

# Oregon Statewide Coordinated Statement of Need, 2012

January 2012



## Introduction:

### ► Why Create a Statewide Coordinated Statement of Need (SCSN)?

Language in Section 2617 (b) (6) of the Ryan White HIV/AIDS Treatment Modernization Act of 2006 (Ryan White HIV/AIDS Program) requires grantees to develop a Statewide Coordinated Statement of Need (SCSN). The SCSN planning process provides a collaborative mechanism to identify and address significant care and treatment issues related to the needs of people living with HIV and AIDS (PLWH/A), and to maximize coordination, integration, and effective linkages across all Ryan White Program Parts.

### ► What is in the Statewide Coordinated Statement of Need (SCSN)?

Oregon's 2012 Statement of Need is organized into the following sections:

- *Developing Oregon's Statewide Coordinated Statement of Need*—a description of participants and the collaborative process we used;
- *Overview of HIV/AIDS in Oregon*—a description of the latest trends in HIV epidemiology statewide and a discussion of emerging service populations and populations with special needs;
- *Unmet Need in Oregon*—an estimation of the number of PLWH/A in Oregon who are aware of their infection, but not receiving medical care, and information about people who receive their HIV diagnosis late in the course of their disease;
- *Oregon's HIV Continuum of Care*—a description of services currently provided to PLWH/A statewide, as well as a discussion of service needs and gaps identified by PLWH/A and providers through client interviews, regional Listening Sessions and other data collection efforts;
- *Needs of Special Populations*—a description of the needs of special populations, including but not limited to adolescents, people who inject drugs, homeless individuals, and transgender individuals.
- *Cross-Cutting Service Goals and Issues*—important service issues identified by the SCSN Advisory Group and our shared goals related to those issues;
- *Appendices*—the appendices include additional data, such as a full list of SCSN Advisory Group members, SCSN timeline and tasks, a list of data sources used to create this document, and data from regional Listening Sessions (including number and type of participants; identified themes).

## **Developing Oregon’s Statewide Coordinated Statement of Need:**

### **► Who Participated and What Planning Process was Used?**

The Oregon HIV Care and Treatment Program (the Part B grantee; part of Oregon Health Authority) was responsible for convening partners across the Ryan White continuum of care, facilitating the development/update of the SCSN, and submitting the SCSN to the Health Resources and Services Administration (HRSA). The SCSN Advisory Group included people living with HIV and AIDS (PLWH/A) and representatives from public agencies, federally-recognized Indian tribes, and all Ryan White grantees. A full list of Advisory Group members is available in Appendix A.

The Part B grantee designated Program Design & Evaluation Services (PDES), a public health research and evaluation group affiliated with both the Oregon Health Authority and the Multnomah County Health Department, to facilitate the process.

The planning process took place between May and December of 2011. Stakeholder input was gathered in three key ways:

- In-person feedback at two full-day Oregon HIV Care Coalition (OHCC) meetings, in May and November 2011. OHCC is a statewide body comprised of service providers, consumers, and other stakeholders;
- In-person feedback from HIV+ consumers at Listening Sessions in Eugene and Medford, and through phone interviews with consumers from frontier and rural counties in Eastern Oregon and the Oregon Coast. Data from six community forums conducted with consumers in the Portland metropolitan area during April and May 2011 were also included;
- E-mail feedback, from August – December 2011, from the SCSN Advisory Group, an ad-hoc body that included PLWH/A and representatives from public agencies, federally-recognized Indian tribes, and all Ryan White grantees.

A full timeline showing key deadlines, tasks, and responsible parties is provided in Appendix B.

## Overview of HIV/AIDS in Oregon:

Understanding the epidemiology of HIV/AIDS in Oregon is a key component of health services planning. Data presented in this “Overview” section are drawn from the 2009 Epidemiological Profile.

### ***HIV/AIDS Prevalence in Oregon***

#### ► **How Many People are Infected with HIV in Oregon?**

From 1981 through 2009, 8,467 Oregonians were diagnosed and reported with HIV infection, and 41 percent (n=3,466) had died. Since 1997, approximately 275 new diagnoses have been reported each year in Oregon, and an average of 85 Oregonians with HIV died each year. The number of Oregon cases living with HIV increased each year, from 2,717 in 1997 to 5,001 in 2009.

The actual number of people living with HIV infection in Oregon is about 21% higher because many people who already have HIV infection have yet to be tested and do not yet know they are infected (MMWR 2008). Furthermore, an additional, unknown number of people with HIV who were diagnosed elsewhere and moved to Oregon after diagnosis may also require HIV-related services in Oregon, but would not be reflected in the official surveillance used in this section.

#### ► **What are the Characteristics of People Living with HIV in Oregon?**

Of the 5,001 living cases reported at the end of 2009, 87% were men and 49% were aged 35-49 years. Among men living with HIV disease, 71% reported their transmission risk as sex with men (MSM), 9% as MSM with injection drug use (MSM/IDU), and 8% as IDU alone. Among women, high-risk heterosexual contact accounted for 60% of prevalent cases, and 24% of women reported IDU transmission risk.

#### ► **How are HIV Cases Distributed in Oregon?**

Service delivery in Oregon is divided geographically into the Portland Transitional Grant Area (TGA), which includes five counties in and around the Portland metropolitan area (Clackamas, Columbia, Multnomah, Washington and Yamhill)<sup>i</sup>, and the Balance of State, which includes the remaining 31 Oregon counties stretching to the Washington, California, Idaho, and Nevada borders. Key facts about the distribution of PLWH/A in Oregon<sup>ii</sup> include:

- Most PLWH/A (73%) lived in the Portland TGA at time of initial diagnosis.

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<sup>i</sup> The TGA includes a sixth county: Clark County in Vancouver, Washington. Information on Clark County cases is not included in the Oregon SCSN.

<sup>ii</sup> These data reflect county of residence at time of diagnosis. Because people are mobile, and diagnosis may have occurred many years ago, these data should be considered along with other more current data sources when assessing geographic distribution.

- Fifty-six percent of cases lived in one county: Multnomah. Multnomah County is over-represented in the epidemic, as only 1 in 5 Oregonians live in Multnomah County compared to almost 3 in 5 PLWH/A who lived there at diagnosis.
- Balance of State counties with 50 or more PLWH/A include the following seven counties: Deschutes, Douglas, Jackson, Josephine, Lane, Linn, and Marion. Clackamas and Washington Counties (in the TGA) also counted more than 50 cases.
- Although Oregon is a large, primarily rural state, approximately 90% of PLWH/A receiving Ryan White CARE Act (RWCA)-funded services lived within 25 miles of Interstate 5 at time of diagnosis.

## ***Recent Diagnoses (2005-2009)***

### **► What are the Characteristics of Recent Infections in Oregon?**

Data from cases diagnosed within the most recent five years for which data are available (2005-2009) provide a window into the current state of HIV in Oregon. Key facts about recent diagnoses in Oregon:

- Diagnosis rates were 6 times higher among males than females (13 vs. 2/100,000) during this five-year period.
- Diagnosis rates increased among people aged 20-29 during this period, although the average age at diagnosis was 37 years.
- New diagnosis rates were 3.5 times higher among blacks and African Americans and 1.2 times higher for Hispanics than for non-Hispanic whites.
- 51% of people with newly diagnosed HIV were Multnomah County residents.
- MSM transmission continues to be the leading risk reported in Oregon, accounting for 61% of all new cases diagnosed between 2005 and 2009 and 69% of new cases among men.
- 75% of diagnoses among women during this time period were due to sex with men.

## ***Late Diagnosis***

### **► How Many People are Diagnosed Late and Who are They?**

Many Oregonians continue to be diagnosed with HIV infection at a late stage of disease. Approximately 40% of the 1,380 cases diagnosed during 2004-2008 either had AIDS at the time of their initial HIV diagnosis or they progressed to AIDS within 12 months of initial HIV diagnosis. Late diagnosis was more common among some groups, including:

- Hispanics (compared to non-Hispanic whites)
- Men with injection drug use or unknown HIV risk (compared to MSM)

- Rural residents (compared to urban)
- Older patients—people over age 40, with relative risk of late diagnosis highest among those age 60+ (compared to people < age 40)

## **Comorbidities**

Sexually transmitted diseases (STDs) are indicators of ongoing sexual behavior that could transmit HIV, and having a concurrent STD may increase the likelihood that a PLWH/A could transmit HIV to uninfected partners.

### **► How Many PLWH/A are Diagnosed with Syphilis, Gonorrhea, and/or Chlamydia?**

Rates of early syphilis, gonorrhea, and chlamydia are much higher among Oregon men with previously reported HIV infection than among the general population of Oregon. For example, average annual rates during 2005-2009 were:

- 116 times higher for **early syphilis** (233/100,000)
- 450 times higher for **gonorrhea** (1,351/100,000)
- 3 times higher for **chlamydia** (902/100,000)

### **► How Many PLWH/A are Co-Infected with Hepatitis?**

Co-infection with hepatitis B (HBV) and/or hepatitis C (HCV) is of concern for health services planning, but hepatitis C did not become reportable in Oregon until 2005, so data are limited and should be considered a minimum estimate. Some key facts about HIV and hepatitis co-infection:

- From 2005-2009, at least 5% of deaths among PLWH/A in Oregon were liver-related, most from chronic hepatitis C.
- Prevalence estimates of HCV/HIV coinfection vary, depending on the data source; they range from 7% (Epi Profile, 2011) to 11% (CAREAssist 2009) to 21% (MMP, 2011).
- 5% of PLWH/A in Oregon are estimated to have HIV/HBV co-infection.

### **► How Many PLWH/A are Co-Infected with Tuberculosis?**

Oregon has never observed a substantial number of TB/HIV co-infections. Of 888 TB cases in Oregon since 2001, only 44 (5%) were known to also have HIV.

## **HIV Mortality**

The advent of antiretroviral medications in the mid-1990s dramatically improved treatment outcomes among PLWH/A. In Oregon, five-year survival rates increased from about 40% of people diagnosed in 1990 to about 90% of those diagnosed in 2004.

### **► Do Some People Living with HIV Die Faster than Others?**

After adjusting for age, there were no differences in case fatality rates for PLWH/A diagnosed with HIV in Oregon from 1998-2009 by sex, race/ethnicity, region, or transmission category. Average survival time decreased with age at diagnosis. Differences by age at diagnosis probably reflect differences in duration of infection;

that is, those who are older are likely to have been infected longer. However, it is possible that differences in survival may be related to a decreasing capacity to combat HIV disease as people age.

## Unmet Need for Medical Care in Oregon:

HRSA requires Ryan White grantees to estimate annually the number of PLWH/A who are aware of their HIV infection, but not receiving medical care.

People who are receiving regular, high-quality medical care for HIV/AIDS typically visit their doctors at least three times a year and submit blood specimens for testing the quantity of HIV virus circulating in their blood (“viral load test”) and immune function (typically a “CD4 test”). Laboratory results for CD4 and viral loads are used as a proxy for medical care for the purpose of calculating estimates of PLWH/A who are in medical care and who might have an unmet need for primary medical care.

### ► How Many PLWH/A Have an Unmet Need for Primary Medical Care?

During calendar year 2009, 81% of people living with HIV, not AIDS (PLWH) and 72% of people living with AIDS (PLWA) had at least one CD4 or viral load test reported to the Oregon HIV Surveillance Program.

Overall, 25% of PLWH/A did not have any reported CD4 or viral load tests during 2009, suggesting that up to 1 in 4 PLWH/A are not receiving regular medical care (Table 2).

