EXECUTIVE SUMMARY

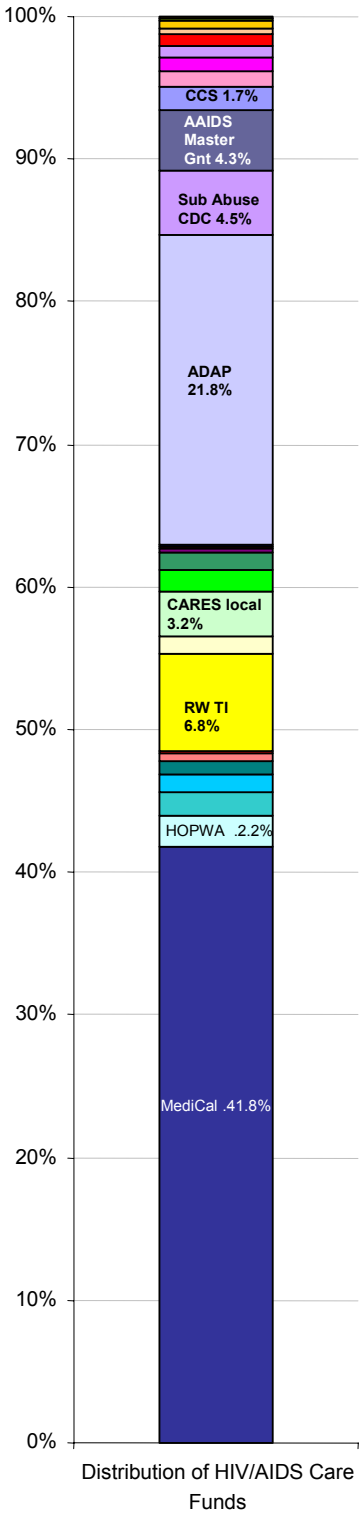
Sacramento EMA 2004 - 2006 COMPREHENSIVE HIV SERVICES PLAN

Prepared by the Partnership For Community Health

For

The Sacramento HIV Health Services Planning Council

August 2003



INTRODUCTION

The 2003 Sacramento Needs Assessment and 2004-2006 Comprehensive HIV Services Plan (Plan) presents a road map for the future planning and implementation of an HIV/AIDS Continuum of Services (HCS) that reduces the impact of HIV/AIDS in the Sacramento EMA (Sacramento, Placer, and El Dorado Counties). It provides information that will assist the Sacramento HIV Health Services Planning Council (Council):

1. Sustain a HCS that will maintain and improve the health status of PLWH/A.
2. Prioritize and fund HIV/AIDS services provided under the Ryan White Care Act.
3. Establish standards for services.
4. Meet the planning and reporting requirements of the Health Resources and Services Administration (HRSA), the federal agency that administers the Ryan White Care Act (RWCA).

The effective and efficient use of Care Act funds becomes essential as the number of PLWH/A increases, while per capita funding decreases. As shown in the bar to the left, RWCA Title I provides nearly 7% of the $38.4 million in public funds earmarked for HIV/AIDS care, and it provides services to those most at need. Care Act funds provide the protective net for those who cannot afford HIV care or don't have other insurance. Further, the Council represents the voice of PLWH/A in the planning process and helps establish standards of care.

The Plan draws from epidemiological, survey, focus group, secondary analysis, and highlights:

1. The current epidemiological status of PLWH/A in the EMA, and their service needs, gaps, and barriers.
2. The goals, objectives and tasks for HIV/AIDS care services in the next few years.
3. Suggestions on how the system will monitor its progress in meeting their goals and objectives.

THE PRESENT

Visions of the Council

The shared vision of the Council is an HIV/AIDS Continuum of Services (HCS) that will assure 100% access to HIV related health care and prevention-for-positives, with 0% disparities among the populations infected and affected by HIV and AIDS. For persons infected with HIV and AIDS, treatment for their infection will be available, accessible, affordable, and culturally appropriate.

HIV/AIDS Continuum of Services (HCS)

The HCS for the Sacramento EMA has seven tracks that addresses the service needs of different populations infected and affected by HIV/AIDS including: A) the general population, B) at-risk individuals who do not know their serostatus, C) HIV negatives, D) HIV positives, E) partners, F) service providers, and G) the grantee of the RWCA. The HCS objectives and outcomes of each of these populations are shown in Table 1.

Table 1 Objectives and Outcomes for HCS

OBJECTIVES	OUTCOME
A. Increasing public awareness of the risk of HIV infection	1. Public support for prevention services. 2. Individual assessment of risk for HIV infection.
B. Outreach to at-risk populations	1. Knowledge of serostatus. 2. Knowledge of related co-morbidities. 3. Increased safer behaviors (condom and needle use). 4. Lower rates of STDs and TB. 5. Understanding about abstinence from sex / drug use.
C. Prevention services to HIV -	1. Maintain negative status. 2. Adopt and maintain safer sex and needle use activities. 3. Lower rates of STDs and TB. 4. Understanding of abstinence from sex / drug use.
D. Care and prevention services to PLWH/A	1. Increased percentage of PLWH/A receive and maintain primary care. 2. Decreased gap between need and utilization of support services related to seeking medical care. 3. Maintain and improve health status of PLWH/A. 4. Maintain and improve the physical and emotional health status of PLWH/A. 5. Increased use of primary care by those who are out-of-care. 6. Improved adherence to drug regimens. 7. Increased LOA for linkages and increased number of referrals to appropriate services. 8. Increased adoption and maintenance of safer behaviors.
E. Prevention and care services to partners where one or both are HIV positive	1. New and implemented protocols for family support services. 2. Increased partner notification. 3. Increased number of mutual commitments to safer sex and needle use strategies.
F. Training and technical assistance services to providers	1. Increased capacity to provide effective care and prevention services.

G. Assessment and evaluation of services by grantee	1. Accountability of funds and services to consumers and funders. 2. Improved client satisfaction and reduction of barriers to care and prevention services.

The HCS recognizes that a primary goal of the care system is to reduce the impact of HIV and AIDS on the overall community. That mean both maintaining and improving the health status of PLWH/A and embracing the need for HIV positive persons to accept their share of responsibility for adopting and maintaining safer practices that limit the spread of HIV.

While services to all of the seven populations are important, the focus of the Council is on HIV/AIDS care services provided to HIV positive persons and their partners, the Sacramento County Department of Health, and providers. The outcomes and services for these tracks are shown in Figure 1. Note that the care services for HIV positive and their partners are divided into: 1) core, 2) primary linking and access, and 3) support services. The numbers beside these services represent the Council 2004-2005 planning priorities. Outcomes and services for general population, high risk, and HIV negative populations, Tracks A – C, are the primary responsibility of prevention and they are discussed in the overall Comprehensive Plan.

Within Title I, the allocation of RWCA Title I funds for each service is shown in Figure 2. Although medical care is the number one priority, MediCal and Medicare pay the majority of those services. However they do not pay for a significant share of case management, and consequently it is not surprising that case management has the largest allocation, 32% ($943,263). It is followed by outpatient medical care with an allocation of 10% ($311,389) and mental health services, with an allocation of 9%. Notably, almost $600,000 is added to the outpatient medical care category from Ryan White Title II funds. After that, dental care and residential or in-home hospice care were each allocated 5%. Food, transportation, and outpatient substance abuse were each allocated 3%.

