EXECUTIVE SUMMARY

Long Beach 2003 HIV/AIDS CARE AND PREVENTION NEEDS ASSESSMENT REPORT[1]

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For
Department of Health and Human Services

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[1] The full report, executive summary, and PowerPoint presentation is available on PCH's website http://www.PChealth.org.

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ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
API	Asian / Pacific Islander
CHS	Continuum of HIV Services
FPL	Federal Poverty Level
HARS	HIV/AIDS Reporting System
HIV	Human Immunodeficiency Virus
IDU	Injecting drug user
IMACS	Information Management of AIDS Clients and Services
LAC	Los Angeles County
MSM	Men-who-have-sex-with-men
PCH	Partnership for Community Health
PLWH/A	Person living w/ HIV/AIDS
SPA	Service Planning Area
STD	Sexually transmitted disease
VA	Veteran's Assistance

INTRODUCTION

This is an Executive Summary of the Long Beach 2003 HIV/AIDS Care and Prevention Needs Assessment Report. The goal of the report is to present the prevention and care needs, gaps and barriers for Long Beach residents living with HIV and AIDS. It presents: 1) a continuum of HIV/AIDS Services, 2) a profile of PLWH/A in Long Beach, including co-morbidities, 3) the outcomes of the care system, including mortality (deaths) and morbidities, 4) care and prevention needs, gaps and barriers to services, and 5) a profile of those out-of-care.

Methods

Four different methods of data collection were utilized by PCH for the Long Beach Prevention-for-Positives Needs Assessment: 1) a review of secondary information, including epidemiological data from the HIV and AIDS Reporting System (HARS) and client data from IMACS as well as past needs assessments, 2) a survey among 213 PLWH/A living in Long Beach conducted over two months from the beginning of March until the beginning of May 2003, 3) a series of five focus groups among target populations, and 4) a provider survey.

CONTINUUM OF HIV/AIDS SERVICES

A Continuum of HIV/AIDS Services (CHS) is the framework for assessing needs, unmet needs, gaps and barriers to services. Table 1 shows the seven prevention tracks of the CHS and their outcomes. Those HIV positive are linked to seven category continuum of HIV/AIDS care.

Table 1 Continuum of HIV/AIDS Services

Prevention tracks	Outcomes	Continuum of Care (for HIV positive)
A. Increasing public awareness of the risk of HIV infection	1. Improving 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. STD treatments and lower rates of STDs. 5. Abstinence from drug use/ sex	
C. Prevention services to HIV-	1. Maintain negative status. 2. Adopt and maintain safer sex and needle use activities. 3. STD treatments and lower rates of STDs. 4. Abstinence from drug use / sex.	
D. Prevention and care services to HIV+	1. Adherence to drug regimens. 2. Adopt and maintain safer behaviors. 3. Linkages to, initiating, and maintaining health care.	1. Primary health care core (outpatient medical, dental, mental health, substance abuse treatment) 2. Services that remove barriers to care like food and housing 3. Patient coordination and language services. 4. Services to enhance economic well being. 5. Enhancement services like psychosocial support.
E. Prevention services to partners (sexual and needle exchange)	1. Adopt and maintain safer behaviors. 2. Commitment safer sex and needle use strategies.	
F. Prevention services to providers	1. Increased capacity to provide effective prevention services.	1. Program Support
G. Assessment and evaluation of services	1. Accountability of funds and services to funders. 2. Improvement of services.	1. Planning Council Support

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PROFILE OF PLWH/A

Epidemiological Estimates and Trends

At the end of 2002 there were an estimated 4,926 Long Beach and 6,774 SPA 8 PLWH/A who were aware of their HIV status. Long Beach had about 11% of the estimated PLWH/A in LAC, and SPA 8 had about 16% of all PLWH/A in LAC.

In Los Angeles County (LAC) PLWH/A increased 18% since 1977. In SPA 8 there has been a 24% increase and in Long Beach a 30% increase. Among those with AIDS, Long Beach accounted for about 9% in 1997, and by 2002 they represented about 11%. When compared to the general population, Anglos and African Americans are over-represented among PLWH/A, while Latinos and, to an even greater degree, API are under-represented. The majority (58%) are Anglo, 24% are Latino, 15% are African American, and three percent are other ethnicities.

