit a cohort of PLWH/A (i.e., a group of PLWH/A who agree to be surveyed repeatedly over time) using a random sampling method. This would allow the programs to more accurately monitor trends and changes in PLWH/A needs over time, and might allow them to respond more effectively to changes and challenges.

Such steps are critical in assuring that PLWH/A in Oregon are able to access the services they need, are receiving high-quality care, and are leading satisfying and healthy lives.