A key factor in understanding the HCS is that the Sacramento EMA has one large community-based provider that supplies the vast majority of the medical services and a large portion of the case-management and wrap-around services. A number of other organizations provide other services such as substance abuse services, housing, transportation, and other wrap-around services that support persons seeking and maintaining medical care.

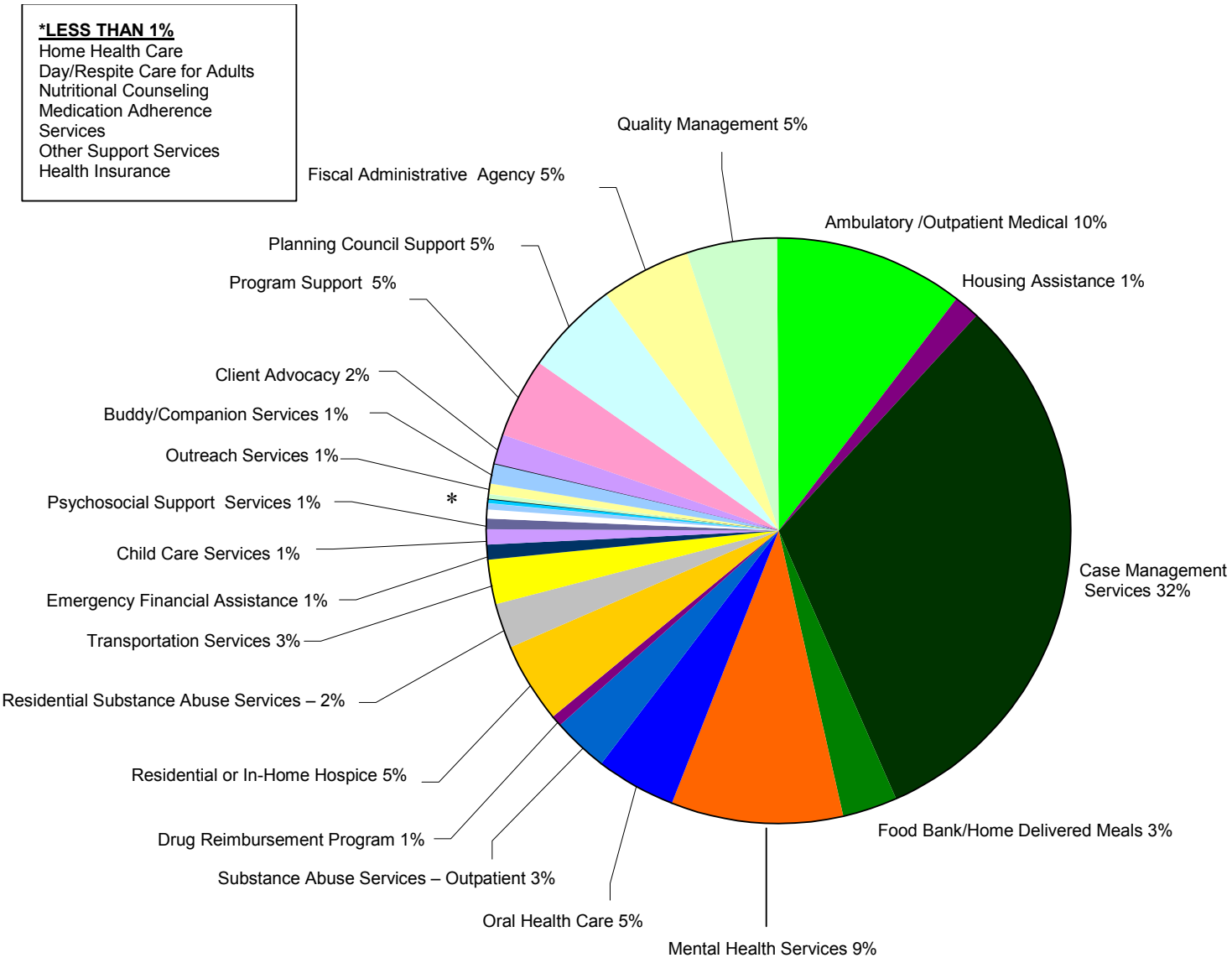
The following subsections summarize the epidemiological and needs assessment data, and they are followed by a summary of the recommended goals, objectives, and methods of monitoring the HCS.

Figure 1 Continuum of Services for Tracks C-F

	Track C: Care and Prevention Services to PLWH/A	Track D: Prevention And Care Services To Partners Where One Or Both Are HIV Positive
Outcomes:	1) Maintain and improve health status 2) Linkages to, initiating, and maintaining health care 3) Commitment to safer behaviors	
	1) Obtain STD treatments and lower rates of STDs 2) Abstinence from sex/drug use 3) Adopt and maintain safer behaviors (condom and needle use) 4) Maintain or improve quality of life	
Prevention Services:	Provide skill-building workshops (Condom use, needle cleaning, partner negotiation). Conduct behavioral modification programs. Provide peer education / support. Circulate newsletters. Offer support groups.	
	Provide adherence programs. Monitor HIV status. Offer 1-1- counseling / prevention case management. Work with criminal justice system.	Develop partner agreements. Partner notification Provide partner negotiation. Partner counseling and referral.
Care Services (for HIV and Partners only) ** Number in Parenthesis is 2004-5 priority.* *** Not ranked*	**Core:** Ambulatory medical, specialty, care & labs (1)* Dental care (3) Substance abuse (residential) (7) Substance abuse services (outpatient, counseling) (9) Mental health services (individual and group) (5) Hospice and residential care (PLWA) (12) Adherence counseling (Pediatric) (14) Home health care** **Primary Linking and Access Services** Case Management (2) Benefits Counseling Advocacy Transportation (voucher and trips) (8) Insurance continuation (15) Outreach** **Support Services** Emergency financial asst (4) Medical reimbursement / medication (non-ADAP) ADAP co-pay assistance Food vouchers, utility assistance, other critical need Housing (Emergency housing, referrals, long term housing) (6) Food bank/home delivered meals (10) Psycho-social support services / groups (11) Nutritional counseling (non-nutritionist) Peer counseling Complementary (acupuncture, chiropractic, massage) Child care (13)	

***OUTCOMES**:* *Increase capacity to provide effective services*	***OUTCOMES**:* *1 Accountability to consumers and funders* *2. Improvement of services*
Services: Training. Infrastructure support. Program development. Newsletters.	Services: Program Monitoring. Needs Assessment. Consumer Satisfaction.

