

V. RWCA SERVICE CATEGORIES IN FOCUS

This section of the report will both organize and elaborate on quantitative findings in Part IV and will elaborate on barriers relating to unmet need through the use of qualitative information for each of the 20 Ryan White CARE Act service categories. The qualitative information is presented by themes of topics discussed in survey comments, consumer focus groups, and provider interviews with regards to consumer unmet need, and system level issues for each respective service. Quotes are included to help illustrate some of the major themes discussed. It is important that the qualitative information is interpreted and analyzed in conjunction with quantitative findings as the information is not representative of all PLWH living in Seattle and King County. However, the information will describe unmet needs for consumers, barriers, sub-population differences, and system-wide issues in the Continuum of Care. In many cases, especially for lower ranked service priorities and gaps, there was little or no qualitative information reported. Services are presented in alphabetical order.

AIDS DRUG ASSISTANCE PROGRAM (ADAP)

ADAP: On-going service/program to pay for approved pharmaceuticals/ medications for persons who are un- or under-insured.

Health Insurance: A financial assistance program to assist eligible low income individuals with HIV disease in maintaining a continuity of health insurance or receiving medical benefits under a health insurance program including risk pools. Assistance is not to be utilized to pay any costs associated with the creation, capitalization, or administration of a liability risk pool and to pay any amount expended by a State under Title XIX of the Social Security Act.

On the survey this service was divided into two sub-categories that were listed as “AIDS Drug Assistance Program (ADAP),” and “Assistance paying for medical insurance premiums.”

Overall service priority, gap, utilization

AIDS Drug Assistance Program (ADAP)	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	3	63%	4	65%
Service Gap	8	19%	7	24%
Service Utilization	3	71%	---	---

ADAP was the only service category that had a significant decrease in priority for providers (down 11% from 2003). However, even with this decrease in percentage of

providers who prioritized this service, ADAP was still ranked as a top five service priority. Providers and consumers ranked ADAP as a top 10 service priority and service gap indicating the magnitude of potential system inadequacies. From 2003, significantly more providers reported a service gap for ADAP (+8%).

A consumer survey respondent described the importance of ADAP and insurance assistance to his substance abuse recovery:

I am frightened to think of where I would be without ADAP or premium payment assistance for health insurance. The costs are so prohibitive. I'm almost a year sober (from crystal meth injection use) and my life is improving quickly. [MSM/IDU FG]

Component services priority, gap, utilization

The ADAP service category currently consists of the AIDS Drug Assistance Program and Health Insurance. In comparing the individual services, consumers were more likely to prioritize ADAP, while providers were more likely to prioritize Health Insurance. In comparing provider versus consumer survey responses, providers were significantly more likely than consumers to prioritize both services, and more providers also identified a service gap in both services.

ADAP	Consumer % (N=436)	Provider % (N=187)
AIDS Drug Assistance Program (ADAP)		
Service Priority	50%	60%
Service Gap	10%	12%
Service Utilization	57%	---
Health Insurance		
Service Priority	39%	72%
Service Gap	15%	21%
Service Utilization	56%	---

Provider survey respondents described the changes to Medicare making access to medical care very difficult for many clients. Clients have to pay more spend-down because EIP is able to pay less due to new Medicare part D rules. A consumer survey respondent stated his frustration with spending down:

I don't have a lot of assets, but those I do have disallow me for assistance with drug/insurance programs. I'm spending down what I have and will soon be broke. [consumer survey]

The ADAP service category was third in ranking of RWCA services in terms of

consumer utilization (71%). About half of consumer respondents indicated use of both services currently provided in the EMA. Populations significantly more likely to utilize ADAP were: foreign born, recently homeless, recently incarcerated, and Latino/a. Foreign born Latinos were significantly more likely to utilize Health Insurance.

There was no significant difference by sub-population in priority or service gap for ADAP.

Unmet need: barriers to accessing ADAP services

Qualification requirements too restrictive

While disability is in no way a requirement for the program, consumer respondents who were not certified AIDS-disabled were significantly more likely to identify gaps to Health Insurance (20%) than those who were certified AIDS-disabled (10%). However, of those who indicated not being certified as AIDS disabled and had unmet need for ADAP services (n=31), 11 had income levels too high for eligibility requirements. A consumer survey respondent who was not certified as AIDS-disabled illustrated the frustration to increasing gaps to insurance coverage:

The biggest thing I have noticed in the last two years is the cut back in funding for much needed programs for those of us living with HIV and all on a very limited income. Now we are being asked to pay out of pocket even more next year? I realize the State has to fund its many programs but when are the cuts going to stop? I truly wonder if people will stop taking their meds due to the sheer inability to pay for them. [consumer survey]

Consumer survey respondents commented on their frustration with the qualification requirements for ADAP services. Eighteen percent of consumer survey respondents who said they needed but could not get ADAP services identified qualification as the barrier to their unmet need. One survey respondent expressed his frustration:

I pay out of pocket my insurance, 1520 every 2 months. That's 1/2 of my monthly income and I have to pay up front just because I'm no longer eligible for insurance help. That's not fair. [consumer survey]

Confusion about availability and changes to services

Even greater barriers to ADAP services for those respondents with unmet need were consumers who did not know that the services existed (47%) and did not know where to go to access these services (27%). This service gap may relate to the issues with caseloads and unmet consumer needs with case management assistance described in the case management section of this report in further detail. Several consumer survey respondents wrote questions about ADAP and Health Insurance on the survey illustrating some of the confusion about eligibility and changes to Medicare.

ALTERNATIVE NON-WESTERN MEDICAL CARE

The provision of primary or complimentary non-allopathic medical care and medicinal treatments designed to enhance the immune system, reduce the incidence of opportunistic infections, relieve debilitating symptoms of HIV/AIDS (such as pain, fatigue, neuropathy and diarrhea), ameliorate medication side effects and provide mental/emotional care to reduce depression, anxiety and despair, including naturopathy, acupuncture, Traditional Chinese Medicine (TCM).

On the survey this service was not divided into any sub-categories and was stated as “Alternative medicine (acupuncture, herbal medicine, naturopathy etc).”

Overall service priority, gap, utilization

Alternative non-Western Therapies	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	9	28%	14	11%
Service Gap	3	30%	8	18%
Service Utilization	14	31%	---	---

Alternative non-Western therapies were ranked the second highest service gap for consumers with a significant increase in service gap from 2003 (+12% of consumers). Consumers were significantly more likely than providers to both prioritize and indicate a service gap for alternative non-Western therapies.

The disparity between consumers and providers indicating a service gap for alternative non-Western therapies increased significantly from 2003. Consumer response also indicates potential system inadequacies with this service ranked both as a top ten service priority and top ten service gap. There was no significant difference between Western-medical providers and non-Western-medical providers prioritizing or indicating a service gap to Alternative non-Western therapies.

Thirty-one percent of consumer respondents indicated using alternative non-Western therapies. Recently incarcerated, female, and non-MSM respondents were significantly more likely to utilize these services.

Unmet need for alternative non-Western therapies

Of those consumer respondents with unmet need for alternative non-Western therapies (n=130), the most common barriers indicated were “Don’t know where to go (47%),” and “Don’t know it exists,” suggesting the need for more education and outreach about available alternative therapy services for PLWH in Seattle/King County. For those who

knew of existing services, the most common barriers described in focus groups and surveys were the financial costs, insurance coverage, and availability.

System-wide issues versus preference of type of care

Some medical providers in surveys noted that if clients were supported by insurance companies to cover the cost of natural products to boost and keep the immune system strong (ie vitamins, minerals, herbs), many would choose to try the naturopathic way before trying the HAART drugs. Consumer survey respondents that had unmet need for alternative non-Western therapies were significantly more likely to also have unmet need for ambulatory/outpatient medical care (11%). Of those consumers that used alternative non-Western therapies (n=135), 93% also used ambulatory/outpatient medical care. Most respondents that had unmet need for ambulatory/outpatient medical care also had unmet need for alternative non-Western therapies (15 out of 20). These findings are likely due to RWCA rules requiring that Care Act dollars only be used to pay for alternative therapies when referred by an ambulatory outpatient medical provider. These findings support the earlier statement that the barriers lie with more system-wide issues to accessing alternative care (insurance, costs, and availability), than a preference between western and non-Western therapies.

Alternative Medicine and Naturopathic medicines, the doctors and clinic apts are available to me, the medicines, even at the discounts offered are non-affordable for me. If I can't afford the meds, why go to the apts? [consumer survey]

Unmet need for MSM of Color/ Recently Incarcerated/ and MSM/IDU

MSM of Color (40%), recently incarcerated (47%), and MSM/IDU (46%) were significantly more likely to have unmet need for alternative non-Western therapies. Providers that work with recently incarcerated clients offered insight into this disparity. Because recently incarcerated PLWH are more likely to be in immediate need of critical services such as housing and basic needs, case managers may be less likely to bring up the possibility of referral to clinics/agencies offering non-Western therapies. In a provider interview, a case manager reported that recently incarcerated folks don't always have the best follow up, so their case managers may be working to establish baseline stability for longer periods of time. Also reported in an interview was the perception among many case managers and medical providers that non-Western therapies are a compliment to primary medical care/essential services, and thus assume a lower priority.

Recently incarcerated, MSM of Color, and MSM/IDU are traditionally underserved populations that often come from more disadvantaged backgrounds. This means they may be less likely to be aware of the existence of non-Western therapies, and if so, less likely to think that these would be available to them at no or low-cost. They are thus less likely to self-refer (i.e., request the service referral from a primary care provider).

Providers who had clients accessing RWCA alternative non-Western therapies described them as stable and having high levels of engagement with the continuum of care in terms of being housed, sober, stable with department of corrections, engaged with mental health

care, and taking HIV medications on time. MSM/IDU and recently incarcerated PLWH, as mentioned above, may need to address their more immediate needs for care before considering alternative therapies.

AMBULATORY/OUTPATIENT MEDICAL CARE (Medical Care)

The provision of professional diagnostic and therapeutic services rendered by a physician, physician’s assistant, clinical nurse specialist or nurse practitioner in an outpatient, community-based and/or office-based setting. This includes diagnostic testing, early intervention and risk assessment, practitioner examination, medical history taking, diagnosis and treatment of common physical and mental conditions, prescribing and managing medication therapy, care of minor injuries, education and counseling on health and nutritional issues, minor surgery and assisting at surgery, well-baby care, continuing care and management of chronic conditions, and referral to and provision of specialty care. The provision of primary medical care must be consistent with Public Health Service guidelines. Such care must include access to antiretrovirals and other drug therapies, including prophylaxis and treatment of opportunistic infections and combination antiretroviral therapies.

On the survey this service was not divided into any subcategories and was listed as “Medical care (doctor, nurse, etc.)” on the questionnaire.

Overall Service priority, gap, utilization

Ambulatory/outpatient medical care	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	2	64%	2	71%
Service Gap	20	4%	16	7%
Service Utilization	1	92%	---	---

Ambulatory/outpatient medical care was ranked as the second highest service priority by both consumers and providers and a greater percentage of providers (71%) prioritized medical care than consumers (64%). White MSM were significantly more likely to prioritize ambulatory/outpatient medical care than MSM of color, or non-MSM.

Ambulatory/outpatient medical care was identified as a lower service gap than most other RWCA service categories by both consumers and providers. A greater percentage of providers indicated that medical care was a service gap (7%) than did consumers (4%). For the most part consumer focus group participants were satisfied with the care they received from their medical provider.

My medical care has been really good too, I go to [name omitted] clinic, and it's been top notch. I've lived in 4 different states and this is the best medical treatment that I've gotten out of all those. [MSM/IDU FG—white male]

Unmet need for ambulatory/outpatient medical care

There were no significantly higher gaps to ambulatory/outpatient medical care by subpopulation.

Stigma about HIV among providers not familiar with the disease

The most common issues with medical care discussed in focus groups had more to do with the treatment environment rather than the effectiveness of treatment. Consumers noted a difference in how they were treated by those Providers who mostly see HIV positive clients versus other providers. Providers who did not regularly see HIV positive patients treated the HIV positive clients differently because of their status. In some cases clients would switch medical providers several times before finding a doctor with whom they were comfortable. Outside of the few medical facilities focusing on HIV in Seattle it was challenging for clients to find medical providers who they felt did not discriminate against them because of their HIV.

I've got doctors literally to my face turn me down saying they will not touch me because I'm HIV positive [WHITE MSM FG]

There is no choice really. I was trying to deliver my son at [hospital name omitted] and they wouldn't even examine me. So, [clinic name omitted] is a great clinic, but its hard to find anywhere else that will touch you. [WOMEN's FG]

The Congress has placed an increased emphasis on the need to identify individuals who know their HIV status but are not receiving HIV-related medical care. The CARE Act was amended as part of the 2000 reauthorization in an effort to get PLWH into care as soon as possible after their HIV diagnosis and to ensure retention in HIV-related medical care.

The consumer survey asked respondents if they used medical care, did not need or want medical care, or needed but could not get medical care. Of the 436 valid responses to this question, 92% of survey respondents reported current use of medical care. This figure is slightly less than the 94% utilization of respondents in 2001 and 2003. Four percent of respondents (17 out of 436) reported that they needed, but could not get medical care, slightly higher than the 2% of respondents with unmet need in 2003. Of the 17 respondents that indicated unmet need for medical care only one respondent indicated that they were certified by their doctor as AIDS disabled (8 indicated they were not AIDS disabled, and 8 others did not know).

Over half of the consumer respondents that indicated unmet need for medical care, also indicated knowing their T-cell count and viral load which indicates that they had some

medical care. Ten of the 17 respondents knew their T-cell count (3 within the range of 200-500, and 7 respondents with counts above 500). Ten of the 17 consumers knew their viral load (4 with undetectable levels, and 6 less than 12,000). Nine of the 17 respondents with unmet need for medical care are taking antiviral medications, 4 are taking drugs for opportunistic infections, and 5 are taking drugs to manage side effects.

The fact that these respondents know their lab results but have indicated unmet need for medical care reflects that their “need” may have to do with the quantity or quality of care they feel they are lacking. Consumer survey comments regarding medical care reflected this sentiment.

I would also like any doctor to be more specific and not rush through my appointment time. Like is there a quota per hour or day that they have to rush you out? [consumer survey]

I have serious concerns about the quality of my healthcare. Existing grievance and state procedures are inadequate as higher-ups and state officials simply ratify the act of providers. There are no independent impartial arbitrators. [consumer survey]

Some focus group participants talked about having problems with poor treatment by front desk staff at medical facilities and medical providers other than their primary medical providers (specialists). It is also possible that the consumers with high T-cell counts and low viral loads have never been put on HAART therapy, which may well be appropriate in these cases. Additionally, consumers may have unmet needs for specialty care. Provider survey comments from medical care providers reflected this unmet need of their clients.

Many of their treatment plans are beyond the scope of our practice. We (they) need financial support to see specialists [provider survey-medical provider]

Sixteen of the 436 consumer respondents said that they “don’t need or want” medical care. Nine of the 16 were certified as AIDS disabled by their medical doctor. The actual utilization of primary care reflects that these respondents may actually have a met need for medical care. Thirteen of these respondents know their last T-cell count (3 below 200, 5 between 200-500, and 6 above the count of 500). Thirteen of the consumers who did not need or want medical care also knew their viral load (7 undetectable, 5 between 1-10,000, 1 above 100,000). Only three of these respondents also indicated that they were not taking any medications. The fact that most of these respondents also have low viral loads and high T-cell counts along with utilization of primary care reflect the possibility that these respondents may have interpreted the question incorrectly, or that because they are healthy they do not need more rigorous medical interventions than the check-ups they are getting.

Quantitative unmet need analyses:

In a separate needs assessment project, analyses of unmet need within the Seattle EMA were conducted by epidemiology staff from the Washington State Department of Health (DOH), with input from Title I Grantee staff and staff of Public Health – Seattle & King County HIV/AIDS Epidemiology Unit. The unmet need calculation process steps include: reviewing and revising methods for estimating HIV prevalence; choosing data sources and calculating preliminary estimates; and reviewing preliminary results and adjusting for bias or missing source data. The framework for calculating unmet need for primary care was adapted from a team from the University of California, San Francisco (UCSF) for HRSA. The adopted definition of “in care” included: evidence of a CD4 count, viral load test or administration of HAART therapy within the previous 12 month period. Persons determined to be “not in care” were those for whom no evidence existed of any of these three clinical markers during the prior year.