In Long Beach, MSM (including MSM/IDU) represent about 73% of the PLWH/A. While heterosexuals represent a small proportion of PLWH/A in Long Beach, they have the largest increase of any risk group over the past three years. Heterosexuals are much more likely to be people of color; 40% are Latinos and 37% are African Americans. More than 70% of the heterosexuals are women. There is a slightly greater percentage of IDUs living with HIV and AIDS in Long Beach than in LAC, and, like LAC, they are disproportionately African Americans. Over 40% of all PLWH/A live at or beneath the federal poverty level (FPL) and over 70% of the women living with HIV and AIDS live at or beneath the FPL. As most of those surveyed were recruited from Ryan White Care providers, it is no surprise that virtually all report annual earnings of 300% of FPL.

While young persons have a reputation for high-risk activities, they are a small minority of PLWH/A. Rather, PLWH/A represent an aging population. Decreased mortality and lower infection rates means that the average age of PLWH/A is over 40. While 15% are under 35, 45% are between 35 and 45, and 41% are 45 and older. Eleven percent (11%) are over 55.

Co-morbidities

Substance Abuse: The association between behaviors that transmit HIV and substance abuse is high and services that reduce the use of “hard” or “party” drugs are likely to have an impact on re-infection and infection rates. Further, the strong relationship between homelessness and poor adherence to drug regimens and drug use further dictate the importance of substance abuse treatment as a priority of both care and prevention.

PLWH/A who identify their sources of infection as IDU or MSM/IDU account for nearly 20% of the PLWH/A, and they continue to be the highest current drug users among PLWH/A in Long Beach, with over a third reporting crack/cocaine and crystal meth. Poppers are much more likely to be used by MSM/IDUs and MSM. While MSM/IDUs are more likely to be Anglo and IDUs are more likely to be African American and heterosexuals.

Homelessness: Those who have accessed care more recently are more likely to be homeless than those with a longer history of care. Eleven percent (11%) of the Long Beach PLWH/A sample report they are currently homeless and 31% report living in some form of transitional housing. Twenty percent (20%) of the PLWH/A in Long Beach report a history of being homeless in the past two years. Fifty-three percent (53%) of African Americans and 64% of IDUs report a history of

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transitional housing, and a very high 66% of those who have been recently incarcerated report being homeless in the past two years.

<u>STDs</u>: STDs are related to increased morbidity among PLWH/A, and are a cofactor in spread of HIV infection. Close to 42% of the IDUs report having had hepatitis A or B in the past year. Nearly 56% of the IDUs report having had hepatitis C in the past year. There is a syphilis outbreak in California, and the rate has increased in Long Beach. While relatively few survey participants (3.8%) report having had syphilis in the past year, a much higher incidence is reported by MSM/IDU (8%). This confirms a statewide trend of increased infection among young gay men, particularly among communities of color.

<u>Mental Illness</u>: For the purpose of this Needs Assessment, mental illness is defined as having a diagnosis of anxiety, dementia, or depression. Almost two-thirds of the PLWH/A (65%) report having been diagnosed with one of these conditions. Serious mental illness is defined as having received inpatient mental health services or receiving medication for psychological or behavioral problems. Over forty percent (44%) report serious mental illness.

OUTCOMES

<u>Deaths</u>

In Long Beach, and throughout LAC, death rates have fallen since 1997. However in Long Beach, since 2001 they have leveled out at about 8% a year. Effective treatment has decreased the progression of HIV to AIDS, with a drop in new AIDS cases from 226 persons in 1997 to 127 persons in 2002, a decline of 44%. Percentages of African Americans and Anglos have fallen over 40% since 1997, while Latinos have fallen about 34%. However, the decline in new Long Beach AIDS cases has not been as steep as the decline in LAC, where the average decrease is over 50%.