Figure 2 Ryan White Title I Allocations



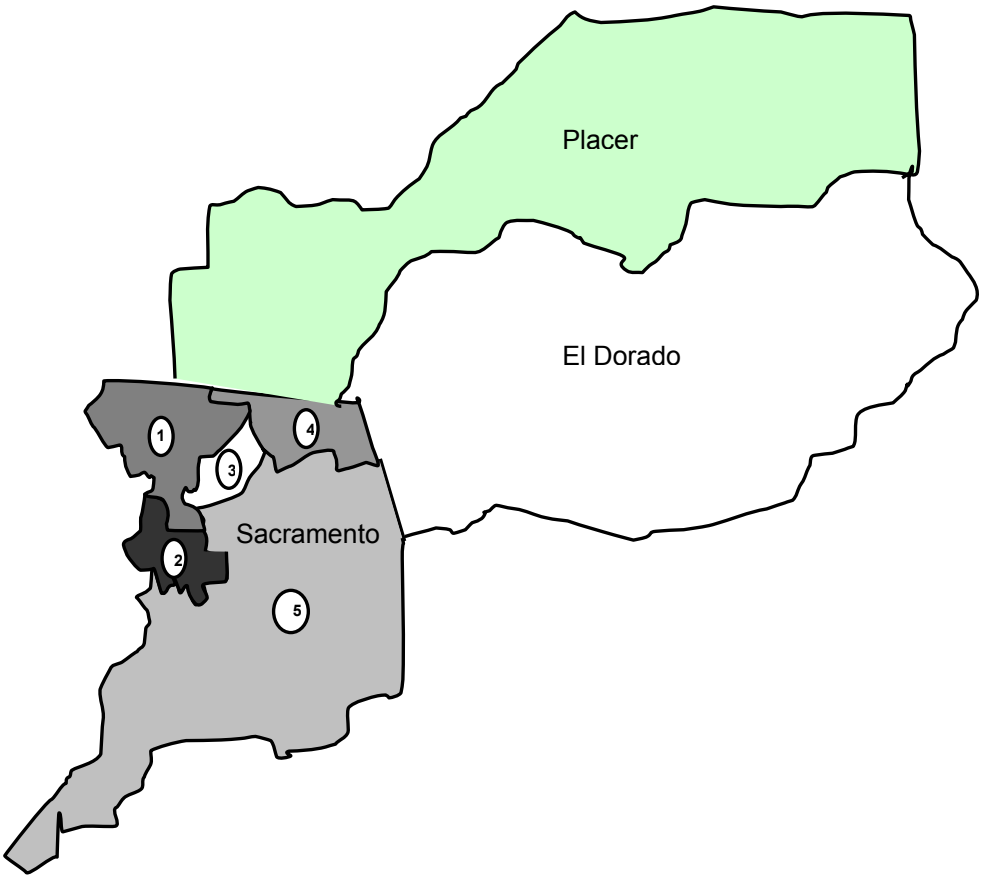
Epidemiology

Sacramento EMA

The Sacramento EMA, located in central California, includes Sacramento, El Dorado, and Placer counties and has a population of 1,699,868. The EMA has both urban and rural characteristics and is geographically, racially, and ethnically diverse with variations in each county.

Sacramento County is divided into five districts. The Board of Supervisors is the governing body of the County of Sacramento and each of the five members of the Board represent one of five districts. In addition, the EMA includes Placer County to the Northeast and El Dorado County to the East. The Council has decided to use the five supervisory districts in Sacramento County plus El Dorado County and Placer County to geographically distinguish the needs of PLWH/A in the Sacramento EMA. A map of Sacramento County's five supervisor districts and El Dorado and Placer Counties is shown in Figure 3.

Figure 3 EMA with Sacramento Regional Districts



PLWH/A

When planning for HIV and AIDS services, knowing the number of persons living with HIV and AIDS and the number currently accessing services provides a theoretical referent for the number of PLWH/A who could seek services in the HCS and the number who have sought services in the past.

The HIV/AIDS Reporting System (HARS) documents 1,435 people living with AIDS as of December 2002, nearly a 20% increase since 1997. There were 180 new AIDS diagnoses in the last two years, or 12% of living AIDS cases. Ninety-one percent (91%) of living AIDS cases is in Sacramento, with about five percent (5%) in Placer and four percent (4%) in El Dorado. Table 2 shows PLWA are disproportionately male, African American, and MSM.

Table 2 further indicates that there is an estimated 3,422 people living with HIV and AIDS in the Sacramento EMA who know their HIV status. At the end of 2002, there were about 1,435 PLWA and an estimated 1,987 people living with HIV (not AIDS) in the EMA (Department of Public Health, 2003). An estimated 95 HIV cases are in Placer and 86 HIV cases in El Dorado County. A disproportionate number of HIV/AIDS cases are among African Americans. They comprise only 8% of the Sacramento EMA's population, yet 22% of living AIDS cases, 29% of estimated HIV infections, and 27% of people newly diagnosed with AIDS.

Table 2 Demos of General Population, PLWA and PLWH

		GENERAL POP*	PLWA 2002**	PLWH 2002+	TOTAL PLWH/A
	Population	**1,699,868**	**1,435**	**1,987**	**3,422**
Gender**	Male	49%	86%	80%	82%
	Female	51%	14%	20%	18%
Race	African American	8%	22%	29%	26%
	Anglo	64%	63%	58%	61%
	Asian/Pacific Islander	9%	1%	1%	1%
	Latino	14%	12%	10%	10%
	Other	5%	2%	2%	2%
Risk Group	MSM	NA	58%	53%	54%
	MSM/IDU	NA	12%	17%	11%
	IDU	NA	15%	10%	16%
	HET	NA	15%	20%	18%

* Census Bureau, 2002 ** HARS + RWCA Title I Application, 2004-2005

In summary:

- MSM represent 58% of living AIDS cases in the Sacramento EMA.
- MSM/IDU account for a larger share of the epidemic in the EMA than in most other parts of the country. They account for 12% of living AIDS cases, and over 40% of all injection-related HIV cases in the EMA, compared to only 6% of national cases.
- 82% are males, 18% are females. Women represent a far greater proportion of African Americans living with HIV/AIDS than other ethnic populations.

- People of color represent about 31% of all AIDS cases prior to 1990, but account for 53% of new cases diagnosed in 2002.
- The majority of the PLWH/A are non-Latino Anglo (61%), followed by African Americans (26%), Latinos (10%), and other ethnicities, including Asian Pacific Islanders and Native Americans at about 3%. People of color as a group, including African Americans, Latinos, Native Americans, and Asian/Pacific Islanders, represent 39%.
- Among Anglos, 93% are male, and 68% percent of them are MSM. Twenty-five percent (25%) report a history of IDU, and 8% are heterosexual.
- African Americans PLWH/A are 44% female and 42% report being heterosexual. Thirty-five percent (35%) report a history of IDU, and 29% report being MSM.
- Latinos have a profile similar to Anglos: Mostly male (88%), about a quarter (23%) with IDU history, and 16% heterosexual.
- 43% of PLWH/A live in District 1.
- 15% of PLWH/A live in District 2.
- African Americans and heterosexuals are more heavily represented in District 2.
- Although there has been a consistent decline in newly diagnosed AIDS cases from 1997 to 2002, since 1997, the decline in AIDS rate has been between 73% and 80% among Latinos, Anglos, and African Americans. Yet, while African Americans have experienced the greatest decline in AIDS rate (80%), in 2002, the AIDS rate among African Americans (9 per 100,000) was more than double that of Latinos (4) and three times the rate among Anglos (3).
- The growing Latino and African American populations in Sacramento are disproportionately impacted by AIDS. While Latinos account for about 14% of the population they account for 16% of the newly diagnosed AIDS cases. Similarly, African Americans represent 8% of the Sacramento population, yet, they account for more than a quarter (27%) of the newly diagnosed cases in 2002.
- Overall, there appears to be a shift in new infections toward heterosexuals in the epidemic where by 2002, heterosexuals account for 31% of the newly diagnosed AIDS cases. Heterosexuals show a decrease in incidence of about 41% since 1997, compared to over an 80% decrease among IDUs, MSM, and MSM/IDUs.
- Heterosexuals represent 18% of all PLWH/A. They are mostly African Americans (11%), with about 5% Anglos, and 2% Latinos and other ethnicities.
- African Americans (22%) are more likely than Latinos (19%) and Anglos (11%) to live with children.
- In terms of absolute numbers, Anglos are not disproportionately impacted by AIDS, yet, they will continue to contribute the largest number of AIDS cases over the next several years accounting for nearly 60% of the new cases in 2002.