Data sources:

Washington State HIV/AIDS Reporting System (HARS): HARS is the statewide registry of HIV/AIDS cases maintained at the DOH and reported through disease surveillance activities. These data are used to determine population sizes of the number of persons presumed living with AIDS and HIV, non-AIDS in the Seattle EMA. Data for the analyses included all cases reported to HARS through August, 2005.

Laboratory Tracking Database, (LTD), Washington State DOH, Office of Infectious Disease & Reproductive Health: LTD is a repository of all legally reportable HIV-related laboratory results. These data are required to be reported by all public and commercial diagnostic laboratories without regard to funding source or patient characteristics, and are considered comprehensive for all patients/clinicians seeking HIV-specific laboratory services in Washington State. Care patterns are established by matching unique individuals in LTD with the HARS surveillance registry.

Adult Spectrum of Disease (ASD) study: The ASD study is a CDC-funded longitudinal medical record abstraction project designed to be representative of HIV-infected patients receiving care in multiple clinical settings. Primary care patterns are adjusted to correct for laboratory results outside of threshold criteria for reporting by utilizing population-specific correction factors empirically determined from the ASD data (ASD student ceased a couple of years ago).

Assessment of unmet need:

Overall estimates suggest that 21.7% (1,516) of the Seattle EMA’s 6,993 persons who are HIV positive and aware of their serostatus are not in care. Sub-population analyses were conducted based on sex, race/ethnicity and HIV/AIDS status. These analyses revealed:

- No statistically significant gender difference emerged regarding unmet need, with 20.3% of males being not in care and 22.1% of females.

- No statistically significant racial differences emerged regarding unmet need, with 20.8% of Whites being not in care, 22.9% of Blacks, and 19.5% of persons of other races (Asians, Pacific Islanders and Native Americans). These three racial groups were combined for analysis due to very small numbers in the ASD sample and for the EMA as a whole.
- Persons who were not Hispanic were significantly more likely than Hispanics to be “not in care” (22.8% versus 14.6%; $p < 0.01$).
- Persons with HIV, non-AIDS are significantly more likely than persons with AIDS diagnoses to be “not in care” (29.7% versus 13.5%; $p < 0.01$).

Related findings in Comprehensive Needs Assessment

In the consumer survey ambulatory/outpatient medical care was a significantly higher gap for non-disabled PLWH. Providers who work with Latino PLWH suggested in interviews that availability and knowledge of many care services are not reaching those PLWH who are not in care in the Latino population.

The big barrier is often finances according to providers. Latinos are working very hard to support their families so when they are feeling ok and have appointments related to their care which would cause them to miss work, they would opt to keep the job and make money, thereby skipping their care appointments.

Subpopulation differences with medical characteristics and medical care

Over the past six years the percentage of consumer respondents taking antiretroviral medications has remained on average between 70-74%. However, other types of HIV-related medications show a decreasing trend over time (Table 8). Medical provider interviews suggested that treatments to prevent opportunistic infections would likely decrease based on increasing T-cell counts in persons treated with HAART. Providers reported that earlier in the epidemic, many PLWH had T-cell counts less than 200, (some < 75), so they would have been on PCP and MAI prophylaxis respectively for those low counts. But after being on HAART for some time, T4 counts would have increased, reducing the need for preventative treatments for opportunistic infections. With new simpler regimens, and new drugs, perhaps fewer consumers need side effect treatments, or being on a regimen for a long time, also over time the body may accommodate and the side effects reduce in severity. Both of these hypotheses, based on interviews with medical providers, seem to be likely explanations for the trend in consumers taking medications.

The most common demographic characteristics and co-morbidities associated with differences in consumer medical characteristics included race/ethnicity, incarceration, substance abuse and homelessness. Consumer focus groups and provider interviews provided insight to some of these disparities.

Barriers to medical care for racial/ethnic minorities

- MSM of color were the only sub-population to be significantly less likely to utilize outpatient medical care.
- By contrast, White respondents were significantly more likely to report being disabled by AIDS (58%), than Black/African American (35%), and Latino/Latina (26%) respondents. This may be due to the significantly higher percentage of White consumer respondents who knew of their AIDS disability certification. White MSM focus group participants were all satisfied with their current medical care.
- MSM of color respondents were significantly less likely to know their T-cell count (34% did not know), than White MSM (17% did not know).
- MSM of Color respondents were significantly less likely to be taking medications for side-effects (25%), than White MSM (35%).

All providers interviewed regardless of type of service provided noted that medication adherence for these populations can be complicated by language barriers, cultural norms about taking medications, and lack of trust in Western medicine. Providers working with MSM of color reported that these clients may not be participants in the larger gay/bisexual community and may not identify as gay or bisexual within their own communities. The dual isolation decreases the chances that this community will feel comfortable accessing medical care and other HIV-related services at agencies that mostly reach the broader gay/bisexual community. Also, because of the strong cohesive nature of their community and the stigma of HIV, they may not take medications because they do not want their families to learn of their HIV status. All providers that work with MSM of color indicated that they were more likely to enter care late after diagnosis when they were sick or had physical health issues related to their HIV.

80% of my Latino/a clients come in late diagnosis. They are showing opportunistic infections at the time that they come into care. They will go to the hospital sick and then be diagnosed with HIV. Culturally they are not accustomed to go to the doctor/hospital until they are sick. [PI, CASE MANAGER]

African American PLWH

Consumers of color report high psychosocial needs. Providers to African American clients discussed the fact that African Americans have dealt with oppression their whole life and are often isolated exclusively to their neighborhood where they can relate to people with shared experience. They do not feel comfortable leaving that niche, and once they have to because of their health they often cannot relate to medical providers who live outside of their niche and their experience. As mentioned earlier in this report, African Americans were significantly more likely to reside in South Seattle, while most of the medical providers we surveyed (who provide care to PLWH) are located within Seattle.

Latino MSM PLWH

The majority of the consumer respondents that identified as MSM of color identified as Latino (44%). According to providers working with clients of this population, when Latinos find out they are HIV positive they have a much greater degree of isolation because they cannot turn to traditional resources such as family and friends due to the stigma about HIV within their communities. In addition, providers to Latinos indicated a substantial fear in the Latino/a population of the side-effects of medication that may prevent them from initially accessing medical care. Therefore they often wait to seek care and also make what providers perceive to be unwise choices about their health. Since they cannot rely on their traditional social networks for support, they expect their primary medical care provider to provide counseling and emotional support but providers most often do not have time. This sentiment was strongly supported in the Latino consumer focus group:

I would like my doctor to call me one time a month to check and see how I'm doing...To show that a person is not just a number but a person.
[LATINO FG]

My current doctor has helped me, but not like the one before. The one before asked me more about how I felt. [LATINO FG]

According to providers serving Latinos, support groups are not appropriate for Latinos because culturally it is not natural to emote publicly in a group setting. One-on-one counseling is the preferred method of providing this support but due to patient loads, it may need to come from someone other than the primary care provider, as discussed by Latino focus group participants. Providers suggested that the clinician has to become a partner with the client about his/her health related decisions.

There are times when a clinician just has to "give orders" because of limited time. More often than not because Latino clients will expect them to just give orders for everything, unless they consciously make the effort to empower and make their clients self-advocates, their overall care will be less effective. [PI, case manager]

This can be challenging, as providers report, for Latino clients who often expect their medical providers to make the majority of decisions about their health. Latino consumers discussed their frustration with this in the focus group:

The first doctor told me everything was dependent on me, I didn't like it and I said I would leave and wouldn't see that doctor anymore. [LATINO FG]

Another barrier to medical care, discussed by many Spanish-speaking Latino focus group participants, was discrimination and poor treatment with front desk or other staff at the clinic/facility, suggesting more cultural competency training is needed for support staff at service agencies.

The front desk staff person at my medical care is rude and made fun of me because of my lack of English. He/she is always bothering me and has problems with those who don't speak English. [LATINO-FG]

Native American PLWH

All 14 Native American respondents reported unmet need for medical care. While this sample population size was too small to calculate statistically significant difference, it was still notable and discussed by providers that work with Native American clients.

Native American women I work with do not want to access medical care at all! There is a big lack of trust in western medical care in their culture. Further, even at [agency] that focuses on the health needs of this population, HIV is not talked about due to the large stigma in the community. [PI, substance abuse treatment provider]

Barriers to medical care for recently incarcerated PLWH

- Recently incarcerated respondents were significantly more likely to have a T-cell count of less than 200 (46%) than non-incarcerated respondents (20%).
- Recently incarcerated respondents were significantly less likely to know their T-cell count (37% did not know) than non-incarcerated respondents (23% did not know).
- Recently incarcerated respondents were significantly less likely to know their viral load (52% did not know) than non-incarcerated respondents (28% did not know).
- Recently incarcerated respondents were significantly more likely to have a viral load greater than 10,000 (25%), and significantly less likely to have a viral load that was undetectable/below 70 (45%) than non-incarcerated respondents (13%).
- Recently incarcerated respondents were significantly less likely to be taking antiviral medications (58%) and they were more likely to be taking meds for opportunistic infections than non-incarcerated individuals (35%).

Providers in interviews reported that recently incarcerated individuals have a consistently higher incidence of homelessness, mental health issues, substance abuse problems and other de-stabilizing factors that impact adherence. According to case managers, medical providers external to the HIV/AIDS system seem much more wary of potential resistance and much more inclined to maintain clients with adherence issues on long term prophylaxis in addition to HAART. Many of these clients were previously prescribed HAART meds, but were not adherent. Those not taking antiretrovirals are more likely to take medications for opportunistic infections. Case managers report that a lot of these people have no recent lab draws or do not return for the results of their labs. Also, some

of these clients are not as educated on the nature and treatment of HIV (largely a result of poor adherence as most patient education is attached to medical care according to case managers).

Clients need more information about care while in prison and when first released if they are HIV positive. Otherwise they are learning myths about the system in jail and on the streets. We try to provide information while they are in prison and also immediately find a transitional space for them to stay so they can safely store their meds. [PI, case manager]

According to providers, when clients first come out of jail they first want a place to stay; identification (they have often lost their belongings), medications (need ADAP immediately), and transportation. HIV is not a priority until their basic needs are met because they literally have nothing when they leave jail or prison. Providers working with incarcerated clients reported that while in prison, clients do not have a confidential space from which to call and 90% of clinics/agencies/providers either do not accept collect calls or have voice menus which make such calls impossible to place. While newly positive clients may choose any clinic/primary care provider in the area with which to establish care, they can only visit Harborview for essential visits while they are incarcerated as the prison will not transport to any other facility/clinic. Patients do have the right to choose any primary care provider for follow-up after release.

Local jail health services provide a confidential space for incarcerated PLWH to set up appointments for their medical care. To improve access to medical care for incarcerated PLWH, Jail Health has a referral system which sets HIV+ persons who are in jail in King County up with services of their choice prior to release. This is not effective for some incarcerated PLWH however because they feel discriminated against:

Clients often feel like they are treated poorly by providers when they go to a hospital in custody as opposed to just wearing street clothes. So they will often not go seek care while in custody in fear of this discrimination. 15% of our clients will actually avoid seeking care in hospitals, while incarcerated, for this reason. These clients very much opt for care in jails. [PI, case manager]

Co-morbidities: barriers to medical care for recently incarcerated, homeless, and substance abusing PLWH

- Recently homeless respondents were significantly more likely to have a T-cell count under 200 (34%) than not-homeless respondents (17%).
- Recently homeless respondents were significantly less likely to know their viral load (43%) than not-homeless respondents (28%).
- Recently homeless respondents were also significantly less likely to have an undetectable viral load (42%) than not-homeless (63%), and significantly more likely to have a viral load above 10,000 (29%) than not-homeless respondents (13%).
- Recently homeless respondents are significantly less likely to be taking antivirals (57%), and/or medication for opportunistic infections (19%) than not-homeless (78% and 31% respectively).

- Injection drug users were significantly less likely to be taking antiviral medications (63%) than both non-injection drug users (74%), and non-drug users (81%).

According to provider interviews, recently incarcerated and homeless clients are more likely to have a high rate of drug use and/or untreated mental illness (which is less likely to be self reported in the surveys). Clients are in a state of chaos in their life so that HIV is the underlying issue rather than being at the forefront. HAART, viral load/ T-cell counts, and knowledge of same are less likely to be prioritized in their list of life's critical issues.

Half of my clients need to be on HAART. Of those who need to be, half are not on HAART because of poor adherence relating to psychosocial issues from homelessness, substance abuse, and mental health. [PI, medical case manager]

Also noted by providers was a more global mistrust of authority and systems in both the homeless and incarcerated populations that makes engagement in care and basic trust of the medical delivery system more difficult. Providers also talked about doctors being reluctant to start clients that are homeless on medications. A physician will not likely prescribe meds without consistent housing out of concern that clients will not be able to manage their medications without a regular schedule, a way to track time, or stable place to keep meds. Poor ability to adhere can harm patients if the medical regimens used poorly results in HIV resistance.

Providers also noted an interplay between drug use and care seeking behaviors; while clients are seeking care they are not using a lot of illicit drugs or any at all. When they start abusing substances heavily they fall out of care until the substance abuse starts affecting other aspects of their life and it becomes dangerous or they get arrested, then they start seeking care again. As they access housing and address these issues with treatment, HIV and their health begins to rise in priority and they are more able to access care. Clients are constantly in and out of care because of these co-morbidities.

In my 14 years of service I have only seen 5 clients go through every care system and achieve permanent housing and total stability. [PI, medical provider]

Barriers to medical care for women

Providers that work with female clients reported that access to medical care was generally not a problem once they decided to engage in care and dealt with multiple co-morbidities including substance abuse and mental health. Female respondents were significantly more likely to *not* know their T-cell count (44%), than male respondents (23%). Providers that worked with foreign-born black clients said that while their clients received their T-cell count, they were not understanding what the numbers meant from their medical provider visits.

Providers who worked with predominantly female clients also discussed community norms as a barrier for women which often delays entry into care after HIV diagnosis. They report that gay men and lesbians have an established community for addressing HIV, while women do not. Women therefore are more closed off and protective (this has been an ongoing trend according to providers). Women initially seek limited care until they can trust the system. Providers working with women talked about spending a lot more time on building trust with women because they don't have that broad based community support.

Providers serving women reported that because female respondents were significantly more likely to reside in South Seattle, transportation was a major barrier to accessing medical care service appointments in Seattle. Childcare, just as in previous years, was a significantly higher service priority and service gap for women. Lack of RWCA funding for childcare is more likely to have an impact on women living with dependent children and their ability to access medical care appointments. Providers in interviews discussed their perception that single women were more likely to access medical care *earlier* after their HIV-diagnosis than women with children.

Cultural barriers for Women of color

Providers who work with women of color living with HIV noted that Latina women will often prioritize their family unit before caring for their HIV. Because of the stigma of HIV within their communities, African American women have a lot of shame, guilt, and isolation due to their HIV status resulting in low self-esteem. Providers speculated that both of these cultural barriers often cause women of color to place others in their family unit as a priority over themselves. These women will often settle for relationships that involve domestic violence because they would rather remain in unhealthy relationships than be single and manage both their family and their HIV. Providers noted that Latina clients are mostly in relationships with unspoken rules such as no divorce, which creates a sentiment of dealing with unhealthy relationships. Providers who worked with women of color talked about the role of domestic violence in preventing access to medical care and other vital HIV-related care services.

Because they have shame with HIV, these women believe and internalize that no man would want them, so they settle for abusive relationships. I work with a lot of women that have low self-esteem because of domestic violence issues. Women need to learn to protect themselves. If you don't have power in a relationship, your care can be very much controlled by your partner [PI, case manager].

CASE MANAGEMENT

A range of client-centered services that link clients with health care, psychosocial and other services to ensure timely, coordinated access to medically appropriate levels of health and support services, continuity of care, and ongoing assessment of the client's and other family members' needs and personal support systems, and in-patient case management services that prevent unnecessary hospitalization or that expedite discharge, as medically appropriate, from in-patient facilities.

Key activities include: initial comprehensive assessment of the client's needs and personal support systems; development of a comprehensive, individualized service plan; coordination of the services required to implement the plan; client monitoring to assess the efficacy of the plan; and periodic reevaluation and revision of the plan as necessary over the life of the client. This may include client-specific advocacy and/or review of utilization of services.