**Table 2: Oregon Estimate of Unmet Need, 2009**

<b>Population Sizes</b>	<b>Value</b>	<b>Percent</b>	<b>Data Source</b>
A. PLWA aware of infection, 1/1/09-12/31/09	3,280	65%	eHARS (%= A/A+B)
B. PLWH aware of infection, 1/1/09-12/31/09	1,781	35%	eHARS (%= B/A+B)
<b>Care Patterns—Met Need</b>	<b>Value</b>	<b>Percent</b>	<b>Data Source</b>
C. PLWA who received CD4 or VL testing in 2009	2,365	72%	eHARS and Orpheus (%= C/A)
D. PLWH who received CD4 or VL testing in 2009	1,434	81%	eHARS and Orpheus (%= D/A)
<b>Calculated Results—Unmet Need</b>	<b>Value</b>	<b>Percent</b>	<b>Data Source</b>
E. PLWA who did NOT receive CD4 or VL testing in 2009	915	28%	A-C (%=E/A)
F. PLWH who did NOT receive CD4 or VL testing in 2009	347	19%	B-D (%=F/B)
G. PLWH/A who did NOT receive CD4 or VL testing in 2009	1,262	25%	E+F (%=G/(A+B))

### ► What are the Characteristics of PLWH/A with Unmet Need for Medical Care?

Some people were more likely to have an unmet need for primary medical care:

- People with AIDS were 1.6 times more likely to have unmet need compared to people with HIV (28% PLWA vs. 19% PLWH)
- Hispanics (36%), Native Americans (36%) and Blacks or African Americans (33%) were more likely to have unmet need than whites (23%)

- Males with IDU risk (37%) or MSM/IDU risk (38%) had more unmet need than MSM (23%); female IDUs (27%) had more unmet need than females with heterosexual transmission risk (19%)
- Rural cases (33%) had more unmet need than urban cases (24%)
- Foreign-born cases (31%) had more unmet need than US-born cases (24%)

► **Why are PLWH/A in Oregon Out of Care?**

Qualitative data from interviews and group sessions conducted in 2011 indicate that many current Ryan White clients in the Part B area of Oregon were not receiving HIV medical care at some point in their infection, despite knowing their status. Overall, clients reported that their reasons for being out of care were mostly personal, rather than system-related. The main reasons clients cited for being out of care—some for periods of 1 to 15 years post-diagnosis—included denial and depression, side effects of HIV medications or fear of starting medications, and alcohol and drug abuse. A few clients mentioned that issues with their doctor caused them to fall out of care.

The two leading reasons clients gave for entering HIV medical care (or re-entering it after falling out of care for a while) were 1) being forced into care because of illness and 2) being connected through the efforts of a family member, friend, or another individual who reached out.

Based on these data from PLWH/A, we believe some of the needs of people aware of their HIV+ status but not in HIV medical care include mental health services, alcohol and drug treatment services, better education regarding HIV medicines and treatment, and social support/early intervention services that can provide a smoother transition between testing and entry into care.

► **What are the Needs of People Infected But Unaware of their Status?**

It is difficult to identify people who are HIV infected but unaware of their status and comprehensively describe their needs. One assessment that provides insight into the needs of this population in Oregon involved newly reported HIV cases who identified as Hispanic. We focused on this population because Hispanics are often diagnosed late, and may have specific cultural and linguistic needs in addition to those faced by all people who are infected but unaware of their status.

In March and April 2010, a bilingual, bicultural interviewer made follow-up telephone calls to 56 individuals who were reported with HIV between October 1, 2009 and March 31, 2010 and listed on the case report as Hispanic. Three individuals were determined to be ineligible because they told the interviewer they were not Hispanic. Of the remaining 53 potential respondents, the interviewer completed 23 interviews (43%), discovered 12 disconnected telephone numbers, and was unable to reach 18 potential interviewees after multiple attempts. There were no refusals. Most interviews (83%, n=19) were conducted in Spanish.

Most respondents did not report barriers to getting HIV tested or to accessing medical care once infected. At the time of interview, all respondents but one were receiving

HIV medical care, and the one who was not had been diagnosed less than one month and was in the process of getting enrolled.

However, many respondents reflected a social norm of not accessing medical care unless one is sick. About 4 in 10 said they did not receive health care prior to HIV diagnosis because they felt there was no need for it. Likewise, 43% of respondents got HIV tested only because they were ill, including seven who were tested at the hospital when their HIV infection was likely very advanced.

Social support around HIV appeared to be lacking among this group of interviewees. About half had disclosed their HIV status to at least one person and about half reported knowing someone else with HIV, but there was no correlation between status disclosure and knowing someone with HIV. Respondents commonly identified fear of rejection or HIV stigma as a barrier to status disclosure—and likely to HIV testing and status awareness. In addition, only one respondent reported participation in an HIV support or education group.

Similar to those who reported being out of care after knowing their status, our limited data indicate that the barriers to learning one's HIV status or entering care in Oregon are not classic systemic issues, such as lack of insurance, but rather interpersonal issues such as denial or social norms that discourage medical care unless sick.

## **Oregon's HIV Continuum of Care:**

The Ryan White HIV/AIDS Treatment Modernization Act of 2006 directs state and local grantees to spend at least 75% of grant funding on core medical services, defined by HRSA as: outpatient and ambulatory health services; health insurance premium assistance; pharmaceutical assistance; oral health care; substance abuse outpatient services; medical nutritional therapy; home health care, community-based health care, and hospice services; mental health services; early intervention services; and medical case management, including treatment adherence services. The remaining 25% of funding may be spent on a wide range of support services, defined as “services needed to achieve outcomes that affect the HIV-related clinical status of a person with HIV/AIDS.” Important supportive services provided in Oregon include non-medical case management, housing, medical transportation, psychosocial support, linguistics, and food and nutritional assistance.

The “HIV Continuum of Care” section details key core medical and supportive services provided across the HIV continuum of care in Oregon, and documents identified needs of PLWH/A related to the specific service area. Data in this section are drawn from a wide range of sources, listed in Appendix C. Two of the main data sources are the HIV Medical Monitoring Project and the 2009 CAREAssist client survey, both described in the text. A third data source is client feedback gathered in the 2011 listening sessions, community forums, and interviews as part of this SCSN process. A summary of those data are provided in Appendix D.

## ***Challenges in the HIV Service Environment***

The dire economy has dramatically impacted clients seeking HIV services in Oregon. Like others with limited resources, HIV clients are negatively affected by the rising costs of food, fuel, and housing. HIV service providers report increased anxiety among their patients; clients report difficulty competing for scarce resources within the larger service sector.

### **► How Great is the Demand for Services among Oregon's General Population?**

In 2010, 1 in 4 Oregon adults (n=754,845) received services from the Oregon Health Authority or Oregon Department of Human Services, including cash assistance (n=105,340, 3.6% of Oregon adults), medical assistance/health insurance (n=333,565, 11% of Oregon adults), and nutrition assistance through the Supplemental Nutrition Assistance Program (SNAP) (n=572,375, 19% of Oregon adults). Clearly, the demand for services has increased among all sectors of the population, not just people living with HIV. For example, 11% percent more households received SNAP benefits in July 2010 compared to July 2009.

### **► Challenges within the Public Health System**

The public health infrastructure is also severely challenged by the economic crisis. Local health departments and the State Oregon Health Authority and Department of Human Services are operating with huge deficits. Both have already experienced cuts in

services and/or personnel, and more are expected in the next biennium. Community-based agencies are reporting a decrease in private donations and grant dollars that decrease their ability to provide the same level of services that clients have received in past years. For various reasons, including lack of capacity, many local health departments in Oregon's Balance of State (BOS) have opted out of providing Ryan White Program-funded case management and supportive services over the years, transferring the authority and responsibility for providing these services to the Oregon Health Authority. This has created both challenges and opportunities for delivering high-quality services in a new regional model of HIV care coordination.

SCSN Advisory Group members identified coordination and collaboration among service providers and across HIV care and prevention as key challenges within the HIV service environment. Both clients and providers say that the delivery of HIV care separate from other chronic diseases hinders quality care by creating administrative burdens for staff and confusion for clients, and by introducing unnecessary complexities into the system of care with inefficient and potentially duplicative service delivery. There have already been changes in health insurance for Oregonians dependent on public systems, and this has disrupted continuity of care for many PLWH/A. As Oregon moves forward with health reform, more dramatic changes are anticipated, and will require a high level of coordination and integration across all service systems.

HIV clients in Oregon have always depended on a continuum of services that extend beyond Ryan White Program-funded services, and use the Ryan White Program as a payer of last resort. However, the options available to them beyond Ryan White funds are shrinking—and need for the services has grown dramatically among the general population in Oregon since the last SCSN was developed in 2008. For this reason, descriptions of services available in the HIV continuum of care are generally limited to RWCA or other specifically HIV-related services.

## ***Outpatient Medical Care in Oregon***

The full range of primary care services are provided to PLWH/A through a combination of public and private health systems and community-based agencies. Individuals with private or public insurance access primary care through their designated health care providers.

### **► How Many Medical Providers Manage HIV Medical Care in Oregon?**

As of April 2011, there were 70 medical providers working in 36 facilities across Oregon who actively manage HIV medical care for one or more PLWH/A. These providers include 65 MDs, two DOs, two nurse practitioners, and one physician assistant. About 6 in 10 providers (59%) are located in the Portland TGA, 22% are in the Part B service area served by HIV Alliance, and 19% are sited in the remainder of the Part B service area. This distribution is roughly similar to the distribution of PLWH/A in Oregon.

However, there are several geographic areas where PLWH/A might be underserved in regards to HIV care. There are few or no providers located in many rural communities in Eastern Oregon and along the North and South Coast areas, which means the small numbers of patients who live there must travel significant distances to access HIV medical care.

► **What are the Characteristics of Medical Facilities Providing HIV Care in Oregon?**

According to a 2007/2008 assessment of medical facilities in Oregon, most HIV facilities providing HIV medical care (69%) are private sector practices; the rest are a combination of public and community-based entities. About 1 in 3 facilities—particularly facilities serving higher numbers of PLWH/A—have some type of social support provider (e.g., health educator, social worker, case manager) co-located with their HIV medical care providers. In addition, about one-third of the facilities offer additional medical support services like treatment adherence help, risk reduction counseling, or an on-site pharmacy. Very few offer important ancillary services like dental health, mental health, or substance abuse care within the facility.

► **The Ryan White Parts C & D Clinic: Multnomah Co. HIV Health Services Center**

The HIV Health Services Center (HHSC) is the largest provider of HIV care in the state of Oregon, serving over 1,000 clients in 2010—an estimated 1 of 4 people living with HIV in the Portland metropolitan area. HHSC has been a Ryan White provider since 1990, and has long participated in HIV/QUAL data collection. The clinic has existing linkages and partnerships with many community-based agencies and is the only Parts C and D provider in Oregon. All clinical providers at HHSC have a minimum of ten years' experience, and support staff members have received specialized training in HIV services. Services provided include: primary medical care; medications adherence support; dental/oral health assessment and referral; nutritional assessments and counseling; substance abuse and mental health assessments and treatment, referral and counseling; case management; high resolution anoscopy and infrared coagulation treatment; peer mentoring; and hepatitis education. In addition, HHSC has been an AIDS Education & Training Center (AETC) clinical training site for a five-state region since 1999, providing preceptorships for physicians, nurses, and pharmacists.

HHSC provides medical care and support services within the context of a health department initiative called Building Better Care (BBC). The BBC model is designed to improve health outcomes through a proactive, patient-centered medical home model that is accessible and cost-effective. The model's foundation is team-based care and rigorous, continuous quality improvement.

HHSC currently has four care teams. Each team includes a medical provider, community health nurse, medical assistant, and a medical case manager. Provider teams are also supported by a pharmacist, a pharmacy tech, a part-time psychiatric nurse practitioner, a part-time mental health consultant, front office staff, peer mentors, and administrative staff. Each team provides care to an assigned panel of patients, in order to promote strong relationships between patients and clinic staff. Everyone on the team maximizes his or her contribution by fully utilizing individual skills and abilities in

support of the work, and patients benefit from better continuity of care and increased adherence to medical regimens.