PLWH/A in Care

According to the SEMAS database, there are over 1,770 PLWH/A accessing CARE-funded services. People of color make up 39% of clients receiving Title I-funded services (in contrast to representing about 36% of all PLWH/A), women make up about 18%, and IDUs represent about 16% of the PLWH/A in care.

The trend in the epidemiology suggest that as African Americans and Latinos become a larger proportion of PLWH/A services must be designed to meet their needs and be provided in a culturally appropriate fashion. While women continue to represent about a fifth of the epidemic their numbers are increasing rapidly. They are disproportionately African American and likely to have families.

Another increasing population is MSM/IDU and MSM non-injection drug users. If the current trend continues, they will be a significant force in increasing the infection rate among MSM and the HCS is likely to need a greater capacity for substance abuse services for this population.

For the immediate future, however, Anglos MSMs will continue to represent a majority among those seeking and services. As the HCS adjusts to current trends, the need to service this core population must be maintained.

Out-of-Care

There is no reliable count of those out-of-care. Using the recommended CDC estimate that 25% of all those infected don't know their status, there would be an estimated 4,600 PLWH/A in the EMA. Based on the estimate that 96% of the PLWH/A accessing Ryan White Care services are at or below 300% poverty level, nearly 4,400 would be eligible for Ryan White funded services. The SEMAS system shows about 1,770 clients receive services funded by Ryan White Care. For all services that would suggest that about half of PLWH/A who know their status and have an income of 300% of the federal poverty level are not receiving Ryan White funded services, but they may be accessing services through other sources.

While the number of out-of-care cannot be reliably estimated from current data, the reasons for being out-of-care have been explored. Delayed care seeking is related to education, and the data indicates that those with less education are more likely to name lack of knowledge as a barrier to seeking care. Low literacy and Spanish language campaigns to inform person about where and when to seek care could make a significant impact. Delayed care seekers and those out-of-care are much more likely to have been recently incarcerated, and there is ample evidence to show that care in jails is not adequate.

Those currently out of care are much more likely to say that reasons for not going to care is some problem with a provider and a feeling that there are few alternatives. Where there are

few alternatives for where to access care, providers need to assure that there is an accessible grievance procedure.

Access to Health Care

Overall access to services in the Sacramento EMA is good. The vast majority of PLWH/A, whether insured or not, access medical care through a number of clinics and community organizations in Sacramento. By far the largest medical provider to PLWH/A is the community clinic at CARES but UC Davis, private doctors, VA, Kaiser, ER, and other clinics offer HIV/AIDS care as well. UC Davis has the largest pediatric program.

Twenty percent (20%) of the PLWH/A who were surveyed reported having no form of insurance. Because the sample was selected from Ryan White Care providers, it may over-represent the uninsured. A curious finding was that women (23%) and MSM/IDU (26%) are more likely to report not having insurance than other populations of PLWH/A. Women generally have greater access to insurance so this is unexpected. Upon further investigation, 87% of the women with at least one child report having insurance. One likely reasons for other women being less insured, then, is that Sacramento has a fairly large proportion of Female IDUs, and females are more likely than men to have a history of homelessness and mental illness, and this population, like MSM/IDUs have are more likely to be under insured and have higher needs.

The distribution of non-insurance benefits presents no surprises. Up to 44% of the PLWA report having drug reimbursement and up to 30% don't know if they have drug reimbursement. This lack of awareness speaks well for the seamless drug dispensing services that is linked to CARE.

Like other EMAs there are a relatively high number, 24%, of PLWH/A on disability. Indicative of the low income of PLWH/A, more than one-third (39%) report receiving SSI and 17% report receiving housing subsidies. IDUs, heterosexuals, African Americans, and symptomatic PLWH are more likely to receive SSI. In addition, women are much more likely than men to receive rent supplements.

Although a major source of funding for AIDS services, the effective drug regimens are likely to slow disease progression among PLWH, and, unless there is a legislative change, the newly infected will not be eligible for disability and consequently at a time that Ryan White funds are remaining constant or decreasing, there will be a growing demand for emergency funds among HIV positive who are uninsured.

Those unconnected to care name structural problems with getting into the system as greater barriers, and it is clear from the data that basic home and food needs trump HIV/AIDS care services as necessities.

Co-morbidities

Homelessness

Nearly 17% of those interviewed currently report currently being homeless or living in transitional housing. Thirty-one percent (31%) of PLWH/A interviewed have been homeless in the past two years, and nearly 40% indicate unstable housing in the last two years.

African Americans, women, and recently incarcerated are more likely to report homelessness or unstable housing than other populations of PLWH/A.

Substance Use

Drug use is significantly correlated with symptomatic HIV, suggesting that those who use opiates such as heroin or crack and frequent users of marijuana and alcohol may not be seeking adequate prophylactic treatment and that drug use may be related to the manifestation of symptoms. Based on the survey, those self-medicating with crystal meth or speed show little impact on stage of infection, but heavy use of crystal meth or speed can be harmful by encouraging higher risk behaviors, having negative health consequences, and adding a considerable expense to persons already at or near the poverty level.

Sacramento has relatively high drug use, particularly for opiates, crystal meth, and party drugs. Fifty-five percent (55%) of the PLWH/A report using crack/cocaine in the past with 14% of those who have used it in the past saying they used it in the last six months. Twenty-three percent (23%) report using heroin sometime in their life, and 12% of those have used it in the last 6 months.

STDs

As expected, a history of STDs is a significant co-morbidity among PLWH/A. What is surprising, however, is that Latinos report one of the highest levels of STDs. This may be a function of the small sample size, but it does suggest that these high levels of STDs among Latinos be further investigated.

- Nearly one quarter of the PLWH/A report having been diagnosed with hepatitis C in the last year. Predictably, the incidence of hepatitis is significantly higher among IDUs (65%) and MSM/IDU (37%).
- Syphilis and gonorrhea, while at relatively low rates, are highest among heterosexuals and MSM/IDUs.

Mental Illness

For the purpose of this needs assessment mental illness was defined as having a self-reported diagnosis of anxiety, dementia, or depression. More than two thirds of PLWH/A (69%) reported having been diagnosed with one of these conditions.

- Depression has been diagnosed among 61% of PLWH/A in the past two years, and it is the most frequently diagnosed mental illness reported by PLWH/A. It tends to be highest among men (62%), Anglos (62%), symptomatic PLWA (71%), and MSM/IDU (72%).
- Forty–three percent (43%) of PLWH/A report a diagnosis of anxiety in the past two years. Anglos (51%) and MSM/IDU (53%) tend to have received a diagnosis of anxiety more than any of the other race and risk groups.
- There is a significant relationship between substance use and reported mental health problems. Those using crack/cocaine and crystal meth are much more likely to report mental heath problems.