<u>Medication & Adherence</u>

As expected, there is a strong relationship between stage of disease and taking medication. Thirty-six percent (36%) of PLWH and 85% of PLWA report ever taking antiretroviral and/or protease inhibitors. Men are much more likely to take medication than women, and heterosexuals and homeless PLWH/A are much less likely to take medication. Forty-nine percent (49%) of PLWH/A in Long Beach report having stopped taking their medication for some period in the past —14% with the advice of their doctor. Women, African Americans, and MSM/IDU have more difficulty adhering to their medical regimen. The primary reasons for not adhering to a medication regimen are forgetting to take medications (42%) and side effects (28%). Not wanting to take the medication is the third reason for not adhering to medication (23%). Being homeless was cited by 10% of PLWH/A as a reason not to take their medication.

<u>Physical and Mental Health</u>

Overall, based on improvement in both physical and emotional health, the care system is making an impact. Over 60% of those with AIDS report that their physical health is better than when they first sought treatment. Three-quarters feel that it is the same or better. Virtually all (97%) of those who are HIV positive and asymptomatic report doing better (60%) or the same (37%). On a more negative note, almost 60% of those who are HIV positive and symptomatic, but not progressed to AIDS, report their physical health as the same (29%) or worse (29%) compared to when they first sought treatment.

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About half the PLWH/A report that their emotional health is better than when they first sought treatment for HIV infection. About 72% of those who are living with AIDS report their emotional health as better (46%) or the same (26%). Over 90% of those who are HIV positive and asymptomatic report that their emotional health is better (58%) or the same (40%).

ACCESS TO SERVICES

Insurance and Disability

In Long Beach, 80% of PLWH/A report having some form of insurance – a considerably higher percent than in LAC where about 60% report having insurance. Medi-Cal / Medicaid is reported by 57% of PLWH/A and 29% report Medicare. Eleven percent (11%) of PLWH/A say they have some type of private insurance. There is a considerable overlap, with 22% of PLWH/A reporting both Medi-Cal and Medicare. Twenty-five percent (25%) of PLWH/A report being on long term disability. As expected the rate of disability is higher among those infected earlier, such as males and Anglos. Surprisingly, MSM report the lowest percent receiving long-term disability. Instead, MSM/IDU and IDUs report the highest percent on long-term disability.

Entitlements and Benefits

SSDI is the most common form of supplemental income reported by PLWH/A. Thirty-two percent of PLWH/A report receiving SSDI, with Anglos (46%), MSM (36%), and men (33%), being more likely than other groups to receive this benefit. Indicative of the low income of PLWH/A, close to one-third (31%) report receiving SSI and 21% report receiving housing subsidies. About 9% of PLWH/A report receiving rent subsidies. Less than one percent of the PLWH/A report receiving direct emergency financial assistance (DEFA) usually used for utilities, rent, or emergency medical treatment. 12% report receiving food stamps and two percent report receiving TANF/CalWorks. Women (21%), African Americans (20%), and MSM (37%) are much more likely than other PLWH/A to receive food stamps. About six percent of the PLWH/A report VA benefits and less than one percent report receiving CHAMPUS, a form of Veterans Assistance for non-military personnel. Two out of the five recipients of VA benefits report having no insurance.

NEEDS, GAPS, AND BARRIERS

Four of the top ten most needed services are within the medical care services core. They include outpatient care (83%), dental care (74%), nutritional supplements, education and counseling (70%), and medication reimbursement (57%). The second most needed service was case management (78%). Men tend to report a greater need for these services than women. Overall the PLWH/A in Long Beach and LAC rank services similarly, with a slightly larger percentage of Long Beach PLWH/A tend to say they need case management and medical services, while those in LAC are more likely to report a need for wrap-around services. All rankings are shown in Figure 1.

Gaps

Lower demand relative to the perceived need may reflect a lack of knowledge about where to go for services or a belief of ineligibility for the service. The need-ask gap is relatively high with more than a quarter of the services having a difference of 10% or more. Services with a large unmet need are independent housing (13%), legal services (13%), food vouchers, rental subsidy, dental care, and nutritional education (all at 12%).

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The ask-receive gap suggests services where the system is not meeting the expectation of the PLWH/A. The largest gaps are in financial assistance (20%), food vouchers (17%), and rental assistance (14%). Other housing services (information and independent housing) have gaps of between 10% and 15%.

