CITY OF
LONG
BEACH

LONG BEACH HIV/AIDS CARE AND PREVENTION NEEDS ASSESSMENT REPORT
2003

Department of Health and Human Services

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ABBREVIATIONS

ADAP	AIDS Drug Assistance Program
Af Am	African American
API	Asian / Pacific Islander
ASD	Adult/Adolescent Spectrum of Disease
ASO	AIDS Service Organization
CHHS	Commission on HIV Health Services
CHS	Continuum of HIV Services
EMA	Eligible Metropolitan Area
FPL	Federal Poverty Level
HARS	HIV/AIDS Reporting System
HAV	Hepatitis A
HCV	Hepatitis C
HERR	Health Education Risk Reduction
HET	Heterosexual
IDU	Injecting drug user
IMACS	Information Management of AIDS Clients and Services
LAC	Los Angeles County
MSM	Men-who-have-sex-with-men
MSMC	Men-who-have-sex-with-men of color
Native Am	Native American
OAPP	Office of AIDS Programs and Policy
OI	Opportunistic infection
PCH	Partnership for Community Health
PLWH/A	Person living w/ HIV/AIDS
PP&E / P&P	Planning, Priorities, and Evaluation renamed to Priorities and Planning Committee
RWCA	Ryan White Care Act
SHAS	Supplemental HIV/AIDS Study
SPA	Service Planning Area
STD	Sexually transmitted diseases
TB	Tuberculosis
TG	Transgender
VA	Veteran's Assistance
WCB	Women of Childbearing Years
Youth	PLWH/A 24 years of age or younger

ACKNOWLEDGEMENTS

This Prevention Needs Assessment has benefited from the collaboration of many persons and organizations. First, and foremost, it reflects the opinions of the 213 PLWH/A who participated in the survey, focus groups, and other primary data collection tools used in developing the 2003 Needs Assessment Plan. It further acknowledges those who participated in various other studies and tracking tools used for secondary analysis, such as the Los Angeles 2002 Needs Assessment and Comprehensive Plan.

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1. INTRODUCTION

The Long Beach Department of Health and Human Services contracted the Partnership for Community Health to provide a comprehensive needs assessment for the City of Long Beach that would complement the Los Angeles County HIV/AIDS Comprehensive Needs Assessment plus add a component on prevention-for-positives.

As an initial task PCH developed a continuum of prevention and care services and that is presented in the following section. It is an outcome-based continuum that addressed seven constituencies: 1) the general public, 2) high-risk populations, 3) individuals who know they are HIV negative, 4) Individuals who know they are HIV positive, 5) sexual partners – both same HIV status and different HIV status, 6) service providers, and 7) grantees and administrators of HIV services.

Following the continuum, there is a detailed section on the methodology used in the data collection, including the secondary analysis, consumer survey, provider information forms, and focus groups.

Knowing the number numbers of individuals that have to be served is a critical component of the planning process. Section 4 is a profile of PLWH/A in Long Beach including estimates of the PLWA and PLWH divided by different key ethnic and risk group populations. This report notes both similarities and differences in the profile and needs of PLWH/A in Long Beach and the County of Los Angeles. Note that the LA County Needs Assessment data was not derived from a random sample, and therefore may not be representative of all persons living with HIV and AIDS in LA County.

Section 5 discusses the co-morbidities of substance use, poverty, homelessness and STDs. These socio-economic and health risks often accompany HIV infection and make its treatment considerably more complex. Section 6 provides data on outcomes of the care and prevention system. It presents data on HIV/AIDS mortality and morbidity, progression of HIV to AIDS, adherence to medical regimens, and physical and emotional health status. Section 7 addresses access to care, including insurance, benefits and entitlements.

Sections 8 and 9 document consumer perceptions on care and prevention needs, unmet needs, gaps, and service delivery barriers. These are based on consumer surveys and focus groups.

Because out-of-care is such an important topic, Section 10 provides a stand-alone demographic profile, and discusses the care and prevention needs and barriers for the out-of-care.

Finally, the last section is a summary of the report. It includes a recommendations based on the qualitative and quantitative data that will be used by the Long Beach HIV Planning Group to improve prevention and care services.

2. CONTINUUM OF HIV/AIDS SERVICES

What is a Continuum of HIV/AIDS Services (CHS)?

The Continuum of HIV/AIDS Services (CHS) is for both HIV negative and positive individuals and their partners. It represents a comprehensive range of prevention and care services.

Why have a formal CHS?

Every health jurisdiction – Eligible Metropolitan Area (EMA) County, State -- has some form of continuum of HIV/AIDS services. The goal of prevention services is to stem the spread of HIV infection, and the goal of care services is to assure that all persons who are HIV positive receive care regardless of ability to pay.

When a CHS system is formalized it helps identify:

- Clear prevention and care goals for the system.
- An agreed upon array of coordinated services for PLWH/A.
- Clear eligibility and standards for services that are easily understood.
- Quantifiable outcomes that can be measured.

Creating a formal CHS is a process that gives health planners and providers an opportunity to create a vision for HIV services that is based on creating multiple measurable goals and outcomes, specifying different services to meet goals and establish eligibility and standards for each service. It helps in the process of allocating resources for maintaining needed services, identifying gaps in services, and adding anticipated services, and shifting resources as the need for some services increase and others decrease.

Goals of a CHS

A CHS should specify and show the linkages between a full range of cost-effective services aimed at improving general public knowledge and support of HIV services and providing prevention services to those at-risk for becoming infected and those more likely to spread HIV infection. It should link effective prevention and care services. An effective CHS assures that services are:

- Available throughout communities at-risk for HIV infection.Accessible to those eligible for services.Affordable to those eligible for services.Appropriate to the cultural norms of the community and to the cognitive abilities of the recipients of services.Accountable to the funders of prevention programs.

The objectives of the prevention services in the CHS are shown in Table 2-1.

Table 2-1 Objectives and Outcomes for Prevention Services in a CHS

OBJECTIVE	OUTCOME
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 sex / drug use.
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 sex / drug use.
D. Prevention services to HIV+	1. Adherence to drug regimens. 2. Adopt and maintain safer behaviors. 3. Linkages to, initiating, and maintaining health care.
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.
G. Assessment and evaluation of services	1. Accountability of funds and services to funders. 2. Improvement of services.

Process Outcomes of a CHS

The process outcomes for the CHS are specified to assure that the planning, delivery, and assessment of services are:

1. Community-centered: At-risk communities must have input into defining their needs, assessing services, and modifying/changing services to meet their needs. This is achieved by assuring the
   1.1. Participation of at-risk communities in the planning process,
   1.2. Feedback from at-risk communities through needs assessment and consumer satisfaction surveys and an accessible grievance procedure.

2. Proactive: The Long Beach HIV Planning Group and providers must anticipate the changing needs of communities at-risk and the system has to be flexible to meet new needs. Based on the epidemiology they must anticipate the growing rates of infection among women, heterosexuals, and communities of color, and the need to reach PLWH/A who remain sexually active.

3. Comprehensive: A comprehensive CHS includes more than prevention and care services funded by the County or State through CDC funds or services funded through the Ryan

White Care Act. It includes other programs with an impact on the spread of HIV infection by promoting abstinence of drug use and unprotected sex and risk reduction through using condoms, clean needles, and promotion of other safer sex and drug use behaviors. For example, STD and TB prevention services, family planning, substance abuse programs, law enforcement, media campaigns, and sex education curriculum might be included in a CHS. A comprehensive system:

3.1. Encourages the general public to provide continuing support to PLWH/A through supporting public and private programs that provide prevention services.
3.2. Promotes awareness of HIV status to those at risk of becoming infected or infecting others can adopt appropriate prevention behaviors.
3.3. Include services directed toward compatible goals such as STD prevention, family planning, and substance prevention and treatment services, law enforcement services directed toward commercial sex work and illegal substance use, faith-based efforts to build community.

4. <u>Evidence-Based:</u> Programs and services should be based on best practices as assessed through scientifically assessed services.

5. <u>Dynamic:</u> The system should suggest movement of persons from one service to another depending on infection status and stage of HIV disease. Consumers access services depending on their needs.

6. <u>Accountable</u>: The CHS should have internal systems are in place to monitor, reinforce, and, if indicated, change their plan.

Continuum of HIV Services

As seen in Figure 2-1, the CHS might be visualized as a seven-track system that moves those at-risk of becoming infected and transmitting infection to different services. Each track has eligibility criteria and a desired outcome. The starting point of each track defines the key-identifying factors for the consumer. For example, for those using services on the public advocacy track, the qualification is that they be part of the general public. Anyone in the community is eligible. The services on this tack should lead to improved public support for prevention services and an assessment of their own risk to determine if they should be tested.

Those eligible for the prevention outreach track engage in high-risk behaviors or are members of behavioral risk groups or communities that engage in high-risk behaviors (e.g. MSM, IDUs, “party-drug” users, bath-house patrons, heterosexuals with IDU partners, sexually active heterosexual in high incidence areas, incarcerated, and recently released.) The main services on this track are counseling and testing and the outcome in knowledge of HIV status and related co-morbidities.

For those who know they are HIV negative, they access services to assure that they maintain their negative status. These include a variety of individual- and community-based services. For those who find they are HIV positive, they access a number of services to assure that they do not spread HIV infection or become re-infected.

Because infection is spread by activities of partners, certain prevention services are directed to negative, positive, and discordant couples that allow them to negotiate safer practices, with the outcome being a commitment to use safe practice, and engaging in practices that do not spread HIV infection.

In order to assure prevention services are effectively implemented, providers should be trained and have the organizational skills to provide services. Consequently, there are infrastructure development and training services to increase provider capacity to provide services.

Finally, in any effective CHS there is a feedback mechanism for assuring the system is self-adjusting and dynamic. This involves the assessment and evaluation of services to assure that prevention services are accountable and to modify services to better meet the needs of consumers.

Figure 2-1 Continuum of HIV Services

A. PUBLIC

SERVICES

Place Advertisements / PSAs in mass and small media, billboards, brochures, and leaflets.

Write articles & editorials advocating HIV/AID prevention.

Circulate newsletters.

Conduct group educational intervention such as HIV/AIDS prevention curriculum, drama or theater presentation, and World AIDS day presentation.

Have a hotline or other type of information exchange, etc.

Organize rallies, public meetings, and write-in campaigns.

Use advocacy / educational volunteers or interns.

Provide advocacy / educational training.

Solicit financial support for HIV/AIDS prevention advocacy.

OUTCOMES:
1. Public Support and 2. Personal Risk Assessment

B. HIGH-RISK POPULATIONS

SERVICES

Health education and risk reduction through targeted group and community level interventions including schools, street outreach, house parties, health fairs, public sex venues such as parks or bath houses, bars, STD and health care clinics, etc.

Conduct 1-1 contact with high –risk individuals

Operate a mobile van

Exchange needles

Distribute bleach kits

Distribute condoms

Offer HIV Testing and Counseling

Offer STD testing

Offer TB testing

Offer Substance Abuse treatment, detox, methadone maintenance

Offer 12-step and other abstinence

Offer care at neonatal and other women's clinics

Offer family planning to populations at high-risk for HIV infection

OUTCOMES:
1. Knowledge of serostatus, 2. Knowledge of co-morbidities, 3. Increased safer behaviors (condom and needle use), 4. STD treatments and lower rates of STDs, 5. Abstinence from sex/drug use.

C1. HIV- | C2. HIV+ *(Links to LAC COC) | C3. PARTNERS

SERVICES

C1. HIV-	C2. HIV+ *(Links to LAC COC)	C3. PARTNERS
Offer HIV/AIDS re-test.	Provide adherence programs. Monitor HIV status.	Develop partner agreements. Partner notification
Offer 1-1- counseling / prevention case management.	Offer 1-1- counseling / prevention case management.	
	Provide partner negotiation. Partner counseling and referral	Provide partner negotiation. Partner counseling and referral

C1, C2 and C3 together:

Provide skill-building workshops (Condom use, needle cleaning, partner negotiation).

Conduct behavioral modification programs.

Provide peer education / support.

Circulate newsletters

Offer support groups.

OUTCOMES

C1. HIV-	C2. HIV+	C3. PARTNERS
1. Maintain negative status 2. Adopt and maintain safer behaviors (condom and needle use) 3. Obtain treatments and lower rates of STDs 4. Abstinence from sex/drug use.	1. Adopt & maintain safer behavior 2. Adherence to drug regimen 3. Linkages to, initiating, and maintaining health care.	1. Adopt & maintain safer behavior 2. Commitment to safer behaviors

D1. SERVICES TO PROVIDERS | D2. PROGRAM ASSESSMENT & EVALUATION

	D1. SERVICES TO PROVIDERS	D2. PROGRAM ASSESSMENT & EVALUATION
SERVICES	Training. Infrastructure support. Program development. Newsletters.	Program monitoring. Needs assessment. Consumer satisfaction.
OUTCOMES	1. Increase capacity to provide effective prevention services	1. Accountability to consumers and funders 2. Improvement of services

The CHS is linked to HIV Care services. The Los Angeles Commission on HIV Health Services (CHHS), in which Long Beach participates, has developed a continuum of care shown in Figure 2-2. Conceptually, the Care continuum is composed of a core of primary health services that are essential to improving health outcomes. The CHS is linked to several activities in this core set of services including HIV counseling and testing, partner counseling and referral, and HERR. In addition, adherence programs in outpatient medical, individual and group mental heath, and substance abuse services may have some prevention activities.

The core is surrounded by "wrap-around" services clustered according to the following sets of services:

- Removal of Barriers Services that optimize "critical paths" through access, utilization, retention, adherence, transportation, child care, housing, food services, psychosocial case management, and client advocacy. These key services provide low-income PLWH/A access to care which meets their basic needs and that allow them to focus on their HIV primary health care. Studies have shown that PLWH/A who do not have their basic housing and nutritional needs met, or who have no or poor transportation to services, are unlikely to seek and maintain primary health care. To the degree they provide services to prevention-for-positives programs, they may be critical to prevention services.
- Patient Care Coordination and Language Services offer PLWH/A a choice in care coordination approaches (patient care coordinators, nurse case managers, medical case management, etc.) and language services for non- or limited English proficiency populations. Patient care coordination services respond to the complexity of the health care system and by providing expert guidance to clients seeking and in accessing services provided in the continuum of care. Case management is viewed as critical to assisting PLWH/A obtain and maintain their proper regimens of care. For those who do not speak English or who experience difficulties with English comprehension, translation and interpretation services are an essential factor in patient care coordination. These services are linked to prevention services to assure that referrals are made to appropriate prevention-for-positives programs and that these programs are conducted in a culturally appropriate manner.
- Economic Well-Being Services that create direct, working, effective linkages and collaborations with services and community developments related to amelioration of poverty, workforce re-entry services, health insurance (and other benefits) access and continuation of services. Economic well-being measures include legal services and permanency planning. Both of these types of services significantly impact the continuity of care for families, in particular addressing the needs of HIV positive and HIV negative children of parents who are HIV positive.