Outcomes of Care

Several outcomes are measured in the Needs Assessment including morbidity, mortality, current physical and mental health, and medication patterns.

Mortality

The HCS is having the expected positive impact on mortality and morbidity. There has been a sharp decline in death rates of all PLWH/A. However, the death rate among the African American population has remained higher than that of the Anglo and Latino populations. At the end of 2002, the death rate among African Americans was almost twice as high as that of Anglos and Latinos.

This large discrepancy between African Americans and other ethnic populations is somewhat moderated by the case fatality rates. The "case fatality rate" measures the death rate among a cohort diagnosed with AIDS during a certain calendar year and tracked to determine year of death. When a cohort of those in-care are tracked, African Americans have the same morbidity as Anglos. This suggests that the issue is not the quality of care, but that African Americans are later getting into care or come into care with more serious illnesses.

Physical and Emotional Health

Overall, based on improvement in both physical and emotional health, the care system is making an impact. Well over half of PLWH/A report that their physical and emotional health are the same or better. HIV symptomatic populations report having the worst outcomes.

Morbidity

There has been a decrease in morbidity, with fewer PLWH/A reporting illnesses. Still there is some disturbing patterns.

- Almost 60% of the people reporting OIs said they had herpes or shingles. Latinos and heterosexuals report herpes and shingles more frequently.

- Just over 50% of all PLWH/A who report OIs, and 75% of MSM/IDU say they have had thrush or Candidiasis.
- Over a quarter of those who have had an OI report a history of PCP or pneumonia. It is surprising to see that it is most frequently reported by those newest to the epidemic, heterosexuals and African Americans. It is much greater among women, although this finding may not be reliable due to small sample sizes.

Medication and Adherence

- Eighty-five percent (85%) of all PLWH/A report taking medicines to treat their HIV infection, and there is a linear relationship with the stage of disease, starting with 67% of asymptomatic PLWH taking medication to 99% of symptomatic PLWA taking medication.
- Forty-two percent (42%) of PLWH/A report never skipping their medications, and at the other extreme, ten percent (10%) have stopped taking their medicines. Women are significantly more likely to stop their medication than men.
- Notably, symptomatic PLWA are more likely to skip taking their medication than asymptomatic PLWH/A or symptomatic PLWH.
- Among all groups, forgetting to take them is the most common reason for not taking medications.
- The next two most common reasons cited for skipping doses were side effects of medications and the difficult medication schedules.

Needs And Gaps In Services

Methods

Three data collection methods were used by PCH for the Sacramento EMA HIV/AIDS Care Needs Assessment to determine the needs and gaps in HIV/AIDS care services among PLWH/A.

1. Secondary analysis of existing needs assessments and epidemiological information in order to estimate incidence and prevalence of HIV and AIDS, develop a sampling plan, and obtain mortality and morbidity data as outcome measures for the continuum of care.
2. A consumer survey was conducted among 383 PLWH/A to determine their HIV/AIDS care needs, unmet needs, barriers, and relevant behaviors, such as adherence to medical regimens, drug use, and quality of life.
3. A series of eight focus groups among target populations permitted in-depth discussion of needs and barriers to services that allow a greater depth of analysis by providing support and exceptions to quantitative findings from the survey. In addition, one-on-one interviews were conducted with parents or guardians of HIV positive children and youth. As part of the process several discussions were held with providers.

Needs

Perceived need for services is shown in Figure 4. Consumer rankings, represented by the bars, are the percentage who say they needed the service in the past year. In general, consumer rankings match the Council's priority rankings. However there are significant differences. The Council ranks housing 2nd, but the consumers place it relatively lower on their list of needed services. Given reports of high levels of homelessness and difficulty finding stable housing other factors then the consumers' perceived need is reflected in the Council's ranking. Another difference is the approach to case management. Consumers understand that their access to services is often through their case manager, and it is not surprising that they rank it among their most needed services. That is followed by food and outpatient care. The Council perceives case management as a means to access services, so ranked it lower than direct medical services. From the consumers' point of view, however, because they perceive case managers as the gatekeepers to care, it is logical that their need for it would be very high.

Figure 4 further shows that:

- Three of the top ten highest priorities are in the case management category, and two of the top ten are in outpatient medical care and food. The top two most needed services[1] are not within health care: 1) case management and 2) food vouchers. Notably in 2003, case management received the greatest RWTI allocation.
- Outpatient care is top ranked by the Council and is needed by the third largest number of PLWH/A.
- Dental care is among the top services needed by PLWH/A.
- Taxi vouchers and transportation are important, but in the second tier needs by both PLWH/A and the Council.
- Notably, the perceived need by PLWH/A for substance abuse treatment is relatively low even among drug users. While ranked higher among IDUs, it is not a top need, with far more saying they need outpatient medical care, food pantry, rental assistance, and case management. It was perceived as more important by the Council, justified by the high non-IDU drug use and strong relation to poor adherence and high service needs.
- Nearly 54% of PLWH/A reported they needed one-on-one mental health counseling. Still it was not among the top services needed by all PLWH/A, and the other mental health services, family counseling and bereavement counseling, were needed by under 20% of PLWH/A. However, the Council is likely to have responded to the very high incidence of depression, anxiety, and other emotional problems reported by PLWH/A, in giving mental health services a ranking of 5 out of 21 services.

In a subgroup analysis:

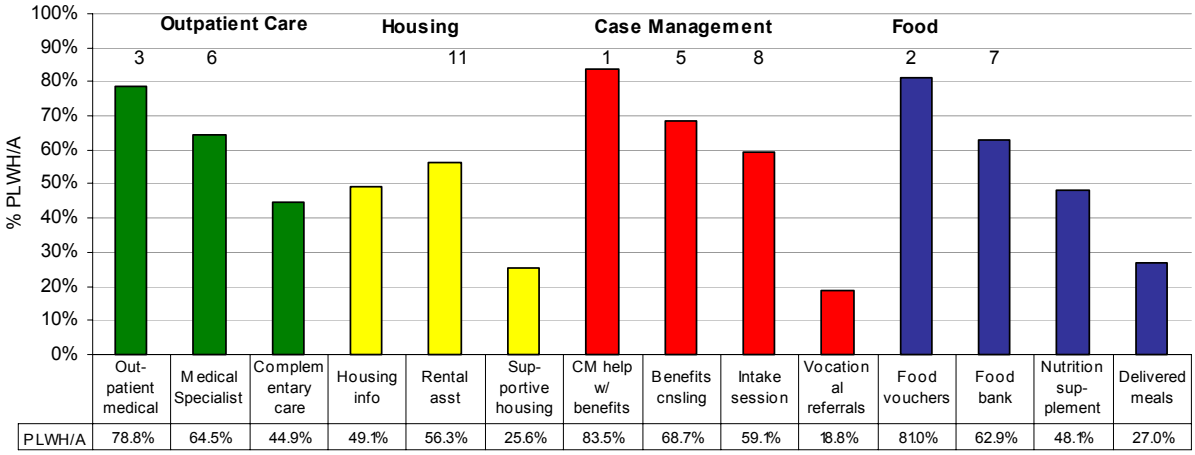
- Men perceive a greater need for medical care, and women perceive a greater need for support services. For example, among the top perceived needs, women report a much

[1] "Most needed" refers to aggregate ranking of consumers who say they needed each service; it is not the report of individual rankings or sorting of services.