Service Delivery Barriers

Individual barriers refer to the individual's knowledge, well-being, ability to communicate with the provider and possible denial of their serostatus. Nearly 60% of the PLWH/A mention inadequate knowledge and poor health as barriers to services. Individual barriers note in the LAC Needs Assessment are similar to those reported by Long Beach residents living with HIV and AIDS.

Structural barriers refer to "rules and regulations" and levels of access. Rules and regulations include insurance coverage, cost of services, bureaucratic challenges ("red tape"), eligibility, and problems navigating the system of care. On average, about 46% of the PLWH/A are likely to have a problem with these types of barriers. PLWH/A in Long Beach have fewer barriers with structural problems than PLWH/A in LAC.

The largest structural problems faced by PLWH/A are the amount of time it takes to get an appointment (57%) followed by navigating through the care system (50%), being ineligible for the service (46%) and cost of the service (45%). These were followed by rules and regulations and red tape (both 42%) and lack of or inadequate insurance coverage (39%).

About a third of PLWH/A responding to the survey mentioned a lack of access to a specialist (36%) and lack of transportation (33%) as problems. Transportation barriers tended to be rated as higher than other barriers. PLWH/A in LAC had greater access barriers than those in Long Beach.

Organizational barriers refer to provider sensitivity and provider expertise. Sensitivity barriers include the provider's response to the PLWH/A's issues and concerns, making the client feel like a number, rather than an individual, and helpfulness of the provider. Forty-seven percent (47%) felt the lack of sensitivity of the organization was a problem they experienced. About 40% of PLWH/A also expressed having been made to feel like a number by their providers and some type of discrimination. About a third felt that providers were not helpful.

Provider expertise includes the perceived experience of providers, ability to provide correct referrals and ability of providers to get along with clients. On average, nearly 40% of PLWH/A note that they have experienced these types of barriers. As with the other barriers, proportionately fewer PLWH/A in Long Beach reported barriers than those in LAC.

Providers' Perceptions of Barriers

The factors that providers feel would have the greatest affect in improving access to care are finding and retaining qualified staff, increasing funding, improving staff ability to talk about sexual and drug use behaviors with their clients, training staff on cultural diversity issues, and knowing where to refer clients for other services.

Providers also feel that addressing consumers' denial regarding their HIV status, the amount of paperwork needed to obtain services, and consumer transportation needs are important in order to increase access.

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Providers and consumers disagree on some individual and structural barriers. For instance, providers feel that high demand and long waiting lists for services only somewhat reduce access to care. Yet, 57% of consumers think this is a moderate barrier. Providers are more likely to say that their client's ability to follow instructions is a greater barrier than the clients perceive themselves. Also, while providers feel that the cost of the service does not really represent a barrier to care and feel that this would only somewhat reduce consumers' access to care, nearly 40% of consumers say cost is as a moderate to big barrier.

Providers and consumers agree on a number of factors that reduce access to care. Providers feel that fear of lack of confidentiality would somewhat reduce access to care and more than one third of consumers (37%) feel that this would be a small to moderate barrier. Language is also not rated as a significant barrier. Providers feel that not being able to communicate in the consumer's language only somewhat reduces access, 33% of consumers agree and feel this is a small to moderate barrier.

OUT-OF-CARE

Demographic Profile

Having a history of being out-of-care is defined as having gone a period of 12 months or longer without seeing a doctor for HIV treatment. Fifty-three of PLWH/A (25%) report being out-of-care sometime in the past, with 11 (5%) currently not having seen a doctor in more than 12 months. Those currently out of care are less likely to be insured.

Although the sample size is small, there is some evidence that Latinos, women, and older PLWH/A are disproportionately currently out-of-care, suggesting that they may face particular barriers or feel they can manage their own care. Over 60% of those currently out of care are MSM of color. One reason why older PLWH/A have a history of being out-of-care is that they simply have been living with HIV longer and have had a greater opportunity to drop out-of-care. A significant greater percentage of PLWH/A with a history of being out-of-care (27%) and the currently out-of-care (73%) report they are looking for work. Their sense of self-efficacy in managing their disease may be a reason for not seeking medical care and instead seeking employment.