► **What Role Do Part C Clinics in Neighboring States Play?**

Because of the lack of medical providers in the large geographic area east of the Cascade Mountains, some PLWH/A in Eastern Oregon travel across state lines to seek HIV medical care. An estimated 14 PLWH/A in Eastern Oregon receive care from the Part C clinic in Boise, Idaho and 17 receive HIV care at the Part C clinic in Walla Walla, Washington because those facilities are closer and easier to access than medical care facilities in Oregon. Other PLWH/A in Eastern Oregon travel long distances within state for their care, either to Portland or other Oregon cities outside their region.

**Overall Needs and Gaps in Medical Care:**

Data for this section were drawn from two main data sources: 2009-2010 medical records and interview data from the HIV Medical Monitoring Project and data from a 2009 survey of CAREAssist (Oregon's AIDS Drug Assistance Program) clients.

► **What is the HIV Medical Monitoring Project?**

The HIV Medical Monitoring Project (MMP) is a national project funded by the Centers for Disease Control & Prevention, and currently conducted in 17 states and 6 cities. These 23 project areas are estimated to include over 80% of the total HIV/AIDS cases in the United States. MMP assesses clinical outcomes and behaviors of HIV+ adults receiving medical care in the United States. Data include patient interviews and information abstracted from medical records.

In Oregon, data collection will cover the years 2007-2014. The most recent data, cited here, were collected from 539 participants and represent PLWH/A who received medical care in Oregon in 2009-2010. MMP participants include people receiving Ryan White-funded services and people who are not. For example, about 50% of MMP participants were enrolled in CAREAssist, but many others were enrolled in private plans and did not receive health insurance premium assistance from CAREAssist.

MMP participants were demographically similar to reported cases of HIV, giving a rough indication that PLWH/A in Oregon are not disproportionately in or out of medical care based on race, ethnicity, gender, age, or sexual orientation.

► **What Data Do We Have from CAREAssist?**

In 2009, a self-administered survey was mailed to all CAREAssist clients (n=2137 at that time); 1210 clients (58%) returned the survey. The survey was provided in both Spanish and English, and special efforts were made to increase response rate among younger clients. The final sample was representative of the CAREAssist population, except that younger clients, particularly those under age 30 were still under-represented. The survey provides data from a large sample of Ryan White clients on important topics like overall health and well-being; co-morbid conditions; use of medical services, antiretrovirals, and lab testing; housing stability; and met and unmet medical and supportive service needs.

► **How Good is Access to HIV Medical Care in Oregon?**

Among MMP participants (who were selected because they received medical care in the year of sampling), access to care was good. For example:

- **98%** reported having health insurance or coverage, and only 6% reported an insurance gap at some point in the past 12 months.
- **100%** reported having a “usual source of HIV care” in the past 12 months.
- **95%** of those diagnosed in the past 5 years had their first HIV medical visit within 3 months of diagnosis; 5% entered care between 3-12 months post-diagnosis.

► **How Far do PLWH/A Travel and How Difficult is it to Get to HIV Medical Care?**

About 2 in 3 MMP participants (66%) said they travel 30 minutes or less each way to get to HIV medical care. However, distances varied greatly among participants, with one-way trips ranging from 1-300 miles. About 1 in 10 MMP participants (12%) said their travel time to HIV medical care is more than 1 hour each way.

About 1 in 9 MMP participants reported difficulty getting to HIV medical care: 10% said that getting to HIV medical care was “somewhat difficult” and another 4% characterized it as “very difficult.”

► **How Often do PLWH/A Seek Care?**

MMP participants had an average of 4 past-year, face-to-face visits with their medical providers (median: 4, range: 1-18).

CAREAssist clients also reported seeing their HIV medical providers frequently; almost two-thirds (61%) reported seeing their HIV clinician four or more times in the past year. Conversely, only 5% reported seeing their clinician less than once every six months; of those, very few (n=5) said they had zero past-year visits to their HIV clinician. CAREAssist clients in the Portland metropolitan area reported seeing their doctor more frequently than those in the Balance of State, possibly because of greater distances between the doctor’s office and home, as well as fewer transportation options in non-metropolitan areas.

► **How Often do PLWH/A Receive CD4 and Viral Load Testing?**

Seventy-five percent of MMP participants had 3 or more CD4 counts in the past year, and 80% had at least one undetectable viral load.

► **How do PLWH/A Rate their Overall Physical Health?**

Several different measures on the CAREAssist survey indicate that CAREAssist clients are experiencing poorer physical and mental health and well-being than the general population. Although 71% of CAREAssist clients rated their health as good or better, the average physical health scores on a standardized measure (the SF-12) were lower than average for the general population.

► **How Many PLWH/A Have Other Chronic Medical Conditions?**

Many PLWH/A in Oregon live with multiple chronic conditions, in addition to HIV disease. Some of these chronic diseases are simply part of the aging process, while others may be complications of long-term HIV infection and/or treatment with HIV medicines.

Eighty percent of CAREAssist clients reported having one or more chronic condition, in addition to HIV disease. Two conditions that can have a dramatic impact on functioning and quality of life were the most commonly reported: over half of clients (54%) reported “depression, anxiety or emotional problems” and more than 1 in 3 (38%) reported chronic pain. About 1 in 5 reported conditions like arthritis/rheumatism, hypertension/high blood pressure, or lung/breathing problems, including asthma. Eleven percent reported co-infection with hepatitis C.

Medical record data from MMP also indicate a prevalence of medical co-morbidities. For example, 39% of MMP participants had documentation of hypercholesterolemia or hypertriglyceridemia, 37% had depression diagnoses, and 28% hypertension diagnoses. More than half of MMP patients (52%) reported chronic pain, and 38% are prescribed medicine to manage their pain.

► **What is the Overall Need for HIV Medical Care in Oregon?**

For those engaged in HIV medical care, the care that is available appears to be accessible and frequently used. Furthermore, there did not appear to be disproportionate barriers for specific demographic groups, although CAREAssist clients in the Balance of State reported fewer medical visits than those living in the Portland TGA.

However, PLWH/A in Oregon are heavily dependent on public systems to fund HIV medical care. The CAREAssist Program eliminates financial barriers to HIV medical care and appears to level the playing field for low-income PLWH/A. This service is used by roughly half of PLWH/A in Oregon.

The high prevalence of serious co-morbid medical conditions also reveals significant health burden among PLWH/A in Oregon, and warns of a correspondingly significant, ongoing need for program services, including outpatient medical care, health insurance and pharmaceutical coverage. Given lower physical health scores, more frequent self-reports of poor or fair health, and the higher prevalence of chronic pain among older CAREAssist clients, demand for medical and pharmaceutical services are likely to remain high and even increase further as the PLWH/A population ages.

► **What are the Barriers to Accessing HIV Medical Care in Oregon?**

Ryan White clients participating in the 2011 Listening Sessions and interviews reported that it is easy to gain entry into HIV medical care for most of those who are ready to access it.

Rural and frontier clients are a notable exception since HIV medical care is simply not available in their home communities. Rural clients said they had no trouble entering care, but long distances between home and doctor—up to 3 to 5 hours’ drive one-way for many in Eastern Oregon, for example—create ongoing barriers to care. Limited choice of medical providers in other areas of Part B Oregon can also create barriers. Clients gave examples of being “fired” from care for missing appointments or having interpersonal problems with

local providers, and then needing to travel out of town to access care through a new provider.

In addition, clients in Part B Oregon reported experiences of stigma and lack of cultural competence while accessing medical care. For example, one client summed it up this way: *“You’re already having trouble being HIV+ in a rural community, and then when you have a physician who treats you like crap, you don’t want to go back. There’s such a limited choice. Why would we want to go back to them?”*

## **Health Insurance**

### **► How are PLWH/A Insured in Oregon?**

The State of Oregon has a unique ability to provide health insurance for virtually every person living with HIV/AIDS in Oregon through the CAREAssist Program (Oregon’s ADAP). The Oregon HIV Care and Treatment Program (Part B Grantee) uses Ryan White ADAP funding to pay health insurance premiums and co-pays for eligible PLWH/A who are not insured through Oregon Health Plan (OHP). By ensuring payment of premiums and providing uninterrupted coverage for these clients, the program leverages the Oregon Medical Insurance Pool (OMIP) to ensure universal coverage for even high-risk clients. Additionally, enrollment into the newly funded federal high risk insurance pool (PCIP) is facilitated by its co-management by OMIP. OMIP/PCIP coverage is available to Oregon residents with qualifying medical conditions that would otherwise restrict their individual health insurance coverage through private insurers. HIV/AIDS is a qualifying medical condition for OMIP/PCIP, and in 2010, OMIP/PCIP covered more CAREAssist clients (41%) than any other single insurer.

### **► How Many People are Served by CAREAssist?**

In 2010, CAREAssist served 2,784 unduplicated clients statewide. There were 435 new CAREAssist clients in 2010, an 8% increase in overall enrollment from 2009. Enrollment has been steadily increasing for years. For example, enrollment has increased 44% since 2007, when the program served 1,928 unduplicated clients.

All CAREAssist clients are low income, with household incomes of less than 300% FPL. About half (46%) are in the lowest income strata, with household income of  $\leq$  100% FPL, and another 39% have income between 101-200% FPL.

### **► What Do CAREAssist Clients Say about the Program?**

The CAREAssist Program last surveyed all clients in 2009 to assess client satisfaction with the program. Overall, 96% of the respondents felt the quality of CAREAssist services was either “excellent” or “good,” with the majority ranking it as excellent (70%).

### **► What are the Challenges to Accessing Health Insurance in Oregon?**

Most clients in a 2011 qualitative assessment said that accessing health insurance was “*very, very easy*” and many expressed intense gratitude for CAREAssist services and the medicines that the ADAP program provides. However, it should be noted that many clients require a significant amount of help from their CAREAssist case worker and community-based HIV case managers in order to re-submit the eligibility documentation every six months that keeps them insured.

Upcoming challenges may include the reorganization of public health care systems in Oregon and nationally. Oregon chose to administer federal funds allocated to Oregon for the Pre-existing Conditions Insurance Pool (PCIP) under health care reform legislation. As noted, OMIP and PCIP currently insure almost half of all CAREAssist clients for whom CAREAssist pays insurance premiums. As part of health reform efforts, the OMIP and PCIP insurances will be ending on 1/1/14. Local efforts are now focusing on how to transition enrolled ADAP clients to the new system of insurance exchanges that will replace current coverage.

### ***Prescription Drug Assistance***

CAREAssist ensures that PLWH/A have access to antiretrovirals by paying for primary health insurance premiums. In addition, CAREAssist has a published drug formulary which provides other prescription drugs that PLWH/A may need, and for which their primary health plans do not pay. These drugs are available to clients when they fill their prescriptions at a CAREAssist contract pharmacy. CAREAssist’s drug formulary includes a wide range of medicines PLWH/A may need to maintain their health and quality of life, including smoking cessation drugs, and other medications that are not covered by Medicare Part D plans or OHP.

#### **► What is the Demand for Prescription Drug Help among Ryan White Clients?**

Most MMP participants (89%) reported current use of antiretrovirals. Because of the high prevalence of co-morbid health conditions, many PLWH/A take prescription drugs for other conditions, as well. For example, 38% said they took prescription drugs for chronic pain.

In 2010, the CAREAssist Program paid 105,951 prescription co-pays for clients.

#### **► Challenges Related to Pharmaceuticals and Pharmacy Services**

In 2011, CAREAssist streamlined its pharmacy services, in an effort to control costs. Most pharmacy services are now provided through contracted pharmacy vendors or through a contracted mail-order only. Some exceptions allow other pharmacies to be used, such as for pain medications or short-term acute care needs.

In a qualitative assessment conducted in 2011, some Part B clients reported difficulty accessing HIV medicines through pharmacists in small towns, due to stigma/discrimination issues or simply a lack of privacy.