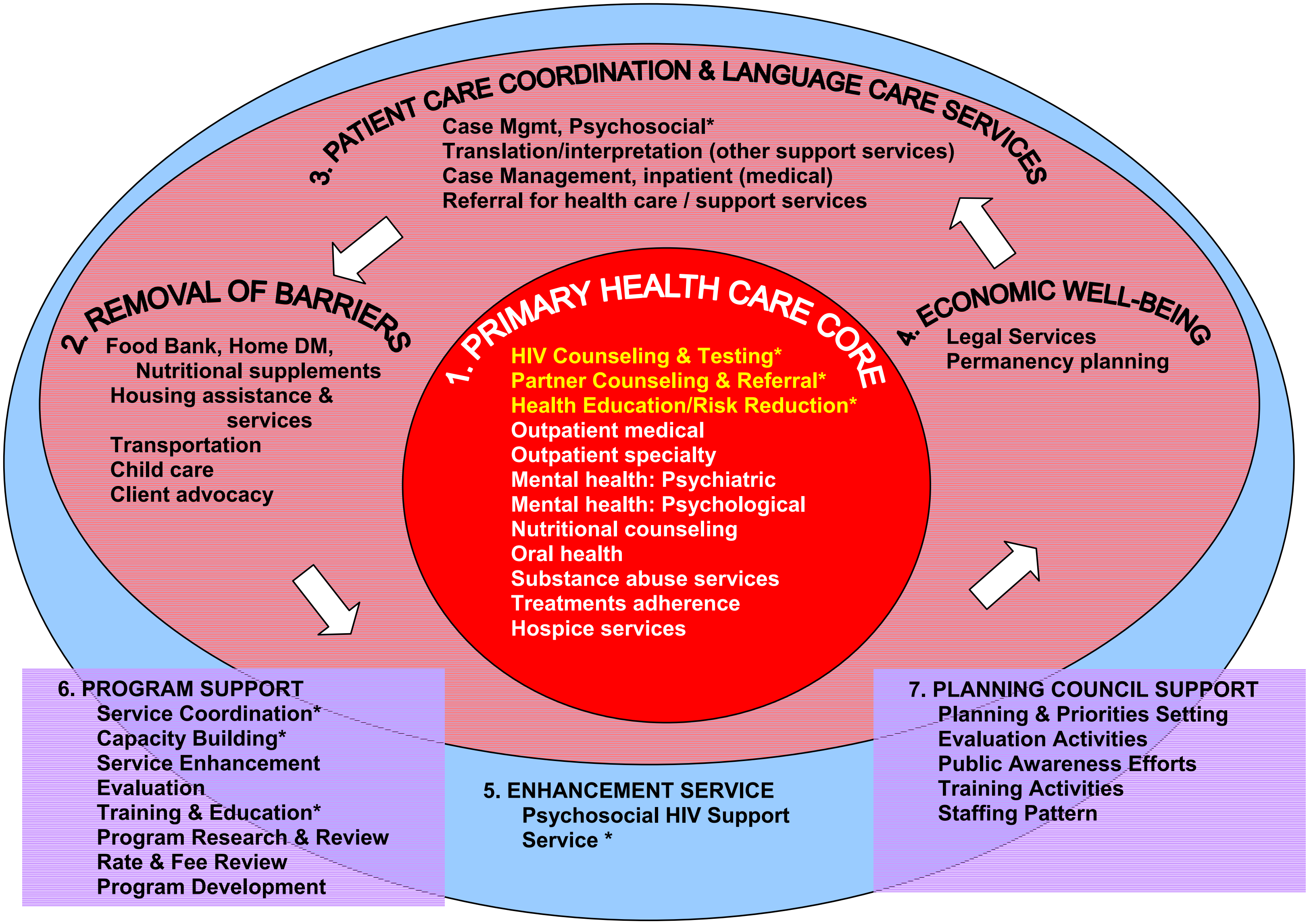
The third tier of services, "self-enhancement", are designed to enhance the core and wrap-around services, and the quality of life for PLWH/A. The wrap-around and self-enhancement services are intended to mitigate disparities in care and ensure client access to appropriate primary health care services. Self-enhancement services improve clients' quality of life through activities such as self-help services, peer support, buddy companion services and pastoral care. These services are directly linked to prevention services.

Figure 2-2 LA EMA Continuum of Care Model

County of Los Angeles, Department of Health Services, Office of AIDS Programs and Policy, www.LAPublicHealth.org/AIDS

Only funded service categories are listed.

*Prevention Services (outpatient care includes adherence services, mental health and substance abuse groups and can include prevention messages).



1. PRIMARY HEALTH CARE CORE
- HIV Counseling & Testing*
- Partner Counseling & Referral*
- Health Education/Risk Reduction*
- Outpatient medical
- Outpatient specialty
- Mental health: Psychiatric
- Mental health: Psychological
- Nutritional counseling
- Oral health
- Substance abuse services
- Treatments adherence
- Hospice services

2. REMOVAL OF BARRIERS
- Food Bank, Home DM, Nutritional supplements
- Housing assistance & services
- Transportation
- Child care
- Client advocacy

3. PATIENT CARE COORDINATION & LANGUAGE CARE SERVICES
- Case Mgmt, Psychosocial*
- Translation/interpretation (other support services)
- Case Management, inpatient (medical)
- Referral for health care / support services

4. ECONOMIC WELL-BEING
- Legal Services
- Permanency planning

5. ENHANCEMENT SERVICE
- Psychosocial HIV Support Service *

6. PROGRAM SUPPORT
- Service Coordination*
- Capacity Building*
- Service Enhancement
- Evaluation
- Training & Education*
- Program Research & Review
- Rate & Fee Review
- Program Development

7. PLANNING COUNCIL SUPPORT
- Planning & Priorities Setting
- Evaluation Activities
- Public Awareness Efforts
- Training Activities
- Staffing Pattern

Given that the City of Long Beach, Department of Health and Human Services and the Los Angeles County Department of Health, Office of AIDS Policy and Programming provide program support and planning council support for prevention and care, links between the CHS and Care Continuum could make operations more effective. In order to manage the continuum of care, program support assures that there is a system-wide program and evaluation infrastructure in place to coordinate services, build capacity, measure outcomes, assess programs and provide the necessary training, education and technical assistance to providers and consumers facilitating consumer access and ensuring high quality of care.

3. METHODOLOGY

Four different methods of data collection were utilized by PCH for the Long Beach Prevention-for-Positives Needs Assessment:

- 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. The 2002 LAC Needs Assessment data included a survey of 205 persons (31 of those living in Long Beach) and focus forums among 308 PLWH/A of whom 22 live in Long Beach. This information was used to estimate the prevalence of HIV, the sampling frame, and the number of units of service provided by the care system. A bibliography of secondary sources is included as Attachment 1.
- A survey among a representative sample of PLWH/A living in Long Beach drawn from providers and from outreach to find those out-of-care and other difficult-to-reach populations. The survey allowed updated estimates of the demographics of PLWH/A, including co-morbidities, and current estimates awareness of services and perceived knowledge, need, demand, utilization, and barriers related to services. Surveys were conducted over two months from the beginning of March until the beginning of May 2003.
- A series of five focus groups among target populations. They permit in-depth view of needs and barriers to services and allow a greater depth of analysis by providing support and exceptions to findings from the survey. An additional segment in the focus groups discussed effective methods for prevention among positive individuals.
- A provider survey. The purpose of the provider survey is to provide information on the prevention services provided, to positive populations, and provider perceptions of barriers in accessing PLWH/A into care.

A Coordinated Prevention Network (CPN) and the Long Beach HIV Planning Group was involved in the planning of the project and provided feedback on survey and focus group tools and draft reports. Decisions regarding content and length were approved Preventive Health Bureau Manager, Nettie DeAugustine and Teresa Ayala-Castillo, Prevention Network Coordinator.

Consumer Survey

The survey instrument was designed and approved by March 3, 2003. The process included a draft submitted by PCH and several rounds of revisions based on comments, specification of the DHHS, and input from interviewers. The consumer survey is shown in Attachment 2**.** The initial part of the questionnaire captured key demographics, insurance and benefits, level of care, stage of infection, medication and adherence, and quality of life. Question 38 measures awareness, current need, demand, and utilization of services. The list of barriers was developed based on the Los Angeles EMA Needs Assessment using a multidimensional schema developed by PCH and further detailed in the Barriers Section of this report. The questions related to the barriers appear as Question 39 of the consumer survey. Respondents were also asked about "other" barriers using an open-end format and these responses were coded. Prevention service needs and barriers, as well as behaviors related to HIV infection, were asked in questions 39a through 50. Questions 51 through 54 captured drug use and residency.

The survey instrument was pre-tested with the interviewers during the instrument training session. The consumer survey was translated into Spanish by PCH and checked by a second Spanish translator.

The consumer survey was an interviewer-assisted questionnaire. Trained interviewers were available at all sites where the survey was administered to provide guidance and assistance to participants.

Sampling

The sampling process was designed to draw a representative sample of clients from 50 Ryan White-funded AIDS service organizations (ASO), clinics, and other sites where PLWH/A were known to gather. A stratified quota sample plan to interview 200 participants was developed based on race and risk group (see Attachment 3). The goal of the plan was to have sufficient cell sizes to analyze each major risk and ethnic population by male and female. Every effort was made to select participants randomly from a wide variety of venues. Providers and recruiters were given detailed instructions on selecting participants randomly.[1]

For the purpose of this Needs Assessment and to assure that there were sufficient numbers of respondents to analyze, special effort was made to include populations that are disproportionately affected by the epidemic including females, heterosexuals, and Latinos.

Recruitment

The study team produced a list of client demographics by agency through the IMACS database in order to determine where clients that met the quota sampling were receiving care. This list was particularly helpful to identify the agencies frequented by the hard to reach populations including females, Latinos, and IDU males. Agencies were requested to call clients to ask them to participate in the project. In addition, with the permission of the providers, individuals were recruited when they sought services.

In order to recruit a representative sample while maintaining confidentiality, participants were recruited by personal invitation, through the collaboration of case managers, receptionists, and other staff of these agencies and through outreach. The Ryan White funded agencies were directly contacted through personal visits and various memoranda from the research team describing the Needs Assessment project and underscoring the need for assistance locating particularly hard to reach populations. Flyers were also distributed and posted at various agencies around the Long Beach area. Those participants called the project team directly to schedule their participation or were notified of a group interview time at which the consumer would be able to participate under the supervision of an interviewer. To decrease the costs of

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[1] Due to small numbers of Latinos and difficulty finding some of the target populations like IDU women, certain subpopulations were recruited through snowball techniques. Thus the sample is not completely selected using a stratified random method. However, the stratified quota of PLWH/A was used to over-sample populations such as women, Latinos, and heterosexuals in order to have a sufficient sample size for subpopulation analysis.

taxi vouchers for transportation, much of the recruitment and actual interviewing took place at the location of the service.

Considerable efforts were made to reach eligible individuals among those hardest to reach including women and Latinos through outreach and working with provider staff. In addition to appointments made by providers, “intercept” interviews were conducted at five different agencies in the EMA.[2] Notably, those clients who were homebound or were seriously disabled with dementia are underrepresented in the sample.

No contact with clients was initiated by the project team without the explicit permission of the PLWH/A in order to protect their confidentiality.

Table 3-1 displays the profile of the PWLH/A recruited. It deviates most significantly from the plan in the recruitment of more MSM, fewer female IDUs, and slightly fewer male heterosexuals. Still, the success in over sampling difficult to reach populations allows the analysis to describe most of the key and special populations.

Table 3-1 Sample of PLWH/A Recruited

Risk Grp	MSM	MSM/IDU	IDU		Hetero		Total	Sample
Sex	Male	Male	Male	Female	Male	Female		%
Total (HIV/AIDS)	77	33	19	25	18	41	213	100.0%
Race								
African Am	23	9	6	8	8	19	73	34.3%
Anglo	26	16	5	10	3	8	68	31.9%
Latino	23	7	6	4	7	12	59	27.7%
API/Other ethnicity	5	1	2	3	0	2	13	6.1%
Stage of Infection								
HIV Asymptomatic	20	5	6	5	7	10	53	24.9%
HIV Symptomatic	12	6	4	5	4	17	48	22.5%
AIDS Asymptomatic	10	6	2	2	2	4	26	12.2%
AIDS Symptomatic	33	15	7	11	5	10	81	38.0%
Special Populations								
Rec Incarcerated	7	11	11	9	7	13	58	27.2%
Homeless	14	9	6	14	7	7	57	26.8%
Out-of-care	6	0	0	2	1	3	12	5.6%

Interviewer Training

Seventeen community interviewers were trained to administer the consumer survey. Interviewers were recruited from the California State University in Long Beach as well as via internet-based postings, particularly on www.craigslist.org and www.monstertrak.com. Candidates were asked to submit a resume for review and qualified candidates were selected to come to the interviewer training session in which the group was further reduced. Interviewers were selected based on their previous experience working among HIV/AIDS populations and previous

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[2] “Intercept interviews” are when the respondent is recruited based on the stratification criteria at the time he or she sought service, and is interviewed immediately after recruitment.

experience in interviewing. Interviewers attended a training session conducted by Dr. Mitchell Cohen. During the session the interviewers were introduced to the process and the survey was reviewed.

Services categories were reviewed, and the difference between knowledge (awareness), current need, demand, and utilization were reviewed. Basic procedures such as circling responses and answering all applicable questions were emphasized. In those questions with a “yes”, “no” option, interviewers were asked to check each questionnaire to assure that each item was complete.

As part of the training, potential interviewers were asked to complete the survey so they would experience the survey first hand through their participation. They were asked to note any questions that confusing or not clear to them.

After the training a few interviewers proved unable to administer the survey or had conflicting schedules and were not given assignments. Interviewers that were given assignments were asked to report to Ms. Irene Hung via telephone or email communication as well as coordination with Ms. Teresa Ayala-Castillo. Due to availability and based on the review of the interviewers’ work, the initial pool of seventeen interviewers was subsequently reduced to six. The review assessed interviewers’ performance in administering the surveys including accurate data collection and ability to work independently in the field. Those who did not receive assignments were compensated for their attendance of the training session.

Interviewers were instructed to check each questionnaire for completeness before providing the incentive, and questionnaires were checked again by field supervisors prior to sending them to PCH’s New York City offices for data entry.

Interviewing

There was no centralized location for interviewing. Participants were interviewed in private spaces arranged by the agencies. When participants could not travel or were concerned about their confidentiality, interviews were conducted by telephone.

Quality Control

Needs assessment surveys with incentives are vulnerable to duplicate respondents who would like additional incentives. Confidential identifiers, unique fixed codes using an algorithm created at the time of survey administration, allowed the early identification of duplicate surveys unless the respondent cleverly lied on the survey to create two separate confidential ID’s. Six duplicate surveys were removed prior to analysis. A few interviews were not entered that were found to be largely incomplete by the interviewer and the participants were unwilling to complete the survey. A total of 213 completed surveys were used in the analysis.

Incentives

Participants of the consumer survey received a $20 grocery food certificate. These included gift cards to Ralphs, Vons, Target, McDonald's, and AMC Theaters. Anyone unable to complete the entire consumer survey for reasons such as illness or fatigue still received the incentive.

Focus Groups

The focus group outline was developed and approved in March 2003 and is shown in Attachment 4. The purpose of the focus groups was to supplement the quantitative findings of the consumer survey and to gain greater insight into the perception of needs, gaps, and barriers as well as create discussion on effective methods for prevention among positive individuals. Five focus groups were held with consumers from the target population shown in Table 3-2.

Table 3-2 Focus Group

RECRUITMENT CRITERIA	# of participants
1. MSM	12
2. MSM of Color	10
3. Substance Abusing Men	4
4. Substance Abusing Women	7
5. Out-of-Care	6

The research team attempts to have between eight and ten individuals in a group, however sizes vary depending on recruiting efforts and high rates of no-shows. More than 10 participants in a group make it difficult for every one in the group to have an opportunity to share their viewpoints and opinions. In addition to the $20 food voucher for completing the survey, focus group participants received a $20 grocery food certificate as their incentive.

Two primary methods were used to select and recruit participants for focus groups, while maintaining their confidentiality. First participants were recruited through an initial contact from their case manager. Using IMACS, the project team produced lists of clients to be called and invited to participate in the focus groups. When the client was unreachable, recruiters were instructed to substitute the intended client with another client with similar demographics. Second, participants were recruited through flyers distributed at various agencies. Those participants called a member of the research team directly to schedule their participation.

All focus groups were audio taped and were held at various locations in Long Beach chosen for convenience for consumers to access. These locations include Being Alive on 4th Street in Long Beach, the conference room at the City of Long Beach, West Facilities Center, and a private room in the Department of Health and Human Services.

Provider Information Form

There is no systematic information about prevention-for-positives for PLWH/A in Long Beach. In order to inventory the existing prevention-for-positives programs available a Provider Information Form was developed and sent to providers in the Long Beach Area. The form was created to match the Continuum of Prevention Services discussed in CONTINUUM OF HIV/AIDS SERVICES, page, 2-1. Prevention Network Coordinator, Ms. Teresa Ayala-Castillo and Preventative Health Bureau Manager, Ms. Nettie DeAugustine, provided guidance in the creation of the form, shown in Attachment 12. It was approved on April 15, 2003.