The information and assistance component of the program is the entry point to other case management services and is also responsible for promoting community awareness of program services. Information and assistance is provided to individuals with HIV infection who (a) are able to locate and access needed services with sufficient information, or (b) do not require ongoing case management but need someone to assist them or act on their behalf in order to obtain needed services or benefits or (c) need to be screened to determine if they should be referred for a comprehensive assessment. Key activities include: information giving, screening, service referral and assistance (when client will not receive other case management services), client advocacy and community resource information systems.

Case management is designed to assist persons with HIV to live as independently as possible; maintain and improve their health; reduce behaviors that put the client and others at risk; and gain access to needed medical, psychosocial, educational, and supportive services. All case managed clients receive a thorough and on-going assessment of multiple needs. These issues can range from the practical needs of medical care, insurance, food, shelter, and transportation to the more complex needs of mental, emotional and sexual health, substance use, and legal and social support. Assessments ascertain the client's ability to access and maintain services on their own or the extent to which they will need assistance.

On the survey this service was not divided into any sub-categories and was stated as "Case manager/social worker."

Overall service priority, gap, utilization:

Case Management	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	1	69%	1	83%
Service Gap	17	6%	14	12%
Service Utilization	2	82%	---	---

Case management was ranked the highest service priority for both consumers and providers. A significantly greater percentage of providers (83%) prioritized case management than consumers (69%). Case management also showed the most significant increase in priority among consumers (up from #4 in rank and 11%) from 2003 and has increased in consumer priority over the past four years (50% in 2001; 57% in 2003; and 69% in 2005). Respondents who indicated that their doctor certified them as AIDS disabled, were significantly more likely than non-AIDS disabled respondents to prioritize case management. Approximately 4 out of 5 consumer respondents said they utilized case management, making it the second most utilized RWCA service for consumers.

Case management is key! [MSM/IDU FG]

Case Management is the most important. A profession that is very overworked and offers so much to the client. [Latino FG]

Unmet need for case management

As in previous years, both providers and consumers considered case management to be a high priority and low service gap in comparison to the other RWCA funded services. For the 26 respondents who needed but could not get case management, the greatest barriers identified were they did not know where to go (n=8), did not know it exists (n=7), and five respondents indicated “other.” There were no significant differences in priority or gap by subpopulation in the quantitative portion of the assessment. Despite the high priority, utilization, and lower service gap, consumer focus groups and provider interviews offered insight into some of the major issues and concerns with case management.

Higher case management caseloads lead to inadequate service provision

The most compelling statistic from the provider surveys that would explain some of the barriers consumers described in focus groups was the high provider caseloads. There was a dramatic increase in the average caseloads reported by case managers, from 78 in 2003 to 137 in 2005. This fact was very apparent from provider interviews.

We could use two times as many case managers and we would still have too many clients [PI, case manager].

Further, as discussed in the housing section of the report, there is no central agency to coordinate services in general which duplicates the paperwork requirements for clients and is inefficient with limited financial resources. Case managers in interviews discussed that the documentation for all services for case management continues to increase which cuts into time to deliver client care.

There are too many meetings which take away from client care (housing etc.), Case management caseloads are increasing as documentation demands increase. We need more case managers. [provider survey-case manager]

Case managers are feeling the pressure from the decrease in availability of services while there is an increase in consumer demand and paperwork requirements.

There is less and less available of everything and more need and I spend way too much time on stupid documentation to justify the bare minimum of help I can give my truly desperate clients. The regulations are NOT helping they are making people lie. If you're hungry you'll lie for bread. [provider survey-case manager]

As caseloads have been increasing for providers, consumers report feeling that while case management is an important service for their care, their needs are not being met in terms of quality of service. Some specific needs that consumers say are not being met are: education about available options and services, assistance with paperwork, and communicating about medical appointments or referrals. In some cases information was given by providers but due to rushed conversations and appointments, often not understood clearly by consumers. This miscommunication led to consumers not accessing services for which they may have been eligible. Consumers in focus groups also felt that case managers took much longer to respond to questions or needs for assistance, which delayed their ability to access important services. More consumers, as a result, had to become self-advocates to access appropriate information which they felt was traditionally provided by their case managers.

I got a caseworker that basically gave me a handful of papers. Well it's really good for someone who has crippling depression and thinks, "well, I should just off myself now," to be handed this pile of papers with no assistance in filling it out. [WHITE MSM FG]

I feel like I have to take care of myself cause' I don't have a choice. [FOREIGN-BORN BLACK FG]

As a result of feeling they did not receive adequate services, consumers talked about relying on friends or other clients within the care system for appropriate information with regards to eligibility for services. A suggestion that came from focus groups was that the overloaded system needed an additional provider, such as a client advocate or other service, to fill the increasing gaps to important assistance that case managers are no longer able to accommodate. Case managers and other providers in interviews suggested the need for more case managers to manage the increasing caseloads.

Disengagement between case managers and clients

It feels it is more chaotic, less responsive and a lack of case manager-individual support relationship. [consumer survey]

The consumer comments on surveys and focus groups indicate that the overloaded case management system is causing a greater disconnect between consumers and their case managers as perceived by consumers in focus groups. Providers report that there is more staff turnover due to the burnout in the current case management system. As a result, a client may have multiple case managers over time. This leads to discontinuity of case managers working with their clients. Consumers with complex needs have to negotiate between multiple systems in the continuum of care (substance use, mental health, corrections, etc). Consumers may not bring up specific issues related to their health because they assume their new case manager already knows about them from reading their chart. Consumers with more experience in navigating the continuum of care expressed frustration with having to “train” new case managers about services.

A new case manager arrived and didn't call me for a whole year. When I went to meet with them they didn't have experience or training to help me. [LATINO FG]

Case managers interviewed talked about increasing levels of stress and burnout associated with their overwhelming caseloads. From the consumer's perspective in focus groups, this impacted the quality of service provision. Focus group participants talked about being treated with disrespect. They felt like those case managers who used to care about the work they did became apathetic and disengaged. This made the clients less comfortable in even attempting to work with their case managers.

I wasn't a number off a calendar desk. I was a person. And that was something I was not getting from my case manager. [MSM OF COLOR FG]

They treat you like a dog. You have to do what you are told to do. If you complain and bitch long enough they might do something about it. [RECENTLY INCARCERATED FG—black male]

He's very lax, and too relaxed in a sense of what he's doing in reaction to the severity of my case and what I need right now. I don't need it 10 days from now, I need it right now. [MSM OF COLOR FG]

Consumers felt case management was becoming unhelpful because of all of the issues they were facing with over-worked staff. Case managers were viewed more as gate keepers to services by some focus group participants, as opposed to advocates helping clients to attain services.

More and more times that I feel like that I'm sitting in a position as if they're Gods to me. They can give it or they can take it away. They give you that air of sometimes a condescending attitude or they look down at you...make you feel like you have to beg for services [MSM OF COLOR FG]

Consumers felt that because case managers were overworked, they would show favoritism to those clients that were easier to work with and had less severe needs.

Others felt that case managers only paid attention to those with severe needs and let lower needs clients slip through the cracks. Satisfaction with case management for focus group participants varied by case manager and was not consistent as a service overall. Focus group participants were frustrated with the paperwork and process they had to go through if they did decide to get a different case manager.

Some consumers who felt they were forced to access services on their own, found that they could not access services without a call because case managers are gatekeepers to some services. The requirement for referrals from case managers for services such as housing and day/respite care increased the delay or created a barrier to accessing those services.

They just have too much power. Cause, I mean, [agency] won't talk to you unless your case manager tells them. [housing facility] housing won't do anything til case managers talk to you. [MSM OF COLOR FG]

The thing is, I want to be able, not just to help myself, but to help others, but the system pulls me back and says, "no, you gotta let me do this." But it's like pulling teeth and waiting forever for it to happen when I know I can do this faster myself, but only if I had resources and the information needed to do it. 'Cause I'll do it and I'm willing to help others. [Women's FG]

Sub-Population differences: Cultural barriers for Consumers of Color

Barriers for African American PLWH

While there were no differences by subpopulation in terms of priority, gap, or utilization, from the consumer survey, consumer focus group data indicated differences with case management by race/ethnicity. Some consumers in focus groups perceived that the case management system has become too professionalized and bureaucratic, making it less sensitive to the needs of diverse groups of people. Focus group participants, particularly African American consumers (MSM of Color, Women FG), had issues with their case managers not only because they were gatekeepers, but also because they were not from and did not have an understanding of their culture. This made it challenging for consumers to be able to address or relate to specific cultural issues.

I think that case management does not have enough cultural competency to provide services effectively to black folk and I think that it needs to be worked on to be more sensitized to the needs of folks of color. [MSM OF COLOR FG-African American]

African American focus group participants talked about seeking information and accessing services at agencies where there were more providers of color for this reason. Providers of color, particularly case managers in the interviews, echoed this consumer sentiment. Providers stated that clients often do not understand what the case manager is really saying and are too intimidated to ask further questions. Both the perceived lack of cultural competence, and the power dynamic of case managers as gatekeepers creates additional barriers to consumers of color in obtaining services.

More case managers of color are needed, not only by merit but because they come from a place they can relate to the client experientially and culturally. [PI, case manager]

As stated above, providers of color indicated that their clients of color, particularly African Americans are often not comfortable in working with providers outside of their race. Further, focus group participants discussed that the more “professionalized” the care system became the harder it was to access services.

I’ve had really good case managers in the past who were black, but you know the ones that I’ve had recent times are not connecting and it just seems as the system became more professionalized, it got worse. The system is harder to access. [MSM OF COLOR FG]

Clients feel they often do not have a choice of providers. As a result they would rather not seek care to begin with unless it is an absolute need. They report often seeking other services such as support groups because these services more often have staff of color and consumers that can relate to their experience. They use those services in lieu of case management to address their needs when they do not feel comfortable with their case managers.

When I make the statement that “there is need and a need is no greater than it is right here right now,” I don’t need nobody to tell me the moment that I start talking with them, “well, darling, that’s not me. You have to go to so and so.” They keep sending you to one more door, and when that door’s open, they’ll send you to one more door. It just seems like the list is never ending. It’s their way of shuffling the books and shooing you away. [MSM of Color FG]

Barriers for foreign-born Black PLWH

In complete contrast to African American sentiment above, foreign-born black focus group participants emphasized that having a case manager from their community of origin is a large barrier for them and preferred someone who was not from their community. This was due to the substantial stigma associated with HIV within their communities. Fear of information not remaining confidential within their own communities was even greater than concerns of cultural awareness with providers outside of their community. Participants spoke of information going back not just to African communities in the US, but in some cases, all the way back to their family in Africa.

In my country being HIV positive is like being thrown into the ocean. And because we have this feeling of collectivism, of togetherness, it’s very isolating if people in your community know you are HIV positive. [foreign-born black FG]

I don’t want anybody from West Africa to be my caseworker. Or do anything. I hear my friend, from the same country, works as a nurse down there. As soon as I heard it, I say, “ok, I think I’m out.” [foreign born black FG]

Barriers for Latino PLWH

As discussed earlier, more clients reported that they have to become self-advocates within the currently overloaded case management system. Providers that primarily serve PLWH of color, especially foreign-born Latino/a clients, discussed how lacking in self-advocacy skills can be an immense barrier to receiving appropriate services within the case management system for these sub-populations. Latino clients often expect providers to give them direction/instruction which the clients can then simply follow. They are not used to making decisions for their health. Class can play a lot into this and is particularly an issue for low income Latino clients. Clients coming from other countries often do not feel entitled to receive services. As a result, they expect their providers to make all the decisions about their health. This can create a barrier in terms of identifying client needs.

Providers working with Latinos report that their non-US born clients do not feel entitled to services, and therefore do not seek out those services. As a result, providers may do some or all of the decision making. Providers who work mostly with Latino/a clients in interviews discussed the need for including more self-advocacy training for clients by providers who function as gatekeepers within the continuum of care. Just as providers who work with African American clients discussed, providers who serve Latino clients indicated the need for an environment in which it is ok to be HIV positive and Latino; a place where Latinos feel welcome with diverse staff who are aware and sensitive to Latino culture.

CHILDCARE

Home-or community-based non-medical assistance designed to relieve or replace the primary care giver responsible for providing day-to-day care of the client or client's children.

On the survey this service was not divided into any sub-categories and was stated as "Childcare during HIV related appointments."

Overall service priority, gap, utilization

Childcare	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	20	4%	19	2%
Service Gap	17	6%	13	13%
Service Utilization	20	3%	---	---

Childcare was ranked as one of the lowest service priorities for consumers and providers. However, women and Black/African American respondents were significantly more likely to prioritize childcare (22% and 13% respectively).

Providers were significantly more likely than consumers to indicate a service gap for childcare. While only six percent of consumers indicated a service gap, women, foreign-born, and Black/African American consumer respondents were significantly more likely to indicate a service gap for childcare services, with one out of four women identifying a gap.

Three percent of consumers indicated using childcare services; however, these were not RWCA childcare services because currently there is no funding for this service category. Those consumers who indicated using childcare services were significantly more likely to be female.

Unmet need for childcare

Of the 27 consumer respondents who reported unmet need for childcare, the most common barriers reported were "don't know it exists (n=9)," and "don't know where to go (n=7)." This is supported by the fact that there is currently no RWCA funding allocation for childcare services.

Importance of childcare for women living with HIV

Even though currently there is no funding allocation for RWCA childcare services locally, just as in previous years women were significantly more likely to prioritize, as well as report unmet need for childcare. Women were significantly more likely than men to report having dependents living with them (64% of females versus 24% of males). Foreign-born Black women reported that as part of a communal culture, they often take care of each other's children and family members who do not count as dependents because they are not technically living with them. Also, many are helping to take care of family members who are living in their country of origin.

At times as an African I have family/children that I take care who are not living with me and this means they don't qualify as dependent because I don't live with them at home. As a result its hard for me sometimes to even pay for my medical co-pay, rent and utilities. [consumer survey-FEMALE]

All providers interviewed who work with women, as well as women with children in focus groups emphasized the importance of childcare to their ability to access medical care and other HIV-related support services. Providers noted seeing younger women with children seeking services as well. These providers also said that having voluntary childcare on-site when feasible during service provision increased the likelihood of women participating or accessing their services. This however was rarely provided due to a lack of volunteers or staff that could provide this service.

CLIENT ADVOCACY

A client-centered, single-issue service provided on an intermittent basis. Service provided might include assistance in obtaining: financial/benefits counseling, interpreter services, and peer or client advocacy. To prevent duplication of case management services, client advocacy does not involve coordination and follow-up on medical treatments or other ongoing psychosocial needs, assessment of individual need, provision of advice and assistance in obtaining medical, social, community, legal, financial and other needed services.

On the survey this service was not divided into any sub-categories and was stated as "Peer or client advocacy (other than case manager)."

Overall service priority, gap, utilization

Client advocacy	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	17	11%	15	7%
Service Gap	9	19%	16	10%
Service Utilization	11	35%	---	---

In comparison to all the available RWCA services, client advocacy was a low priority for both consumers and providers. Consumers were significantly more likely to indicate a service gap for client advocacy than providers and it was also a top ten ranking service gap for consumers. Recently incarcerated, MSM/IDU, IDU, and Latino/as were significantly more likely to prioritize this service. This may be a higher priority service for Latino/a PLWH because of client advocates are more likely to be native Spanish speakers according to consumers in the Latino focus group.

Thirty five percent of consumer respondents indicated using client advocacy services. Female, Black, and Latino consumers were significantly more likely to use client advocacy. As discussed in the case management and medical care sections of this report, these underserved populations often seek client advocacy because there are more service providers of this provider type with whom they had a shared understanding of historical context and culture. As case managers report higher case loads and less time per client to address numerous needs, more consumers, especially underserved populations, may be likely to utilize client advocacy to address some of their needs.

Unmet need for client advocacy

Of those consumer respondents who reported unmet need for client advocacy (n=84), almost half (49%) indicated the barrier to accessing this service was “don’t know it exists,” and 28% said “don’t know where to go.”

MSM/IDU and IDU were both significantly more likely to prioritize client advocacy as well as significantly more likely to indicate unmet need for this service. Because substance abuse can often hinder an individual’s ability to access and maintain HIV-related care, providers report that the provision of a client advocate is even more necessary for this population.