## **Medical Case Management**

Medical case management consists of assessment, coordination of services and linkages to services inside and outside the Ryan White system of care. All clients have access to medical case management services that include treatment adherence assessment and coordinating timely access to appropriate levels of medical and supportive services, through ongoing client assessment and care plan development. Statewide, Medical Case Management (and non-medical case management) is performed by teams of nurses, social workers, and other professionals.

### **► What is the Need for Medical Case Management in Oregon?**

Sixty percent of MMP participants (which include a mix of Ryan White clients and non-Ryan White clients) reported needing HIV case management services in the past year. Of those, about 55% received case management services, and 5% reported unmet needs for HIV case management. The main barrier to receiving case management services reported by those with unmet needs was confusion about where to go or whom to call for services.

In 2010, 959 clients in the Balance of State received Part B-funded HIV medical case management services. Demand for case management services in the Balance of State has increased steadily, and enrollment has increased 15% since 2007.

In 2010, 1,750 clients in the TGA received Part A-funded medical case management services; enrollment has increased by 17% since 2007.

### **► How is Medical Case Management Delivered in the TGA?**

Part A-funded providers deliver services using the Chronic Care Model as the framework for the HIV care provided. The components of this model include community, self-management, delivery system design, decision support, and clinical information systems. Together, these components optimize positive outcomes for chronic conditions by creating an environment in which productive interactions and relationships thrive, resulting in patients and communities that are informed and active, and providers and community partners that are prepared and proactive (Jenkins 2011).

Specialty case management services are also offered in conjunction with primary case management services; this includes nursing case management, intensive case management for high acuity Latino and African and African American clients, and services for clients living in transitional housing units to ensure they are able to maintain housing, thereby impacting their ability to maintain medical care and medication adherence.

### **► How are Medical Case Management Delivered in the Balance of State?**

Medical case management services in the Part B areas of Oregon are delivered through a combination of local county health department-based services and a regional service delivery model.

Since the last SCSN in 2008, some local county health departments in the Balance of State have opted out of providing Ryan White Program funded case management and supportive services, simultaneously transferring the authority and responsibility for providing case management and other supportive services to the Oregon Health Authority. This has created both challenges and opportunities for delivering high-quality services in the Part B-funded areas of Oregon.

The Oregon Health Authority contracts with an AIDS service organization, HIV Alliance in Eugene, to provide HIV care coordination services and medical and non-medical case management to clients in an eight-county region. The region includes areas on the South Coast, southern I-5 corridor, and along the California border. HIV Alliance also provides non-medical case management in Marion County, which has the second largest number of HIV clients in the Part B area, as well as a large Latino and monolingual Spanish-speaking population; Marion County Health Department provides medical case management services in partnership with HIV Alliance.

HIV Alliance and Marion County Health Department provide medical case management services through AIDS-certified registered nurses located throughout the service region, and provide care coordination/non-medical case management and supportive services primarily by phone, administered through a Care Coordination Center in Eugene. Client surveys in the affected counties, conducted prior to and one year after the changes were implemented, indicate that client satisfaction has remained high in all counties and increased significantly in Marion County. Clients report a high level of access to care coordinators and services, as well as high levels of confidence that their needs will be met by staff at HIV Alliance.

Clients in the large geographic areas in Eastern Oregon are served by another community based organization following the same regional Medical Care Coordination model, Eastern Oregon Center for Independent Living (EOCIL). Additionally, 10 Part B counties continue to be served by local health department staff, primarily public health nurses. All Part B clients have access to services delivered by nurses (medical case management) and case managers/care coordinators providing non-medical case management and access to supportive services.

## **Oral Health Care**

Comprehensive dental care is provided by a range of practitioners, some of whom specialize in treating HIV positive patients. Services include diagnostic, preventive and restorative care, oral surgery and emergency care resulting from pain and infection. Crown and bridge procedures are also provided, with some limitations.

### **► What is the Need for Oral Health Care in Oregon?**

For many years, dental care has been consistently cited as the number one unmet need for services among HIV clients. Seventy-nine percent of MMP participants reported needing dental care in the past year.

In 2010, 307 BOS clients received oral health services through Part F-funded services provided by Clock Tower Dental Clinic. In 2010, Clock Tower provided 920 diagnostic, 633 restorative, 461 preventative, and 75 adjunctive services. In addition, the following number of clients received specialized dental services through Clock Tower: periodontics (n=316), prostodontics (n=315), oral surgery (n=245), and endodontics (n=82).

In 2010, 28 additional clients in the Balance of State received oral health care assistance utilizing local Part B funds; 124 received dental services and 44 received initial dental assessment through the State Managed Service Program.

In 2010, 885 clients in the TGA (including 220 new clients) received oral health services through Part A & Part F-funded services at OHSU's Russell Street Dental Clinic. In 2010, Russell Street Dental Clinic provided 1305 diagnostic, 1454 restorative, 1000 preventive, and 222 adjunctive services. In addition, 673 periodontic, 826 prosthodontic, 283 oral surgery, and 95 endodontic services were provided.

► **How is Oral Health Care Delivered in the TGA?**

In the TGA, Oregon Health and Science University (OHSU) participates in the Part F Dental Reimbursement program at their community-based Russell Street Dental Clinic. This program provides partial payment for unreimbursed costs of HIV care provided by the clinic. OHSU also has a Dental Community Partnership Grant that funds HIV clinical rotations for dental students, expanding access to services for PLWH/A. OHSU coordinates outreach for the grant with the two largest Part A primary care and support services providers, Multnomah County Health Department and Cascade AIDS Project. Part A contributes oral health care funding to help fill the gap in resources for the majority of PLWH/A without dental insurance.

► **How is Oral Health Care Delivered in the Balance of State?**

In the Balance of State, PLWH/A in 17 counties receive Part-F funded services through the Clock Tower Dental Clinic in Eugene and its regional satellite clinics. In addition, clients who are unable to access Clock Tower can receive dental services through local private dental providers funded through Part B funds. Part B funds may also be used for dental services not covered by Part F reimbursement.

► **What Challenges do Clients Face Related to Oral Health Care?**

More than 1 in 4 MMP participants (27%) said they needed dental services in the past year, but could not get them. The two barriers to dental care cited most frequently among MMP participants were cost/lack of insurance and not knowing where to go or whom to call for services. Similarly, 30% reported that they do not have a "usual dentist" and 23% said that their last dental visit was "more than 2 years ago."

Clients in 4 of 6 Part A community forums reported no gap in dental care. Some clients in the other two groups reported long wait times for appointments and a limited spectrum of services available.

Data from Part B Listening Sessions and interviews indicate that Clock Tower Dental has filled the previously yawning gap in dental care services for many PLWH/A in the Balance of State. Clients reported high levels of satisfaction with services provided through Clock Tower and clients living in Eugene reported no access difficulties whatsoever. Rural clients reported some access difficulties due to distance. Clock Tower provides services through a mobile unit and satellite clinics that bring preventive and other oral health services to local communities beyond the Eugene area. This makes basic oral health care available to many rural clients, but some types of procedures can only be completed in their Eugene clinic. This can create logistical barriers for rural clients, although Clock Tower does try to mitigate transportation-related barriers by providing bus tickets and other assistance.

## ***Substance Abuse Treatment***

Ryan White-funded substance abuse treatment services include assessment, individual and group counseling, as well as engagement and coordination in outpatient treatment for clients in alcohol and drug-free housing.

### **► What is the Need for Substance Abuse Treatment Services in Oregon?**

There are no definitive data related to the prevalence of substance abuse among PLWH/A in Oregon, but various data sources indicate a substantial need.

In 2009-2010, 15% of MMP participants reported binge drinking on one or more days in the past month. Binge drinking was defined as 4 or more drinks in one day for women and 5 or more for men.

In addition, 29% reported use of other drugs in the past 12 months, including recreational use of marijuana<sup>iii</sup> (26%), other non-injection drugs (15%), and injection drugs (5%). Almost 1 in 10 participants (9%) reported daily recreational marijuana use. Past-year use of substance abuse treatment services was noted in 10% of MMP participants' medical records in 2007-2008, the most recent MMP data available on this topic, and 2% of MMP participants reported past-year use of inpatient drug and alcohol treatment.

In 2009, 7% of CAREAssist clients self-reported a “problem with drugs or alcohol.”

An older study found that 30% of Medicaid-insured PLWH/A had been treated for a substance abuse issue over a two-year period (1999-2000); 20% had been treated for both substance abuse and mental health issues (PDES, 2002).

In 2010, 2 clients in the Balance of State received Part B-funded substance abuse treatment services.

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<sup>iii</sup> Recreational marijuana use was measured separately from medicinal use of marijuana to treat HIV symptoms or side effects.

In 2010, 27 clients in the TGA received Part A-funded substance abuse treatment services.

These numbers have always been somewhat low because of challenges discussed below. However, changes in health insurance related to the parity act now allow these services to be billed through insurance plans, which may also decrease the numbers served through Ryan White Program funds.

► **How is Substance Abuse Treatment Delivered in the TGA and Balance of State?**

Substance abuse treatment services are provided by local providers and contracted substance abuse treatment agencies. Recruitment into mental health and substance abuse treatment services by peer mentors is also funded through a joint mental health and substance abuse treatment project in the TGA. The HHSC also offers a harm-reduction based treatment group open to any PLWH/A, regardless of where they receive medical care or whether they live in the TGA.

Nearly all CAREAssist clients are eligible to receive substance abuse treatment services as defined within the primary health insurance coverage purchased by CAREAssist or to which the client has access. CAREAssist pays deductibles and/or copayments on behalf of the client.

► **What Challenges do Clients Face Related to Substance Abuse Treatment?**

Only 1% of MMP participants reported an unmet need for drug and alcohol counseling and treatment in 2009-2010. However, low service utilization levels combined with high levels of self-reported drug and alcohol use would indicate that more PLWH/A may have benefited from services than those who sought them.

Case managers and other service professionals working with PLWH/A report multiple client-level and system-level barriers to getting HIV positive clients enrolled in substance abuse treatment services. These include a client's lack of treatment readiness, lack of providers who will accept a client's insurance, mismatches between treatment modalities and clients' needs, lack of education about HIV in the mainstream behavioral health care system, and limited availability of behavioral health providers with an HIV focus or cultural competence dealing with the LGBTQ population, especially within certain geographic areas. In addition, funding in-patient treatment is a challenge because Ryan White funds cannot be used, and most clients lack other options. Clients echoed these themes in the 2011 Listening Sessions and interviews.

## ***Mental Health Services***

Ryan White-funded mental health services include assessment and on-site or at-home counseling (individual/couple/family), group counseling, crisis intervention, and medication management for PLWH/A. Mental health services are delivered by mental health professionals (psychiatrists, psychiatric nurse practitioners, licensed social workers, or licensed professional counselors).

► **What is the Need for Mental Health Services in Oregon?**

About half of CAREAssist clients (54%) reported “depression, anxiety or emotional problems” in 2009, and the average emotional health score on the SF-12 (a standardized measure) was 41 for CAREAssist clients, indicating that they have somewhat poorer emotional health compared to the general adult population (average=50).

About 1 in 3 MMP participants (36%) reported needing mental health services in 2009-2010. In addition, 35% of MMP participants reported being diagnosed or treated for depression and 24% for anxiety in the past year. Just over 1 in 4 MMP participants (28%) showed moderate to severe depression on a standardized measure (the PHQ-9 scale) based on reports of their mood over the past two weeks.

Two percent of MMP participants reported past-year admission to an inpatient mental health facility.

An older study found that 20% of Medicaid-insured PLWH/A had been treated for both substance abuse and mental health issues over a two-year period (1999-2000) (PDES, 2002).

In 2010, 129 clients in the TGA received Part A-funded mental health services, about 23% fewer than in 2007. Providers report this is largely due to implementation of mental health parity laws so clients do not need to access Ryan White funds to complete their treatment.