Sampling

A comprehensive list of 58 agencies was developed from both Ryan-White funded agencies compiled from the IMACS database, and other agencies known to provide services by the Department of Health and Human Services. Although all agencies provided services to PLWH/A in Long Beach, several were located outside of the city of Long Beach. The list of these agencies/ programs is seen in Attachment 13.

Fielding

Considerable effort was made to identify the person in the agency with responsibility for prevention-to-positive programs. A letter from Ms. Nettie DeAugustine, Preventive Health Bureau Manager, was included in the mailing to encourage participation. The majority of these agencies were sent the form through the mail on April 25, 2003. An electronic mail version of this form was also made available and was offered as an alternative to the paper document.

The instructions asked for the document to be sent or faxed to Ms. Ayala-Castillo, or could request the electronic version from Ms. Irene Hung from PCH. The deadline was set on May 9, 2003. Unfortunately, the response rate was very low. Follow-up telephone calls were made between June 5 and 14. Among the 58 agencies contacted, 12 agencies responded with a completed form. The twelve agencies, however, serve most of the Long Beach residents. For example, St. Mary's CARE clinic serves 36% of all Long Beach clients, City of Long Beach Case Management (14%), Tom Kay Clinic (10%), Being Alive Long Beach (5%). The agencies not responding who serve substantial number of PLWH/A in Long Beach include AIDS Health Care Foundation (7%) and Harbor UCLA (5%). The results presented in Provider Information, Section 9, page 9-21, are based on this limited sample analysis

Analysis

Quantitative Analysis

The survey was analyzed using the statistical package Statistical Program for Social Sciences (SPSS). Analysis of the data was done by the "total sample" and key demographic, geographic, and stage of infection subpopulations shown in Table 3-3 below.

The overall size of the sample and diversity of clients obtained through quota sampling, and the weighting back of the over sampled populations to their appropriate proportion in the population (based on PLWH/A), permits the analysis of care and prevention needs, unmet needs, and barriers among different key populations. It also permits the estimates of co-morbidities including homelessness, substance use, STDs, mental illness, and tuberculosis among PLWH/A, and sexual and drug use behaviors that are related to HIV infection. For the total sample analysis, subpopulations are weighed back to their proportion in the estimated HIV population. Also, when subpopulations are compared, the weighted sample is used. When special populations are analyzed, unweighted data is presented because they are purposefully over sampled to obtain adequate sample sizes for analysis.

Table 3-3 Analysis Populations

1. Total
2. Gender 2.1 Male 2.2 Female
3. Race 3.1 Anglo 3.2 African American 3.3 Latino 3.4 API and other ethnicities
4. Mode of Transmission 4.1 MSM 4.2 MSM/IDU 4.3 IDU 4.4 Heterosexual (not IDU)
5, Stage of Infection 5.1 HIV, asymptomatic 5.2 HIV, symptomatic 5.3 AIDS, asymptomatic 5.4 AIDS, symptomatic
6. Recently Released
7. Homeless
8. Medical Visit Out of medical care more than 6 months

The population estimates are based on epidemiological information, and are shown in Table 3-4. The unweighted sample shows the over-sampled populations, while the weighted sample is very close to the projected population estimates of PLWH/A.

Table 3-4 Sample Frame

	% Total Pop (2003)*	Weighted %	Unweighted %	Unweighted N = 213
Gender**				
Male	91.9%	88.1%	69.0%	147
Female	8.1%	10.5%	31.0%	66
Ethnicity				
Anglo	52.5%	51.6%	31.9%	68
African American	20.1%	21.2%	34.3%	73
Latino	24.9%	24.7%	27.3%	59
Asian/Other ethnicity	2.6%	2.5%	6.1%	13
Risk Group***				
MSM	74.0%	72.0%	36.2%	77
MSM/IDU	9.0%	8.7%	15.5%	33
IDU	9.5%	10.3%	20.7%	44
Hetero	7.5%	9.0%	27.7%	59
Stage of Infection				
HIV, asymptomatic	NA	22.3%	24.9%	53
HIV, symptomatic	NA	16.4%	22.5%	48
AIDS, asymptomatic	NA	13.8%	12.2%	26
AIDS, symptomatic	NA	45.7%	38.0%	81
Special Populations				
Recently Released	NA	16.6%	27.2%	58
Homeless	NA	20.8%	26.8%	57
Out-of-care (6 mo. or more)	NA	5.6%	5.6%	12

*Epidemiological data is based on HARS 2002. Weight is adjusted for PLWH based on estimates reported in the 2003 Title I application.

**Three PLWH/A reported “other” sex.

***The risk categories have been adjusted to exclude "other" modes of exposure.

The following sections of this report analyze demographics, stage of infection, medication and adherence, outcomes, and care and prevention service needs and unmet needs, barriers. The prevention section is limited to prevention-for-positives. Selected analysis is shown in graphic and table form in the text.

For those interested in further analysis of the data, the basic demographic, services and barriers cross tabulations by each of the analysis populations are shown in Attachment 5 through Attachment 10, and they contain a wealth of data not reported in the body of this report.

Qualitative Analysis

Focus groups were audio taped and transcribed. All focus group participants were informed about the purpose and use of the recordings and the confidentiality of all participants was assured. Using the coding scheme shown in Attachment 11**,** PCH staff coded each comment by relevant demographic group, service, and barrier. Study team members sorted these comments based on services and barriers and they were selected for inclusion in the report based on the comments ability to substantiate and add depth to the quantitative findings or show a view of consumers that is contradictory or different from the quantitative findings. In reading these comments, recall that they are not representative of all PLWH/A.

4. PROFILE OF PLWH/A IN LONG BEACH

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 upper limit for the number of PLWH/A who could seek services in the continuum of care and the number who have sought services in the past. Of course, not everyone who is positive seeks prevention or care services, so a better estimate of need is a combination of past history and demand for services.

Table 4-1 shows that currently there are about 5,500 PLWH/A living in Long Beach who know their status and thus are in need of some care services. The number living with HIV is an estimate as HIV reporting began this year in California.

Table 4-1 ESTIMATE OF PLWH/A

	LA EMA[1]	SPA 8[1]	Long Beach[2]
Living with AIDS	16,547	2,652	1,880
Estimated Living with HIV (not AIDS)	26,458	4,122	3,046
Living with HIV/AIDS in Los Angeles EMA, who know they are infected	42,994	6,774	4,926
Estimated Total PLWH/A[3]	52,512	8,274	5,546

1. From HARS (2001)
2. From HARS (2003)
3. Includes an additional .33 of PLWA who do not know they are infected.

In theory, the need for CARE Act funded services is measured by first understanding the current utilization of services outside of the CARE Act funded services, and then calculating the "residual" as the number needing CARE Act funded services.

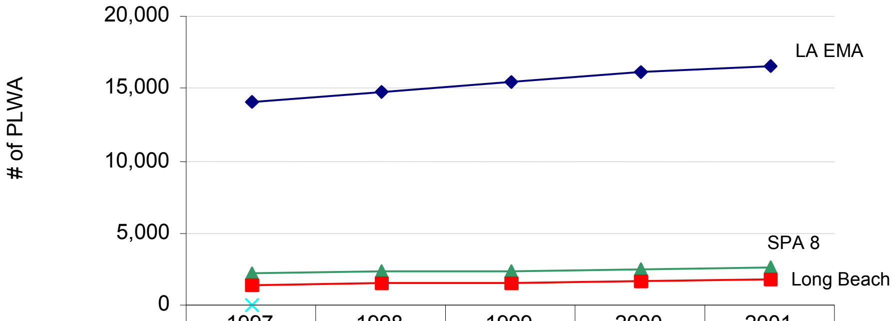
Based on data obtained from the client tracking system (IMACS) and the estimates presented in Table 4-1, 2,111 PLWH/A and collaterals are receiving at least one CARE Act funded service. Consequently, 3,435 PLWH/A, about 62% of those who know their status are not seeking care through a CARE Act funded Long Beach provider.

Persons Living With AIDS

In planning HIV/AIDS services, the HIV/AIDS continuum of care will need to provide services to an increasing number of PLWH/A. While the rate of transmission is dropping, it is more than offset by the declining mortality rate. Consequently, the number of PLWA in Long Beach has grown from 1,389 in 1997, to 1,880 in 2002, and the number of people living with HIV is likely to have shown an even more dramatic increase.

As shown in Figure 4-1, since 1997, the number of PLWA has increased 18% in the Los Angeles EMA, about 24% in SPA 8, and 30% in Long Beach. While PLWA in Long Beach accounted for about 9% of all PLWA in the EMA in 1997, by 2002, PLWA represented about 11% of all PLWA in the EMA.

Figure 4-1 People Living with AIDS by Area



	1997	1998	1999	2000	2001
◆ LA EMA	14,049	14,787	15,494	16,074	16,547
▲ SPA 8 South Bay/ LB	2,142	2,276	2,413	2,534	2,652
■ Long Beach	1,389	1,473	1,586	1,696	1,801
% of LA EMA	**9.9%**	**10.0%**	**10.2%**	**10.6%**	**10.9%**

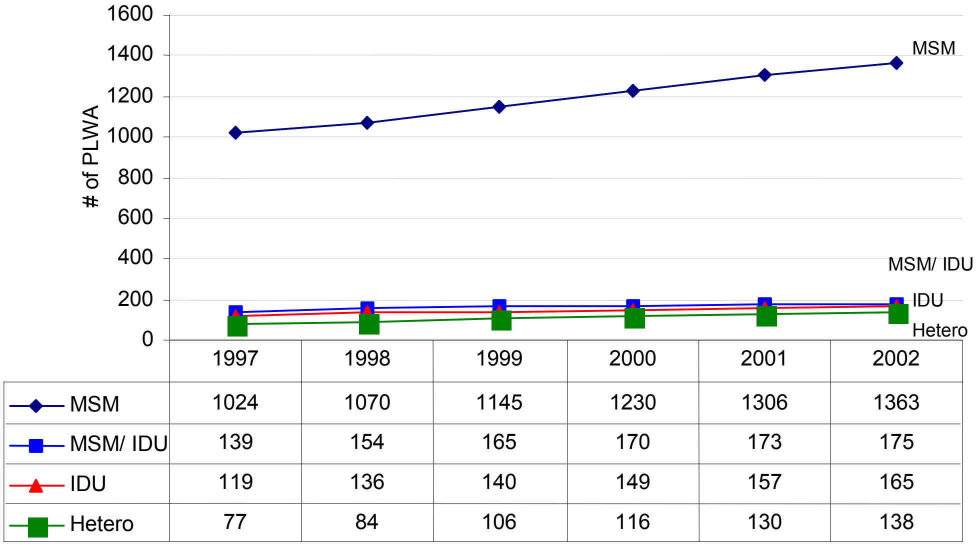
Risk Group Profile of PLWA

The AIDS epidemic in Long Beach is predominantly among men-who-have-sex-with men (MSM). MSM represent over two-thirds of PLWA, and as shown in Figure 4-2, the percentage of MSM living with AIDS has remained relatively constant at about 73% from 1997 through 2002. With over 1,500 MSM (including MSM/IDU) living with AIDS in 2002, MSM will continue to comprise the vast majority of PLWA for the foreseeable future. Of all MSM living with AIDS in 2002, approximately 58% are Anglo, 24% are Latino, 15% are African American, and three percent are other ethnicities.

Like MSM, the proportion of IDUs has remained constant, representing about 10% of the PLWA. In 2002, of the 175 PLWA who are IDUs, about 42% were African American compared to 37% Anglo, and 21% Latino. Given the much lower percentage of African Americans in the population, they contribute a disproportionate number of IDUs living with AIDS to the overall epidemic.

The proportion of heterosexuals (non-IDU) living with AIDS has increased slightly from just over 5% in 1997 to 7%, or about 138 heterosexuals living with AIDS at the end of 2002. Since 1997, this number represents nearly an 80% increase from the 77 cases reported in 1997, and is the largest increase in PLWA of any risk group over the past three years. Heterosexuals are much more likely to be people of color, with about 40% being Latinos and 37% African American. More than 70% of the heterosexuals are women.

Figure 4-2 Living with AIDS by Risk Group

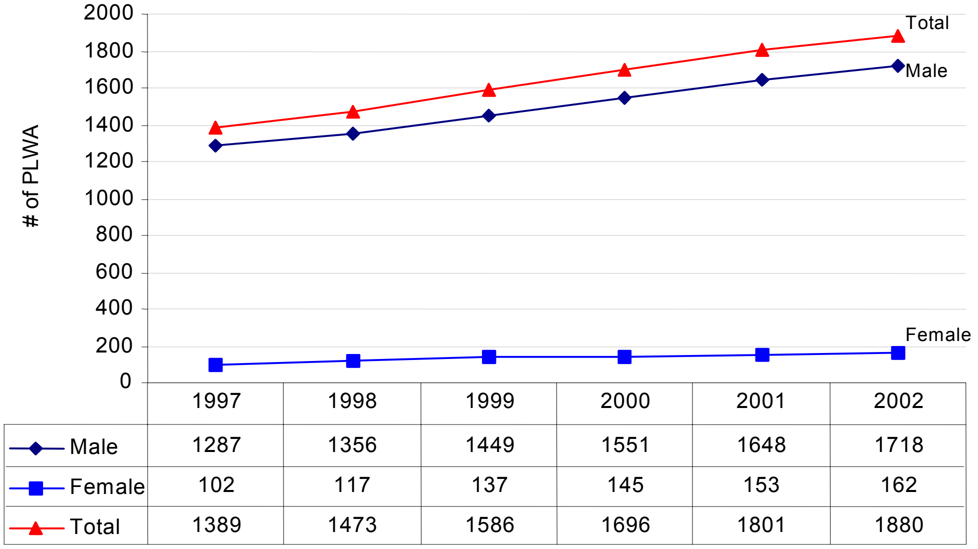


	1997	1998	1999	2000	2001	2002
◆ MSM	1024	1070	1145	1230	1306	1363
■ MSM/ IDU	139	154	165	170	173	175
▲ IDU	119	136	140	149	157	165
■ Hetero	77	84	106	116	130	138

<u>Gender Profile of PLWA</u>

As shown in Figure 4-3, males continue to represent more than 90% of PLWA. However, females living with AIDS have increased by about 60% since 1997, compared to about a 33% increase among men. In 2002, women account for the vast majority (70%) of heterosexuals living with AIDS and about 30% of the IDUs. Since 1997, the proportion of women PLWA has increased slightly from about 7% to 9% in 2002.

Figure 4-3 PLWA by Gender



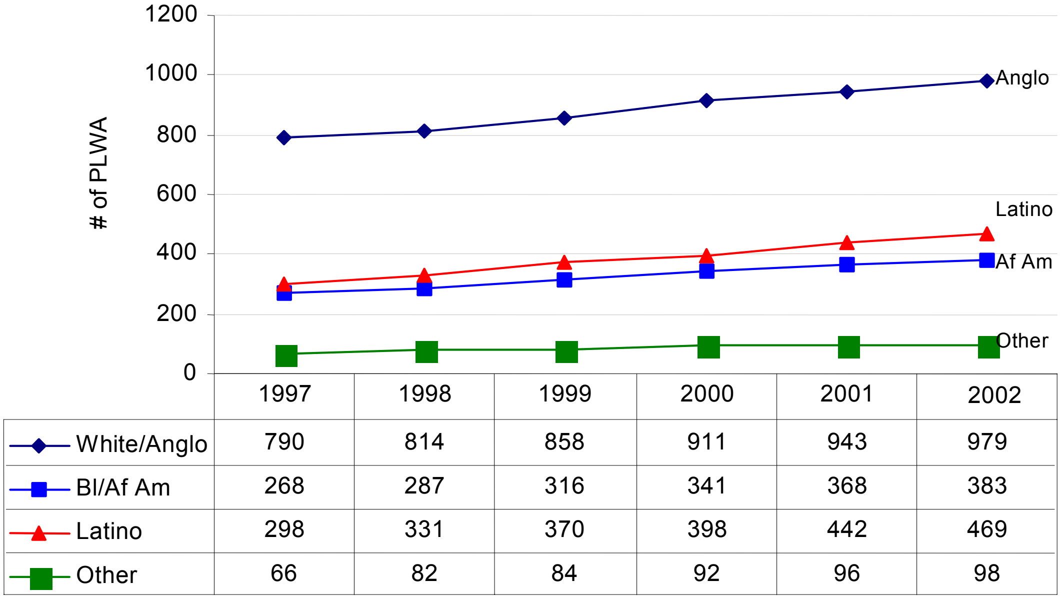
	1997	1998	1999	2000	2001	2002
◆ Male	1287	1356	1449	1551	1648	1718
■ Female	102	117	137	145	153	162
▲ Total	1389	1473	1586	1696	1801	1880

Ethnic Profile of PLWA

The racial/ethnic makeup of Long Beach is 36% Latino, 33% Anglo, 15% Asian/Pacific Islander, 14% African American, and 2% American Indian. Figure 4-4 shows, that the HIV/AIDS epidemic has affected ethnic groups quite differently, and shows the epidemic is continuing to shift from the Anglo communities to communities of color.