DAY/RESPITE CARE FOR ADULTS

Facility-based therapeutic, nursing, supportive and/or compensatory health services provided in accordance with a written, individualized plan of care. Adult day health/day care services are those services or activities provided to adults who require care and supervision in a protective setting for a portion of a 24-hour day. Component services or activities include opportunity for social interaction, companionship and self-education, health support or assistance in obtaining health services, counseling (including mental health and substance use counseling), medication management, recreation and general leisure time activities, meals, personal care services, plan development and transportation.

On the survey this service was not divided into any sub-categories and was stated as “Adult day healthcare.”

Overall service priority, gap, utilization

Day/respite care for adults	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	14	14%	8	30%
Service Gap	16	8%	20	4%
Service Utilization	18	16%	---	---

Twice as many providers, as consumers prioritized day/respite care for adults. While providers were significantly more likely to prioritize this service, they also ranked this as the lowest service gap in the Continuum (20th in rank).

MSM/IDU respondents were significantly more likely to prioritize day/respite care for adults. Day/respite care has been a very beneficial service for PLWH who use meth according to substance abuse treatment providers. This service provides a structure meth users need for their HIV-related care, especially while they are addressing their substance abuse early on.

Day/respite care provides answers to all questions I have about my health.
Regarding bumps, bruises, aches and pains or anything else I notice about myself that I think is wrong or different. [consumer survey-MSM/IDU]

Twice as many consumers as providers indicated a service gap for day/respite care for adults. There was also a significant increase in the percentage of consumers who indicated unmet need for this service compared to 2003 (+4%). Conversely, there was a significant decrease in the percentage of provider-indicated service gaps for day/respite

care for adults (-10%). MSM of Color, foreign-born, and Latino/a respondents were significantly more likely to indicate a service gap for day/respice care for adults.

Sixteen percent of consumer respondents indicated using day/respice care for adults making this one of the lowest ranking service in terms of utilization in the Continuum (18th of 20) Recently homeless and Black/African American respondents were significantly more likely to utilize this service.

Unmet need for day/respice care for adults

Of the 34 consumer respondents who reported unmet need for day/respice care for adults, the most common barriers indicated were, “don’t know it exists (n=13),” “don’t know where to go (n=8),” and “don’t qualify (n=5).” While MSM of Color, foreign-born, and Latino/a respondents were significantly more likely to report unmet need for day/respice care, there were no qualitative data to explain some of the specific barriers.

EMERGENCY FINANCIAL ASSISTANCE

The provision of short-term payments to agencies, or establishment of voucher programs to assist with emergency expenses related to utilities. These allocations must be monitored to assure emergency needs, limited amounts, limited use, and for limited periods of time.

On the survey this service was not divided into any sub-categories and was stated as “Emergency assistance with utility bills.”

Overall service priority, gap, utilization

Emergency financial assistance	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	12	18%	19	2%
Service Gap	5	27%	14	12%
Service Utilization	16	22%	---	---

Consumers were significantly more likely than providers to report emergency financial assistance as a service priority. However, from 2003, this was the only service category that reflected a significant decrease in the percentage of consumers prioritizing the service (10% fewer consumers than in 2003). Recently incarcerated, female, Black, and Latino/a respondents were significantly more likely to prioritize this service.

Emergency financial assistance was a top five service gap in the Continuum for consumers and a significant increase from 2003 (+6% of consumers). As with service priority, consumers were significantly more likely to indicate a service gap than providers for emergency financial assistance. From 2003, providers were significantly less likely to indicate a gap for this service (13% less than in 2003). The disparity between the percentage of providers and consumers indicating a service gap for emergency financial assistance increased significantly from 2003. MSM of Color, foreign-born, and Latino/a respondents were significantly more likely to have unmet need for this service.

Twenty-one percent of consumers reported using emergency financial assistance making it 16th in rank by utilization out of 20 services in the Continuum. According to provider survey comments and barriers reported on the consumer survey, this lower rank in utilization was largely because of qualification requirements, not knowing the service existed, and limited availability of services.

Unmet need for emergency financial assistance

Of the 115 consumers who indicated unmet need for emergency financial assistance, the most common barriers indicated were “don’t know it exists (28%),” and “don’t know where to go (20%),” and “don’t qualify.” There was no qualitative information from consumer focus groups or survey comments to explain barriers for populations significantly more likely to have unmet need.

Provider survey comments suggested that this was a low priority because a number of clients either did not qualify or the assistance did not adequately meet their needs. Providers also reported that the need was often not HIV-related and therefore a lower priority than other needs. Conversely provider interviews suggested that in winter months, having proper utilities was critical to PLWH especially those who had severely compromised immune systems.

FOOD BANK/HOME DELIVERED MEALS

The provision of food, meals, grocery vouchers or nutritional supplements (not finances to purchase nutritional services).

On the survey this service was divided into three sub-categories that were listed as “Bags of groceries,” “Emergency grocery vouchers,” and “Prepared meals (home delivered or for pick-up).”

Overall service priority, gap, utilization

Food bank/home delivered meals	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	5	55%	12	18%
Service Gap	2	31%	11	13%
Service Utilization	4	69%	---	---

While not a core medical service, consumer surveys reflected food bank/home delivered meals to be paramount towards supporting their HIV-related care. This was the second highest ranked service gap for consumers and a top five service priority. Three times the percentage of consumers than providers indicated this as a service priority. Three times the percentage of consumers, than providers also indicated food bank/home delivered meals to be a service gap. This service category reflected the greatest increase in disparity between the percentage of providers and consumers indicating there to be a service gap than any other service in the Continuum.

Food bank/home delivered meals was the only service category ranked as both a top five service priority and a top five service gap for consumers which reflects potential system inadequacies. MSM/IDU and Black consumer respondents were significantly more likely to prioritize food bank/home delivered meals. MSM/IDU, foreign-born, and MSM of color consumer respondents were significantly more likely to report unmet need for food bank/home delivered meals.

Almost seven out of ten consumer respondents reported using food bank/home delivered meal services, making this the fourth most utilized service in the Continuum.

Component services priority, gap, utilization

Food bank/home delivered meals	Consumer % (N=436)	Provider % (N=187)
Bags of groceries		
Service Priority	42%	11%
Service Gap	11%	8%
Service Utilization	56%	---
Emergency grocery vouchers		
Service Priority	21%	3%
Service Gap	24%	7%
Service Utilization	32%	---
Prepared meals (home delivered or for pick-up)		
Service Priority	21%	10%
Service Gap	10%	6%
Service Utilization	34%	---

Four times the percentage of consumers, than providers prioritized bags of groceries; seven times the percentage of consumers, than providers prioritized emergency grocery vouchers; and two times the percentage of consumers, than providers prioritized prepared meals. In terms of service gap, the only significant variation between consumers and providers was that consumers were significantly more likely than providers to indicate emergency grocery vouchers as a service gap.

In comparing the three services, twice as many consumers prioritized bags of groceries, than either prepared meals or emergency grocery vouchers. Providers were significantly more likely to prioritize bags of groceries and prepared meals, than emergency grocery vouchers. While consumers were more likely to prioritize bags of groceries, they were significantly more likely to report unmet need for emergency grocery vouchers than the other two service components.

Unmet need for food bank/home delivered meals

Access to food services for PLWHA

As an increasing number and percentage of consumers are living outside of Seattle, even if food banks are available, accessing them can be a greater challenge. Consumers report that this barrier is even greater for those who have very low T-cell counts or poor health.

Of the consumer respondents that reported unmet need for food bank/home delivered meals that also knew their T-cell count, 29% (n=91) had T-cell counts below 200. This was a significantly higher proportion of consumers than the overall consumer survey respondents with low T-cell counts (17%). The importance of nutrition and having groceries and meals delivered for this population was reflected in some consumer survey comments.

When you have an extremely low T-cell count like I do, it would be very helpful to have groceries from [agency] delivered [Consumer Survey].

Culturally appropriate foods

Consumer respondents who were MSM of color and foreign born were significantly more likely to have unmet need for food bank/home delivered meals. Significantly fewer foreign born respondents utilized bags of groceries. In both the foreign born black and Latino consumer focus groups, participants discussed that while they knew of food services being available for PLWH, they would not access them because the provided food was not what they were used to eating in their native culture. Providers that worked with Latino clients also discussed culturally inappropriate foods being a reason many of their clients refused to utilize these services.

A majority of food from [agency] is not food we eat. [Consumer survey- FOREIGN BORN BLACK]

HEALTH EDUCATION/RISK REDUCTION

Education and other risk reduction interventions targeted to individuals living with HIV to reduce the spread of HIV or the acquisition of STDs or new strains of HIV. Services must be provided to HIV+ persons in the context of one of the following HIV care service programs: HIV ambulatory/outpatient medical or alternative care, case management, mental health therapy/counseling, or substance use treatment/counseling. Services must be acceptable and appropriate to the individual client. Strategies used should be considered effective for the target population according to scientific literature on HIV prevention. (1) Provision of information, including the dissemination about medical and psychosocial support services and counseling or (2) preparation/distribution of materials in the context of medical and psychosocial support services to educate clients with HIV about methods to reduce the spread of HIV.

On the survey this service was not divided into any sub-categories and was stated as “Safer sex information or support (such as one-to-one prevention counseling).”

Overall service priority, gap, utilization

Health education/risk reduction	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	18	9%	13	12%
Service Gap	19	5%	17	7%
Service Utilization	13	33%	---	---

There was no significant difference between the percentages of consumers and providers indicating health education/risk reduction as a service priority or service gap. For both consumers and providers, this was a relatively low ranking priority in the Continuum, although a slightly higher service priority and service gap from the providers' perspective. There were no significant consumer sub population differences in prioritizing this service. Thirty-three percent of consumers reported using health education/risk reduction services.

Discussion of health education/risk reduction

The consumer survey asked respondents to indicate if they had a specific discussion about their sexual health or sexual activities related to HIV transmission in the last 12 months with any of the following provider types:

Over half of consumer respondents (55%) indicated discussing sexual health/risk reduction with their primary medical care provider in the past 12 months. From 2003 to 2005, consumers were significantly more likely to discuss their sexual health with their primary medical providers (42% in 2003 to 55% in 2005) and case managers (24% in 2003 to 31% in 2005), with little variation in discussing sexual health with other provider types. Recently incarcerated, recently homeless, and IDU were significantly more likely to discuss sexual health/risk reduction with their case manager. IDU were significantly more likely to discuss sexual health/risk reduction with their substance abuse treatment counselors. Black/African American respondents were significantly more likely to discuss sexual health/risk reduction with their client advocate. This finding may be due to the comfort of talking and relating culturally with client advocates, as discussed by Black/African Americans in the MSM of Color focus group (also discussed in the case management section of this report.) This may also be due to Minority AIDS Initiative programs which combine client advocacy with health education/risk reduction and treatment adherence support. Because these are combined programs, with the staff providing all three functions, client advocates are contractually obliged to provider health education/risk reduction.

Unmet need for health education/risk reduction

Of the 23 respondents who had unmet need for health education/ risk reduction, the most common barrier listed was “don’t know where to go.”

There were no significant sub-population differences for gaps to health education/risk reduction. However, Latino/a consumer respondents were significantly less likely to discuss health education/risk reduction with their mental health providers, and less likely overall to utilize health education/risk reduction. Black/African American respondents on the other hand were significantly more likely to utilize health education/risk reduction.

Barriers for Latino/a PLWH

Providers who primarily work with Latino/a clients talked about the need for educational materials specifically targeting Latino/as. Because of the stigma of HIV in the community, non-gay identified MSM and women in this population often do not relate to the educational messages that target MSM. Providers noted that in addition to language barriers, even if Latino/a PLWH have access to interpreter services it is not comfortable for these clients to discuss personal health issues with their providers when a third party is present.

Barriers for Women living with HIV

In the women’s focus group and on the consumer survey, many consumers discussed not being able to have enough education about HIV/AIDS to have conversations with their children and families about it. This was both due to the stigma of HIV in their community, and feeling like providers only provided this information to MSM while they had to initiate the conversation if they were going to receive any useful information.

I never met anybody that had it, so it seemed like it was rare. I used to take tests all the time, but I didn’t go back to find out the results. I was like, if I had it, they’ll let me know. [WOMEN’S FG]

Need more training and information about HIV/AIDS and the language to communicate and to understand. [consumer survey- FEMALE]

HOME HEALTHCARE

Therapeutic, nursing, supportive and/or compensatory health services provided by a licensed/certified home health agency in a home/residential setting in accordance with a written, individualized plan of care established by a case management team that includes appropriate health care professionals. Component services can include durable medical equipment, homemaker, home health aide and personal/attendant care, day treatment or other partial hospitalization services; intravenous and aerosolized drug therapy, including related prescription drugs; routine diagnostic testing administered in the home of the individual; and appropriate mental health, developmental and rehabilitation services.

On the survey this service was not divided into any sub-categories and was stated as “Home healthcare aide.”

Overall service priority, gap, utilization

Home healthcare	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	18	9%	17	4%
Service Gap	14	11%	10	16%
Service Utilization	19	7%	---	---

Consumers were significantly more likely than providers to prioritize home healthcare and 6% more consumers prioritized this service than in 2003. However, home healthcare was one of the lowest ranking service priorities in the Continuum (18th in rank) for consumer respondents and neither a top ten service priority or a top ten service gap. Women were significantly more likely to prioritize home healthcare.

Providers ranked home healthcare as a top 10 service gap, and were more likely to indicate a service gap than consumers (not significantly higher). With 7% of consumer respondents indicating using this service, this was one of the least utilized services for consumers in the Continuum.

Unmet need for home healthcare

Of the 46 consumer respondents who reported unmet need for home healthcare, the most common barriers indicated were “don’t qualify (26%),” and “don’t know it exists (33%).” IDU, MSM of Color, foreign-born, and female respondents were significantly more likely to have a unmet need for home healthcare. There was no qualitative information from focus groups, and consumer surveys to explain this variation by sub-population.

HOUSING ASSISTANCE/RELATED SERVICES

Background

Assistance locating, obtaining and/or maintaining suitable emergency, transitional or on-going shelter (such as assisted and/or group living situations, Section 8 programs). This includes costs associated with finding a residence and/or subsidized rent in the form of short term or emergency financial assistance to support temporary housing to enable the individual or family to gain and/or maintain medical care.

Housing assistance: Limited to short-term or emergency financial assistance to support temporary and/or transitional housing to enable the individual or family to gain and/or maintain medical care. Use of funds for short-term or emergency housing must be linked to medical and/or health care services or be certified as essential to a client's ability to gain or maintain access to HIV-related medical care or treatment.

Housing-Related Services: Assessment, search, placement, and advocacy services provided by professionals who possess an extensive knowledge of local, state and federal housing programs and how they can be accessed.

Housing assistance/related services, consists of three component services that were listed in the surveys as: "Assistance finding housing/transitional housing"; "emergency assistance paying rent"; and "emergency hotel vouchers."

Overall service priority, gap, utilization

Housing assistance/related services	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	6	47%	6	46%
Service Gap	1	38%	4	43%
Service Utilization	10	41%	---	---

You can't take your meds and try and be "healthy" when you're house surfing. If you're homeless, if you're couch surfing -- I think the housing comes before the health, which came before trying to get clean or not trying to get clean. [MSM/IDU FG - White Male]

While housing is not currently defined as a core service by HRSA, the findings from both provider and consumer surveys above illustrate that housing is important to the care of PLWH. Not only was it ranked a high priority for PLWH and providers, it was also ranked as the highest HIV care service gap for consumers. The lower utilization of housing assistance/related services (ranked 10th in utilization out of 20 service categories) may be indicative of housing services that exist outside of the AIDS system. Also,

clients may not know whether the services they are receiving are specifically RWCA or not.

Both consumers and providers (almost half) indicated that housing was a high priority among the current Ryan White Care Act (RWCA) service categories in King County (6th in rank of 20 RWCA services). There was no significant difference ($p < .05$) between consumers and providers in prioritizing housing services and no change from the percent of respondents who prioritized housing in 2003. Sub-populations of consumers significantly more likely to prioritize housing were: Recently homeless (72%); Black/African American (68%); Recently incarcerated (65%); MSM/IDU (64%); IDU (59%); and MSM of Color (58%).