Physical and Mental Health

The out-of-care are a little more likely to report fair or poor physical health. The currently-out-of-care report better emotional health than all PLWH/A. This suggests that while the physical results of being out-of-care may be worse, the sense of control in determining their own care regimen may improve their emotional outlook.

Co-Morbidities

The out-of-care are more likely than other PLWH/A to have had herpes (9%), syphilis (7%), chlamydia (6%), and gonorrhea (3%) in the past year, suggesting they are more sexually active. Besides alcohol, the top substances used by out-of-care PLWH/A are marijuana (34%), crystal meth (20%), poppers (14%), and crack/cocaine (12%), further supporting the hypothesis of an active substance using population

Service Needs and Barriers

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While housing information services and medication reimbursement are more important for the out-of-care than for other PLWH/A, for other top ranked services the out-of-care tended to have similar rankings for service needs as all PLWH/A.

Not surprisingly, out-of-care PLWH/A tend to report greater barriers to care than other PLWH/A. Eight out of the top ten barriers to care for the out-of-care PLWH/A are individual barriers. That is, the PLWH/A feel that it is either their mental or physical state or their lack of knowledge that limits them from accessing care. Moreover, 79% of the out-of-care feel that their own state of mind is the biggest problem in accessing care, with an average score of 3.2, representing a moderate to big problem for them. The organizational barriers of provider experience and waiting for an appointment were also in the top 10 barriers for the out-of-care.

Prevention Needs for Out-of-Care

The out-of-care tend to have behaviors that place others at greater than average risk of HIV infection, with over a quarter reporting high or moderate risk behaviors. As other sexually active PLWH/A, however, they are more likely to use condoms and they are more likely to mention using condoms than their partner. While they are more likely to have made a commitment to themselves to only have safer sex, they are also heavier party drug users, and over 30% say that when they are high on drugs they don't think much about transmission of HIV infection to others. Still, they say (somewhat in contradiction to their reported substance use) that they are less likely than all PLWH/A to be high on alcohol or drugs when they have sex.

Those currently out-of-care report a greater than average need for HIV testing, outreach, Internet services, individual counseling, and free condom distribution. As noted above, about three-quarters report a need for testing, suggesting that there is a high degree of denial among this population.

Half of the currently-out-of-care say they need individual counseling, and 31% need Internet services and outreach (32%). Both these services have a higher than average need. There is a very small gap between those currently out of care saying they need Internet services and individual counseling and receiving it. There is a large, gap however, for outreach where 18% say they need it, but did not receive it.

Qualitative comments emphasize the many reasons PLWH/A have being out of care, including drug abuse, denial, lack of confidentiality, a sense that providers did not have the proper expertise or were being insensitive, and too long waiting period.

RECOMMENDATIONS FOR PREVENTION-FOR-POSITIVES

Examining the needs for prevention programs for HIV positives was part of this needs assessment. Recommendations are noted below:

- Efficient prevention-for-positive programs will only target those individuals at risk of transmitting infection.
- Prevention has to be on the agenda of PLWH/A. Public awareness and group efforts raise the awareness of prevention.
- At this point, knowledge and awareness about prevention-for-positives programs remains a substantial barrier.
- There should be an integrated model of prevention-for-positives that builds on the care model and relies heavily on social support and peer pressure to maintain safer activities.