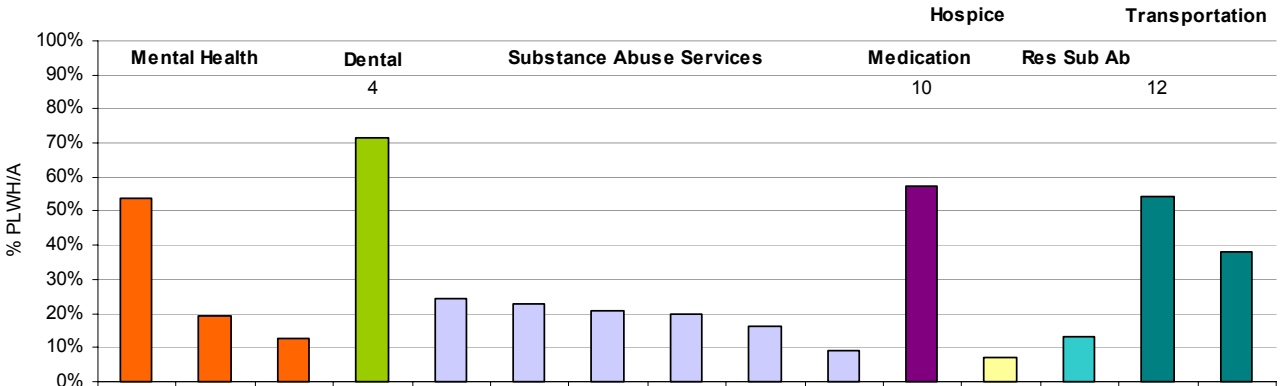
greater need than men for transportation and mental health services. For the most part, men and women have about the same rankings for other top services.

- Most of the largest differences in perceived need between men and women are among the services with lower overall need. As might be expected there is a greater perceived need among women for childcare. However, there is also a greater perceived need for bereavement counseling, adult day-care and respite care, and emotional support from buddies.
- Anglos and then Latinos perceive a higher need for medical services, including dental care. Anglos perceive a higher need than Latinos or African Americans for mental health services and complementary care.
- African Americans perceive a higher need for most support services, particularly substance abuse services, including assessment and group sessions, and transportation services. Reflecting the disproportionate number of African American women infected, they also have a higher need for childcare and family counseling.

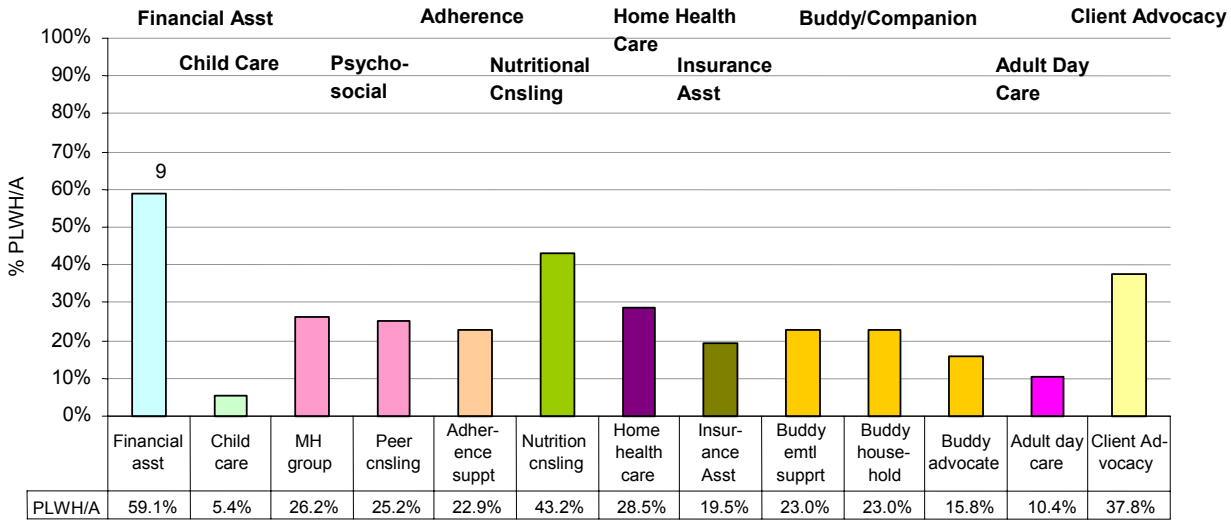
Figure 4 Ranked Service Needs



	Out-patient medical	Medical Specialist	Complem entary care	Housing info	Rental asst	Sup-portive housing	CM help w/ benefits	Benefits cnsling	Intake session	Vocation al referrals	Food vouchers	Food bank	Nutrition sup-plement	Delivered meals
PLWH/A	78.8%	64.5%	44.9%	49.1%	56.3%	25.6%	83.5%	68.7%	59.1%	18.8%	81.0%	62.9%	48.1%	27.0%



	MH 1-1	Family cnsling	Bereave-ment cnsling	Dental care	SA cnsling	SA Grp	SA 1-1	SA peer grp	SA assessm nt	SA family cnsling	Meds Reimb	Hospice Care	SA - Resi-dential	Taxi vouchers	Trans-portation
PLWH/A	53.7%	19.3%	12.9%	71.7%	24.3%	23.0%	21.0%	19.9%	16.1%	9.1%	57.2%	7.3%	13.0%	54.3%	38.2%



	Financial asst	Child care	MH group	Peer cnsling	Adher-ence suppt	Nutrition cnsling	Home health care	Insur-ance Asst	Buddy emtl supprt	Buddy house-hold	Buddy advocate	Adult day care	Client Ad-vocacy
PLWH/A	59.1%	5.4%	26.2%	25.2%	22.9%	43.2%	28.5%	19.5%	23.0%	23.0%	15.8%	10.4%	37.8%

Service Gaps

Three gaps are measured:

1. A service gap exists when there is a large difference in perceived need and reported demand. The need-ask gap reflects an expectation on the part of the consumer that the service is available, but that the system was unable to provide it.
2. There is a gap reporting demand and utilizations, suggesting that the HCS is not meeting expected demand.
3. There is a gap between those who are aware of a service and not asking for it. The "aware-ask" gap shows that consumers say they need but do not report asking for the service.