Forty-one percent of consumers reported using housing assistance/related services. This was similar to the utilization by consumers in 2003 (41%). Housing services were ranked 10th in utilization out of 20 RWCA services. All of the core services with the exception of substance abuse treatment were ranked higher than housing for consumer utilization. Consumers living outside of Seattle were significantly less likely to utilize housing services. This is important because provider surveys indicate that more and more of their clients are residing outside of Seattle over the past four years. The percent of clients reported living outside of Seattle has increased from 23% in 2001 and 29% in 2003, to 36% in 2005. The non-Seattle residence of provider caseloads include 5% from East King County, 9% from South King County, and 6% from North King County.

Respondents who are currently or have been homeless within the past year were significantly more likely to have gaps in housing services. Seventeen percent of respondents reported being homeless with no permanent place of residence within the past year (the same as in 2003 and a 6% increase from 2001). Recently homeless respondents were significantly more likely to be younger. Twenty percent of the respondents were either between the ages of 14-24, or 25-29 compared to only 3% of respondents who were not homeless. Homeless youth likely have even greater difficulty accessing housing services due to lack of information about available resources.

Housing was ranked as the number one service gap for consumers, with 38% of consumer respondents needing but not being able to get housing. A larger percentage of providers than consumers indicated that housing was a gap for their clients (43%), however, housing was ranked 4th as a service gap below mental health treatment (1), oral health care (2), and substance use treatment (3). Despite the variation in percentage and rank, there was no significant difference between providers and consumers identifying unmet need for housing services. Providers did not rank housing services as high in gap as consumers and also a significantly lower percentage of providers ranked this as a service gap than in the past. However, housing services were still ranked as a top five service gap by providers. Over the past two years, the disparity between provider and consumer-identified gaps for housing assistance/related services reduced more than any other service category (from 34% difference in 2003 to only a 5% difference in 2005).

Comparing service gaps with service priorities helps determine the magnitude of potential system inadequacies and supports strategic planning and resource allocation

decisions. In looking at the top ten consumer service category priorities, housing services had the second highest service priority-to-gap ratio (rank 6 in priority and 1 for gap) for consumers in the continuum of care.

A major issue confronting Seattle is a critical, and deepening, housing crisis. Census data from 2005 show that vacancy rates in King and Snohomish Counties (especially central Seattle) are extremely low. In the King County housing market, Fair Market Rent (FMR) on a one-bedroom apartment is \$729 per month. The National Low Income Housing Coalition estimates that a worker in King County earning minimum wage (\$7.16) would need to work 80 hours a week to afford a one-bedroom apartment at FMR. For an individual living on Social Security Income (SSI) of \$564 per month, the FMR on a one-bedroom apartment is \$165 more than his or her monthly income. Waiting lists and waiting time for available AIDS housing have steadily climbed over the past two years. At least 89% of PLWH responding to the FY 05 needs assessment are living at or below 200% FPL which means that these persons would be paying a minimum of 45% of their income for a FMR apartment.

Component services priority, gap, utilization

Housing/assistance related services	Consumer % (N=436)	Provider % (N=187)
Assistance finding housing/transitional housing		
Service Priority	30%	39%
Service Gap	20%	38%
Service Utilization	30%	---
Emergency assistance paying rent		
Service Priority	28%	12%
Service Gap	26%	21%
Service Utilization	28%	---
Emergency hotel vouchers		
Service Priority	9%	9%
Service Gap	16%	12%
Service Utilization	13%	---

Within the Ryan White service category for housing, the survey asked about three component services: Assistance finding housing/transitional housing; emergency assistance paying rent; and emergency hotel vouchers. The table above shows that

between the three services, assistance finding housing/transitional housing was prioritized higher by both providers and consumers; emergency assistance paying rent was a significantly higher priority and gap for consumers. Emergency hotel vouchers were a lower priority for providers and consumers and also reflected significantly lower utilization by consumers.

Providers were significantly more likely than consumers to prioritize and indicate a service gap in assistance finding housing/transitional housing, while consumers were significantly more likely to prioritize and indicate a service gap for emergency assistance paying rent. Providers and consumers were similar in indicating emergency hotel vouchers as a lower service priority and gap.

Unmet need for housing/services

Consumer respondents with unmet need for housing (n=165) were asked to indicate the type of barrier preventing them from accessing the service from a list of six common barriers along with the option to mark “other.” Only five of these respondents with unmet need for housing were Ryan White ineligible, due to income.

Of the consumers with unmet need for assistance finding permanent or transitional housing, the most common barriers indicated were the waiting period (29%), not qualifying (29%), or not knowing where to go (25%). For those consumers with unmet need for emergency assistance paying rent, the most common barriers indicated were that they did not know it exists (21%), they did not know where to go (18%), and they did not qualify (15%). Finally, for those consumers with unmet need for emergency hotel vouchers, the most common barriers were not knowing that the service exists (42%), and not knowing where to go (27%).

Among those consumers who had unmet need for housing, 36% reported being certified as AIDS disabled indicating that the barriers related to accessing housing. However, 22% of the respondents with unmet need for housing also reported living currently in AIDS qualified housing implying that the barriers also relate to maintaining housing. Sub-populations of consumers significantly more likely to have unmet need for housing assistance and related services were: Recently homeless (60%); Foreign-born (53%); MSM/IDU (52%); and MSM of Color (48%). Consumer focus group participants with unmet need offered insight into their experience with accessing housing within the continuum of care. The following themes emerged from these groups and provider interviews in relation to barriers to accessing housing services mentioned above.

“WAITING PERIOD”

Lack of affordable housing stock

Many PLWH feel the effects of the shortage of affordable housing. Many do not know if there is a difference between low-income housing specifically reserved for PLWH or just low-income housing, but most feel that because of their HIV status stable housing is essential to maintain their health. PLWH cannot find affordable housing on the open market and are frustrated by long waiting lists for subsidized housing:

I was on [housing facility] housing list for a year and a half. My case manager told me, “they accepted your application, but they have no vacancies.” So I’m like, “what do I do now?” I didn’t know when they were going to have a vacancy. I didn’t want to couch surf for the rest of my life. [MSM/IDU FG- black male]

The housing seems to be out there, but it’s just the waiting list. Once you’re on, you just have to wait, sometimes for years. [HOMELESS FG – male]

Housing is probably the biggest thing. Because when you’re a single parent, especially being female in our position where some of us can’t work—I’m on disability—there’s no way I can afford three times rent just to qualify to walk into an apartment. They’ve got a waiting list: 5 years. That’s ridiculous. Just to be on subsidized housing, it’s 2 years. So that’s probably my biggest dilemma because if I don’t move out of my apartment by March 3rd, they’ll raise it up - 2 bedroom one bath apartment - to a 1000 dollars a month. I cannot afford that. But I cannot afford to walk into a private home and pay 1000 dollars rent. There’s no way. [WOMEN’S FG – Latina]

In addition, the lack of affordable subsidized or non-subsidized housing forces people to move further away from where they obtain services. Black/African American respondents (20%) were significantly more likely to live in South King County where rents are the lowest in the County, than Latino/Latina (9%), and White (7%). Women were also significantly more likely to reside in South King County (26%), than male respondents (7%).

PLWH living in King County outside of Seattle were significantly less likely to utilize any of the services in this category. Providers reported seeing a higher percentage of clients in King County outside of Seattle than appear in King County PLWH estimates which note residence at time of diagnosis. This trend has been apparent over the last four years from provider surveys. The percent of clients reported living outside of Seattle has increased from 23% in 2001, and 29% in 2003, to 36% in 2005. The most significant difference in residence over the past two years was King County providers indicating the increase in their caseloads of clients residing outside of King County, from 6% in 2003 to 15% in 2005.

Because many services are concentrated in Seattle and RWCA transportation services were cut back in 2005 during the time the survey was conducted for PLWH, consumers want to live in the city and prioritize this above living in outlying areas and getting transportation into the city.

Lack of appropriate housing

Many PLWH state that even if they are able to access housing, the housing that is available is often inappropriate. Consumers don't just want a roof over their heads; they want housing and an environment that is *healthy*. They recognize the primary role that housing has in their ability to maintain their health and that access to medical care or prescription drugs is meaningless unless they have safe and secure housing.

You may be terminally ill and low income, but what's society or the community supposed to do about it. "We can't just afford to set you up in your own condominium." And I understand that but that's just one of the major, most problematic issues that people with HIV have to deal with -- if you're single and living alone -- is your environment. [HOMELESS FG – male]

I haven't had subsidized housing since I lived in [*housing facility*], but I had to leave. I couldn't be in that environment. It was just so unhealthy, and so I left. And I said, I would rather be homeless. [HOMELESS FG – male]

Another consequence of the lack of openings in permanent housing is that a bottleneck is created in the system. People who manage to find transitional housing stay there instead of moving to permanent housing. This in turn prevents others from accessing transitional housing.

Well the housing is the challenging part. I'm coming up on 2 year deadline in March. I've been at this place for 2 years for single moms and moms to be. I'm a little scared 'cause I applied everywhere. I've been on a waiting list for section 8 for 3 years now, low income 2 years. Everything around that area for a year and a half or so, I mean everything, and nothing. [WOMENS FG – African American]

And above all, people desire single occupant living spaces they can call home. People want housing where they can welcome their community and family, and live in an emotionally healthy environment.

Having a place that I don't have to worry about, even welcoming family members of mine, and they have to be gone at a certain hour of the night if they chose to want to stay the night. Not having my life policed and governed by the bureaucracy of a flop house versus the fact of living in my own house or apartment. They want to stick you in second rate, poor neighborhoods and expect you to be able to deal with that mentally and emotionally and be able to financially afford the shit every month. And it's impossible. [MSM OF COLOR-FG]

“DO NOT QUALIFY”

Housing eligibility requirements too restrictive

The interplay of homelessness, incarceration, and substance abuse was apparent from consumer survey findings. Recently incarcerated respondents were significantly more likely to be homeless in the past year (51%) than were non-incarcerated respondents (14%). Both injection drug users (27%), and non-injection drug users (22%) are significantly more likely to have been homeless in the past year than non-drug users (7%). Recently homeless respondents were significantly more likely to have been incarcerated in the past year (28%) than not-homeless respondents (6%).

These co-morbidities in many PLWH create an extensive barrier to accessing housing services. Both recently incarcerated and MSM/IDU sub-populations raised concerns regarding their specific barriers to housing because certain eligibility requirements eliminate them. Background checks eliminate those with a felony record and dry/sober housing eliminates people who are currently using or who relapse.

If you have felony convictions and HIV, they don't want nothing to do with you. They accept people with children, but I am by myself, so I have to wait, so I will be dead by then. [Recently incarcerated FG - female]

The interplay of these co-morbidities as a vicious cycle was also discussed extensively in provider interviews. While incarcerated, clients do not have a confidential place from which to call and 90% of clinics/agencies/providers either do not accept collect calls or have voice menus which make such calls impossible to place according to providers. This on top of the standard discrimination based on incarceration history or HIV-not AIDS status that bars them from housing means they do not find a safe secure place right away. So they end up going back to drug community/friends where they relapse into substance abuse, which then leads to recidivism or missing appointments for HIV-related care services.

Many housing facilities will not accept clients who have had a felony within the past three years, regardless of the type of felony. What is more problematic is that there is no separation of types of crimes (property vs. violent) for consideration. The over-representation of African Americans in the criminal justice system also translates into higher gaps for PLWH with housing services. Black/African Americans were significantly more likely to have been incarcerated in the past year than non-Black/African American respondents.

Persons who were not disabled by HIV/AIDS indicated significantly greater gap to assistance finding housing than those who reported themselves as having received certification of disability from their doctors (16% of disabled PLWH versus 26% of non-disabled PLWH). Current policy for AIDS housing limits most services to those who are disabled by AIDS. Providers report that a physician will likely not prescribe meds

without consistent housing out of concern that clients will not be able to manage their medications without a regular schedule or way to track time, or a stable place to keep meds.

Provider interviews suggest too that the housing and HIV care systems have guidelines to accessing services that are stringent and they are not willing to consider clients individually.

My client was very hard working until his health caused him to lose his job and ultimately become homeless. Once he became homeless his medical provider was reluctant to provide medications because he did not have stable housing. While the client was medically close to an AIDS diagnosis he did not meet the exact medical criteria. As a result AIDS housing was not an option. The housing system would ask the medical provider to give the AIDS diagnosis for eligibility. The medical provider would ask the housing system to provide housing because the client was close to an AIDS diagnosis. My client was a perfect candidate for housing but the objectivity of the systems inevitably required his health to become worse.
[PI- case manager]

The thing that makes me mad is the housing qualification. You have to be on your death bed in order to get the help. [WOMEN FG – African American]

Because subsidized housing is limited, and demand outweighs supply, consumers perceive that housing programs have implemented increasingly strict requirements which limit choices for RWCA-eligible PLWH.

I'm at *[housing facility]*. I been there 6 months. It's not very good. It's a crack house actually. When you've got HIV and no income, you don't got a lot of choice. And now they cut out Section 8, it's pretty bleak – the future for housing. So either you gotta have a strong will to stay away from what's going on around you or you gotta suffer along with the rest of the people who live there. And for people who are terminally ill, and should be living a cleaner lifestyle, that's all that's available to you.
[HOMELESS FG – male]

Need for collaboration between systems

Providers spoke to the need for a more collaborative effort between agencies to improve access to services. They felt systems are becoming more complicated to navigate for clients. Housing providers in interviews discussed that there is no central agency to coordinate mental health, substance abuse, and HIV care services which often duplicates paperwork requirements for clients and is a waste of limited financial resources. Beginning in 2005, Title I set aside money for service enrichment in transitional housing, and HOPWA did the same for permanent housing. Some agencies have begun to have mental health or substance abuse treatment specialists on site at housing facilities. While this service enrichment has been very helpful for clients and providers, the challenges arise when there is confusion about who does what within the systems.

I had a client that had HIV, was using meth, and had clinical depression. His physician would not prescribe him meds while he was using meth. I promised the client that [care service] could help him with his medical management. His case manager was very upset with me because the process of getting services at [agency] is complicated and one that could only be guaranteed with a case manager's referral. Meanwhile the staff at this agency are all complaining to me that 75% of their program clients are on meth. If the systems are so disjointed and objective (case manager referral requirement) then you lose clients who really need the service. [PI, chemical dependency provider]

Housing providers also discussed that far too many clients are simply using housing services and not making an effort to improve in other areas. In these cases transitional housing services are not accomplishing medical goals. According to housing providers, lots of money is being spent in this area that could serve other clients who really want to improve their lives.

Providers report that confusion is also caused by turnover of service providers. Sometimes agencies (substance abuse, mental health, housing) will provide trainings to explain their specific intake requirements and procedures. As staffing changes occur more frequently providers lose track of who knows what. Having a specialist on-site makes it easier to coordinate services clients needed due to other providers' lack of information about the criteria.

“DO NOT KNOW WHERE TO GO”/“DO NOT KNOW IT EXISTS”

Issues with case management

The most common reported barriers for consumers with unmet need for housing were not knowing where to go and not knowing housing services existed. This could explain some confusion reported by consumers on the role of case managers versus housing advocates in finding housing. Most consumer survey responses and discussions in focus groups indicated that consumers expected more assistance from their case managers with finding housing and as a result were frustrated with their case managers.

Many focus group participants who expressed frustration with obtaining housing identified good case management to be critical. People who had case managers who they felt advocated strongly on their behalf fared much better than people who felt disconnected from their case managers. Case managers are important because the application process for all of the various housing programs is too complicated for many clients to manage on their own or people cannot even enter housing without a referral from a case manager.

As scary as the [housing facility] is, you can't get in there unless you have a case manager that refers you. [MSM/IDU-FG]

We need to have some kind of person, a middle person between the social worker, the case worker, and the client to facilitate and help them find clean and sober housing. That's part of the responsibility of the case manager. [MSM/IDU-FG]

In addition, people felt that case management needs to be more comprehensive and provide people with the skills to obtain and maintain housing. They wanted more help with finding housing.

We need to have people that are trained folks go out and find clean and sober housing and to show them. And most of us who are addicts have not had that kind of training. [MSM/IDU-FG white male]

In many ways, clients often perceived case managers as gate keepers to housing. People often felt that they had limited access to housing because their case managers were not advocating enough for them or didn't provide them with enough information.