Figure 4-4 shows the increase in PLWA by ethnicity. While the proportion of Anglo PLWA has declined since 1997, in 2002 Anglos continue to represent the majority (52%) of PLWA, followed by Latinos (25%), and African Americans (20%). Notably, there is a considerable increase in Latinos living with AIDS since 1997. While Anglos have increased from 790 living cases in 1997 to 979 cases in 2002, there's been a 57% increase in Latinos living with AIDS from 1997 to 2002. Nonetheless, in 2002, there is more than twice the number of Anglo PLWA than Latino PLWA in need of services. African Americans have increased from 268 to 383, representing a 43% increase. Together, Asian Pacific Islanders and Native American/Alaskans (noted in graphic as Other) comprise about 5% of PLWA in 2002.

Figure 4-4 Living with AIDS by Ethnicity



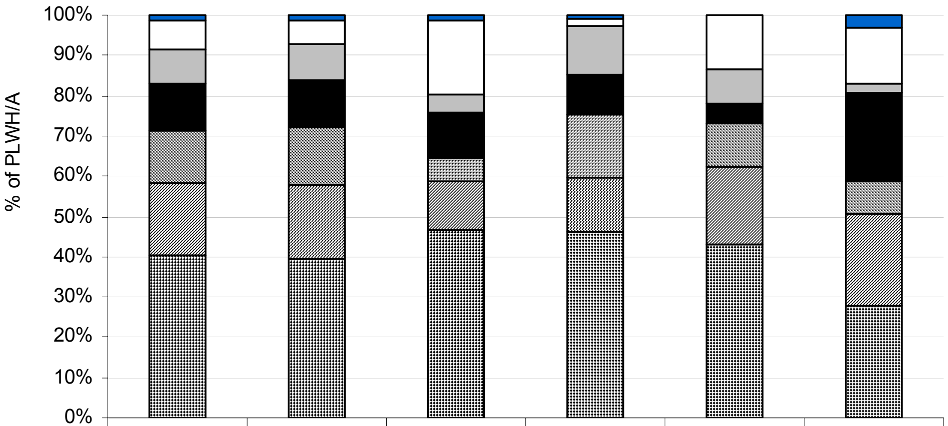
	1997	1998	1999	2000	2001	2002
◆ White/Anglo	790	814	858	911	943	979
■ Bl/Af Am	268	287	316	341	368	383
▲ Latino	298	331	370	398	442	469
■ Other	66	82	84	92	96	98

Employment Status

Figure 4-5 and Figure 4-6 shows employment status by gender and ethnicity and by risk group. The figures show the following:

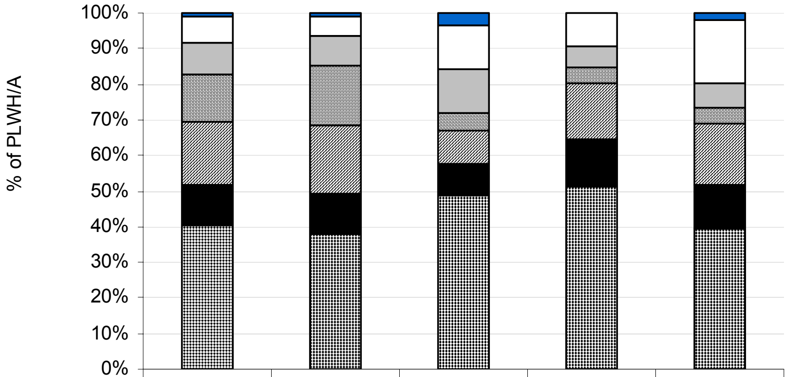
- The majority of PLWH/A who were surveyed reported not working (82%). That compares to 80% who report not working in the LA County Needs Assessment Survey. Sixteen percent (16%) of those not working report actively looking for work, 7% are students or homemakers, 13% are retired, and 40% are not looking for work. About 20% are either employed part- or full-time.
- Women are slightly more likely to not be working, with 18% being homemakers or students and 47% not looking for work. While men and women are almost equally likely to be employed full-time, men are more likely than women to be employed part-time.
- Among ethnic populations, Latinos living with HIV or AIDS are more likely to be employed than other PLWH/A from other ethnic communities. Nearly one quarter of Latinos currently working in some capacity. Also, more Latinos (23%) report looking for work than any other ethnic group.
- Among risk groups, MSM/IDU have the lowest percent of persons employed full-time (9%), but the highest percentage working part-time.
- MSM are more likely than any of the other risk groups to be retired.

Figure 4-5 Employment Status by Gender and Ethnicity



	Total	Male	Female	Anglo	African Am	Latino
🟦 Other	1.2%	1.2%	1.5%	0.9%	0.0%	3.1%
□ Not working - student/homemaker	7.4%	6.0%	18.3%	1.9%	13.4%	13.9%
▣ Employed part-time	8.6%	9.1%	4.5%	11.9%	8.8%	2.4%
■ Employed full-time	11.5%	11.6%	11.2%	9.8%	4.5%	22.1%
▩ Retired	13.2%	14.1%	5.6%	16.0%	11.1%	8.0%
▨ Not working - but looking	17.8%	18.5%	12.2%	13.5%	19.2%	22.8%
▦ Not working - not looking	40.3%	39.5%	46.7%	46.0%	43.0%	27.8%

Figure 4-6 Employment Status by Risk Group



	Total	MSM	MSM/ IDU	IDU	Hetero
🟦 Other	1.2%	1.1%	3.4%	0.0%	1.8%
□ Not working - student/homemaker	7.4%	5.2%	12.3%	9.4%	17.7%
▣ Employed part-time	8.6%	8.7%	12.3%	6.0%	7.2%
▩ Retired	13.2%	16.5%	5.2%	4.5%	4.1%
▨ Not working - but looking	17.8%	19.3%	9.3%	15.6%	17.4%
■ Employed full-time	11.5%	11.5%	8.6%	13.0%	12.4%
▦ Not working - not looking	40.3%	37.7%	48.9%	51.5%	39.3%

5. CO-MORBIDITIES

HIV and AIDS are often not the only challenge confronting PLWH/A. HIV infection often co-exists with substance abuse, poverty, homelessness, and STDs.

Substance Use

Initially the HIV and AIDS epidemic was fueled by sexual behavior among gay men and early detection was among Anglo gay men. Other early infections appeared among intravenous drug users, but IDU was not the major mode of transmission, and today in Long Beach it accounts for about 9% of the epidemic (in contrast to about 12% of IDUs for LA county) with MSM/IDU representing another 9% (in contrast to about 6% for LA County). HARS data for 2002 indicates that about 14% of the newly diagnosed AIDS cases and 18% of the living AIDS cases, including MSM and heterosexual IDU, are attributable to injection drug use. The 2002 Needs Assessment data indicates that IDU and MSM/IDU account for about 19% of PLWH/A.

Still, infected drug users are among the most vulnerable populations as substance use is often accompanied by other co-morbidities such as homelessness, mental illness, hepatitis and other STDs, and poverty.

Substances measured in the survey include drugs that are typically injected such as heroin and crystal meth, and also non-injecting substances such as marijuana and "party drugs" such as ecstasy and poppers. Recreational use of these drugs is related to unsafe sexual practices that place individuals at high risk for contracting or exposing others to HIV infection or

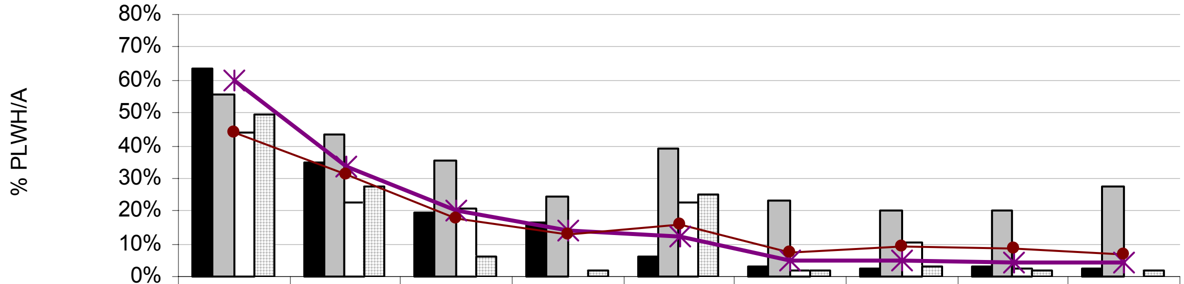
Substance use in the past year is relatively high in Long Beach. The lines in Figure 5-1 represent Long Beach and Los Angeles County, and the patterns are similar with alcohol, marijuana, and crystal meth being the top drugs used, followed by poppers, crack/cocaine, speedball, and heroin.

- Long Beach PLWH/A are more likely to report taking the so-called "party drugs" in the past year, while less likely to use the crack/cocaine, speed, heroin, ecstasy and GHB.
- The majority of PLWH/A (60%) report using alcohol during the past year.
- Marijuana is the second most commonly used substance, with more than one third of PLWH/A reporting using it in the past year. Latinos report the lowest use among the three ethnic groups.
- Among risk groups, the MSM/IDU stand out as the most likely to use all the different drugs, with the exception of alcohol. MSM report the highest use of alcohol. The substances most commonly used by MSM/IDU are alcohol (55%), marijuana (44%), crack/cocaine (39%), crystal meth (37%), and GHB (27%).
- Twenty percent of the PLWH/A report using crystal meth, with 30% of Anglos using this substance with in the last 12 months.
- IDUs and heterosexuals have similar drug use patterns, but IDUs, as might be expected, are significantly more likely to use heroin and crystal meth.

Figure 5-1 shows the percentage of PLWH/A by ethnic group who have used drugs during the past year. It shows that:

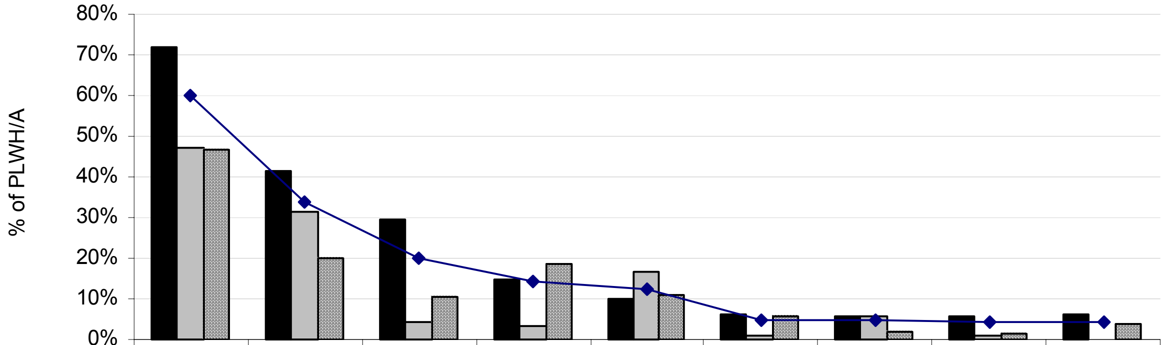
- There is relatively high use of poppers among Latinos (19%).
- There is relatively high use of crack/cocaine among African American PLWH/A (17%).

Figure 5-1 Substance Use Among PLWH/A by Risk Group



	Alcohol	Marijuana	Crystal Meth	Poppers	Crack/ cocaine	Speedball	Heroin	Ecstasy	GHB
■ MSM	63.7%	34.9%	19.5%	16.5%	6.3%	3.3%	2.3%	2.8%	2.2%
▨ MSM/ IDU	55.4%	43.6%	35.4%	24.2%	39.2%	23.1%	20.3%	20.3%	27.4%
□ IDU	44.2%	22.5%	21.1%	0.0%	22.6%	1.6%	10.3%	2.4%	0.0%
▤ Het	49.7%	27.8%	6.3%	1.7%	24.9%	1.7%	2.9%	1.7%	1.7%
—✳— Long Beach	59.9%	33.8%	19.9%	14.2%	12.3%	4.7%	4.7%	4.1%	4.1%
—●— LAC	43.9%	31.3%	17.5%	13.0%	15.9%	7.3%	9.3%	8.5%	6.5%

Figure 5-2 Substance Use Among PLWH/A by Race / Ethnicity



	Alcohol	Marijuana	Crystal Meth	Poppers	Crack/ cocaine	Speedball	Heroin	Ecstasy	GHB
■ Anglo	72.0%	41.6%	29.5%	14.8%	10.2%	6.0%	5.7%	5.9%	6.0%
▨ Af Am	46.9%	31.2%	4.5%	3.4%	16.7%	1.1%	5.7%	1.1%	0.0%
▤ Latino	46.4%	20.0%	10.5%	18.7%	10.8%	5.6%	1.7%	1.6%	3.8%
—◆— Total	59.9%	33.8%	19.9%	14.2%	12.3%	4.7%	4.7%	4.1%	4.1%

Poverty

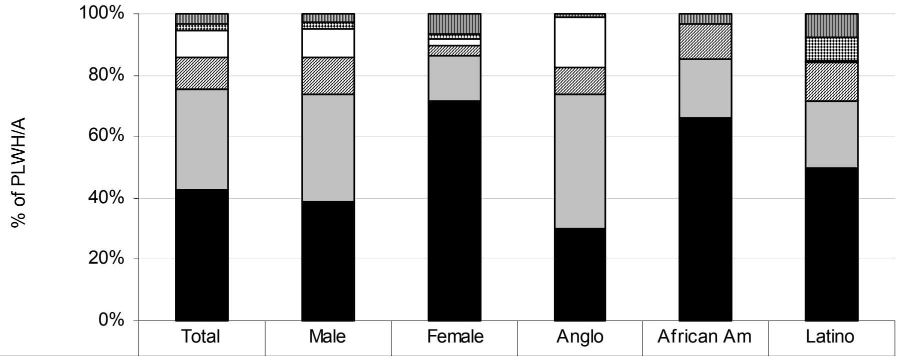
Persons living in poverty often cannot afford basic needs such as food and housing, health care or insurance that would pay for health care, or, if they have insurance, the co-pays that often accompany claims. Poverty is related to unemployment, homelessness and substance use, and these, in turn are related to HIV.

According to the Long Beach Department of Health and Human Services 2000 report, 17% of Long Beach residents live in poverty – about the same proportion that live in Poverty in LA county. In 2002, poverty level for one-person households is $8,860 and 300% of federal poverty level (FPL) is $26,580.

Figure 5-3 shows income levels by gender and ethnicity. It indicates that:

- In general, those participating in the survey report low incomes, with about 97% earning 300% below poverty level or less, and approximately 43% earning less than $8,600.
- Women report significantly lower income than men with over 71% of women reporting an annual income of $8,600 or less.
- Similar to HIV infection rates, poverty rates are also disproportionately high for people of color in Long Beach. Nearly two thirds of African Americans earn less than $8,600 and, while they represent 9.8% of the County's population, they represent more than 20% of those living in poverty.
- Also, almost half of the Latinos report earning $8,600 per year or less.
- Anglos report the highest income of any group, with 17% earning $16,500 or more per year.