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- Effective prevention is individualized, monitored and culturally appropriate.
- Most persons accept the need to use condoms, but many do not accept the responsibility to initiate use or negotiate safer behaviors.
- While people fear that a partner will think that suggesting condom-use will be interpreted as infidelity, the data suggests that it is rare that partners perceive bringing up the subject of condom use as evidence of infidelity.
- There needs to be a shared sense of responsibility to use protection by the PLWH/A and their partner(s).
- Combine prevention-for-positives information with medical visits. If possible monitor behavior and use a prevention-case-management model (i.e. sustained and individualized prevention programs.)
- While over half of all PLWH/A say they have enough prevention information, over half of African American, MSM/IDU, and IDUs say they need more.
- Where prevention-for-positive services can be part of a more general array of health services, the important issue of confidentiality could be addressed.
- Convenient times and locations for prevention-for-positives programs will greatly improve attendance.
- Friends play a critical role in providing information and, more importantly in providing social support for sustained prevention activity.
- For adolescents and young adults, peer and mass media are considered as important as medical providers. Peer pressure and acceptance is one of the most important motivators.
- Formalize HIV prevention-for-positives in abstinence programs.
- Increase availability of needles and condoms through harm reduction.
- There is a misperception that HIV/AIDS is not a serious disease and some people are genetically immune. Emphasize the seriousness of HIV/AIDS among those who are asymptomatic and that nobody is immune.
- Disclosure is important but is not a substitute for behavior. Having persons talk and agree about safer behavior will result in adopting safer practices.

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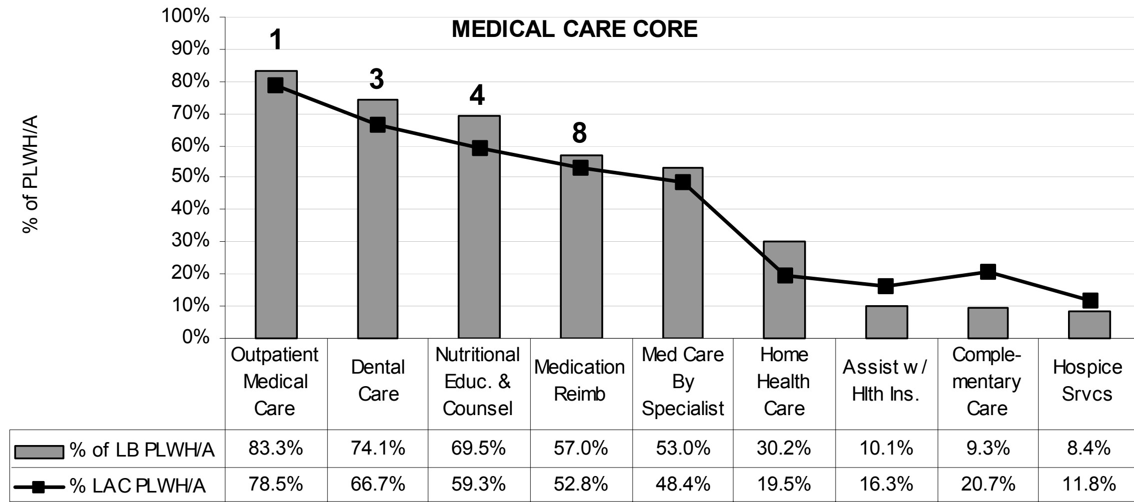
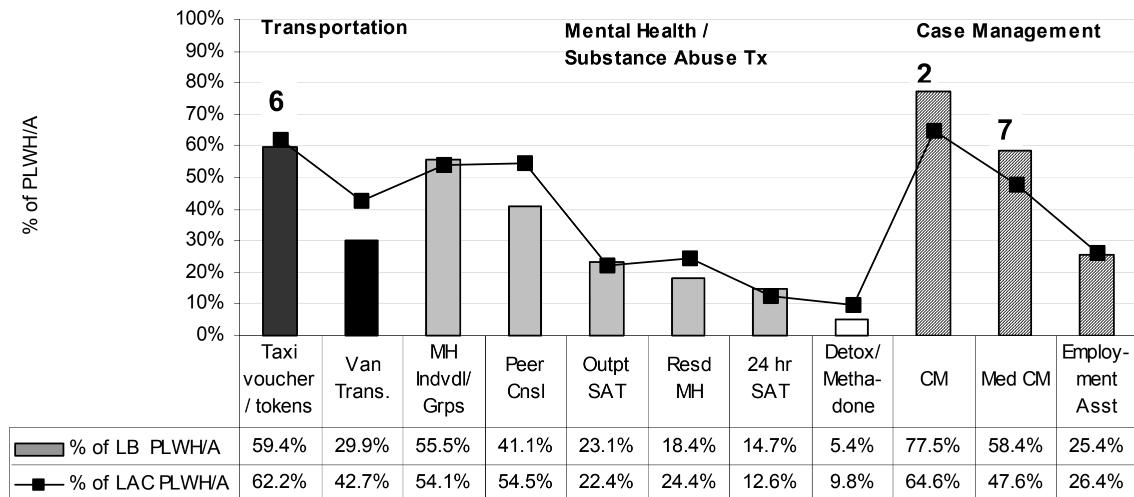
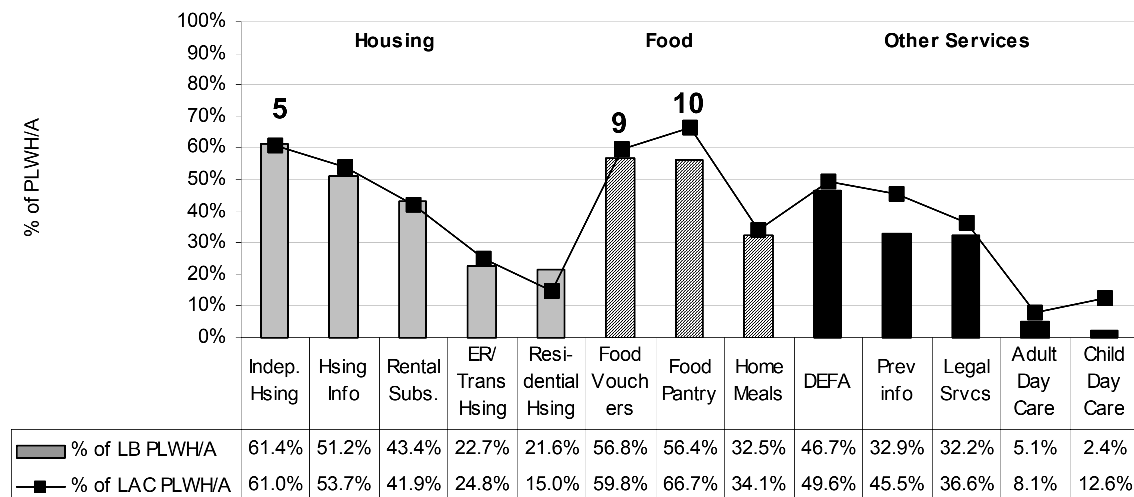
Figure 1 Ranked Service Needs