In 2010, 5 clients in the BOS received Part B-funded mental health services.

Similar to substance abuse services, the numbers accessing Ryan White Program-funded mental health services have always been somewhat low because of challenges discussed below. However, changes in health insurance related to the parity act now allow these services to be billed through insurance plans, which may also decrease the numbers served through Ryan White Program funds.

The state’s Part B ADAP (CAREAssist) purchases insurance—the vehicle by which some clients access mental health services. CAREAssist pays deductibles and copayments behind the primary health insurance (including OHP and Medicare Part B) on behalf of the client. Because Medicare Part B pays at a low percentage on mental health services, the annual allocation to medical service copayments provided by the CAREAssist program may be exhausted prior to the end of the coverage year. In this case the responsibility for paying the copayments may default to other Ryan White funds.

► **How are Mental Health Services Delivered in the TGA?**

Mental health treatment services are provided by contracted mental health agencies and through a mental health provider stationed at Cascade AIDS Project, supported through Oregon HIV Behavioral Health Initiative (OHBHI) HOPWA grant funds. Recruitment into mental health and substance abuse treatment services by peer mentors is also funded through a joint mental health and substance abuse treatment project in the TGA.

The HHSC provides mental health services by a Psychiatric Nurse Practitioner, as well as limited counseling from a Part D-funded social worker.

► **How are Mental Health Services Delivered in the Balance of State?**

Mental health treatment services are provided by private providers.

► **What Challenges do Clients Face Related to Mental Health Services?**

Eleven percent of MMP participants reported needing but not getting mental health services in 2009-2010. Some participants (14% of those with unmet need) said they were in the process of accessing the service, but had not received it yet. The main barriers to receiving mental health services were psychological (e.g., not feeling ready), not knowing where to go or who to call, and cost/lack of insurance.

As with substance abuse services, case managers and other service professionals working with PLWH/A report multiple client-level and system-level barriers to getting HIV positive clients enrolled in mainstream mental health services. These barriers look similar to those identified by MMP clients, and include a client's lack of treatment readiness, lack of providers who accept a client's insurance, mismatches between treatment modalities and clients' needs, lack of education about HIV in the mainstream behavioral health care system, and limited availability of behavioral health providers with an HIV focus or cultural competence dealing with the LGBTQ population, especially within certain geographic areas. Lack of availability of Spanish speaking counselor has also been mentioned as a barrier. In 2011, clients in Part B Listening Sessions also identified access to "HIV-knowledgeable" mental health providers as an unmet need.

## ***Early Intervention Services***

Early intervention services (EIS) focus on newly diagnosed individuals and persons who have fallen out of care. Programs provide counseling and referrals to medical care. Referrals to mental health and substance abuse treatment services are also provided, as appropriate. EIS is currently available in the TGA only.

► **What is the Need for Early Intervention Services in Oregon?**

According to MMP data, clients who are currently in HIV medical care were able to access care quickly after initial diagnosis. Among those diagnosed in the past 5 years, 95% had their first HIV medical visit within 3 months of diagnosis; the other 5% entered care between 3-12 months post-diagnosis.

However, HIV surveillance data indicate that 40% of PLWH/A in Oregon are diagnosed late in their infection, and 25% of PLWH/A were considered "out of medical care" in 2009, based on a lack of reported CD4 or viral load labs.

Qualitative data from Part B Ryan White clients, collected in 2011, indicate that being out of HIV medical care at some point after learning one's diagnosis was a common experience. Most clients reported delaying care, while others said they had fallen out of

care at some point after starting. Many clients reported being out of care for significant periods of time, such as 1 - 15 years. The main reason clients gave for being out of care was denial and depression. Others cited side effects of HIV medications or fear of starting HIV medications, alcohol and drug abuse, and problems with doctors as reasons for being out of care.

In 2010, 74 clients in the TGA received Part A-funded early intervention services, a 16% increase from 2007.

EIS is not a funded service in the Balance of State.

► **How are Early Intervention Services Delivered in the TGA?**

The EIS program in the TGA began in July 2007 and has focused on PLWH/A who are out of care and the newly diagnosed, many of whom come into care later in their disease progression with a variety of co-factors including mental health and substance abuse issues.

EIS services are offered through two programs in the TGA: through the Disease Investigation Specialists (DIS), housed at the STD Clinic at Multnomah County Health Department, and through Cascade AIDS Project, the largest AIDS Service Organization in Oregon. The DIS receive information regarding all new HIV diagnoses in the county, follow up with those individuals to ensure they are linked to medical care, and recommend HIV testing for all known partners. Being housed in the STD clinic also provides the opportunity to work with clients who come in for STD treatment and are found to be out of care for their HIV disease. Such patients are assisted with linkage into HIV medical care. DIS also assist with partner notification. CAP staff work with clients who have fallen out of care or need extra assistance to get into care, specifically individuals coming out of corrections or who have mental health/substance abuse issues or may be homeless.

► **How are Early Intervention Services Delivered in the Balance of State?**

There are no Ryan White Part B-funded early intervention services in the BOS. Disease Intervention Specialists, funded through non-Ryan White sources, provide follow-up for newly diagnosed people, linkage to care and treatment services, and partner notification.

The CAREAssist Bridge Program is another way that early intervention service needs are being addressed in both the TGA and BOS. The Bridge program is a medical-provider driven program where clients who are entering care or returning to care can receive a limited number of medical services and prescription drugs.

► **What Challenges do Clients Face Related to Early Intervention Services?**

In 2011, clients involved in Part B Listening Sessions and interviews indicated that they primarily got into care for the first time or re-entered care after falling out of care for two reasons: 1) they were forced into care by serious illness or 2) a friend, family, member or other individual reached out and got them connected (or re-connected) to

care. For the most part, these reconnections were incidental rather than systematic. Indeed, Part B clients clearly indicated a need for early intervention services, which they referred to as a “patient advocate” or peer support, particularly after initial diagnosis.

## **Housing**

This service category includes emergency and transitional housing assistance to PLWH/A and their families. Eviction prevention, information and referral, tenant education, housing placement, and housing case management enable clients to access and remain in transitional and permanent housing. Alcohol/drug-free housing is also provided for PLWH/A while enrolled in outpatient substance abuse treatment.

There are also three Housing Opportunities for Persons with AIDS (HOPWA) grantees in Oregon: the State of Oregon (which has both formula and competitive grants), the City of Portland (formula and competitive), and Our House of Portland (competitive). Between these three sources, housing services are provided throughout the state of Oregon.

### **► What is the Need for Housing Services in Oregon?**

Among MMP participants, 71% reported having a stable place to live in the past year, with no past-past year moves. About 1 in 10 MMP participants (11%) reported moving more than once in the past year, 6% reported past-year homelessness, and 4% reported incarceration, which can often lead to homelessness or unstable housing once released.

In 2009, a majority of CAREAssist clients, though by no means all, reported living in safe and stable housing situations. More than three-fourths (78%) characterized their current housing as very safe, 19% said somewhat safe, and 3% said it was not safe at all. Most CAREAssist clients (77%) reported living in their own house or apartment at the time of the survey (either singly or with a partner) and 16% reported living in someone else’s house or apartment (e.g., the residence of a parent, other family member, or friend). Four percent reported living in other stable housing, such as a rented room or hospice facility and 2% reported currently living in unstable housing, like transitional housing or a shelter or welfare residence. The unstable housing category also included respondents who reported being currently homeless (n=8). Similar to MMP, 9% reported moving more than once in the past year.

Just over 1 in 10 CAREAssist clients (13%) said they had considered themselves homeless in the past two years.

In 2010, 536 clients in the TGA received Part A-funded housing assistance services, an 11% increase from 2007.

In 2010, 165 clients received Part B-funded emergency and transitional housing services in the Balance of State. Clients with chronic housing assistance needs were referred to Oregon Housing Opportunities in Partnership Program (OHOP), funded

primarily by the Department of Housing and Urban Development (HUD). OHOP provided rental assistance to 160 households in 2010, and there were 124 people wait listed.

► **How are Housing Services Delivered in the TGA?**

Housing services in the TGA include permanent and transitional alcohol and drug-free housing; housing with supportive services for clients with mental illness; permanent subsidized housing for homeless and chronically homeless PLWH/A through Shelter Plus Care grants and Supportive Housing Program grants; housing for homeless women through the *Key Not a Card* program; transitional housing for youth; and permanent housing for formerly incarcerated clients. Other housing services include short term financial assistance for move in costs or eviction prevention, mortgage and utility assistance, case management, tenant education, housing placement, referrals to various applicable housing programs, and priority into subsidized or affordable units.

Our House of Portland, a community provider, delivers a continuum of services covered by public and private resources for advanced stage PLWH/A. Services include 24-hour specialized nursing and end of life care, assisted living in adult care homes, and a neighborhood housing and care program that combines stable housing with integrated in-home medical, occupational therapy, and social work services.

The Oregon Health Authority also contracts directly with Cascade AIDS Project (CAP) to deliver HOPWA SPNS OHBHI and HOPWA SPNS OSSCR services in the TGA as they are a project sponsor of those competitive grants. Through this partnership, CAP provided tenant-based rental assistance to an additional 25 households in 2010. Approximately 20 additional households receive rent assistance through a leveraged Shelter Plus Care grant in Multnomah County.

The Portland Housing Bureau contracts directly with Cascade AIDS Project to deliver a range of HOPWA housing services including: tenant based rent assistance, project based rent assistance, short-term rent mortgage utility assistance, Working Choices program, furniture assistance, and case management services. Approximately 250 households receive housing assistance through these HOPWA funds and 60 households receive employment assistance. CAP partners with a variety of housing agencies and property managers for leveraged rent assistance including Shelter Plus Care in Clackamas County and Multnomah County, supportive housing funds from the Multnomah County Continuum of Care, and project based rent assistance through the local housing authority, Home Forward.

Portland Housing Bureau received a HOPWA SPNS grant to serve approximately 60 households with short term rent assistance, extend the working choices program, and integrate HOPWA services into mainstream services. This is effective January 1, 2012.

CAP is also funded by Ryan White to provide short term rent assistance, tenant education, housing placement and planning, and case management to serve 350 people.

Leveraged rent assistance includes Home Forwards STRA (short term rent assistance) program and Shelter Plus Care in Washington County.

► **How are Housing Services Delivered in the Balance of State?**

Clients residing in the BOS may receive limited Ryan White Part B-funded emergency and transitional housing services through local case management contractors.

Long term permanent supportive housing is provided through the OHOP Program. OHOP is designed to assist people living with HIV/AIDS in creating a continuum of stable, sustainable housing, in order to improve access to and engagement in HIV care and treatment and to act as a bridge to long-term assistance programs, such as Section 8. Additionally, through 3.6 FTE Housing Case Management staff, the OHOP program assists clients in 31 Oregon counties in locating and/or securing suitable rental housing, identifying other related housing and community based resources that may be available to clients, and providing housing information and referral to those housing resources.

Additional supportive services are provided to clients participating in the HOPWA/SPNS-funded Oregon Housing and Behavioral Health Initiative (OHBHI), Oregon Statewide Supportive Community Re-entry Project (OSSCR) and the Supportive Housing Program for homeless individuals. OHBHI assists clients with HIV and co-occurring behavioral health issues that present barriers to accessing and maintaining stable housing with additional mental health and case management support while OSSCR provides additional case management and service coordination to persons post incarcerated. OSSCR represents a uniquely collaborative client service model that includes the effort of supporting professionals such as local and state corrections. Finally, the Supportive Housing Program provides additional case management, to include frequent home visits to chronically homeless and homeless individuals.