Figure 5-3 Income by Gender and Ethnicity

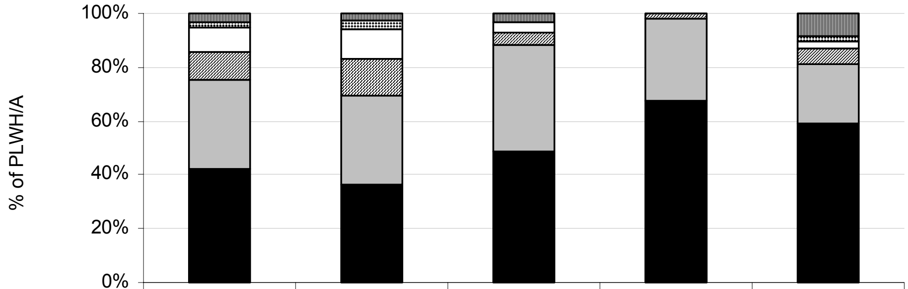


	Total	Male	Female	Anglo	African Am	Latino
▩ Greater than $26,001	3.1%	2.7%	6.5%	1.2%	3.1%	7.6%
▦ $23,201 to $26,000	2.2%	2.2%	1.9%	0.0%	0.0%	7.6%
□ $16,501 to $23,200	8.7%	9.5%	1.9%	16.0%	0.0%	0.9%
▨ $11,601 to $16,500	10.8%	11.7%	3.4%	9.3%	11.4%	12.4%
▫ $8,601 to $11,600	32.7%	34.9%	14.5%	43.4%	19.5%	21.8%
■ $8,600 or less	42.5%	39.0%	71.7%	30.1%	65.9%	49.7%

Figure 5-4 shows income by risk group.

- Among risk groups, virtually all of the IDUs and the vast majority of MSM/IDU (93%) have incomes of $16,500 or less per year.
- MSM have the highest income with 17% making more than $16,500 followed by heterosexuals (13%). While MSM living with HIV/AIDS are at every income level, 97% report earning less than $35,440 (400% below poverty) which is the usual limit to qualify for ADAP.

Figure 5-4 Income by Risk Group



	Total	MSM	MSM/ IDU	IDU	Hetero
▩ Greater than $26,001	3.1%	2.9%	3.5%	0.0%	8.2%
⊞ $23,201 to $26,000	2.2%	2.8%	0.0%	0.0%	2.4%
□ $16,501 to $23,200	8.7%	11.4%	3.5%	0.0%	2.4%
▨ $11,601 to $16,500	10.8%	13.4%	4.6%	2.2%	5.9%
▒ $8,601 to $11,600	32.7%	33.4%	39.9%	30.3%	22.2%
■ $8,600 or less	42.5%	36.2%	48.6%	67.5%	58.9%

Homelessness

Stable housing is often a prerequisite for a PLWH/A who are trying to adhere to a difficult medical regimen and improve their quality of life. Living in shelters and inconsistent access to food and proper nutrition further aggravates the difficulty adhering to medications. In many cases, HIV/AIDS is both a cause and a result of homelessness. It is believed that HIV infection in homeless communities varies from 3% to 19.5% with a significantly higher rate of infection in subgroups such as communities of color, intravenous drug users, women, and youth. Overall, the County of LA HIV Epidemiological Department estimates that 4.6% of the currently homeless populations in infected with HIV.

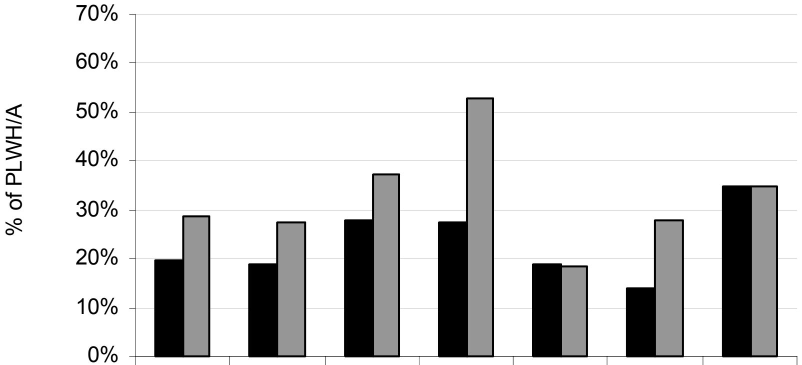
The 2003 Needs Assessment survey further supports this finding and indicates that among the PLWA diagnosed in 2000 or later, 11% are currently homeless and an additional 31% report living in some form of transitional housing. Transitional housing includes living in a single-room-occupancy (SRO) with or without tenancy, living in a group home or residence including residential drug therapy, a halfway house, or transitional housing. The newly infected are a much more vulnerable population and are more concentrated among lower income individuals. The data indicates that 11% of the newly diagnosed PLWA are homeless compared to less than 3% of all PLWA.

The instability of housing becomes evident when PLWH/A are asked if they have been homeless or in transitional housing in the last two years. Based on the 2003 Needs Assessment, 20% of PLWH/A in Long Beach have been homeless sometime in the last two years, and 29% have lived in some form of transitional housing. Overall, about 15% of all PLWH/A interviewed feel that their current housing situation is unstable. Populations that report the highest vulnerability to homelessness are the recently incarcerated, the out-of-care, and IDUs. African American PLWH/A are more likely to report unstable housing than are PLWH/A from other ethnic populations.

Figure 5-5 and Figure 5-6 based on the 2003 Needs Assessment Survey confirm that:

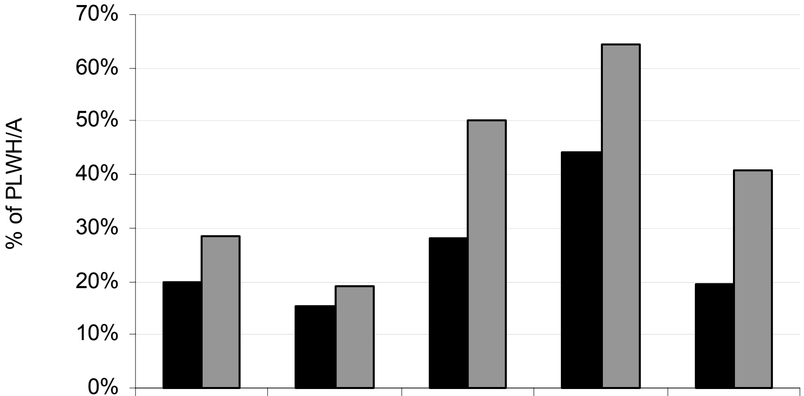
- Unlike PLWH/A in LA, women in Long Beach are much more likely to have a history of homelessness or living in transitional housing than men.
- Latinos (14%) report a much lower incidence of homelessness.
- Among risk groups, IDUs and MSM/IDU are much more likely to have been homeless or lived in transitional housing than MSM or heterosexuals.
- Not shown in the graphs is that recently incarcerated PLWH/A are far more likely to experience a period of homelessness than other populations. Sixty-six percent (66%) of those who have been incarcerated in the last two years report a history of homelessness. This may reflect the financial challenges and rules and regulations of public housing one faces after being released from the jail system.

Figure 5-5 Homelessness & Transitional Housing by Gender and Ethnicity



	Total	Male	Female	African Am	Anglo	Latino	API and other
■ % w / homeless history	19.8%	18.8%	28.0%	27.6%	18.6%	14.1%	34.7%
▨ % w / transitional history	28.5%	27.5%	37.3%	52.7%	18.6%	27.8%	34.7%

Figure 5-6 Homelessness & Transitional Housing by Risk Category



	Total	MSM	MSMIDU	IDU	Hetero
■ % w / homeless history	19.8%	15.4%	28.0%	44.1%	19.4%
▨ % w / transitional history	28.5%	19.3%	50.3%	64.2%	40.8%

STDs

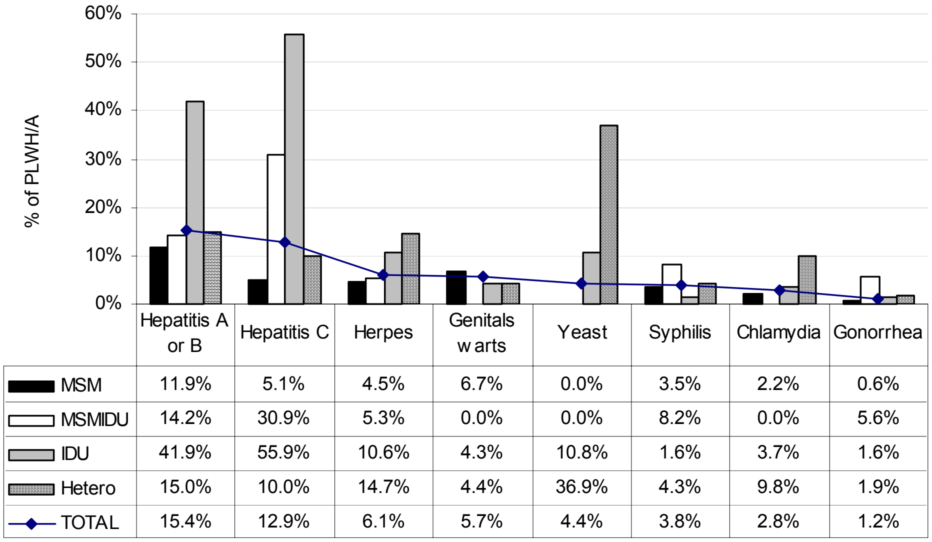
Since the beginning of the AIDS epidemic, researchers consistently have suggested an association between HIV/AIDS and other STDs. Numerous national studies have indicated at least a twofold to fivefold increased risk for HIV infection among persons who have other STDs. STDs have a dual impact on PLWH/A and those at risk for HIV infection. Individuals with a history of STDs are likely to have a compromised immune system and more likely to contract opportunistic infections (OIs). Also, manifestations of STDs such as open sores and genital ulcers make a person more vulnerable to HIV infection or re-infection. From an epidemiological perspective, a rise in STD rates, particularly gonorrhea and syphilis, indicate a rise in unprotected sexual intercourse that can lead to higher infection rates. Hepatitis, particularly hepatitis C, is associated with needle sharing and is an indication of risk of HIV infection among IDUs.

The recent outbreak of syphilis in Los Angeles County and Long Beach appear to be continuing into 2003. The State Report, STD 2000, indicates that rates jumped in the Los Angeles Health District from .9 per 100,00 in 1999 to 1.5 per 100,000 in 2000. In Long Beach the rates were significantly higher – 2.4 cases per 100,000 in 1999 and 4 cases per 100,000 in 2000. According to recent statistics, there was an increase from 4 cases in January 2003 to 11 cases in January 2003; that is a 175% increase. In comparison LA Country had an increase from 54 to 94 cases, or a 75% increase.

Figure 5-7 and Figure 5-8 show the percentage of PLWH/A who report being diagnosed with STDs in the last year. They indicate that:

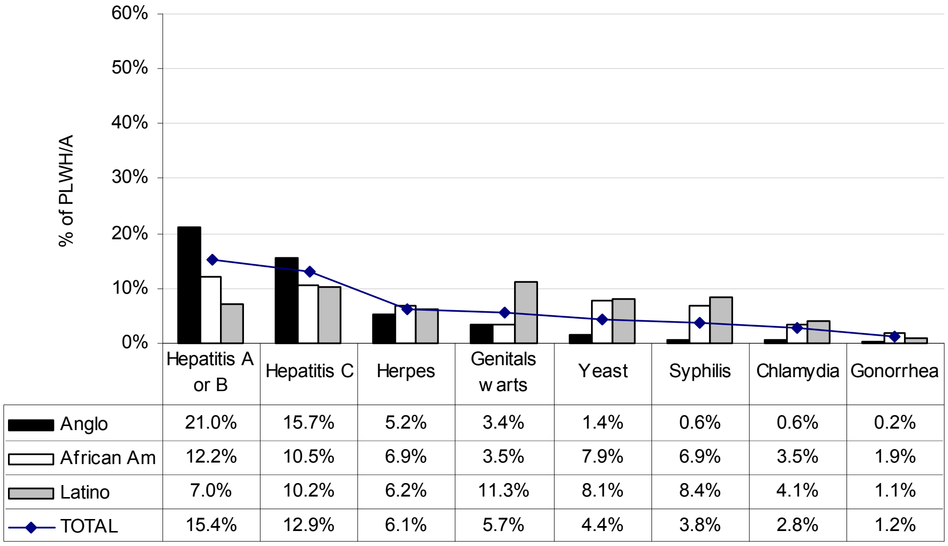
- Over 15% of the PLWH/A report having been diagnosed with hepatitis A or B in the last year. Close to 42% of IDUs report having had hepatitis A or B in past year. Among ethnic communities, the incidence of hepatitis A or B is highest among Anglos (21%).
- Next highest incidence of STDs is hepatitis C (13%). Predictably, it is significantly higher among IDUs (56%) and MSM/IDU (31%). Among the ethic populations, Anglos tend to report a higher incidence of hepatitis C.
- Herpes is the third most frequently reported STD (6%) and it is highest among heterosexuals (15%).
- Syphilis is reported among 3.8% of all PLWH/A. Over 8% of the MSM/IDU report having syphilis in the past year. In contrast, 3.5% of the MSM and 4.3 of the heterosexuals report syphilis in the past year. The Needs Assessment Survey from LA follows the same pattern with the highest reported STD rates among MSM/IDU. Among MSM, the Latinos and African Americans report higher rates that Anglos.

Figure 5-7 STDs among PLWH/A by Mode of Transmission



	Hepatitis A or B	Hepatitis C	Herpes	Genitals warts	Yeast	Syphilis	Chlamydia	Gonorrhea
MSM	11.9%	5.1%	4.5%	6.7%	0.0%	3.5%	2.2%	0.6%
MSMIDU	14.2%	30.9%	5.3%	0.0%	0.0%	8.2%	0.0%	5.6%
IDU	41.9%	55.9%	10.6%	4.3%	10.8%	1.6%	3.7%	1.6%
Hetero	15.0%	10.0%	14.7%	4.4%	36.9%	4.3%	9.8%	1.9%
TOTAL	15.4%	12.9%	6.1%	5.7%	4.4%	3.8%	2.8%	1.2%

Figure 5-8 STDs among PLWH/A by Ethnicity



	Hepatitis A or B	Hepatitis C	Herpes	Genitals warts	Yeast	Syphilis	Chlamydia	Gonorrhea
Anglo	21.0%	15.7%	5.2%	3.4%	1.4%	0.6%	0.6%	0.2%
African Am	12.2%	10.5%	6.9%	3.5%	7.9%	6.9%	3.5%	1.9%
Latino	7.0%	10.2%	6.2%	11.3%	8.1%	8.4%	4.1%	1.1%
TOTAL	15.4%	12.9%	6.1%	5.7%	4.4%	3.8%	2.8%	1.2%

Mental Illness

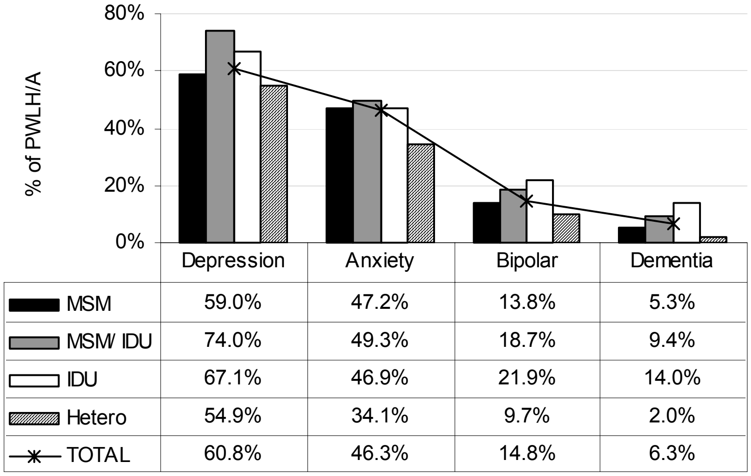
Mental illness covers a broad array of mental disabilities. Many people living with HIV and AIDS, particularly substance users, have had mental disabilities prior to becoming infected. For others, the diagnosis of HIV infection or its manifestations has led to mental service needs. For the purpose of this Needs Assessment mental illness is defined as having a diagnosis of anxiety, dementia, or depression. Almost two-thirds of the PLWH/A (65%) reported 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%) of the survey participants report serious mental illness.