Although my case manager is great and everything, I had to come up with housing on my own. I'm my own case manager in a lot of ways. [HOMELESS-FG male]

I maintained a period of being homeless for almost 2 and a half years to come to find out that [*housing facility*] had been open and operating all that period of time and my case manager -- he held back even telling me that until about six months ago when I heard it through the grapevine by sitting in the doctor's office in the lobby area hearing other people talk about it. [MSM of Color-FG]

My boyfriend's been homeless for 3 years and he's full blown. And the case manager we had, you know, she didn't do nothin' for us, you know. And he's still getting letters from when she was there in the mail - she never even sent them to him. He's getting them from different case managers. These case managers don't care. It's like they don't tell you a lot of things. We have to learn from other people, some of our friends. [WOMEN-FG - White]

“OTHER”

Discrimination in non-HIV-specific housing

Focus group participants felt that there was a lot of stigma and ignorance associated with HIV in non HIV-specific housing facilities creating an unsafe environment. This was exacerbated by a lack of support or grievance procedures to address their concerns.

Those with ignorance, those uneducated about HIV, are the ones who are afraid. I was ready to get kicked out of [housing facility] because I got in fight with one of them. I am open about my HIV status so I got into a fight. They didn't want me to return because other people are not comfortable with it because I am outspoken about it. They kicked the other guy out for fighting. They wanted me to wait until people who were bothered with it moved on, but there was no attempt made to educate others in house.
[RECENTLY INCARCERATED- FG - male]

Both MSM of Color, and recently incarcerated (specifically black) felt discriminated against in housing situations because they had been identified as part of a specific population. Interestingly, these groups did not feel discriminated against because they had HIV, only because they were either black or recently incarcerated.

There's a lot of discrimination in housing and black men in particular have been criminalized within the housing system without being convicted of any crimes. I've had to file a discrimination suit against my building because they denied me access to my caregiver who lives on a different floor. Because they said, and I quote, that they "suspect that I may have been involved in illegitimate activities because of the times of day or night that I'm out." I didn't know that there was any bedtime in the building, so as a black man, I feel very discriminated against within the housing situations – it added another layer of stress in addition to HIV, that I deal with in the place I live at. [MSM OF COLOR- FG]

LEGAL SERVICES

Legal services that are directly necessitated by a person's HIV status including: preparation of Powers of Attorney, Do Not Resuscitate Orders, wills, trusts, bankruptcy proceedings, and interventions necessary to ensure access to eligible benefits, including discrimination or breach of confidentiality litigation.

On the survey this service was not divided into any sub-categories and was stated as "Legal assistance (for non-criminal matters)."

Overall service priority, gap, utilization

Legal services	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	13	17%	18	4%
Service Gap	7	21%	12	13%
Service Utilization	15	28%	---	---

Consumers were significantly more likely than providers to prioritize legal services. Foreign-born, and Black/African American consumers were significantly more likely to prioritize legal services.

Consumers were also significantly more likely than providers to report a service gap for legal services, ranking as the 7th highest service gap out of 20 RWCA service categories.

Twenty-eight percent of consumers indicated using legal services with no significant differences by sub-population.

Unmet need for legal services

Of the 91 consumer respondents who reported unmet need for legal services, the most common barriers indicated were: "Don't know it exists (40%)," "don't know where to go (26%)," and "other (17%)." This finding was echoed in consumer survey comments.

Despite having tried for 3 years I remain unable to receive legal assistance
[consumer survey]

MSM of Color, foreign-born, and Latino/a respondents were significantly more likely to have unmet need for legal services.

Importance of legal services for foreign-born PLWH

Providers who work with both foreign-born Latino/a and foreign-born Black clients talked about the need for legal services of this population due to immigration issues and fear of HIV affecting their immigration/naturalization process. The importance and unmet need for legal services was conveyed in the Latino focus group and consumer surveys:

At the moment I am on Medicaid and get SSI but as from March 2008 this will stop. Reason: I have to become a US Citizen (now I am an asylee) to keep getting the benefits. It is hard for me because I do not have money to hire an immigration attorney and I will still need these services. So I need help in dealing with this issue. [consumer survey-foreign born Latino]

MENTAL HEALTH SERVICES

The psychological and psychiatric treatment and counseling services, including individual and group counseling, offered by a licensed, professional mental health provider licensed or authorized within the State, including psychiatrists, psychologists, clinical nurse specialists, social workers and counselors.

On the survey this service was not divided into any sub-categories and was stated as “Professional mental health counseling or therapy.”

Service priority, gap, utilization

Mental health services	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	7	34%	3	66%
Service Gap	10	17%	1	49%
Service Utilization	8	45%	---	---

Both consumers and providers indicated that mental health services were both a top ten service priority and a top ten service gap. Providers were significantly more likely to prioritize mental health services (32% more providers and 4 higher in rank) than consumers. White MSM (42%) were significantly more likely to prioritize mental health services than MSM of Color, and non-MSM.

Since the inception of the comprehensive assessment process in 1995, providers have been far more likely than consumers to identify mental health counseling as a service priority. This trend continues over the past two years. Both in 2003 and 2005, providers were almost twice as likely to prioritize mental health counseling (66% versus 34%). While the disparity has been consistent for this core medical service, both providers and consumers increased mental health as a service priority by both percentage and rank over the past two years. Many providers in key informant interviews reported increased

severity of their dually and triply diagnosed clients (HIV/mental illness/chemical dependency), coupled with client resistance to and/or lack of access to these services. Mental health also reflected the second largest disparity between consumers and providers indicating this service as a gap (49% providers versus 17% consumers).

Mental illness:

The consumer survey asked respondents to indicate if they had ever been diagnosed with a mental illness and more specifically what their mental health diagnosis was. Forty-eight percent of the respondents indicated having ever been diagnosed with a mental illness and 73% of those identified the specific diagnosis. Of those that more specifically identified their diagnosis, 74% indicated a single diagnosis, 21% dual diagnoses, and 5% identified 3 or more diagnoses of mental illness.

Of the total mental health diagnoses noted by consumer respondents (179), here was how mental illness was characterized: Depression (64%)-including general, manic, chronic, clinical, severe, minor/mild/moderate; Bipolar (16%); Anxiety related (7%); Schizophrenia (6%); Post Traumatic Stress Disorder (PTSD) (4%); and ADHD (3%)

Mental health providers report an increased number of clients that are both HIV positive and acutely mentally ill. Thirty-five percent of all provider caseloads were diagnosed with a mental illness. These patients present unique challenges for care providers. The high levels of depression reflected in the consumer survey were confirmed by providers in interviews. Most clients may not proactively recognize mental health issues or seek mental health services for themselves without providers recognizing and screening for diagnoses. This may explain why, for those consumer respondents who indicated needing but not being able to get mental health services (n=77), 34% said “they did not know it exists”, and 35% said “they did not know where to go.” Depression can cause clients to put off accessing HIV-related care as well. Providers felt that those who were engaging in mental health care services were more often doing well with accessing their HIV-related care. Providers reported that much of the depression they saw was related to consumers feeling isolated as a result of their diagnosis. Consumers also recognized the impact of depression on their care:

Because of my depression I have trouble dealing with things and people (especially in a timely fashion). [consumer survey]

While depression was more commonly expressed by consumers than other mental health diagnoses, providers felt that more severe mental illnesses function as greater barriers to accessing and maintaining the clients HIV-related care in addition to differences with adhering to medications and making appointments. Paranoia is associated with some types of mental illnesses, and this often creates a barrier for clients in accessing care. A housing provider talked about one of their tenants diagnosed with schizophrenia not staying at their housing facility and remaining homeless, because of the facility’s, proximity to the courthouse. Another provider talked about one of their mentally ill clients not accessing medical treatment because they felt needles were intentionally contaminated with arsenic.

Some case managers and mental health providers suggested that ideally there should be a psychiatrist/psychologist assigned to every consumer, just as there was an assigned case manager. However, the current system is thought to be too fragmented between community mental health case managers and HIV case management. Providers felt that better integration was critical. According to mental health providers, in the current mental health system, services tend to be offered for more severe cases such as when the person is in the act of self-harm or is disabled. The severity of mental illness has increased across the population of PLWH. More resources (time/effort from providers) are taken up by fewer patients. Therefore providers are seeing fewer patients per year, yet providing the same number of visits. This may also explain the decrease in average PLWH caseloads of mental health providers over the past two years based on the provider survey (47 per year in 2003, to 33 per year in 2005).

Although we have psychiatrists within the clinic, they will only see “defined” patients and are not available for emergent issues. [Medical Provider-provider survey]

This limitation was also reflected from the clients’ perspective on the consumer survey:

They [mental health providers] can help only if it is inside their box, don't ever ask them to step up to the plate for a client. [consumer survey]

Unmet need for mental health services

Interplay of substance abuse and mental health

Based on the consumer survey response, drug users (both those who inject drugs ([61%] and those who use drugs in another way [50%]) were significantly more likely to be diagnosed with a mental illness than non-drug users (39%). IDU were also significantly more likely to utilize mental health services. Substance abuse compounds mental health issues creating further barriers to accessing HIV-related care. Providers indicated seeing more clients who have both mental health and substance abuse issues, particularly with crystal meth abuse. Providers who work with recently incarcerated PLWH talked about how these co-morbidities often result in recidivism. Recently incarcerated consumer respondents were significantly more likely to indicate a service gap for mental health services (33%).

Based on the provider survey, MSM-IDU PLWH make up a larger proportion of provider caseloads than their representation in King County estimates. There has been an increasing trend in the average caseloads of MSM/IDU over the past four years for providers: 2001 (9%); 2003 (13%); 2005 (18%). MSM/IDU consumer respondents were also significantly more likely to indicate a service gap for mental health services (25%). Both mental health and substance abuse treatment providers talked about the need for more dual-diagnosis programs and more coordination between disjointed systems of mental health and substance abuse treatment. Focus group participants talked about these disjointed systems from their personal experience:

I abuse drugs for mental health reasons. 99% of psychiatrists won't take you if you're using, so it is a big vicious circle. [RECENTLY INCARCERATED FG]

If you're a drug user, mental health service providers will not see you unless you've done rehab and have it on paper to show, which to me is bullshit. In the mental health profession, certain people are very close minded. I understand how drugs can make us more crazy or amplify all that stuff, but a lot of people in the psychiatric community are close minded towards, number one, intravenous drug users, and people who just use drugs. [MSM/IDU FG]

The substance abuse treatment section of this report discusses some of the challenges created by these co-morbidities. Substance abuse treatment providers discussed the importance of accessing mental health services in preventing relapse or triggering initial use/abuse of harmful substances.

Mental Health barriers for People of Color

Latino/a consumer respondents were significantly less likely to utilize mental health services. Latino providers suggested that mental health is often seen as a service for higher class people and is foreign to most low-income immigrants who have few resources available for even basic care. Latino providers also noted that one-on-one counseling is a preferred method of providing support compared to support groups for this population because it is not natural culturally to emote in a public or group setting. For this reason the presence of an interpreter can pose a challenge to having a productive session for Latino/a clients.

Interpreters are helpful but not sufficient because Latinos do not feel comfortable sharing personal information with a third party present especially with concern of small community and word leaking out. [PI, case manager]

Providers report that the more fluid in Spanish the interpreter is during a session (i.e. giving the impression of not being there at all), generally the more satisfied the client is with the service. There are fewer bi-lingual mental health providers available locally necessitating the use of interpreters. In general Latinos report wanting to find more culturally competent service providers, not only those that speak Spanish, but also those who understand their culture.

Cultural competency issues were also discussed in the foreign-born Black focus group:

I am supposed to see a psychiatrist at [medical facility]. I have so far not seen the psychiatrist. All [providers] say is, "oh, you are depressed because of the holiday." I say, "I am Muslim, I don't celebrate Christmas. I don't have the holiday blues." I have asked for a new person, but they are gone for the holidays and it's hard to switch to some one else. [Female-Foreign Born Black FG]

Providers who primarily work with African Americans said both women and men of this population will almost never proactively seek mental health services without strong provider influence. Often these clients do not believe in the value of psychology or mental health therapy. African American consumers with mental health needs were more

willing to talk about those needs with their doctor than a mental health professional. Mental illness for this population was understood and addressed differently according to providers:

My African American clients who are dealing with depression would not refer to it as such, but instead say “I had the blues and didn’t want to be bothered” for example. They prefer to work it out with friends and family. [PI, case manager]

According to Providers who worked predominantly with women perceive women of color to have strikingly different views about mental health. There was much more shame with a mental health diagnosis resulting in much lower access to mental health services.

Even though women of color are involved in their medical care, they usually ignore anything related to mental health status, either it is not an issue or they don’t believe it exists. [PI, social service provider]

ORAL HEALTH CARE

The diagnostic, prophylactic and therapeutic services rendered by dentists, dental hygienists and similar professional practitioners.

On the survey this service was not divided into any sub-categories and was stated as “Dental care.”

Service priority, gap, utilization

Oral Health Care	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	4	62%	10	28%
Service Gap	4	28%	2	48%
Service Utilization	6	59%	---	---

Oral health care was ranked both a top ten service priority and top five service gap among the 20 RWCA service categories by both consumers and providers. Consumers were significantly more likely to prioritize the service than providers (which included dentists). Oral health care also increased in priority among providers over the past two years (+5%) and has continued to be one of the top five priority services for consumers over the past two years.

Despite similarity in rank as a service gap between providers and consumers, providers were significantly more likely (by percentage) to identify oral health care as a service gap. However, there was a significant increase in the percentage of consumers who indicated unmet need for oral health care since 2003 (+12%).

The service was also used by over half of consumer respondents (6th most used out of the 20 current RWCA service categories). There were no significant sub-populations differences for prioritizing oral health care.

Unmet need for oral health care

Limited knowledge of available resources

Oral health care was ranked as both a top five service priority and top five service gap, indicating both the increased need for more comprehensive dental care and current system inadequacies. From the consumer survey, PLWH who had been recently homeless, and those not certified as AIDS disabled, were significantly more likely to have gaps to oral health care.

Of those with unmet need for oral health care (n=121), 33% (42) of consumer respondents indicated they “did not know where to go” to access this service, and 27% (35) “did not know this service existed” in the Ryan White continuum of care. These barriers were reiterated in most of the consumer focus groups. Consumer focus group participants discussed not knowing there were RWCA funded services for oral health care, or if there was financial assistance available for dental premiums. In fact, Ryan White funds cannot be used to pay for private providers. The confusion was created because in the past for quite some time, the Evergreen Health Insurance Program (EHIP) was paying for dental insurance premiums until it was determined that this was not allowable. Also the Early Intervention Program (EIP) provided funds for private provider dental care. Even though this is no longer the case, consumers had grown accustomed to having a private provider and miss having this service, or they have heard from others who had this service in the past, creating further confusion about the availability of this service.

Some who used to receive oral health stated that they were not able to access services at community health clinics funded by RWCA due to there not being any openings. Consumers also discussed having limited options for providers and often having to go to a clinic completely separate from their medical care, or at a location far from either their home or their medical care.

I have Medicaid. For some reason they referred me from [medical facility] but they didn't refer to [same medical facility] dental. They referred to someone else. I was taken by a cab somewhere in [city] at [clinic] and my experience was terrible. I was very angry. [Foreign-born Black FG] (note: this person lives outside of Seattle and was referred to a different city)

The loss of dental care and limited access to dental care was a barrier discussed extensively by the MSM/IDU focus group participants. Because of their methamphetamine use and resulting oral health problems, access to dental care was critical to their physical and emotional health and thereby managing and accessing substance abuse treatment.

A few years ago I had complete dental care and now I have nothing. So I went from having everything to I haven't even had my teeth cleaned in about 3 yrs. Especially if you are exposed to any kind of drug use, methamphetamines, your teeth are vital. And the problems that you're going to have are going to affect your life. [MSM/IDU FG]

Other comments from focus groups and consumer surveys suggested that the unmet need for oral health care was less for basic services and more for oral surgeries including root canals, crowns, dentures, and periodontal surgery.

Barriers for homeless and recently incarcerated PLWH

In the homeless and recently incarcerated focus groups participants spoke a lot about being told that RWCA dental services were not accepting new clients and having a bad experience at a RWCA funded service provider.

Poor treatment, need for a greater selection among dental providers

Those consumers who receive dental care wanted more choices of providers and felt there needed to be alternative facilities to the few clinics that primarily serve low income clients. Consumer focus group participants reported that only community health clinics had dentists that would take Medicaid and RWCA did not offer a broad enough selection of providers to choose from.