- For the most part, consumers know what services they are eligible for. The biggest "need – ask" gap is for food services, particularly nutritional supplements, and food bank and delivered meals.
- Other services with relatively large need-ask gaps are complementary care, client advocacy, benefits counseling, dental care, transportation, financial assistance and rental assistance.
- For the "ask – receive" gap (services consumers ask for but do not receive), housing has by far the largest gap. More consumers ask for but do not receive housing information and rental assistance, and financial assistance. After that food vouchers and food banks have a greater than 5% gap.
- The largest "know-ask" gaps are for substance abuse and mental health counseling. As noted earlier, even among IDUs, the perceived need for substance abuse services is low, and this provides further evidence that the barrier is not lack of knowledge.
- Many PLWH/A who perceive a need for complementary care do not ask for it. However, once asked for, they are fairly likely to receive it.
- There is over a 10% gap between those consumers who perceive a need but do not ask for client advocacy, benefit counseling, dental care, and transportation. In each of these instances, once consumers ask for the service, most report receiving them.
- The opposite pattern is found for housing services. There is a substantial gap between those who ask for but do not receive housing information and rental assistance, but a smaller gap between those who need it and ask for it.
- Four percent (4%) of PLWH/A received outpatient medical care without asking for it, whereas three percent (3%) of them expressed a need for outpatient medical care but did not ask for it. One explanation for this discrepancy is the fact that most PLWH/A automatically seek out medical care with the knowledge they are eligible for service.
- Consumers sometimes may be aware of a service, but do not ask for it.
- Case management is ranked as the most needed service, yet 18% of PLWH/A who were aware of it did not ask for it.
- The two services with the highest "need-ask" gap are nutritional supplements and food bank services. For nutritional supplements, 48% say they need it and 28% say they asked for it. For food bank services, 63% of PLWH/A indicated that the food bank is a need

but only 49% have asked for it. Complementary care, client advocacy, delivered meals, and dental care and benefit counseling have similar "need-ask" gaps.

- Certain services such as dental care and financial assistance for housing, utilities, and/or insurance premiums, although known and needed by PLWH/A, were not asked for by PLWH/A. This is likely due to eligibility constraints.

Barriers

PLWH/A were asked to rank problems on a scale ranging from "not a problem" to a "very big problem". They ranked thirty potential problems. Two analyses are presented. First is the percent who have a problem. Second, is the size of the problem. The barriers are classified into the more general categories of "organizational", "structural", or "individual" barriers. Individual barriers are those that the PLWH/A attribute to themselves and they can hope to control. Organizational barriers tend to be rooted in the practices and attitudes of the providers such as their procedures or the attitudes and sensitivity of their staff. Structural barriers tend to be those that are controlled through the legislative and administrative dictates of the government or other regulatory bodies.

The largest percentage of PLWH/A report individual barriers. Over 60% of PLWH/A said that not knowing about treatment and their own state-of-mind were barriers. The size of these barriers was moderate.

- Over 55% said that not knowing who to ask for services was a barrier. Among those, it was a moderately high barrier.
- About 46% said that the lack of knowledge of needed services was a barrier, and for them it was a moderately high barrier.
- Among structural barriers, over 50% of PLWH/A have some problem with "waiting for appointments or to see someone" and transportation. Between 40% and 50% have a problem with navigating the care system, the amount of red-tape, rules and regulations, including eligibility rules, and availability of a specialist.
- On average, among structural rules and regulation barriers, none were ranked as a big barrier. Yet, for those having a problem with the lack of adequate insurance, cost, eligibility, and rules and regulations represented moderate barriers.
- For the 50% of PLWH/A who noted that transportation was a problem, over forty percent (40%) said it was a big problem. The need for transportation was consistently voiced in the focus groups.
- Fifty percent (50%) of PLWH/A said that waiting and navigating the system was a problem, and for them, over a third said it was a big problem.
- Among organizational barriers, sensitivity of the organization, feeling like a number, and provider expertise are reported as a barrier by over 50% of PLWH/A. Among those naming these barriers, provider sensitivity is reported to be a moderate barrier. This topic was frequently discussed in the focus groups. A number of participants noted that they received excellent care from staff, particularly from physicians. However, it should be

noted that there were a number of negative comments about case managers in the focus groups.

- Lack of referrals and fear of losing confidentiality were also perceived as moderately high among those naming them as barriers.
- Forty percent (40%) of PLWH/A named discrimination by "the persons or organizations providing services" as a barrier and ranked it as a relatively high barrier. Sixteen percent (16%) of those with a problem said it was a big problem. In focus groups, persons of color and IDUs were most likely to mention discrimination.

Severity of a Problem

Although the highest average barrier was rated as a moderate barrier, different populations reported considerably higher barriers. Important differences are highlighted below.

- Overall, males were more likely to report barriers than females, but among women who reported barriers they rated them as slightly bigger than men. Men were significantly more likely to report structural problems than women, particularly red tape, rules and regulations, eligibility, and navigating the system. They were also more likely to report individual-level problems than women, including knowledge about service treatment, their own state-of-mind and physical health.
- Among risk groups, IDUs tended to report more problems than other risk groups, particularly individual and organizational barriers. MSM are more likely to report structural barriers particularly waiting for an appointment, red tape, and rules and regulations. Heterosexuals are less likely to report barriers than other risk groups.
- For those reporting barriers, MSM/IDU tend to report bigger barriers, particularly related to problems with the justice system (along with IDUs), confidentiality, insurance, and transportation. IDUs tend to report that getting along with their provider is a bigger barrier than for other risk groups.
- African Americans, while less likely to mention barriers, generally reported higher barriers than other ethnic populations when they were mentioned, particularly regarding individual and organizational barriers.

THE GOALS, OBJECTIVES AND TASKS

Following the HIV/AIDS Continuum of Services (HCS), The Comprehensive Plan established forty goals and specific objectives for:

- System wide issues
- Core services
- Primary, linking and access services
- Support services
- Services to providers
- Program administration and assessment / evaluation services.

For each objective, the Plan suggests who will implement it and when it should be started.

The goals are noted below. Details on the objectives are shown in the Plan.

System-Wide
1. Adopt an HIV/AIDS Continuum of Services with emphasis on recent HRSA directives to bring those with unmet need into care and to coordinate prevention-for-positives with ongoing care.
2. Adopt service standards for all services and enforce standards through outcome-based reporting and monitoring.
3. Advocate for increased access to the community-wide resource guide by making it more widely available and accessible in paper and on-line formats in English and Spanish.
4. Coordinate care across providers for PLWH/A.
5. Integrate STD testing and medication into outpatient standards of care and directives in accordance with PHS guidelines.
6. Integrate protocols for treatment adherence into outpatient care standards and directives.
7. Plan for increased caseloads as a result of intensified case-finding and procedures bringing those out-of-care into care.
8. Improved ability to track clients, services, and costs system-wide.
9. Understanding of unit cost and cost reimbursement programs used.
Core Services
Primary Care *Early intervention*
10. Bring those out-of-care into care.
11. Improve the entry and maintenance to care to those testing positive.
Outpatient Care
12. Coordinate primary HIV/AIDS outpatient care with substance abuse services.
13. Target those with difficulty adhering to regimens for adherence counseling and support.
14. Integrate health education/risk reduction counseling into medical visits.
15. Improve services to special populations to improve their access to and maintaining care.