► **What Challenges do Clients Face Related to Housing Services?**

Some CAREAssist clients were significantly more likely to report recent homelessness and unstable housing. Nonwhites (23% vs. 15%,  $p = .002$ ), clients with less education (e.g. 22% with less than high school vs. 9% of college grads,  $p = .004$ ), and younger clients (e.g. 36% under 30 vs. 8% age 60 and older,  $p < .001$ ) were significantly more likely to report homelessness or past-year unstable housing. There were no differences by gender or region. Younger clients and those with less education remained significantly more likely to report homelessness or unstable housing when controlling for the other demographic factors in a logistic regression model; race was no longer significantly associated with unstable housing.

As of October 2011, the OHOP program for the BOS had 123 households awaiting long term housing assistance who were homeless or at risk of becoming homeless. In the TGA, the primary provider of HOPWA-funded services has waitlisted or turned away more than 70 clients in the last year.

Section 8 waiting lists are extremely long or simply closed in most communities, which results in clients remaining on HOPWA programs for longer periods of time than

expected. In addition, the recession and high unemployment rates have resulted in more competition for scarce housing resources.

## ***Food and Nutrition***

This service category includes emergency food assistance (e.g., food vouchers/grocery gift cards, home delivered meals), nutritional supports, and medical nutritional therapy.

### **► What is the Need for Food and Nutrition Services in Oregon?**

Forty percent of MMP participants said they needed meal or food services in the past year; of those, 90% received the needed service.

In 2007, HIV case management clients in the Part B service area were asked about their food needs as part of the annual client satisfaction survey; 57% (n=220/388) said they had needed financial help getting food or groceries in the past 12 months. The percentage needing help with food and groceries in 2007 was higher than the 49% identified in the 2005 Needs Assessment survey. The most common source of financial help for food came from food stamps, accessed by 47% of respondents. Other common sources of help were food banks/food pantries (27%), friends and family (25%), and grocery vouchers from case managers (23%).

In 2010, 47 clients in the TGA received Part A-funded food and nutrition services in the form of home-delivered meals, a 23% decrease from 2009.

In 2010, 33 people received Part B-funded medical nutritional therapy by a licensed dietician in the Balance of State, 226 received RN-authorized food vouchers provided in support of the nutritional plan developed by the RN and the client, and 323 received emergency food assistance.

### **► How are Food and Nutrition Services Delivered in the TGA?**

Food and nutrition services in the TGA include home-delivered meals. The home-delivered meal program has restructured to adjust to more stringent client requirements around medical necessity for this service, and there have been no cost-of-living increases to the category. As a result, the home delivered meals program now delivers a week's worth of frozen meals to clients once a week; the program is able to ensure that each client in the program has a microwave to heat the meals.

Esther's Pantry, located in the Portland metropolitan area and administered by Our House of Portland, is the only food bank in Oregon specifically serving PLWH/A. It was founded in 1985 "to provide financially challenged individuals living with HIV/AIDS access to food and personal care items," and serves approximately 200 PLWH/A each month. The Pantry is unique in that it has always maintained a policy of allowing clients to select the food they want from well-stocked shelves, rather than handing out pre-packaged food boxes, which is a standard procedure at most emergency food programs. However, Esther's Pantry does not receive any Ryan White funding, only serves the Portland metropolitan area, and has had to limit services over

the years due to budget constraints. The Tod's Corner program provides clothing, household goods, pet food, cleaning and personal care items.

► **How are Food and Nutrition Services Delivered in the Balance of State?**

Emergency food assistance is provided to Part B clients through their HIV care coordinators and case managers. Nutritional counseling and supports is delivered by medical case managers and medical nutritional therapy is delivered by private licensed dietitians.

► **What Challenges do Clients Face Related to Food and Nutrition Services?**

Focus groups conducted in 2007 identified a number of themes surrounding food-related needs and gaps. First, as supported by the scientific literature, PLWH/A have unique nutritional needs that extend beyond health promotion and disease prevention. Nutritional problems caused by ART, including nutritional deficiencies, malabsorption, elevated cholesterol, and lipodystrophy are common, as are digestive problems such as nausea, vomiting, acid reflux, and diarrhea. Identified barriers to eating for optimal health included lack of transportation, lack of appetite, depression, and fatigue, but the most commonly cited barrier was lack of income. Although participants shop at discount stores, buy in bulk and pool resources, in order to stretch limited resources, they are often still short at the end of the month and some buy food on credit cards—a necessary stopgap, but an unsustainable long-term strategy. Although many communities in Oregon are served by food banks, food distribution programs through churches, and congregate meal programs, PLWH/A found these resources only marginally helpful. Most had used these programs, but cited multiple barriers including lack of access, long waits, concerns about food safety and the types of food offered, and feelings of stigma and discomfort related to competing for scarce resources with other individuals and groups in need, particularly women with small children. And, as noted previously, these “mainstream” resources are being stretched thin as record numbers of Oregonians have become dependent on them.

***Medical Transportation***

This service includes assistance with transportation to and from medical appointments, using the most cost-efficient means available for the client's locale.

► **What is the Need for Medical Transportation Services in Oregon?**

Just over 1 in 4 MMP participants (28%) said they needed transportation assistance in the past year.

In 2010, 442 PLWH/A received Part B funded medical transportation services.

► **How are Medical Transportation Services Delivered in the TGA?**

Coordination of medical transportation for TGA clients is provided through medical case management. Case managers determine client needs and link them to the most appropriate resources, which are usually transportation resources outside of the RWCA-funded system. Most TGA clients live in Portland or the areas immediately surrounding it, and most Part A-funded services are also located in this area. Tri-Met provides an extensive public transportation system, including buses and light rail in Clackamas,

Multnomah and Washington Counties. Case managers can provide gas vouchers or bus/rail tickets for those who use public transportation and can reimburse other types of transportation (e.g., taxi, gas cards, and other medical transport) for clients unable to use public transportation.

► **How are Medical Transportation Services Delivered in the Balance of State?**

Most Balance of State clients have fewer public transportation options and greater medical transportation needs. Some clients in Eastern Oregon, for example, drive 3-5 hours each way to access HIV medical care. Medical transportation assistance is provided in the Balance of State through gas cards, public transportation (e.g., bus tickets), taxi fare, and, occasionally, special medical transport for clients who need a higher level of assistance due to serious illness and/or mobility limitations.

► **What Challenges do Clients Face Related to Medical Transportation Services?**

Transportation options are limited in the nonmetropolitan areas of the state. As described in other parts of this document, clients living in rural and frontier areas of Oregon must travel long distances for medical care and other supportive services because no local options exist. Even clients in the more populated areas of the state outside of the Portland metropolitan area report having to travel for care sometimes because of few local HIV doctors. For example, clients may choose to see a different provider or be “fired” from care for a variety of reasons, requiring travel to another town. Clients outside of the Portland or Eugene areas may also need to travel to access dental care. Winter weather and mountain passes provide additional challenges.

Clients across Oregon (parts A and B) are challenged by the rise in fuel costs, which make transportation by both private car and public transit far more expensive than in past years.

## ***Psychosocial Support Services***

Psychosocial support services offer stability for a marginalized population; this leads to more consistent participation in HIV care and treatment services.

► **What is the Need for Psychosocial Support Services in Oregon?**

Just over 1 in 4 MMP participants reported needing peer group support; of those, about half received the service and half reported an unmet need.

Qualitative data from listening sessions and interviews conducted in 2011 indicated a great unmet need for psychosocial support in the Part B areas of Oregon. Part B clients identified a need for peer support, support groups, and patient advocates.

► **How are Psychosocial Support Services Delivered in the TGA?**

In the TGA, a drop-in day center serves PLWH/A who have difficulty dealing with activities of daily living, many of whom have substance abuse and mental health issues and are homeless or living in temporary housing. The center provides regular supportive activities, meals, peer support, and a place for clients to meet with social service providers. Another center provides services for women and their families,

including child care while women participate in support groups and other center activities.

With funding through Ryan White Part D, CAP also provides psychosocial support to children and families affected by HIV through Kids' Connection. Kids' Connection provides: 1) developmentally appropriate HIV education and disclosure, 2) a multi-session family group called Families Together that focuses on HIV education, disclosure and family communication, 3) Family Days that provide parenting skills workshops paired with free and fun family activities and social/recreational events for families affected by HIV to help build community and support. Kids' Connection also partners with the Pediatric HIV Clinic at OHSU to provide support and education for families when their children are seen for medical care at the clinic. Finally, Kids' Connection and Part D provide support for teens living with HIV through age appropriate education and risk reduction counseling as well as through a twice-monthly group called Always Looking Up.

► **How are Psychosocial Support Services Delivered in the Balance of State?**

Some communities in the Part B areas of Oregon have support groups, but most do not. No communities in the Balance of State currently have peer support programs.

► **What Challenges do Clients Face Related to Psychosocial Support Services?**

Clients outside of the more populated cities of Oregon (e.g., Portland metropolitan area, Eugene) reported feelings of isolation because they have no opportunities for connection to others with HIV. Some said they don't know anyone else with HIV; most say that formal opportunities for social connection and social support are nonexistent.

Part B clients advocated strongly for support groups and other types of 1-1 peer support (such as a "buddy program"), but there is no infrastructure for starting or maintaining these types of services.

Both Part A and B clients suggested that the Oregon AIDS Hotline might also be used as a resource for providing psychosocial support.

## **Service Needs of Special Populations**

Several special populations may have additional service needs or needs that are not currently being addressed by the current HIV continuum of care. We briefly address the service needs of seven special populations below.

### **PLWH/A Aged 50 Years or Older**

In Oregon, 38% of PLWH/A were aged 50 and older, as of 3/31/2010, and an additional 38% of PLWH/A were aged 40-49, representing the next wave of older PLWH/A.

Population increases within this age category are due to both the success of antiretroviral medications in treating HIV/AIDS and increases in the number of persons

aged 50 and older being diagnosed with HIV/AIDS for the first time; almost 1 in 5 PLWH/A diagnosed in 2009 (18%) were aged 50 or older.

Many older PLWH/A face serious co-morbid medical conditions, including cardiovascular disease, diabetes, certain cancers, osteoporosis, chronic pain, and depression. These conditions complicate HIV medical care, may require multiple pharmaceuticals, and can compromise quality of life.

Gaps in care that are unique to this patient population include social support groups targeted to their needs; increased outreach, testing, and prevention services to decrease the rates of incidence within this population and bring infected people into care as soon as possible; increased coordination with aging and disabilities services; and increased access to specialists for treatment of conditions associated with aging.

Transitioning clients to Medicare is of major importance. CAREAssist staff, in partnership with HIV case managers, provide coordination and enrollment services for persons enrolling in Medicare Part D. CAREAssist staff monitor age and disability status of 2,224 eligible Medicare clients (as of January 2010), assuring that persons transition smoothly from the Oregon Medical Insurance Pool (OMIP) or the Oregon Health Plan (Medicaid) to Medicare coverage. CAREAssist fully supports Medicare policies to include premiums, prescription co pays and non-prescription co pays. Since 2009, CAREAssist has been covered by Oregon's Statewide Pharmacy Assistance Program (SPAP) so all co-pay assistance made for Medicare Part D client's counts toward the client's out-of-pocket expenses and allows CAREAssist to buy a client through the Medicare Part D "donut hole." Additionally, the program continues to pay for medical service co pays and deductibles which reduces barriers for seniors and older PLWH/A's so that they can receive treatment for the whole spectrum of health care conditions associated with aging, not only HIV.

## **Women**

As of December 31, 2009, women comprised 13% of PLWH/A statewide, including 10% of PLWH/A in the Portland TGA and 19% in the Balance of State. Women with HIV in Oregon are more likely to have HIV than AIDS.

The age-adjusted annual risk of death for female PLWH/A is 11 times higher than for Oregon women overall. Women need accessible primary care providers who have specialized knowledge of HIV and women's health, as well as coordinated access to specialists for treatment of HIV related illnesses and common co-morbidities such as mental disorders and co-infection with hepatitis or STD. The higher proportion of female PLWH/A with current or past history of IDU requires access to substance abuse treatment services, and may indicate greater levels of poverty and/or social isolation. Case management services are particularly important for this population to help coordinate care and keep clients engaged. Women need to receive HIV prevention and early intervention messages in conjunction with their HIV care, and in places where they congregate. All services for female PLWH/A must be gender and culturally

appropriate, and childcare should be available to clients while they are receiving other services.