There's not really a selection. There are two providers. And one was just so traumatic that I haven't been back because I don't want to put my body through that trauma again, but I don't want to lose my teeth either. It's frustrating trying to find decent dental care. [HOMELESS FG]

When you say you want to keep it between [clinic #1] and [clinic#2] then you're dealing with limited services. And with this disease, don't limit me, I'm already limited. [MSM/IDU FG]

The limited choice for dental providers who work with low-income clients, especially the lack of private providers, resulted in clients feeling they had to settle for inadequate care or completely stop accessing the service. This was one of the major discussion points for barriers to dental care in the foreign-born Black focus group. Participants talked about having to wait for up to two hours to see a dentist even with an appointment and being treated very rudely by staff:

I was referred by [referral agency] to go to public clinic in [location]. They treated me bad but I don't know if it was because of HIV. I left the clinic in tears. It was so painful. The process was not comfortable... better to discontinue care...I won't go to next appointment. [FOREIGN BORN BLACK FG]

The dental services I didn't like at all. I felt like the staff thought these people are just getting free services so they will put up with whatever... "you poor folk, better not whine." [FOREIGN BORN BLACK FG]

I had two appointments to clean my teeth and keep them from falling out. The first time they looked and didn't do anything. The Dentist didn't introduce himself, he just ignored me. The dental assistants were talking in their language and joking and chatting to each other, they didn't introduce themselves either. The Dentist was very arrogant and did not even explain what he was doing to me. For second appointment, I called [case manager] and told her I'm not going. I was very angry. [FOREIGN BORN BLACK FG]

PSYCHOSOCIAL SUPPORT

Individual and/or group support services other than professional mental health counseling, which is provided to clients, family and/or friends by non-licensed counselors. This may include psychosocial providers, peer support/support group services, caregiver support/bereavement, and/or drop-in support.

On the survey this service was divided into two sub-categories that were listed as "One-on-one emotional support program," and "Support groups."

Overall service priority, gap, utilization

Psychosocial Support	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	8	30%	9	29%
Service Gap	6	25%	6	25%
Service Utilization	7	48%	---	---

Psychosocial support was ranked both a top ten service priority and a top ten service gap for both consumers and providers. While not a defined core service, this finding signifies both the importance of this service as well as the potential system inadequacies. There was no significant difference between consumers and providers in service priority and service gap for psychosocial support. Women were significantly more likely to prioritize psychosocial support (42%).

Psychosocial support was the seventh most utilized HIV-related care service by consumer respondents with 48% indicating currently using this service. Women, foreign born, non-

MSM, IDU, and Black/African American respondents were significantly more likely to utilize psychosocial support services.

Component services priority, gap, and utilization

Psychosocial support services	Consumer % (N=436)	Provider % (N=187)
Support Groups		
Service Priority	25%	20%
Service Gap	14%	15%
Service Utilization	40%	---
One-on-one emotional support program		
Service Priority	14%	18%
Service Gap	21%	21%
Service Utilization	31%	---

Support groups were a significantly higher service priority and a significantly lower service gap for consumers than one-on-one emotional support. Support groups were more utilized for consumers as well. There was no significant difference between consumers and providers reporting either service as a priority or a service gap. In 2003, there was a significantly higher gap for this service for Latinos, but this was no longer the case in 2005. There were no statistically significant differences in gap by sub-population.

Foreign-born, females of color, and injection-drug-using consumer respondents were significantly more likely to utilize support groups, while females, IDU, and Black/African American respondents were significantly more likely to utilize one-on-one emotional support. Based on the consumer survey Non-MSM were significantly more likely to utilize both services than MSM.

Unmet need for psychosocial support services

For those consumer respondents who had unmet need for support groups (n=61), 41% indicated the barrier was “don’t know where to go,” 26% indicated “other,” and 25% indicated “Don’t know it exists.” For those respondents with unmet need for one-on-one emotional support programs (n=94), 49% indicated “Don’t know it exists,” 32% indicated “Don’t know where to go,” and 15% indicated “other.” Several consumer survey respondents reported need for these support services to manage living with HIV.

I can’t find counseling or emotional support. I would like to have at least some one-on-one counseling just to be able to talk about HIV and learn more about it. I also would be very much interested in support groups. [consumer survey-black female]

In many of the focus groups, discussions lead to clients gaining information about services of which they were previously unaware. As a result, consumers would relate the focus group experience to the value of having support groups to empower them to work for themselves and to get information from each other. In light of the over-loaded case management system, support groups were discussed as being a more valuable resource for consumers.

The kinds of things that work in this system are when you bring together people like this focus group, or the group that [program] brings together, when you bring together people to enable them to empower and to work for themselves and to get information from each other. Those are the kinds of things that have been most effective in the HIV care system, but those are the things that are least supported. [MSM OF COLOR FG]

Barriers for Women

Female consumer respondents were significantly more likely to prioritize psychosocial support as well as utilize psychosocial support services. Providers who work predominantly with women (both psychosocial support and other providers) reported that the major barriers to accessing these support services were lack of childcare, and transportation. This was also reflective of findings from the consumer survey, in which women were significantly more likely to reside in South King County and significantly more likely to prioritize and indicate childcare as a service gap. As mentioned earlier, system inadequacies were also suggested by consumers and providers, ranking psychosocial support services as both a top ten service priority and a top ten service gap.

There are no support groups on the eastside. There is only one support group that I can attend right now, and it is in Capitol Hill. Transportation and commuting during rush times discourage me to participate more fully. [consumer survey-FEMALE]

Most women with low-incomes cannot afford childcare. Ryan White Care Act does not currently provide childcare in Seattle/King County that women need to access support services.

I had to stop coming to the groups here because of childcare and transportation.
'Cause it's hard to put yourself first when you're looking out for someone else.
[WOMEN'S FG]

Types of support groups

Psychosocial support providers working with HIV positive women noted a trend that more of their clients preferred to have co-ed support groups. The standard support groups for women have shown a decrease in participation over the past year. Providers noted that in most cases this has to do with the large need for transportation to access the support group as well as childcare assistance needed from their partner during a support group. Transportation support for services other than medical appointments was eliminated half-way through 2005. Most women who have children who cannot access childcare reported that they did not attend support groups for this reason. Often for women with families, co-ed support groups alleviate these barriers because their partners may provide transportation and childcare; also having the family unit remain together is preferred. However, providers of support groups for women noted Latina women specifically almost never attended co-ed support groups. They preferred attending support groups integrated with other women rather than separate as Latina support groups. Their partners might assist with childcare at the support group venue, but were not participants within the support group.

Women focus group participants who were mothers discussed the great need for support groups specifically for mothers living with HIV. It was less important if the women were single or not, but more important to discuss issues related to raising children while managing their HIV. Participants discussed issues that would be useful for mothers to discuss in a support group including: how to address the child turning out HIV positive; how to explain their HIV status to their children; how to have a conversation about HIV and what to say to their children.

Referral for healthcare services

The act of directing a person to a medical, dental, or other provider, in person or through the phone, written or by other types of communication.

On the survey this service was not divided into any sub-categories and was stated as "Telephone referral program to doctors and dentists."

Overall service priority, gap, utilization

Referral for healthcare services	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	15	12%	16	5%
Service Gap	11	17%	19	6%
Service Utilization	9	44%	---	---

Consumers were significantly more likely than providers to prioritize referral for healthcare services and also significantly more likely to prioritize this service than in 2003 (7% more consumers).

Consumer respondents ranked referral for healthcare services as a top ten service gap in the Continuum (out of 20 service categories). Consumers were significantly more likely than providers to indicate a service gap. IDU and MSM/IDU were significantly more likely to have unmet need for this service.

Referral for healthcare services was the 9th most utilized service in the Continuum with 43% of consumers reporting using this service. There were no significant sub-population differences in utilization of this service.

Unmet need for referral for healthcare services

Lack of knowledge of available service in the Continuum

While currently this service category includes specifically a referral program for doctors and dentists, the comprehensive needs assessment in 2005 reflects a system-wide gap about knowledge and availability of RWCA services. The most common barriers indicated by consumers (N=436) for all RWCA services were “don’t know where to go” (39%), and “don’t know it exists” (38%). Three times the percentage of consumers than providers indicated a service gap to referral for health care services. Across all focus groups, when a list of available services was provided, almost every participant talked about not knowing one or more services existed.

I’m still new to HIV, so I don’t know anything. Like, a lot of the services and stuff I heard of today is new. [WOMEN’S FG]

Of the 78 consumers who reported unmet need for referral for healthcare services, half of the respondents indicated the barrier “don’t know it exists,” and 28% indicated “don’t know where to go.” IDU and MSM/IDU were significantly more likely to indicate unmet need for this service.

Providers in interviews talked about the fact that recently incarcerated, recently homeless, and substance abusing PLWH and their providers, would be more inclined to focus on the clients most basic and severe needs first such as housing, case management, chemical dependency treatment, and medical care. Therefore, other services became less of a priority for immediate need and were left off the radar of these consumers as well as their providers. Consumers would therefore learn about most support services from their peers or word-of-mouth.

Foreign born and Latino consumers in focus groups discussed the difficulty in navigating the Continuum and the lack of knowledge about available services, both because of language barriers as well as the cultural norm of depending on their providers to give them information rather than proactively seeking services.

It was difficult to figure out how to get services. [LATINO FG]

Women and heterosexual focus group participants and survey respondents expressed the frustration of not getting information about services in their community because they were not gay and they felt the information was widely distributed and targeted towards MSM.

They just seemed to have so much for guys. So sometimes I'm like, "Man, if I was a guy, I wonder if I would have housing, I wonder if I would have more money, I wonder if I would have a caseworker that you know." They do try once in a while to get women involved, it just for some reason, it doesn't work. It makes me feel left out some times. [WOMEN'S FG]

Those consumers that did access the referral program reported having a much easier time navigating the care system and accessing services.

Without [program], I wouldn't know anything about the system. I mean, those people told me more than my case worker told me. They was telling me something, and I ask my case manager about it, and [he/she] go, "how'd you find out about that?" I said "Well, hell, they told me at [program]." [MSM OF COLOR FG]

Consumers in focus groups offered the suggestion of having providers (such as case managers) be more proactive in providing their clients with information about all available services, even if eligibility is an issue. In addition, consumers wanted to see more education and outreach about available resources in the format of fliers and brochures for those who were more likely to not access agencies or were proactive self-advocates about their health. Consumers talked about wanting to be more resourceful when information was not provided by their caseworker, but there was not enough information in publications, online, or in pamphlets.

There is a lot more out there that I don't know. I learned a lot through word of mouth. I wish professionals or doctors could get out info better more flyers in doctors offices. [RECENTLY INCARCERATED FG]

We need all the information compiled so we can get to it and have it be accessible to us—and the right information. I'm willing to go through books and agencies and people but I know that there's a list out there but we're never told about them – we're not told where to look. [WOMENS FG]

SUBSTANCE ABUSE SERVICES

The provision of treatment and/or counseling to address substance abuse (including alcohol, legal and illegal drugs) problems, provided in an outpatient or residential health service setting.

On the survey this service was divided into two sub-categories that were listed as “Methadone vouchers,” and “Drug and alcohol counseling or treatment.”

Substance Abuse Services	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	15	12%	5	62%
Service Gap	15	9%	3	44%
Service Utilization	17	19%	---	---

Since the inception of the comprehensive assessment process in 1995, providers have been far more likely than consumers to identify substance abuse services as a priority. This trend continues. In both 2003 and 2005, providers were more than five times more likely to prioritize substance abuse services (62% of providers versus 12% of consumers). This service category also had the most significant increase in percentage for providers prioritizing it, up 28% from 2003 (when 34% of providers listed it as a priority), making it a top five service priority again as it was in 2001 and prior.

While the disparity has been consistent for this core service, more providers and consumers ranked substance abuse services as a priority than in previous years. Substance abuse services were prioritized by 12% of consumers in 2005, up from 7% in 2003. Many providers in key informant interviews reported increased severity among their dually and triply diagnosed clients (HIV/mental illness/chemical dependency), coupled with client resistance to and/or lack of access to these services. Foreign-born PLWH (21%) and MSM of Color (17%) were significantly more likely to prioritize substance abuse services.

While the disparity between consumers and providers also exists in their identifying a gap to substance abuse services (44% of providers versus 9% of consumers), from 2003 to 2005 the disparity between consumer and provider response diminished by 10%. However, as in the past, for providers substance abuse services was ranked a top ten service priority as well as a top ten service gap signifying potential system inadequacies.

Component services priority, gap, and utilization

Substance Abuse Services	Consumer % (N=436)	Provider % (N=187)
Methadone Vouchers		
Service Priority	4%	11%
Service Gap	5%	9%
Service Utilization	8%	---
Drug and alcohol counseling or treatment		
Service Priority	9%	59%
Service Gap	8%	48%
Service Utilization	16%	---

Currently, the RWCA service category of substance abuse services includes two component services, methadone vouchers and drug or alcohol counseling/treatment. The disparity between consumers and providers is much more apparent with counseling/treatment compared to methadone vouchers in terms of both priority and service gaps. Providers are significantly more likely to prioritize and indicate a service gap for counseling/treatment than consumers. MSM of Color (15%) and MSM/IDU (29%) were more likely to identify a gap in drug and alcohol counseling/treatment.

Almost twice as many consumer respondents indicated using counseling/treatment services compared to methadone vouchers. IDU, recently-incarcerated, and female respondents were significantly more likely to utilize methadone vouchers. Recently-

homeless, recently-incarcerated, and Black/African-Americans were significantly more likely to utilize other drug/alcohol counseling/treatment.

Substance abuse characteristics

Consumer survey respondents were asked to report if they had used drugs in the past 12 months. They were then asked to identify the type of drug and type of drug use behavior (injection drug use, versus non-injection drug use, or both). The following table illustrates the consumer survey response.

INJECTION DRUG USE HISTORY (n=436)				
Injection drug use in past 12 months		49	11%	
INJECTION VERSUS NON-INJECTION DRUG USE (n=436)				
DRUG NAME		% INJ	%NON-	%BOT
Marijuana	30%	NA	30%	NA
Methamphetamine	19%	7%	10%	3%
Cocaine	15%	3%	11%	1%
Poppers/inhalants	13%	NA	13%	NA
Heroin	7%	5%	2%	<1%
GHB/K/Party drugs	6%	1%	4%	<1%
Ecstasy	5%	NA	5%	NA
Downers	2%	NA	2%	NA

Demographically, consumer respondents who identified as White, female, recently homeless, or recently incarcerated were significantly more likely to have injected drugs in the past year. Injection drug users were more likely to use cocaine, heroine, and methamphetamine than non-injection drug users. Both injection drug users (82%), and non-injection drug users (88%) were significantly more likely to reside in Seattle than non-drug users (72%).

Methamphetamine use was significantly higher for consumer respondents who were recently homeless, recently incarcerated, male, MSM, or White MSM. Poppers/inhalant use was significantly higher for consumer respondents that were male, White, or White MSM.

From 2003, the greatest increase in the types of drugs used by consumers were methamphetamine (+4%), cocaine (+3%), and poppers (+3%).

Cocaine Use

Cocaine use was significantly higher for consumer respondents who were Black/African American, Female, recently homeless, recently incarcerated, MSM of color, or non-MSM. Providers in interviews noted that the clients who were women of color, particularly Black/African American and Native American women, were much more

likely to be using cocaine and alcohol. Some consumers who wanted treatment for cocaine use reported issues related to accessing substance abuse services on the consumer survey.

I'm sure that a lot of people, including myself, need help to get off of crack cocaine, for which there's no [effective] treatment that I'm aware of.[consumer survey- Black/African American female]

Methamphetamine Use

Methamphetamine use was significantly higher for consumer respondents who were recently homeless, recently incarcerated, male, MSM, or White MSM. Substance abuse creates additional needs and barriers for clients in the continuum of care.

Methamphetamine (meth) is a significant problem, and meth injection is the principal type of injection drug use associated with HIV infection in King County among MSM. According to epidemiologists, the HIV seroprevalence rate among MSM meth users is estimated at 35% for injectors, and 20% for those who smoke or snort the drug. These rates are higher than for any other sub-population. In the Council's assessment of prevention with positives, Prevention Project 2004, 23% of MSM interviewed reported using meth. In the 2005 care needs assessment, most providers interviewed, regardless of service type, reported that they are seeing not only increased numbers of meth users becoming positive, but an increased number of HIV+ persons beginning meth use.