	Outpatient Medical Care	Dental Care	Nutritional Educ. & Counsel	Medication Reimb	Med Care By Specialist	Home Health Care	Assist w / Hlth Ins.	Comple-mentary Care	Hospice Srvcs
% of LB PLWH/A	83.3%	74.1%	69.5%	57.0%	53.0%	30.2%	10.1%	9.3%	8.4%
% LAC PLWH/A	78.5%	66.7%	59.3%	52.8%	48.4%	19.5%	16.3%	20.7%	11.8%



	Taxi voucher / tokens	Van Trans.	MH Indvdl/ Grps	Peer Cnsl	Outpt SAT	Resd MH	24 hr SAT	Detox/ Metha-done	CM	Med CM	Employ-ment Asst
% of LB PLWH/A	59.4%	29.9%	55.5%	41.1%	23.1%	18.4%	14.7%	5.4%	77.5%	58.4%	25.4%
% of LAC PLWH/A	62.2%	42.7%	54.1%	54.5%	22.4%	24.4%	12.6%	9.8%	64.6%	47.6%	26.4%



	Indep. Hsing	Hsing Info	Rental Subs.	ER/ Trans Hsing	Resi-dential Hsing	Food Vouchers	Food Pantry	Home Meals	DEFA	Prev info	Legal Srvcs	Adult Day Care	Child Day Care
% of LB PLWH/A	61.4%	51.2%	43.4%	22.7%	21.6%	56.8%	56.4%	32.5%	46.7%	32.9%	32.2%	5.1%	2.4%
% of LAC PLWH/A	61.0%	53.7%	41.9%	24.8%	15.0%	59.8%	66.7%	34.1%	49.6%	45.5%	36.6%	8.1%	12.6%

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