The types of mental disorders that have been diagnosed are shown in Figure 5-9 and Figure 5-10. They indicate that:

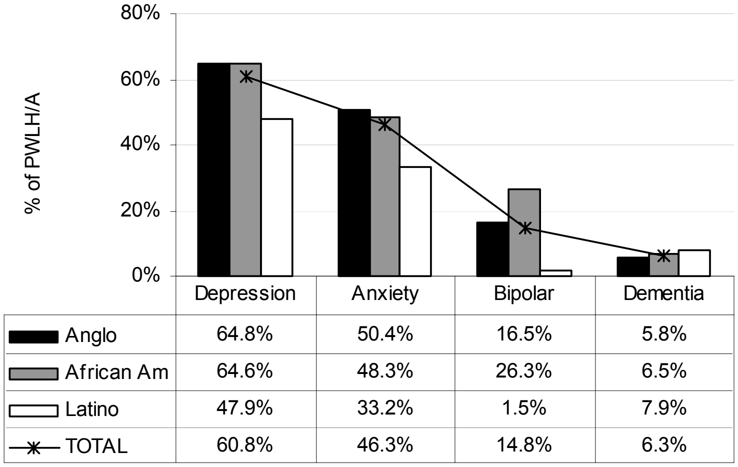
- Depression has been diagnosed among 61% of PLWH/A in the past two years, and it is the most frequently diagnosed mental illness reported by PLWH/A. It tends to be highest among MSM/IDU (74%) and IDU (67%) PLWH/A. Latinos (48%) report less than the average incidence of depression. Attachment 5 further indicates that women (64%) have a higher incidence of depression than men, and asymptomatic PLWA (57%) report the lowest incidence of depression.
- Nearly one half of PLWH/A (46%) report a diagnosis of anxiety in the past two years. Heterosexuals (34%) and Latinos (33%) are less likely to have received a diagnosis of anxiety than any of the other race and risk groups. Attachment 5 further indicates that PLWH/A who have been out-of-care for more than six months (18%) and asymptomatic PLWH (36%) tend to report the lowest incidence of anxiety. This may reflect actual incidence or that they are less likely to see mental health professionals for a diagnosis.
- Fifteen percent of PLWH/A report bipolar disease, with IDUs (22%) and African Americans (26%) reporting a higher incidence than any of the other target populations. Attachment 5 further indicates that the recently incarcerated (38%), the homeless (35%), and the asymptomatic PLWA report a much higher than the average incidence of bipolar disease.
- About six percent of the participants report the more acute diagnosis of dementia. Serious dementia may be undercounted because they would not have been able to complete the survey.

Figure 5-9 Mental Illness Among PLWH/A by Risk Group



	Depression	Anxiety	Bipolar	Dementia
MSM	59.0%	47.2%	13.8%	5.3%
MSM/ IDU	74.0%	49.3%	18.7%	9.4%
IDU	67.1%	46.9%	21.9%	14.0%
Hetero	54.9%	34.1%	9.7%	2.0%
TOTAL	60.8%	46.3%	14.8%	6.3%

Figure 5-10 Mental Illness Among PLWH/A by Race/Ethnicity



	Depression	Anxiety	Bipolar	Dementia
Anglo	64.8%	50.4%	16.5%	5.8%
African Am	64.6%	48.3%	26.3%	6.5%
Latino	47.9%	33.2%	1.5%	7.9%
TOTAL	60.8%	46.3%	14.8%	6.3%

Sixty-seven percent of PLWH/A reported having received mental health counseling or treatment since having been infected with HIV. Heterosexuals (76%), women (75%), symptomatic PLWH (72%) and symptomatic PLWA (71%), African Americans (71%), recently incarcerated (71%), and PLWH/A with a history of homelessness (70%) tend to report the greatest need for mental health services after been infected with HIV. Consistent with their medical care health practice, the out-of-care PLWH/A (28%) tend to receive less mental health treatment than other populations analyzed.

Among PLWH/A who have received mental health counseling or treatment, 68% have received medication for psychological or behavioral problems and 25% have been hospitalized for their mental illness. A much higher percent (74%) of PLWH/A report receiving individual counseling than group counseling (56%).

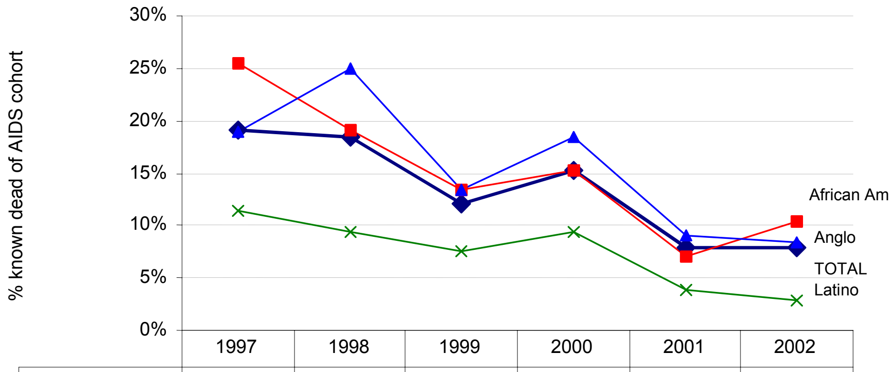
6. OUTCOMES

To assess the success of a continuum of care, medical and social outcomes must be measured and tracked. Basic outcomes for the HIV/AIDS continuum of care are mortality, morbidity, and quality of life.

The large discrepancy in death rates between African Americans and other ethnic populations is somewhat moderated by examining the fatality rates shown in Figure 6-1. This "case-fatality rate" measures the death rate among the cohort diagnosed with AIDS during a certain calendar year. While death rates show the disproportionate impact of AIDS on the African American community, the case fatality rates show the survival rate once a person is diagnosed with AIDS is in the care system. For more recently diagnosed cases receiving current medication and care, it would be expected that case fatality rates would decline. Differences in case fatality by ethnic groups could indicate a disparity in service.

As shown in Figure 6-1, although fatality rates have fluctuated from 1997 to 2002, overall rates have declined among all ethnic groups. Since 1997 Latinos have had the lowest fatality rates, well below the overall fatality rate for all PLWA. African Americans have had the highest mortality rates in 3 of the 6 years tracked in Figure 6-1, including 2002, the last year of available data. Anglos have had the highest mortality rate in the other 3 years, peaking in 1998 at 25%. The differences in case- fatality rates among ethic populations suggests that although African Americans are disproportionately diagnosed with AIDS and die at a higher rate, once diagnosed with AIDS, African Americans and Anglos are all surviving at about the same rate. The very low rate for Latinos requires further investigation. One possible explanation for the low fatality rate is that Latinos may go back to their country of birth and their death may not be report in the Long Beach system.

Figure 6-1 Case-Fatality Rates



	1997	1998	1999	2000	2001	2002
◆ TOTAL	19.0%	18.5%	12.1%	15.3%	7.8%	7.9%
■ African Am	25.5%	19.1%	13.5%	15.2%	7.0%	10.3%
▲ Anglo	19.0%	25.0%	13.4%	18.4%	9.1%	8.3%
× Latino	11.3%	9.3%	7.5%	9.3%	3.9%	2.9%

Progression from HIV to AIDS

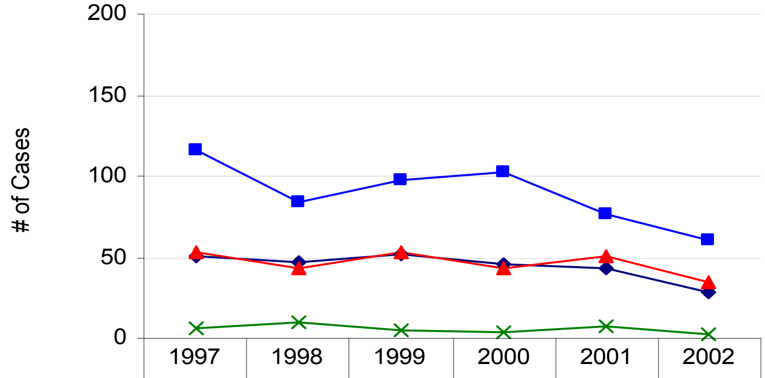
In addition to declining death rates, early treatment of HIV disease has greatly reduce the progression of HIV to AIDS. In 1997, 226 persons were diagnosed with AIDS in Long Beach, while in 2002, 127 persons were diagnosed, representing a decline of about 44%.

New AIDS Cases by Ethnic Populations

Unlike the overall sharp decline in newly diagnosed cases noted in LA County from 1997 to 2002, Figure 6-2 shows that the decline in Long Beach among communities of color has not been as dramatic, particularly among Latinos. For instance, since 1997 the AIDS rate among Anglos and African Americans has declined more than 40% while the decline among Latinos has been 34%. In 2002, Latinos account for 28% of the newly diagnosed cases in Long Beach, compared to 44% in LA County.

In terms of absolute numbers needing services, Anglos represent the largest number of newly diagnosed cases in Long Beach. In 2002, there were 60 newly diagnosed Anglos, out of a total of 127 in Long Beach. Similar to LA County, African Americans account for almost one quarter of the newly diagnosed cases in Long Beach. In planning services for the newly diagnosed, the most units of service have to be allocated for the Anglos living with HIV and AIDS. At the same time, the system has to prepare for a growing number of African Americans and Latinos living with HIV and AIDS.

Figure 6-2 AIDS Cases by Year of Diagnosis by Race

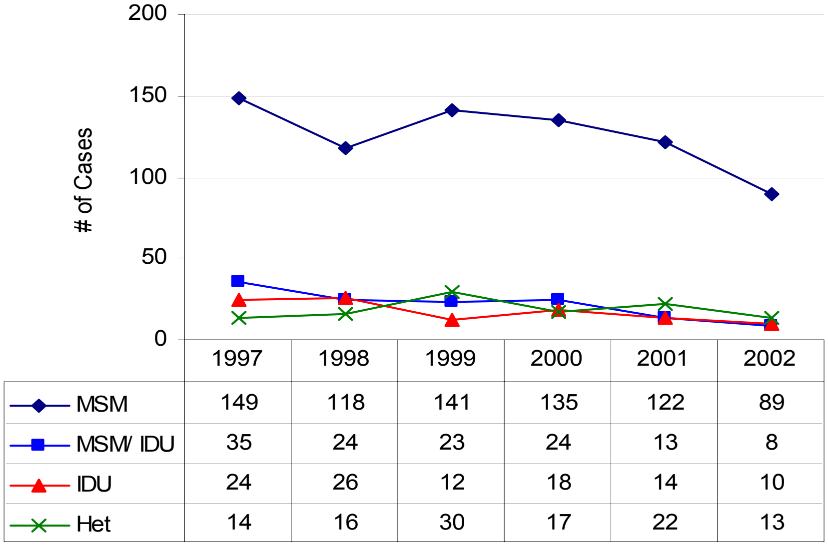


	1997	1998	1999	2000	2001	2002
◆ African Am	51	47	52	46	43	29
■ Anglo	116	84	97	103	77	60
▲ Latino	53	43	53	43	51	35
× Other	6	10	5	4	8	3

New AIDS Cases by Risk Group

Figure 6-3 shows an overall decline in diagnosed AIDS cases for risk groups. Similar to LA County, MSM continue to account for the large majority of the newly diagnosed cases. However, the rates vary significantly among the various populations. For instance, MSM/IDU show a decline of almost 80%, going from 35 cases in 1997 to eight cases in 2002. On the other hand, while the number of heterosexuals has remained low, this number has remained constant with a decline of less than 10%.

Figure 6-3 AIDS Cases by Year of Diagnosis by Risk Group

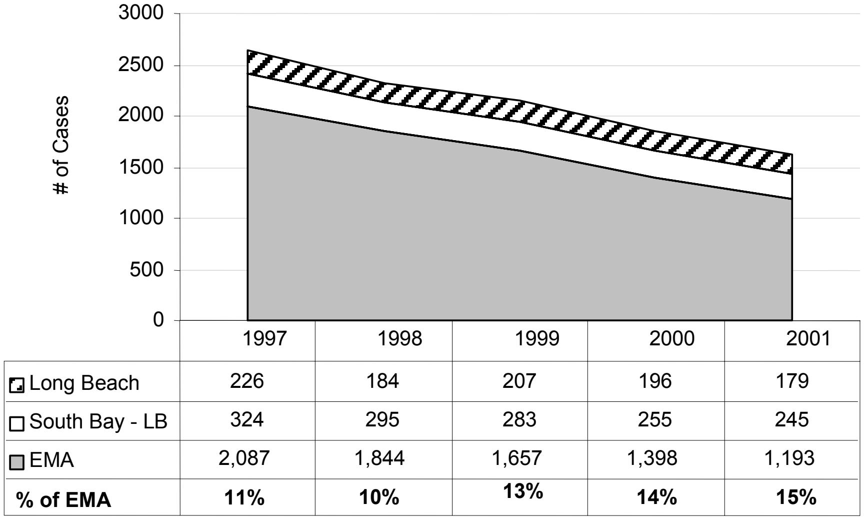


	1997	1998	1999	2000	2001	2002
◆ MSM	149	118	141	135	122	89
■ MSM/ IDU	35	24	23	24	13	8
▲ IDU	24	26	12	18	14	10
× Het	14	16	30	17	22	13

New AIDS Cases by Geographic Location

Figure 6-4 displays the decline in AIDS cases reported yearly in the Los Angeles County, SPA 8 and Long Beach. Also shown in the figure is the percent of new cases in Long Beach relative to the LA EMA. It shows that while the number of new cases has declined in the area, the proportion of new cases in Long Beach has increased. In 1997, Long Beach represented 11% of the new cases in the EMA, by 2001, Long Beach accounts for 15% of the cases.

Figure 6-4 AIDS Cases by Year of Diagnosis LAC and Long Beach



	1997	1998	1999	2000	2001
▨ Long Beach	226	184	207	196	179
□ South Bay - LB	324	295	283	255	245
▩ EMA	2,087	1,844	1,657	1,398	1,193
% of EMA	**11%**	**10%**	**13%**	**14%**	**15%**

Medication and Adherence

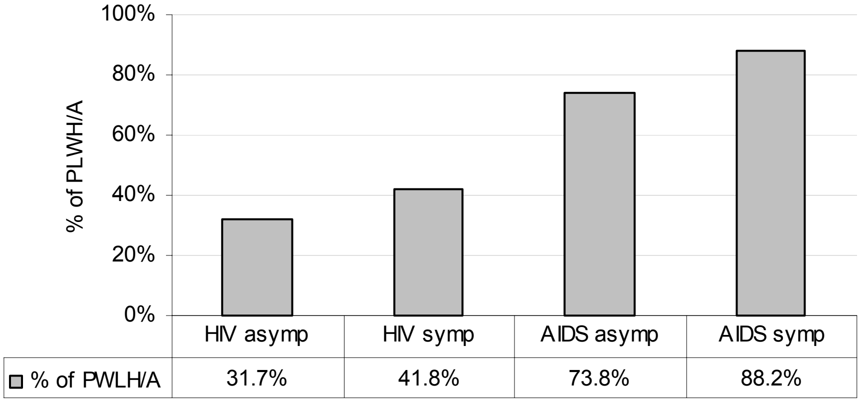
Another outcome of the system is adherence to medication. Despite the availability of adherence programs, PLWH/A report mixed results.

Taking Medication

The use of combination therapy and prophylactics to prevent opportunistic infections has greatly improved the length and contributed to the quality of life of PLWH/A. Continued and improved health status outcomes will depend, in part, on the availability, access, and adherence to properly prescribed medical regimens.

Based on data from the 2003 Needs Assessment survey, 36% of PLWH and 85% of PLWA report ever taking antiretrovirals and/or protease inhibitors. As shown in Figure 6-5, symptomatic PLWA (88%) are much more likely to report taking medication than are asymptomatic PLWH (32%).

Figure 6-5 Medication by Stage of Infection



Men (68%) are more likely than women (45%) to have taken HIV medications, reflecting, in part their longer length of HIV infection. It may, however, also represent lower levels of awareness or other barriers for women. These are discussed further in the barriers section of this report. The currently homeless (46%), Latino MSM/IDU (43%), and heterosexuals (42%) report a lower use of medication than any other population. This may be due to a number of factors including unstable housing situation, substance use, and/or poor access to health care.