While providers in King County have experience in working with people who use meth, behaviors, attitudes, and health outcomes associated with the drug are a barrier to care and to successful outcomes including medication adherence. According to a substance abuse service provider, meth use results in severe tooth decay. This gives current users social anxiety because of a poor self-image. These negative emotions can also trigger former users to relapse and is often why people using meth come into care late after their diagnosis of HIV. The majority of current users have depression, memory loss, and are not hydrating or eating well. For these reasons, providers report dental care and nutrition are important services for meth users with HIV.

Dental is so crucial! If you do meth, they'll fall out of your mouth – and when you start losing your smile you lose your self-esteem. When you lose your self esteem, you do more drugs. And it's a vicious cycle. [MSM/IDU FG]

Additionally, in Prevention Project 2004, meth use was associated with higher numbers of anonymous sex partners, and higher rates of unprotected anal intercourse, which increases risks of acquiring additional STIs, such as syphilis, which according to the STD clinic has increased among MSM (and especially HIV+ MSM) at an alarming rate in the past two years. Providers report that meth use is associated with periods of extreme paranoia, which often prevent users from seeking or accepting care and has a huge impact on the client's ability to make decisions.

Fewer women are using heroin than in the past but more women are using meth. According to a provider that predominantly works with women living with HIV, 60-80% are abusing substances and as a result falling in and out of care depending on sobriety.

Day/respice care has been a very beneficial service for PLWH who use meth, according to substance abuse service providers. This service provides a structure meth users need for their HIV-related care, especially while they are just starting to address their substance abuse.

Unmet need for substance abuse treatment services

Need more education, outreach, and availability of treatment options

Based on the provider survey, MSM/IDU PLWH represented a greater proportion of provider caseloads than of their representation in King County estimates. Providers report an increasing proportion of their caseloads are MSM/IDU: 2001 (9%); 2003 (13%); 2005 (18%). Thirty-nine percent of providers reported having clients with a history of chemical dependency.

Forty-one percent of those with unmet need for counseling/treatment services (n=14) reported not knowing where to go, and 27% (n=9) reported not knowing services existed. These were also the biggest barriers for those consumer respondents who had an unmet need for methadone vouchers.

Providers discussed the need for more education and treatment options for crystal meth abuse including support groups for meeting peers going through similar issues. They noted that people who can get outpatient and/or inpatient treatment do a lot better with their medical care. Consumers in the MSM/IDU focus group emphasized the importance of treatment availability and choices:

I believe that everyone needs to go into inpatient and should have that access if they want to be clean and sober. It's the only way to go! Then to follow up with out patient for another 28 weeks. [MSM/IDU FG]

If I want to deal with my addiction, then I think I should be able to choose how to do it. [MSM/IDU FG]

Providers report that people can generally get outpatient treatment, but inpatient treatment takes a lot longer to access. Clients have to wait weeks to months especially for inpatient treatment programs. This delay directly affects their medical care as providers are reluctant to prescribe HIV medications because of the person's inability to adhere to them. So PLWH with chemical dependency issues end up not getting needed medical care until they are sober. This delay in accessing treatment compounds the risk for relapse for meth users.

Clients are getting services but not quick enough. There is more demand and less availability. It often takes 2-3 weeks for any inpatient treatment program and this period is too long and patients (clients, consumers) are vulnerable to relapsing with meth. It should be 2-3 days. [PI, Substance Abuse Treatment provider]

Chemical dependency providers in interviews also suggested that those engaged in peer support groups other than 12 step groups were much better able to access medical care and care services. These groups help stabilize meth users and there has been an increase in demand by consumers over the past few years. Participants of the MSM/IDU focus group talked about the effectiveness of peer support groups and the need for more outreach to PLWH dealing with substance abuse issues about where to find these groups because a lot of people in the community do not know they exist. According to substance abuse service providers, the integration of harm reduction with traditional recovery has been very effective in stabilizing clients into recovery and accessing their overall HIV care.

Co-morbidities: Need for integration of systems

Consumer surveys illustrated the interplay of substance abuse, mental health, and homelessness. Each of these co-morbidities also has significant impact on the medical characteristics and illness levels of PLWH as emphasized in the medical care section of this report.

- Injection drug users (61%) and non-injection drug users (50%) are significantly more likely to be diagnosed with a mental illness than non-drug users (39%).
- Recently incarcerated respondents were significantly more likely to be homeless in the past year (51%) than non-incarcerated (14%).
- Both injection drug users (27%) and non-injection drug users (22%) are significantly more likely to have been homeless in the past year than non-drug users (7%).
- Recently homeless respondents were significantly more likely to have been incarcerated in the past year (28%) than not-homeless respondents (6%).

Chemical dependency providers report that many of their IDU PLWH clients are homeless upon intake, with approximately 25% - 50% of their male and 10% of their female IDU clients being currently homeless. The rates of incarceration among this population are also extremely high, particularly for drug-related offenses. Based on the consumer survey, recently incarcerated respondents were significantly more likely to have injected drugs within the past year (33%) than non-incarcerated (9%). This would reflect the large number of IDU clients who cycle in and out of jail on probation violations as discussed in provider interviews. Case managers who worked with recently incarcerated clients suggested the need for more dual-diagnosis programs and more coordination between disjointed mental health and substance abuse service systems.

Most clients have both mental health and substance abuse issues. Clients when they first see us after prison have nothing! And the longer it takes them to find stability with their mental health/substance abuse the more likely relapse and recidivism are going to occur. [PI, case manager]

Each of these co-morbidities impact the consumers ability to access and have successful outcomes with their HIV-related care. Providers from each of these systems in interviews indicated these systems exist separately while in reality they are completely

intertwined in the lives of consumers. HIV triggers mental health issues which trigger substance abuse and homelessness and visa versa. Mental health problems such as paranoia and psychotic episodes are often related to substance abuse. More clients are stressed about accessing housing services, rents rising, and Section 8 providing less assistance. This and homelessness often trigger substance abuse and complicates consumers HIV-related care.

Because of my past meth use I have no choice but to be around meth users when I'm homeless. So I could really use housing. [consumer survey]

Providers suggest that the care system is too compartmentalized, with clients having to go to too many different places to get all the care they need (housing, case management, substance abuse/mental health, etc.) They suggest that there be more linkages with agencies to create a "One Stop Center" environment making the continuum easier to navigate for clients. A chemical dependency provider talked about the benefits to his clients of providing counseling services twice a week at a local HIV-care related community based agency. Creating these linkages is challenging because of different established rules and guidelines for each agency. The following was an example that illustrated the challenges within this disjointed system:

I had a client that had HIV, was using meth, and had clinical depression. His physician would not prescribe him meds while he was using meth. I promised the client that [care service] could help him with managing his health. His case manager was very upset with me because the process of getting services at [agency] is complicated and one that could only be guaranteed with a case manager's referral. Meanwhile the staff at this agency are all complaining to me that 75% of their program clients are on meth. If the systems are so disjointed and objective (case manager referral requirement) then you lose clients who really need the service. [PI, chemical dependency provider]

Cultural competency:

MSM and LGBT- friendly treatment

As stated earlier, meth use is much more significant in the MSM population locally. Also, the consumer survey showed that MSM of Color and MSM/IDU were significantly more likely to indicate a service gap for substance abuse services. MSM meth users have a difficult time accessing substance abuse services in which they can feel comfortable in being explicit with their treatment provider or program about issues related to their sexual orientation. Providers and consumer focus group participants in the MSM/IDU focus group stated that inpatient and outpatient treatment programs often tell clients not to reveal their sexual orientation and this makes clients feel unsafe. This can hinder recovery, if they cannot talk about their core issues (which include their sexual orientation) it can interfere with the purpose of treatment.

Based on a recent assessment of substance abuse treatment providers by the MSM Taskforce locally, most existing treatment centers were not culturally sensitive towards MSM and some did not even know what LGBT stood for. Currently a majority of LGBT friendly services are located at one agency and providers felt that there needed to be more

options as demand increased and resources decreased. The substance abuse service system needs to be more culturally competent to address crystal meth in the LGBT community. Consumers in the MSM/IDU focus group confirmed this need:

At [treatment facility], I couldn't address my addiction issues because some of them involve being gay out in the group. So therefore, I got really nothing out of it. If you are sitting in a group and straight guys who don't want to hear about a gay man who goes to a bathhouse and has contracted AIDS– they don't want to hear that. Therefore I can't address my addiction and HIV issues. [MSM/IDU FG]

In fact when asked what was most important to them about their treatment, focus group participants identified the need for an LGBT friendly environment:

I've done [treatment facility] and I've done [treatment facility]. Both inpatient. I'm not a wimp, but it's very intimidating to be around people who are just gotten out of prison after 20 years and homophobic and they don't want to know about the reasons why I turned to drugs in the first place which involves gay issues. [MSM/IDU FG]

Need for harm reduction integrated with traditional recovery by providers

According to substance abuse service providers, most clients who are using substances do have case managers and primary medical care, but these providers are reluctant to actually provide their respective services to these clients because of their substance abuse. Substance abuse service providers suggest that providers in the Continuum of Care need to be trained on how to work with substance using clients and meet them “where they are at.” According to providers, even when they are in medical care consumers that are abusing substances will likely not tell their providers if they are forgetting to take meds or not taking meds. Providers report that consumers are often in denial about substance abuse and are reluctant to share information related to their addiction. Often when engaging in treatment for their substance abuse, consumers are still using drugs because it is a part of their life and they will continue to use drugs until they want to quit themselves.

Consumers will often drop out of care because the provider will not talk to them until they clean up. There needs to be a more harm reduction approach to care.[PI, substance abuse treatment provider]

Consumers in the MSM/IDU focus group talked about most of the treatment programs and providers they had worked with did not really wanting to deal with crystal meth. They talked about the need for specific programs for specific addictions that are also sensitive to the needs of consumers from a wide range of experiences and backgrounds.

Most of these programs don't really deal with crystal meth, they deal with alcohol. When I introduce myself, I say, “I'm so and so, I'm an alcoholic/addict.” I'm not really an alcoholic, but if you don't say alcoholic then they don't really know where to put you. So we need specific programs for specific addictions. [MSM/IDU FG]

TRANSPORTATION

Conveyance services provided to a client in order to access health care or psychosocial support services. These may be provided routinely or on an emergency basis.

On the survey this service was not divided into any sub-categories and was stated as “Rides to medical or social service appointments.”

Overall service priority, gap, utilization

Transportation	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	11	21%	10	28%
Service Gap	13	14%	5	27%
Service Utilization	12	34%	---	---

Increasingly, providers reported seeing clients who reside outside of Seattle, often a significant distance from more centrally located medical and essential HIV-related care services. This may be why providers ranked transportation as a top 5 service gap and a top ten service priority. While there was no significant difference between consumers and providers in prioritizing transportation, providers were significantly more likely than consumers to report a service gap for transportation. From 2003, a significant increase in percentage of consumers (+7%) and providers (+11%) indicated gaps to transportation services.

One-third of consumer respondents reported using transportation. Utilization of transportation related to place of residence of consumers. Female and Black/African American respondents were significantly more likely to reside in South King County. This is likely why female and Black/African American respondents were significantly more likely to use transportation services. Recently homeless and incarcerated respondents were also significantly more likely to use transportation.

Unmet need for transportation

Of the 59 consumer respondents who reported unmet need for transportation, the most common barriers indicated were “don’t know it exists (35%),” and “don’t know where to go (25%).” MSM of Color, foreign-born, MSM/IDU, Black/African American, and Latino/a respondents were significantly more likely to have a gap to transportation services. There was no qualitative information to explain barriers to transportation for these specific sub-populations. However all of these subpopulations with the exception of MSM/IDU were more likely to reside outside of Seattle, especially Black/African Americans who were significantly more likely to live in South King County.

Priority and service gap for women

Fifteen percent of those with unmet need for transportation indicated “not qualifying” as the barrier to accessing this service. Women, who were more likely to reside outside of Seattle and utilize transportation, emphasized transportation issues more than any other sub-population in focus groups. Both providers who work with women in interviews, and consumer participants in the women’s focus group talked at length about the importance of transportation and qualification being the most common barrier to accessing transportation services.

You have to meet certain qualifications. Me and my son wouldn’t qualify for the rides. You have to meet qualifications for those programs. [WOMEN’S FG]

I get [transportation program] because I have emphysema. I can also get a bus pass if I want to, but 95% of the time I can’t ride the bus – it’s just too much. So I qualify because of that, I also qualify for a bus pass, so that’s double, which isn’t fair, ‘cause some people don’t get anything. [WOMEN’S FG]

Women traveling with their young children because of lacking childcare services were even more concerned about not having transportation. Bus transportation was problematic, especially in winter months, for their health and their children’s health. Women who did not have transportation often said they would not engage in medical care appointments and other support services specifically because of a lack of transportation.

Reason I say transportation is most important is we live in a state where it rains and it’s cold. Being out in the rain, because you’re standing waiting for a bus, in the cold weather is probably not the best idea for us. And I’m sorry, I’m not going to walk a mile to the bus stop in a cold rain and worry about whether I’m going to end up being sick, or my child sick. I’d rather not go period.[WOMEN’S FG]

I had to stop coming to the groups here because of childcare and transportation. I had to stop a lot of things support-wise. [WOMEN’S FG]

TREATMENT ADHERENCE SUPPORT

Provision of counseling or special programs to ensure readiness for and adherence to complex HIV/AIDS treatments. This includes treatment information.

On the survey this service was divided into two sub-categories that were listed as “Education about HIV/AIDS treatments, etc.,” and “Treatment adherence support and/or education (help taking HIV meds).”

Overall service priority, gap, utilization

Treatment Adherence Support	Consumer (N=436)		Providers (N=187)	
	Rank	%	Rank	%
Service Priority	10	22%	7	37%
Service Gap	12	14%	8	18%
Service Utilization	4	69%	---	---

Providers were significantly more likely than consumers to prioritize treatment adherence support. However, both consumers and providers reflected an increase in prioritizing treatment adherence support from 2003 (+6% for consumers, and +9% for providers), with providers significantly more likely to prioritize this service since 2003.

While providers ranked treatment adherence support as a greater service gap than consumers, there was no significant difference between consumers and providers indicating this as a service gap. In fact, the disparity between providers and consumers in indicating a service gap reduced significantly from 2003 for this service category. Providers, unlike consumers, reflected potential system inadequacies in ranking treatment adherence support as both a top ten service priority and top ten service gap.

Treatment adherence support was the fourth most utilized service by consumers in the Continuum (69%). Black and Female respondents were significantly more likely to utilize this service.

Component services priority, gap, and utilization

Treatment Adherence Support	Consumer % (N=436)	Provider % (N=187)
Treatment adherence support and/or education (help taking HIV meds)		
Service Priority	8%	26%
Service Gap	8%	14%
Service Utilization	37%	---
Education about HIV/AIDS, treatments, etc.		
Service Priority	17%	17%
Service Gap	8%	6%
Service Utilization	63%	---

There was no significant difference between consumers and providers prioritizing or indicating a service gap for education about HIV/AIDS. Providers were significantly more likely than consumers to prioritize and indicate a service gap for treatment adherence support. Between service components, consumers were significantly more likely to prioritize education about HIV/AIDS, while providers were significantly more likely to prioritize treatment adherence support.

Consumers overall were significantly more likely to utilize education about HIV/AIDS (62%), than treatment adherence support (37%). Black and female consumer respondents were significantly more likely to utilize both of these services. Recently homeless and injection drug users were significantly more likely to utilize treatment adherence support, while non-drug users were significantly more likely to utilize education about HIV/AIDS.

Unmet need for treatment adherence support services

For those with unmet need for education about HIV/AIDS (n=41), the most common barrier reported was “not knowing where to go” to access this service (59%). For those with unmet need for treatment adherence support (n=36), the most common barriers were “don’t know it exists (42%),” and “don’t know where to go (31%).” Both of these suggest that there needs to be an increase in education and outreach about the availability of these services.

Substance abuse and treatment adherence

Those with unmet need for treatment adherence support services were significantly more likely to have used methamphetamine in the past six months (23%). Injection drug users and recently homeless respondents were significantly more likely to use treatment adherence support as well. Providers of all types in interviews discussed the challenges of treatment adherence for homeless and substance abusing PLWH as well as medical provider's reluctance to provide medications to current users (see substance abuse treatment section). Providers reported that without housing and stability, treatment adherence support is vital for homeless and substance abusing PLWH.