Women participating in 2011 Listening Sessions reported feelings of isolation and indicated a need for social support and peer support. Some women participating in the sessions stated that they had never met another woman with HIV, despite being infected for many years.

## **Dual Diagnosis of Mental Illness and Substance Abuse**

No surveillance data are available on co-occurring HIV disease, substance abuse and mental health disorders, but local needs assessment data show high prevalence of these conditions among PLWH/A and a corresponding high need for services.

Because of Oregon's unique combination of universal health insurance coverage for PLWH/A available through CAREAssist and comprehensive mental health insurance parity, the majority of clients are eligible to receive a full range of behavioral and mental health services through their insurance provider. However, PLWH/A with mental illness and/or substance abuse diagnosis still face multiple challenges to initiating, engaging and remaining in care. These include a lack of treatment readiness; a shortage of culturally competent providers, especially in less populated areas of the state; and mismatches between available providers and client insurance type.

High levels of case management and service coordination are required to reduce the interference of psychiatric disorders, medications, and illegal drugs with HIV medical treatment. These services, particularly mental health services, must be designed and delivered in a manner that is culturally appropriate for ethnic and sexual minority populations. As both mental illness and substance abuse are chronic conditions, access to appropriate services must be assured for extended periods of time, and treatment must be adjusted to varying levels of acuity over time. Mental health and substance abuse treatment services must be able to be accessed quickly in the case of an emergency, and must be coordinated with primary HIV care. However, mental health and substance abuse providers do not have a systematic way of knowing the HIV status of their clients, so unless clients disclose their own status, treatment in relation to HIV-specific issues is difficult.

## **People who Inject Drugs**

Nineteen percent of all Oregon cases reported injection drug use (IDU) as a risk factor, either solely or in combination with sexual transmission risk (MSM or females with heterosexual transmission risk). In addition, 3% of Oregon cases reported heterosexual contact with an IDU as their transmission risk for HIV, representing an indirect link to IDU as the source of their infection.

Since 1997, there has been a slow, steady decline in the number of diagnosed HIV cases reporting IDU transmission risk in Oregon. However, many people with IDU risk are diagnosed with AIDS within 12 months of their first positive HIV test. In addition, people with IDU risk are less likely to be engaged in HIV-specific medical care, as

evidence by their lower likelihood of having CD4 or viral load tests reported to the surveillance system compared to people with other transmission risks. Finally, people with IDU risk have a significantly shorter survival time compared to others.

People with IDU risk have service needs for medical care that follows a harm reduction model (e.g., not “firing” clients from medical care for drug use), for drug treatment services, and for access to clean syringes through syringe exchange programs and availability of syringes for purchase without prescription through pharmacies.

## **Homeless/Unstably Housed PLWH/A**

Homelessness is a major risk factor for HIV, and HIV is a major risk factor for homelessness. National data show the prevalence of HIV/AIDS to be three to nine times higher among persons who are homeless or unstably housed compared with persons with stable and adequate housing, depending upon the population and geographic area studied. Furthermore, up to 60 percent of all persons living with HIV/AIDS report a lifetime experience of homelessness or housing instability.

Similar to other parts of the nation, housing for PLWH/A continues to be an area with high service needs and gaps in Oregon. Despite comprehensive housing programs, some PLWH/A in Oregon remain homeless, as competition for limited resources is intense. Section 8 waiting lists are extremely long or simply closed in most communities, which results in clients remaining on HOPWA programs for longer periods of time than expected. In addition, the recession and high unemployment rates have resulted in more competition for scarce housing resources.

Housing status has profound implications for persons living with HIV/AIDS. Data from multiple studies (as well as local experience) show that PLWH/A need stable housing in order to negotiate bureaucracies, file entitlement applications, keep appointments, and access social and medical services. Research indicates that homeless PLWH/A are more likely than stably housed PLWH/A to report a wide range of negative health outcomes, including lower CD4 counts, less likelihood of undetectable viral loads, poorer self-reported ART adherence, and less likelihood of current treatment with ART. Stable, adequate housing is an important factor in promoting consistent ART adherence and avoiding consequent drug resistance.

Consequently, HIV case managers spend a high proportion of service time assisting homeless and unstably housed clients to maintain their health insurance, adhere to HIV medicines, and obtain and retain stable housing.

## **Adolescents**

In 2009, 10% of new HIV diagnoses were among individuals aged 13-24 (n=24 cases).

In 2008, the Oregon State Public Health Lab reported 2605 HIV tests conducted in Multnomah County among youth age 13-24 at Multnomah County Health Department sites (n=1745), Cascade AIDS Project (CAP) (n=62), and Outside In (OI) (n=798); 1.1% of tests were positive (n=28). The most commonly reported risk factors among

testers age 13-24 were MSM (38%), IDU (12%), and partner at risk (5%); 3.3% reported MSM/IDU risk.

Anecdotal information indicates that homeless youth may be a group of adolescents at high risk of HIV infection. Few local data exist related to HIV risk behavior and seroprevalence among homeless youth in the Portland area and/or in Oregon. The most recent local seroprevalence study, conducted between 1994 and 1997, found the HIV seroprevalence among a group of homeless Portland youth to be 0.3%. More recent national estimates vary, ranging from 1.1% -17%, depending on the city, population, and age cohort.

HIV risk factors among homeless youth include survival sex, MSM sexual activity, IDU and other drug use, sexual assault and coercion, and elevated rates of STD infection. Between 20-40% of all homeless youth identify as lesbian, gay, bisexual, transgender, queer, or questioning.

### **Transgender Individuals**

HIV surveillance data only report two genders: male and female. Consequently, we do not know how many PLWH/A in Oregon identify as transgender, nor do we know how many PLWH/A who currently identify as male or female were assigned a different sex at birth.

In 2009, 843 Portland metropolitan area individuals who identified as lesbian, bisexual, gay, transgender, or queer completed the Speak Out survey, which included a range of health data. Transgender-identified individuals reported significant disadvantages in accessing health care, higher rates of mental health issues, and more days of physical and mental disability. However, no transgender individuals identified as HIV+ compared to 18% of those identifying as male and <1% of those identifying as female.

## **Cross-Cutting Service Goals and Issues:**

Members of the SCSN 2011 Advisory Group agreed that the four themes identified in 2008 remained a good way to organize the cross-cutting service goals and issues:

- **Preventing new HIV infections,**
- **Finding HIV+ people who need care and treatment services,**
- **Engaging HIV+ people in care and treatment services, and**
- **Retaining HIV+ people in care and treatment services.**

We acknowledge that there is overlap between these four areas and that actions in one area often affect the others (e.g., engaging and retaining people in care can prevent new infections).

## **Service Needs Identified by the SCSN 2012 Planning Process**

The group identified a need to build stronger links between HIV prevention and care services, in order to prevent new HIV infections and to link newly infected people into care earlier. According to the group, we need to focus on vulnerable populations in order to find HIV+ people who are out of care. We also need to test people in a larger variety of settings and develop effective systems for seamlessly triaging newly diagnosed individuals into care. One important means for developing these stronger links between prevention and care, and achieving our shared goals in the future, will be the new Integrated Planning Group for HIV, a combined statewide HIV care services and prevention planning group in Oregon.

In addition, there is a need to build bridges to “mainstream” social services, in order to engage HIV+ people in care, and to provide a full spectrum of disease management services to HIV+ people as early as possible. Funding shortages coupled with increasing case loads make creation of a parallel HIV service system unfeasible, so there is a need to move clients between the RWCA system and other general social service programs and community services. Referrals outside of the RWCA system can be tricky, however, and provide opportunities for HIV+ clients to “fall through the cracks.” Facilitated referrals work better than simply giving clients a phone number; RWCA providers need to develop better systems for collaborating with a wide range of services for clients and ensuring a smooth transition for clients between programs and services.

Likewise, there is a need for more responsive services for HIV+ people, in order to keep them retained in care. The group said that integrated behavioral health services are needed, since both active substance abuse and untreated mental illness impede medical care. However, there are many barriers to accessing substance abuse and mental health services for HIV+ clients, including limited treatment modalities and insurance difficulties. Services tailored to older PLWH/A are also in ever greater demand, with the aging of the HIV+ population. Each part of the RWCA system is responsible for identifying and working to remove client barriers, wherever possible. Identified needs for system changes included coordinating intake forms, providing client-centered care,

track appointments and making follow up phone calls to clients, soliciting provider input, and triaging clients to specialty and/or “mainstream” providers or disease management programs, where appropriate.

Finally, on a broader scale, the group identified a need for ongoing evaluation and assessment, in order to ensure that we are using our limited funds in the most efficient and beneficial manner. The group also advocated for identification of promising evidence-based models for delivering care and treatment services, without imposing a one-size-fits-all approach onto very different populations across the state. The group called for honest assessments of service capacity in different regions; rural areas face additional challenges related to resources and need creative approaches to service delivery. For the long-term, the group advocated for an upstream approach to service delivery, framing our goals broadly to address specific service needs, but to also address structural factors like poverty, racism, and homophobia, in our efforts to prevent and treat HIV disease in Oregon.

## **Broad Goals Defined by the SCSN 2012 Workgroup**

The group identified the following broad goals within each of the four thematic areas:

1. Preventing New HIV Infections:
  - Develop stronger linkages between HIV care and treatment and HIV prevention
  - Develop and disseminate consistent messages around HIV testing and linkage to care & treatment that:
    - i. can be used in a variety of sites (e.g. private providers/primary care, hospitals, emergency rooms, correctional settings);
    - ii. are consistent with CDC guidelines for routine screening and risk reduction messaging for high risk groups, and
    - iii. harness the power of social media (e.g., Facebook, twitter, online education, other social media).
  - Shore up “prevention with positives” efforts using DIS and other early intervention service modalities.
2. Finding HIV+ People Who Need Care and Treatment Services:
  - Continue to gather data to better understand why people are out of care
  - Develop evidence-based systems to follow up on people who fall out of care
  - When looking for people who may be out of care, go beyond “emerging populations” and consider larger social determinants of disease transmission (e.g. poverty, marginalization, and access to education and health care).
  - Increase access to testing
3. Engaging HIV+ People in Care and Treatment Services:
  - Shore up early intervention services, particularly in the Balance of State
  - Identify and reduce system barriers, particularly in the period immediately following diagnosis (possibly via peer advocates/health navigators)

- Develop flexible models of care that better reflect client needs and do not attempt a “one size fits all” approach. Target disparate populations with culturally relevant approaches to care and prevention.
4. Retaining HIV+ People in Care and Treatment Services:
- Develop client-centered approaches to care and adoption of patient centered medical home models, as health care reform, including adoption of Coordinated Care Organizations, is implemented in Oregon.
  - Implement and promote self-management programs and tools for clients further along disease management continuum.
  - Develop strong linkages between systems so clients don’t fall through the cracks and cross-agency collaborations are maximized.
  - Engage in evaluation/assessment/continuous quality management to ensure that services are accomplishing intended goals.