Oral Health
16. Offer access to emergency dental care. (See Title I - Ryan White HIV Dental Program Operations Manual, 1999).
17. Develop system of dental referrals with area dentists.
18. Reduce waiting time for clients to make dental appointments and receive care.
Substance Abuse Services – Residential
19. To provide residential drug and alcohol treatment for PLWH/A ready to begin treatment in order to increase their opportunities for appropriately accessing HIV primary care and medication therapies and improving health outcomes. (See Substance Abuse Treatment Services. July 1999.)
Substance Abuse Services – Outpatient
20. Provide outpatient treatment designed to reduce or eliminate alcohol and drug use/abuse by PLWH/A in order to allow initiation of or improve adherence to HIV medication regimes. (See Substance Abuse Treatment Services. July 1999.)
Mental Heath
21. Individual or group mental health services to address clinically diagnosed mental illnesses and overcome issues of denial. (see Mental Health Standards. July, 1999.)
Hospice Services
22. To provide hospice service to all PLWH/A who need intensive residential care.
Primary Linking and Access Services
Case Management
23. Outreach to clients in need of case management. (See Case Management Service Standards for Persons Living with HIV/AIDS. July, 2001)
24. Provide culturally and linguistically appropriate case management.
25. Uniform acuity assessment.
Transportation
26. Assess transportation needs of clients and develop long-term transportation plan for services. (See Transportation Services. January, 2003.)
Insurance Continuation
27. If client is eligible, pay insurance premiums to continue insurance coverage.
Support Services
Emergency Financial Assistance
28. Provide emergency financial assistance to clients with pressing emergency needs.
Housing
29. Stabilize living situation to ensure maintenance of medical care and treatment adherence through the provision of short-term housing assistance or rental assistance subsidy.
Food
30. To ensure that that persons with HIV/AIDS who are having difficulty getting nutritious foods have access to proper nutrition to improve health outcomes. (See Objective 34)
30.1. Monitor quality and clients satisfaction of home-delivered meals.

Child Care
31. Provide childcare for PLWH/A in order to improve clients' ability to access and maintain primary and supportive service care. (See Standard on Child Care Services).
Psychosocial Support Services
32. Provide psychosocial support services as identified by need.
Complementary Care
33. Provide massage, acupuncture, and chiropractic services to those eligible. (See Complementary/Alternative Therapies. January 2003.)
Services to Providers
34. Provide trainings to providers on non-HIV sources for services and funding.
35. Use of the most effective and efficient service delivery practices based on research findings.
36. Improve client ability to navigate the continuum of HIV services.
37. Monitor and evaluate new models of outreach and maintaining services for special populations.
Program Administration Assessment and Evaluation
38. Distribute and train providers on client-tracking system.
39. Continuous data collection among PLWH/A.
40. Transparency in costing and reimbursement.

MONITOR PROGRESS TO MEET GOALS AND OBJECTIVES.

The various objectives noted in the previous section can be monitored using a number of different methods. For contract work, existence of RFPs, disbursement of funds in a timely manner, and products (reports, systems, guides, etc.) and events (trainings, meetings, seminars, etc.) can be tracked. For services, number of clients can be tracked as well as outcomes, satisfaction, need and gaps.

In the Plan, there is a recommended method for monitoring and an indicator for each objective. The effectiveness of monitoring depends on having an accessible and accurate client tracking system and the continuous collections of needs assessment and program data. It also suggests audits whose goal is to help making the system more transparent as well as auditing the financial outlays. Those interested in the specific recommendation should refer to the Plan.

OVERALL SUMMARY

The Sacramento EMA is facing at least three simultaneous epidemics with different needs and demographic profiles.

The first is a maturing epidemic populated by gay, largely Anglo men who have a relatively stable, but serious and chronic condition that requires extensive medical monitoring and adherence to an often difficult medical regimen that has toxic side effects. Still, these men tend to have more traditional, insurance-reimbursed access to care and to have their medical

care reimbursed by non-Ryan White CARE funds. They tend to have attained higher levels of education and as long-term survivors have a better understanding of the system and have learned to be astute self-advocates. MSM say they have the largest ask-receive gaps in the areas of nutritional counseling and complementary care – but they also are not likely to ask for these services.

The medical challenges facing them are obtaining dental care, keeping their medication reimbursement, and assuring that they have access to medical specialists as the challenges of long term medication including liver disease and cancer begin to manifest themselves. Surprisingly, those infected longer report the greatest adherence problems – mostly because they forget or have side effects.

A second epidemic is among drug users, IDU and non-IDU, including MSM/IDU. MSM/IDU account for a larger part of the Sacramento epidemic than most other EMAs. Those who were infected through IDU and MSM/IDU account for a quarter of the epidemic. They have in common recent encounters with the penal system, and both say they were denied or have been afraid to seek services due to criminal justice matters.

MSM/IDU and IDUs are, however, different populations. IDUs are more likely to be African Americans and are, on average, older than other risk groups. MSM/IDUs are more likely to be Anglo and younger. They are much more likely to use party drugs, including cocaine, while IDUs are more likely to use heroin and crack/cocaine. MSM/IDUs have one of the highest incidences of STDs and are more likely to report being symptomatic. They report higher needs for substance abuse services including individual and group counseling and residential substance abuse. MSM/IDU have one of the largest adherence problems. IDUs have a greater need for transportation and client advocacy, and rental assistance. Recently incarcerated report the highest abuse of drugs.

Drug use, in addition to being highly correlated to unsafe practices, is related to becoming symptomatic. This suggests the continued linkage of HIV/AIDS care with drug services and an expanded counseling and awareness effort to increase awareness of the dangers of drugs and to change drug use behaviors.

A third epidemic is among the communities of color that are newly infected, who tend to be poor, and are much more likely to be female and have families. Of particular concern is that many of those coming to the epidemic delay treatment. There is a need to improve coordination between testing and moving a person who tests positive into care.

Assuring that those newly infected receive entitlements is critical. Women, particularly, appear to not be fully enrolled in Medi-Cal and SCHIP. A majority of the newly infected are African Americans and they are already suspicious of the medical system. They are also in need of housing assistance, emergency financial assistance, transportation, and food, and report higher barriers to receiving them. Further, they report significant gaps in transportation and housing.

Latinos are less likely to become infected than African Americans, and are more likely to request medical services, including mental health services when they do. They are more likely to work and less likely to ask for social services. This is likely to be more a function of expectations than need, as Latinos are less educated and often poorer than African Americans. It suggests a concerted outreach effort to the Latino community to encourage those at risk to test and seek treatment.

For those who are newly infected or new to the continuum of care, knowledge about treatment and who to ask for services are among the most frequently mentioned barriers to care. The fear of losing confidentiality is also perceived as a barrier, particularly among Latinos and women. Among those who are in the system, red tape, waiting time, and insensitivity are frequently mentioned barriers. From focus group information, it is clear that any payment, including co-payment for care or medication, presents significant barriers for seeking services.

The Sacramento EMA is meeting the basic medical and wrap-around services of PLWH/A. The EMA serves those who have been in the system longest best. With the exception of adherence, those who have experience with the system report doing best.

Several suggestions and areas for improvement in care have been made for drug using PLWH/A, and for those who have more recently entered the continuum of care, including African Americans and women. The data on children and adolescents suggests that they receive excellent care, but need better coordination of benefits, wrap around services, and accessing information and support. Perhaps the most over-riding theme for these individuals is that HIV/AIDS care is important, but competes with many other basic needs. Coordinating general health care with HIV/AIDS care and having more comprehensive case management may improve the outcomes of PLWH/A.

Moving forward, the Council and County Department of Health will collaborate on achieving a number of goals and objectives. The Comprehensive Plan has provided a number of tools and timelines to help them achieve these objectives, including a systematic method of examining priorities and allocations. One key to the success of implementing the plan is to be outcome directed, transparent in financial and allocations, and coordinated in planning efforts.