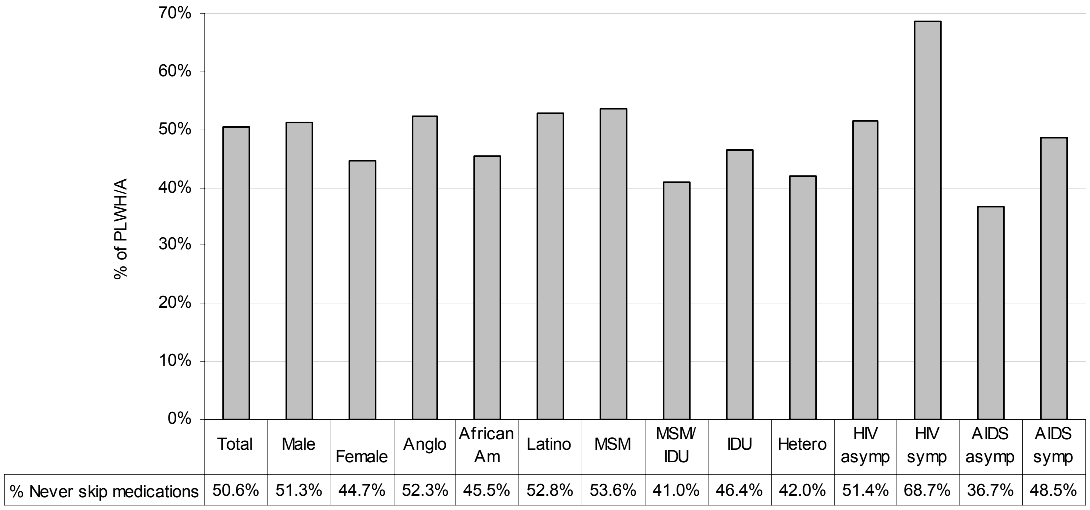
Adherence

Fifty-one percent of the PLWH/A in 2003 Needs Assessment survey report never skipping their medications. At the other extreme, 10% have stopped taking their medication all together.

Figure 6-6 shows adherence to medications across different sub-populations. Data from the 2003 Needs Assessment reveals that:

- Women (55%) tend to have a more difficult time adhering to their medications than men (49%). They are also much more likely (22%) than men (8%) to have stopped taking their medications all together.
- African Americans are less likely to adhere to their medication regimen than any other ethnic populations, and nearly 20% report having stopped taking their medications. Latinos and Anglos report equal rates of adherence, however, Latinos are slightly more likely to stop taking their medications than Anglos.
- Close to 60% of the MSM/IDU and heterosexuals have difficulty adhering to their medications.
- Notably, asymptomatic PLWH are more likely to stop taking their medication than other populations of PLWH at different stages of disease.

Figure 6-6 PLWH/A Who've Never Skipped Their Medications



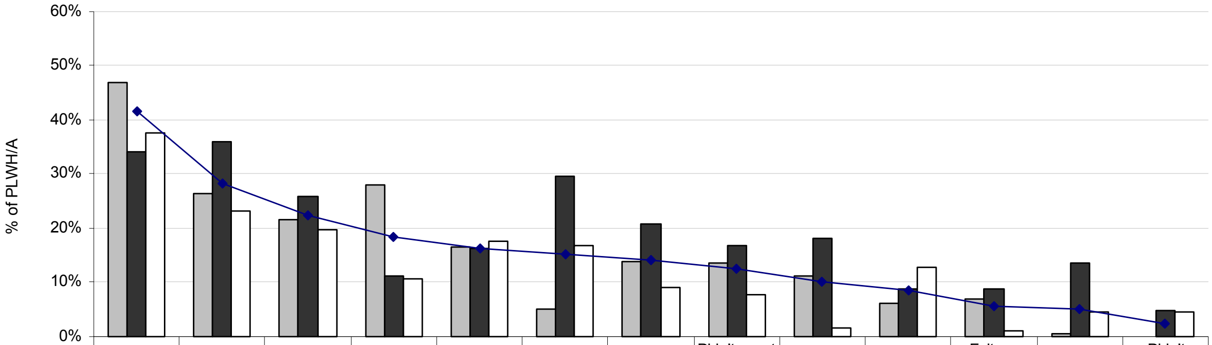
	Total	Male	Female	Anglo	African Am	Latino	MSM	MSM/ IDU	IDU	Hetero	HIV asymp	HIV symp	AIDS asymp	AIDS symp
% Never skip medications	50.6%	51.3%	44.7%	52.3%	45.5%	52.8%	53.6%	41.0%	46.4%	42.0%	51.4%	68.7%	36.7%	48.5%

Figure 6-7 and Figure 6-8 show the top reasons for discontinuing medications for all PLWH/A. It indicates that:

- Forgetting to take medications, side effects and not wanting to take the medications are the top reasons for discontinued or inconsistent use of medications.
- Among all groups, forgetting to take them (42%) is typically the major reason for skipping medication, with Anglos (47%), and MSM (44%), and the symptomatic PLWA being the most likely to forget.
- The next two most common reasons cited for skipping doses were side effects of medications (28%) and not wanting to take medications (23%). MSM/IDU (57%), African Americans (36%), women (35%), and symptomatic PLWA report having a greater problem with side effects than other groups.
- The three least cited reasons for not taking medication include "felt that did not need medications" (6%), "medications did not work" (5%), and "not understanding directions" (3%).

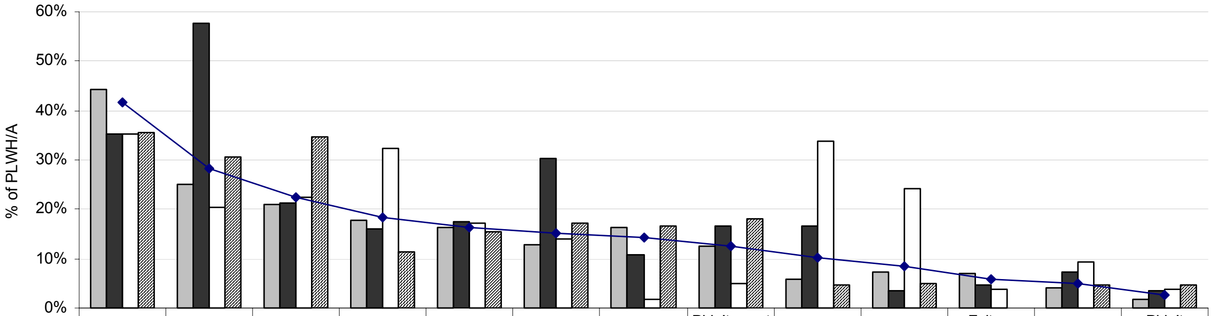
- Ten percent of the PLWH/A reported being homeless as one of their reasons for skipping medications.

Figure 6-7 Reasons for Skipping Medications by Ethnicity



	Forgot	Side effects	Didn't want to take	Ran out	Coordinate with food	Schedule	MD's advice	Didn't want others to see	Homeless	Afforda-bility	Felt no longer needed	Did not work	Didn't understand directions
▭ Anglo	46.9%	26.5%	21.7%	27.9%	16.5%	5.1%	13.8%	13.7%	11.1%	6.0%	7.1%	0.5%	0.0%
■ African Am	34.0%	36.0%	25.8%	11.1%	16.1%	29.7%	20.7%	16.8%	18.1%	8.9%	8.8%	13.7%	4.8%
□ Latino	37.6%	23.3%	19.9%	10.7%	17.6%	16.7%	9.0%	7.7%	1.7%	12.7%	0.9%	4.5%	4.5%
◆ Total	41.5%	28.3%	22.5%	18.4%	16.3%	15.1%	14.2%	12.6%	10.1%	8.5%	5.7%	5.0%	2.5%

Figure 6-8 Reasons for Skipping Medications by Mode of Transmission



	Forgot	Side effects	Didn't want to take	Ran out	Coordinate with food	Schedule	MD's advice	Didn't want others to see	Homeless	Afforda-bility	Felt no longer needed	Did not work	Didn't understand directions
▭ MSM	44.4%	25.0%	20.8%	17.6%	16.2%	12.8%	16.4%	12.4%	5.9%	7.2%	7.0%	4.0%	1.8%
■ MSM/ IDU	35.1%	57.7%	21.2%	16.0%	17.6%	30.3%	10.8%	16.6%	16.6%	3.6%	4.6%	7.3%	3.6%
□ IDU	35.4%	20.4%	22.6%	32.5%	17.1%	14.0%	1.7%	5.0%	33.8%	24.3%	3.9%	9.3%	3.6%
▨ Hetero	35.5%	30.6%	34.6%	11.4%	15.3%	17.2%	16.7%	18.1%	4.7%	4.9%	0.0%	4.6%	4.8%
◆ Total	41.5%	28.3%	22.5%	18.4%	16.3%	15.1%	14.2%	12.6%	10.1%	8.5%	5.7%	5.0%	2.5%

Overall, 14% of PLWH/A report they stopped taking their medications under advice from a doctor. Asymptomatic PLWA (32%), asymptomatic PLWH (25%), African Americans (21%), heterosexuals (17%), and recently incarcerated (15%) and cited this reason more frequently than other groups.

The focus group participants tend to talk about the adverse side effects of the medication while others discussed the dangers of taking the medication. Still there were a slew of individuals who do not suffer from side effects and most focus group participants did not bring up the medications at all. Interestingly, no one provided any in-depth commentary about forgetting to take their medications.

One White Female IDU participant recalls her side effects with medication saying, *"I did not like [the medication]. Kept running to the bathroom…I keep taking the medication from the treatment center. They make me take it and I told them I'm just gonna go vomit. I'll just vomit them out."* A White MSM agreed that, *"The side effects of the drugs of first the cocktail made me nauseated. I think it makes me more sick than the disease itself."*

An IDU White male does not complain about the medications, but does emphasize his physical well being that many people on medications do not share, which proved to be true for the focus groups. He says that, *"okay, you either have to be taking medications…and then there's the medication's side effects, the depression, fatigue. People, they don't realize…yeah, I'm taking meds and I look fine but most of the day I feel like shit. I feel terrible. Right now, I feel like that. People don't see that. And they don't know that. And we don't really share it."*

The following participants express a more mature concern than the immediate side effects, but the actual effect on their body in the long term. This African American IDU male says, *"I would like to see more pamphlets about how dangerous taking medication really is"* showing that he does not believe the medication is really helping.

An African American who transmitted heterosexually shows her disdain for the medication when she says, *" I'd say I'd do it. Even though I haven't got my medications, even though I don't want to be on medication, I still want to know what my t-cells or viral loads. You know, I want to know how they're doing. Even though I just don't want to be on medication. I mean if it was between life or death then okay I'll be on medication."*

This Native American male represents the 14% who say they stopped based on their doctors' advice. He says, "[my] *doctor says there isn't any need to use treatment since my antibodies seem to keep it in check."* He attributes it to his *"ancestors who come from Northern Europe where several centuries ago, they had plague. The survivors picked up antibodies to viral infections. This may have been transmitted from generation to generation. This may explain my stability."*

Quality of Life

Other outcomes measured for the system of care are current and changed physical and emotional health. While no baseline physical or emotional health measures are available for PLWH/A, survey participants rated their current physical and emotional health and then compared it to "when they first sought treatment for their HIV infection" (questions 23 through 26, Attachment 2). Self-report of physical and emotional health is also compared to the 2002 LAC Needs Assessment findings. The assumption tested is that access to care, and in particular to new HIV drug therapies, have a positive impact on the physical and mental health of PLWH/A seeking care. Consequently, improved physical or emotional health after seeking treatment would suggest the care system is meeting one of its major objectives.

Drug therapies, however, may not have the same beneficial affect across all populations, and some PLWH/A may experience severe side effects that compromise both physical and emotional health. Additionally, there are disparities in access to care and treatment that may also impact quality of life. As a result of these factors, it is expected that some of the survey respondents will report decreasing physical and emotional health regardless of the quality of the treatment.

Figure 6-9 and Figure 6-10 report the current and perceived change in physical health and emotional health for PLWH/A in Long Beach. It is divided into three independent groups: 1) PLWH who are asymptomatic 2) PLWH who are symptomatic, and 3) those who report being diagnosed with AIDS. Of those living with AIDS, over three quarters (76%) said they were symptomatic.

- Asymptomatic PLWH in Long Beach report better physical health status than asymptomatic PLWH in Los Angeles. More than 83% of the asymptomatic PLWH in Long Beach are doing “good” to “excellent” compared to 75% in Los Angeles. Asymptomatic PLWH in Long Beach also feel they are doing better than when first diagnosed. Sixty percent (60%) say that their physical health is better now as compared to when they first sought treatment and another 37% say their health is the same.
- On the other hand, symptomatic PLWH in Los Angeles report doing slightly better physically than symptomatic PLWH in Long Beach. For instance, about 45% of symptomatic PLWH in LA report that their physical health is currently good to excellent, compared to 42% in Long Beach. But more significantly, 53% of the symptomatic PLWH in LA, compared to less than 42% of symptomatic PLWH in Long Beach, say that they are doing better than when first diagnosed. This may be connected to their recent diagnosis and start of HIV medications and related side effects.
- PLWA in Long Beach report similar physical health status to the PLWA in LA. While PLWA (13%) are more likely than asymptomatic PLWH (4%) or symptomatic PLWH (6%) to report poor health, half say they have good to excellent health. Sixty percent (60%) of PLWA report improvement in health since they first sought treatment for their HIV infection.
- Overall, the care system appears to be addressing the health needs of PLWH/A and assisting them in maintaining and in many instances improving their health status. Whether it’s due to increased medical monitoring, greater access to social services or heightened awareness about individual health practices, the majority (59%) of PLWH/A report doing better today compared to when they first sought treatment.

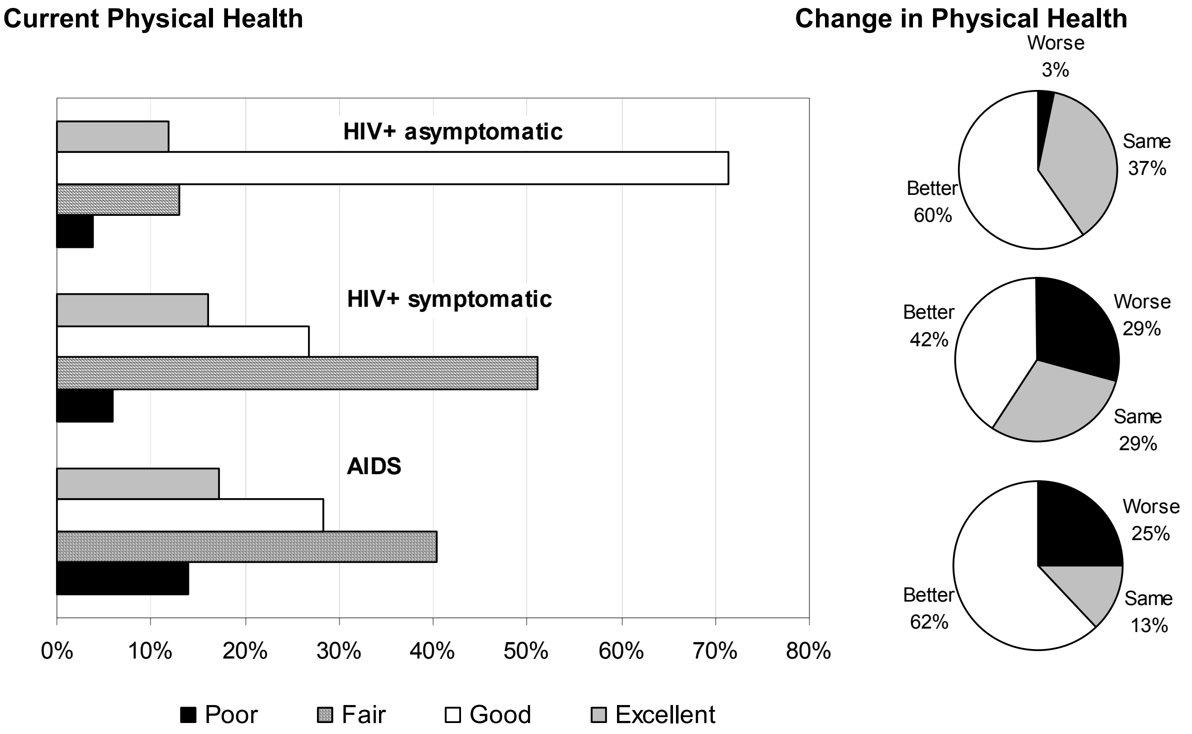
PLWH/A in LA report that their emotional health is better than the reported emotional health of PLWH/A in Long Beach.