## Appendix A: SCSN 2012 Advisory Group Roster

Name	Agency/Affiliation	Title
Annick Benson-Scott	Oregon Health Authority Part B Grantee	HIV Community Services Manager
Jeff Capizzi	Oregon Health Authority HIV Surveillance/Data & Analysis	Epidemiologist
Tom Cherry	Part A HIV Planning Council	Co-Chair/Community Member
Jodi Davich	HIV Health Services Center Part C Grantee	HIV Clinic Manager
Linda Drach	Oregon Health Authority Program Design & Evaluation Services	Research & Evaluation Manager
Robert Duehmig	Oregon Office of Rural Health	Communication Director
Heidi Eidler	Eastern Oregon Center for Independent Living (EOCIL)	Director of Programs & Services
Victor Fox	Oregon Health Authority Part B Grantee	HIV Care and Treatment Program Manager; Co-Chair, CAREAssist Advisory Committee
Alison Frye	HIV Health Services Center Part D Grantee & Part A Planning Council	Program Manager
Ruth Helsley	Oregon Health Authority HIV Prevention	HIV Prevention Manager
Kelly Jurman	Washington Co Health Dept	Program Manager
Kristin Kane	Cascade AIDS Project	Director of Housing and Supportive Services
Veda Latin	Oregon Health Authority HIV/STD/TB Programs	HIV/STD/TB Programs Section Manager
Jude Leahy	Oregon Health Authority HIV/STD/TB Programs	Adult Viral Hepatitis Prevention Coordinator
Dana Lord	Clackamas County Health Dept	HIV Case Manager
Amanda McClusky	HIV Alliance Part F/SPNS Grant	Dental Program Coordinator
Tom McConnell	Oregon HIV Care Coalition	Member, Community Member
Susan McCreedy	Deschutes County Health Dept	HIV Case Manager
Wayne Miya	Our House of Portland HOPWA Provider	Director
Christy Myers	Oregon Health Authority Part B Grantee	Grants Coordinator
Erin Nortrup	Cascade AIDS Project	Manager, CARELink Program
Karen Pancheau	Oregon HIV Care Coalition	Co-Chair, Community Member
Steven Pierson	AIDS Education & Training Ctr	Program Manager
Thomas Rafalski, MD	Private practice AETC clinician	Physician
Margy Robinson	Multnomah County Health Dept Part A Grantee	HIV Care Services Manager Quality Management Taskforce Co-Chair
Stephanie Craig Rushing	Portland Area Indian Health Board: Red Talon Project	Project Director
Valerie Rux	Oregon Health Authority Division of Medical Assistance Programs	Healthy Kids Program Coordinator

## Appendix A: SCSN 2012 Advisory Group Roster (Continued)

<b>Name</b>	<b>Agency/Affiliation</b>	<b>Title</b>
John Scharff	HIV Statewide Planning Group	Community Member
Ann Shindo	Oregon Department of Corrections	HIV & Hepatitis Prevention Coordinator
Robert Skinner	HIV Prevention State Planning Group	Co-Chair, Community Member
Marilee Smith	Kaiser Permanente	Case Manager/LPC
Debbie Spicer	Lincoln County Health & Human Services	Nurse Case Manager
James Strohschein	Oregon Health & Sciences Univ. Russell Street Dental Clinic/Part F	Director
Kim Toevs	Multnomah County Health Dept Part A Grantee	Program Manager, HIV/STD, HCV Programs
Tasha Wheat-Delancey	Cascadia Behavioral Health	Clinical Supervisor
Renee Yandel	HIV Alliance	Program Manager

## Appendix B: SCSN 2012 Timeline and Key Tasks\*

Date/Deadline	Activity	Staff Responsible
5/3/11	OHCC meeting—introduce proposed SCSN process to key stakeholders; solicit feedback on process and Steering Committee membership	PDES
May 2011	Refine SCSN process. Begin to assemble Steering Committee based on input from OHCC/ stakeholders and HRSA guidance	PDES
June 2011	Set Listening Session dates and logistics; promote participation through Steering Committee, case managers, agencies, etc	PDES
August 2011	1st Contact with SCSN Advisory Group: Review roles & responsibilities, timelines, etc	PDES
August/Sept 2011	2 <sup>nd</sup> contact with SCSN Advisory Group: Solicit feedback on Listening Session logistics and guide	PDES
Sept & Oct 2011	Conduct in-person “Listening sessions” in Eugene and Medford. Conduct interviews with clients in Eastern Oregon and other rural parts of the state.	PDES
Sept 2011	3 <sup>rd</sup> contact with SCSN Advisory Group: Discussion of cross-cutting themes	PDES
Oct 2011	Transcribe, compile, and identify themes from Listening Session and interview data.	PDES
	Synthesize Listening Session data with all other data sources (Epi, data from Portland Listening Sessions, etc)	PDES
	4 <sup>th</sup> contact with SCSN Advisory Group: Share Listening Session data and solicit feedback. Continue discussion of cross-cutting themes.	PDES
Oct 2011	5 <sup>th</sup> contact with SCSN Advisory Group: Ask for feedback on continuum of care section of document.	PDES
Nov 2011	Complete final draft of SCSN document	PDES
Nov 2011	Present data in SCSN document to OHCC. Use for development of the Comprehensive Plan.	PDES & HST Program
Dec 2011	6 <sup>th</sup> contact with SCSN Advisory Group: Distribute final draft of SCSN document and solicit feedback during 3 week comment period	PDES
Dec 2011	Integrate feedback. Finalize SCSN document.	PDES
2012	Submit final document to HRSA	HST

\*Oregon conducted the SCSN in 2011, despite HRSA pushing the due date back to June 2012, because we are starting a new integrated HIV care and prevention statewide planning body in January 2012. This body replaces the former groups, OHCC (for care services) and SPG (for prevention). We felt it would be unrealistic and unfair to the new body to ask them to complete the SCSN planning process & Part B Comprehensive Plan during their first 6 months as a group, so we completed the processes early, through the involvement of the existing care group (OHCC) and a representative, ad hoc SCSN Advisory Group.

## **Appendix C: Data Sources Used in Creating the SCSN 2012 Document**

Aidala A. Inequality and HIV: The role of housing. *Psychology and AIDS Exchange*, American Psychological Association, Office on AIDS, 34:3-5; 2005.

Aidala A, Lee G, Abramson D, Messeri P, Siegler A. Housing need, housing assistance, and connection to HIV medical care. *AIDS and behavior* 2007; 11(6 Suppl):101-15.

CAREAssist program data: extracted from Oregon's CAREAssist (ADAP) database in 2011.

Culhane DP, Gollup E, Kuhn R, and Shpaner M. The co-occurrence of AIDS and homelessness: Results from the integration of administrative data for AIDS surveillance and public shelter utilization in Philadelphia. *Journal of Epidemiology and Community Health*, 55 (7): 515-520; 2001.

Drach L. Speak Out Survey 2009: Measuring Health and Wellness among Portland's Lesbian, Gay, bisexual, Transgender, Queer, Genderqueer, and Intersex Communities. Portland, OR: Program Design & Evaluation Services, 2010.

Drach L, Cordova D. Descriptive Epidemiology of Newly Reported Hispanic HIV/AIDS Cases in Oregon. Portland, OR: Program Design & Evaluation Services, 2010.

Drach L, Van't Hof S, Desai N. 2009 CAREAssist Client Survey: A Report on Clients' Health, Well-Being and Experiences with the Program. Portland, OR: Program Design & Evaluation Services, 2010.

Drach L, Greene K, Rumptz M. Eating Right when Money's Tight: Evaluating the Need for Food and Nutritional Assistance among Ryan White Part B Clients. Portland, OR: Program Design & Evaluation Services; December, 2007.

HIV/STD/TB Programs. 2009 HIV/AIDS Epidemiological Profile. Portland, OR: HIV/STD/TB Programs, Oregon Department of Human Services, Public Health Division; 2010.

HIV/STD/TB Programs. Oregon Medical Practices that Provide HIV Care: 2008 Snapshot. Portland, OR: HIV/STD/TB Programs, Oregon Department of Human Services, Public Health Division; April 2008.

Jenkins L. Ryan White Part A Community Forums Report. Multnomah County Health Department: Portland, OR; 2011.

McLaughlin M, Jenkins L, Elman M, Smith C. 2010 STD/HIV/Hepatitis C Program Annual Report. Multnomah County Health Department: Portland, OR; 2011.

Medical Monitoring Project, unpublished data (2009/2010), extracted from MMP dataset in 2011.

Program Design and Evaluation Services. Estimated Prevalence of Mental Health and Substance Abuse Issues among HIV-Positive Oregonians, January 2002 (internal, unpublished document).

Van't Hof S. Behavioral Health Care for People Living with HIV in Oregon. Portland, OR: Program Design & Evaluation Services; October 2008.

## **Appendix D: Summary of 2011 Ryan White Client Listening Sessions and Interviews**

### **Objective:**

To collect qualitative data from Ryan White Parts A and B clients about service needs and gaps and satisfaction with services. In addition, Part B clients were asked about their entry into HIV medical care and experiences, if any, with being out of medical care.

### **Methods:**

Staff members from Multnomah County Health Department conducted Community Forums with groups of Ryan White Part A clients using a semi-structured interview guide. The goal for consumer participation was to obtain a heterogeneous sample of individuals with a cross-section of experience in the Ryan White system. Community Forums took place in April and May 2011.

Staff members from Program Design & Evaluation Services (PDES) facilitated group Listening Sessions and conducted individual telephone interviews with Ryan White Part B clients using a semi-structured interview guide. Interviews and Listening Sessions took place in October 2011.

### **Participants:**

A total of 63 Part A and 43 Part B Ryan White clients participated in these activities, as follows:

- There were a total of 6 community forums in the Portland metropolitan area conducted with 63 members of the following Ryan White Part A sub-populations:
  - Spanish speaking individuals (n=9)
  - Communities of color (n=11)
  - Women (n=12)
  - Men who have sex with men (n=11)
  - Low-income individuals (n=10)
  - Clark County residents (n=10)
- 2 Listening Sessions were conducted in two different geographic areas of the Part B region:
  - Eugene (n=22)
  - Medford (n=4)
- Individual interviews were conducted with 17 clients living in more rural areas of the state, primarily the Central and South Coast, Central Oregon, and Eastern Oregon.

## **Appendix D: (continued)**

### **Summary of 2011 Ryan White Client Listening Sessions and Interviews**

#### **Brief Summary of Part A Community Forum Findings:**

Overall, clients at several forums elaborated upon the need for housing and for dental care. Substance abuse treatment was also mentioned as a necessary service but there was no elaboration on concerns with existing services. While there was an appreciation for the coordination and referrals that case managers offer, clients also expressed frustration with having multiple case managers who specialize in different services (medical, housing, CAREAssist etc.), instead of having one case manager who could meet all of their needs. In addition, clients conveyed that some of their needs may be met through “mainstream” service providers and that there is not always a need for HIV-specific services.

Additional information about the Part A Community Forums is available at: Jenkins L. Ryan White Part A Community Forums Report. Multnomah County Health Department: Portland, OR; 2011.

#### **Brief Summary of Part B Listening Session and Interview Findings:**

Several themes emerged across the interview and listening session data. Overall, clients across the Part B region reported that access to HIV medical care, health insurance, and many supportive services is generally easy for those who are ready to engage with those services. The previously yawning gap in dental care was reported to be mostly filled by services provided by Clock Tower Dental. However, rural clients identified ongoing challenges with remaining engaged in HIV medical care because of transportation difficulties and lack of local options. Even clients in more populated areas of Part B said that travel may be necessary to access certain services, like dental care or mental health services, and this can be a barrier. Also, clients in many areas of the Part B region said that HIV stigma is still common (e.g., among doctors or pharmacists).

Many Part B participants reported having been out of HIV medical care at some point after receiving their HIV diagnosis. The reasons given for being out of care were almost exclusively individual-level reasons, rather than system-level reasons. The main reasons given for being out of care were: denial/depression, side effects of HIV medications and/or fear of starting HIV medications, alcohol and drug abuse, and interpersonal issues with the HIV doctor. Part B clients reported two reasons for entering or re-engaging with HIV medical care: 1) they got very sick, so had no choice or 2) a friend, family member, or another person reached out to them and got them connected.

Themes of isolation and “feeling alone” were common and some also reported feeling confused about how to access services after first diagnosis. Many Part B clients identified a need for peer support and/or peer navigation services to help bridge the gap between first diagnosis and entry into HIV medical care and services.