- For instance, asymptomatic PLWH in Long Beach report poorer emotional health than asymptomatic PLWH in LA. Over 40% of asymptomatic PLWH in Long Beach report poor to fair health, compared to 30% in LA. Also, about nine percent of the asymptomatic PLWH in Long Beach report doing worse than when first sought treatment compared to less than two percent in LA. However, more than half of asymptomatic PLWH, in both LA and Long Beach, report better emotional health than their initial diagnosis.

- In terms of emotional status, symptomatic PLWH in Long Beach are comparable to symptomatic PLWH in LA. Over 45% of symptomatic PLWH in Long Beach are doing good to excellent, compared to about 53% of symptomatic PLWH in LA. While about 30% of symptomatic PLWH in Long Beach are feeling physically worse, emotionally over 58% report doing better emotionally than when first starting treatment.
- About half of PLWA in LA and in Long Beach are doing well emotionally. But a significantly greater proportion (61%) of PLWA in LA than in Long Beach (46%) are feeling better than when first seeking treatment. This is an interesting finding that would require further probing.

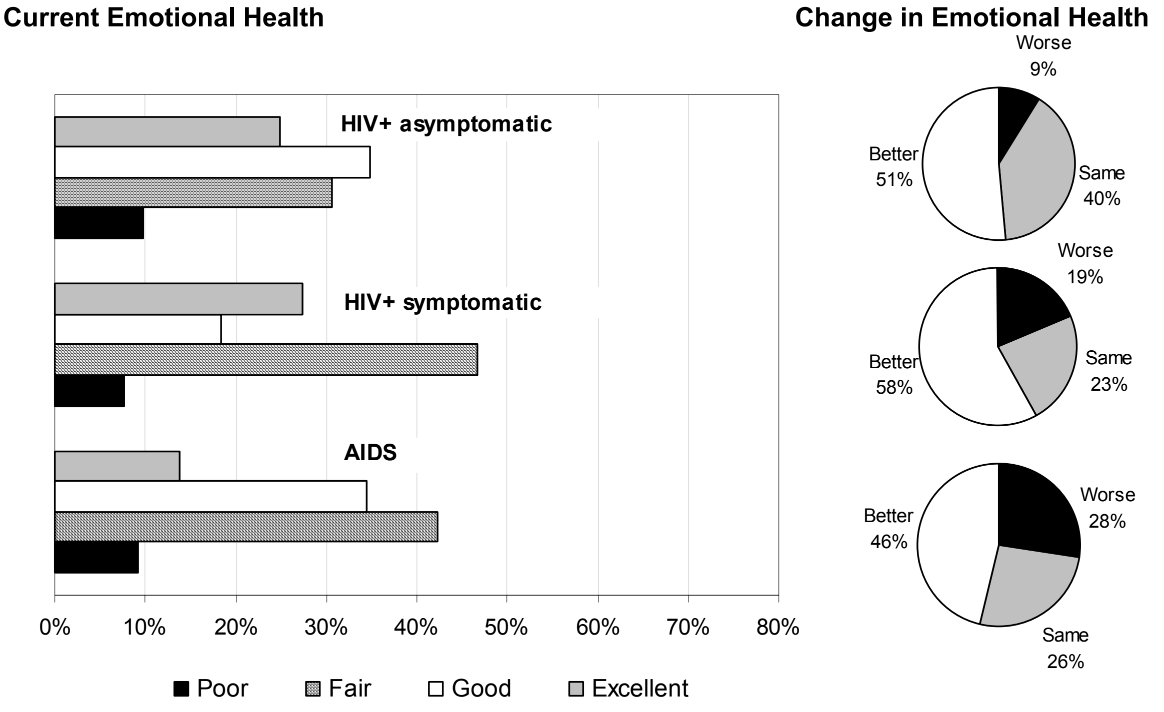
Overall, based on improvement in both physical and emotional health, the care system is making an impact. As a possible indication of the success of aggressive medical intervention, PLWA are able to manage their infection and report the greatest improvements physically amongst the different stages of infection. Also, asymptomatic PLWH, whose physical health has remained relatively constant, have nonetheless benefited from improved emotional health and are the population with the greatest improvements emotionally.

Figure 6-9 Quality of Life – Physical Health


Current Physical Health

Change in Physical Health

Figure 6-10 Quality of Life – Emotional Health


Current Emotional Health

Change in Emotional Health

Focus group participants had positive things to say about their care. It is apparent that while some are having real difficulty with their physical and emotional health because of their diagnosis, the care and help they receive through these programs are the "ups" in their roller coaster ride.

These women have been deeply affected by the care and services they've received. This African American Female IDU says, *"I am receiving great help. My meds are working great and I am in great health and I have strong family support."* A White female who transmitted heterosexually says, *"I feel very lucky that I receive all the service I do and the care I get from the doctors, RN's, case mangers, family and friends. I feel so blessed to have a second chance in life and to be surrounded by such amazing people, my son, and services."* A Latina who also transmitted heterosexually says in Spanish, *"Its good that I've had an opportunity to have a good doctor in the care that I have, that they give me as well as my psychologists. They've helped me a lot in a time when I was really depressed and one day I would like to help other people who find themselves in my situation."*

Still, not everyone reports such positive outcomes whether affected by their care or not. This African American male says he's, "*withered away."*

A White MSM describes his condition in and out-of-care. He says, *"I was in the hospital. I was in really bad shape I went down to a hundred and twenty pounds and couldn't walk right... I was in the hospital for about a week. Until my case manager could help me out. She got my disability going and gave me some hotel vouchers for about six months. Then after that ran out I had to go to the outpatient clinic. I was a drug addict, and then I was in recovery. When I went to the recovery home then I got an apartment on my own in Whittier, and then my disability completely shut off on me and I couldn't get through the system so they keep off disability. Then I stayed with my Mom for a long time until she moved up to Riverside so I came up to [name of agency] and they helped me out a lot."*

Another White MSM tells his story, *"I was first infected in '92, but I'm sure I was positive before that but never went to get tested until '92. In Spring of '98, it went to full-blown AIDS and I had laryngitis, t-cells was down 19, viral was 210,000 and I started treatment at the [name of agency]. In the next six months, my T-cells started climbing and I went undetected. [My agency] saved my life as far as I'm concerned. I got diagnosed with rectal cancer. I went through chemotherapy and radiation and it totally wiped out my T-cells. They went back down to 50. But the last two weeks they jumped up to 195. I've gone through severe panic attacks and anxiety since I was diagnosed with cancer. I was taking XANEX for the panic attacks and it got to the point where I felt worse on the XANEX. And I think a lot of the side effects from the XANEX were the side effects I was feeling with night sweats, shakes, tremors, feeling like I have a fever yet not running a temperature. My blood pressure however has been like textbook, like 120/80- 120/78…I did go to the doctor yesterday and he did a finger exam and it looks like its taken effect. I have to go for a colonoscopy April 18th...I'm scared to death."*

A Native American IDU woman notes the familiar faces at the focus group as she says, *"before I came here, I didn't know who was going to be here. But it's funny it's just kind of coincidental that whenever we go to group or go to medical updates, [it's the same people] interested in improving their health"* which is something to be said about the focus group participant's initiative in improving the quality of their lives.

7. ACCESS TO SERVICES

Insurance

As shown in Table 7-1, 80% of the PLWH/A report having some form of medical insurance.

- Those PLWH/A who are insured are much more likely to report having Medicaid/ Medi-Cal (56%) and Medicare (29%), than private insurance (11%).
- Men and women are almost equally likely to have some form of health insurance, however, men are more likely to have Medi-Cal (57%), Medicare (30%), and private insurance.
- Latinos (70%) are less likely than African Americans (79%) and Anglos (85%) to have health insurance. However, Latinos are more likely than the other ethnic groups to have private insurance, or insurance through work.
- MSM/IDU and heterosexuals report the highest insurance coverage among the risk groups. MSM/IDU are more likely to have Medicaid than the other risk groups. MSM are more likely to have Medicare than the other groups and heterosexuals are more likely to have private insurance.
- As expected, PLWA are more likely to have medical insurance than PLWH. PLWA are also more likely than PLWH to have Medicaid and Medicare.

Table 7-1 Insurance

	% of PLWH/A with Insurance	Medicaid/ Medi-Cal	Medicare	Private
All PLWH/A	**79.6%**	**56.1%**	**28.8%**	**11.1%**
Male	79.4%	56.8%	30.0%	17.8%
Female	80.8%	50.7%	18.6%	11.8%
African Am	78.9%	62.6%	35.5%	11.3%
Anglo	84.8%	55.0%	32.3%	12.0%
Latino	70.6%	45.2%	12.1%	13.5%
MSM	78.6%	53.8%	33.1%	12.5%
MSMIDU	82.9%	74.3%	19.1%	6.7%
IDU	80.7%	59.4%	11.3%	5.7%
Hetero	82.6%	52.4%	22.0%	18.3%
HIV asymp	53.3%	26.5%	18.8%	2.8%
HIV symp	79.1%	54.4%	14.2%	19.0%
AIDS	89.8%	67.9%	37.0%	13.0%

The survey population was derived from people in HIV/AIDS outpatient services, and therefore likely under-represents the proportion of people with HIV/AIDS who do not have insurance.

Benefits

PLWH/A receive a variety of other services, such as food, housing, and financial assistance that are funded through a variety of sources. These entitlement and benefits are triggered by low income and disability. When PLWH/A are asked if they qualify for benefits, four percent report not being eligible for benefits with an additional 14% not knowing whether they qualify or not.

In reading the response to benefits, in these surveys Latinos consistently show a lower level of benefits. To some degree this is because some are illegal immigrants and they do not apply or qualify. But, as discussed in the focus groups, there is also a fairly strong ethic in the Latino community about working. For example, while Latinos reported the lowest need for employment assistance, a Latino male IDU echoed the voice of many seeking jobs, saying, *"I'm on a benefit plan and I don't want to be on it-- I want to go to work."*

Table 7-2 shows the types of benefits and entitlements received by PLWH//A in Long Beach.

General Assistance

Among the most important of the non-federally funded government programs are the General Assistance (GA) programs. GA programs provide cash and/or in-kind benefits to low-income persons who are not eligible for federally funded cash assistance. Each program is financed and administered entirely through the state, county, and/or locality in which it operates. GA programs are often the last resort for many in need. Twenty-nine PLWH/A (or 9% of the weighted sample) report receiving this benefit. Among those who received benefits, men (59%), African Americans (41%), and heterosexuals (31%) are the groups most likely to receive general assistance.

Disability

As shown in Table 7-2 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.

Supplementary Income

Income supplements include Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), Temporary Assistance to Needy Families (TANF), emergency financial assistance, rent assistance, food stamps, and long-term and short-term disability payments. To be eligible for SSDI the PLWH/A would have to meet both earnings and disability requirement. The earning criteria is based on being "insured" through your tax contributions to the Social Security trust fund and therefore is applicable to PLWH/A with an employment history. SSI and TANF are based on family income and SSI also requires a status of disability, however the SSDI earning requirements do not apply. Those on SSI usually qualify for Medi-Cal/Medicaid, although there is a waiting period. Ryan White funds direct emergency assistance, and PLWH/A have to demonstrate need. The program has limited funds and allows limited payments each year.

The proportion of PLWH/A reporting supplemental sources of income is shown in Table 7-2. The data show that:

- SSDI is the most common for of supplemental income reported by PLWH/A. Thirty-two percent of PLWH/A report receiving SSDI, with men (33%), Anglos (46%), and MSM (36%) 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 subsidy. Men and women are equally likely to receive SSI. However, MSM/IDU, IDUs, and African Americans are more likely to receive SSI than other ethnic or risk groups. This pattern does not hold true for rental subsidies. Men are more likely than women to receive rental supplements; Anglos are more likely to receive rent subsidies than other ethnic populations; and IDUs are more likely to receive rental subsidies than other risk groups.
- Less than one percent of the PLWH/A report receiving direct emergency financial assistance (DEFA) usually used for utilities, rent, or emergency medical treatment. Participants were asked if they receive emergency financial assistance. Only three people indicated receiving this benefit. This is an unusually low percent compared to PLWH/A in Los Angeles or any other EMA and would require further investigation.
- Surprisingly, only 12% report receiving food stamps and two percent report receiving TANF/CalWorks. Women (21%), African Americans (20%), and MSM (37%) are much more likely to receive food stamps than any other group.

Entitlements

PLWH/A access healthcare through non-insurance benefits, including Veteran's Assistance (VA), public health services, and WIC.

Veteran's Benefits

About six percent of the PLWH/A report VA benefits and less than one percent report receiving CHAMPUS, a form of VA Assistance for non-military personnel. Two out of five of the recipients of VA benefits report having no insurance.

Women, Infants and Children's Program (WIC)

WIC is the Special Supplemental Nutrition Program for Women, Infants and Children, a 100% federally funded program that provides nutritious food (via prescriptive vouchers), individual counseling, and health care referrals to high-risk, low-income (up to 185% of poverty) women and children up to the age of five. Less than one percent of all PLWH/A receive WIC, but nearly four percent of female PLWH/A receive this benefit.

Table 7-2 Entitlements and Benefits

	Total	Male	Female	Anglo	AfAm	Latino	MSM	MSM/ IDU	IDU	Hetero-sexual
SSDI	32.1%	33.1%	24.3%	46.4%	21.9%	12.2%	35.5%	29.0%	13.6%	29.0%
SSI	30.5%	30.5%	30.9%	30.7%	35.8%	25.8%	27.8%	50.4%	30.4%	32.9%
Long Term Disability.	25.3%	26.6%	14.6%	29.3%	26.7%	17.6%	6.5%	27.4%	26.9%	18.2%
Subsidized Housing	21.3%	21.8%	17.1%	25.1%	20.6%	14.9%	7.5%	20.1%	40.2%	16.0%
SDI	14.7%	14.7%	14.6%	19.6%	12.5%	5.6%	17.4%	16.5%	3.6%	13.7%
Food Stamps	12.4%	11.4%	21.3%	7.1%	20.0%	15.0%	37.1%	9.3%	19.3%	18.0%
General Assist.	9.0%	7.7%	19.6%	6.3%	15.4%	8.4%	5.9%	19.7%	16.1%	15.5%
Rent Supplement	8.6%	8.8%	7.0%	7.3%	5.4%	15.1%	0.0%	9.6%	3.5%	3.8%
VA Benefits	5.6%	6.3%	0.0%	9.4%	2.2%	1.0%	6.8%	0.0%	6.5%	0.0%
Retirement	4.7%	5.0%	1.5%	3.1%	7.7%	4.2%	16.3%	5.9%	0.0%	2.3%
Short Term Dis.	2.5%	2.2%	5.1%	4.0%	2.0%	0.0%	0.0%	2.3%	3.8%	3.6%
BIA	1.6%	1.8%	0.0%	3.1%	0.0%	0.0%	2.3%	0.0%	0.0%	0.0%
TANF/ CalWorks	1.5%	0.1%	12.7%	0.8%	3.5%	1.4%	0.0%	0.0%	0.0%	4.8%
Worker's Comp	1.0%	0.9%	2.3%	0.0%	1.2%	3.3%	0.0%	1.1%	0.0%	2.4%
DEFA	0.8%	0.7%	2.3%	1.1%	1.2%	0.0%	0.0%	0.0%	7.0%	2.4%
WIC	0.5%	0.1%	3.6%	0.2%	1.2%	0.5%	0.0%	0.0%	0.0%	3.6%
Life Ins. Payment	0.4%	0.0%	3.8%	0.0%	1.9%	0.0%	0.0%	0.0%	0.0%	2.4%
CHAMPUS	0.2%	0.0%	1.5%	0.0%	0.8%	0.0%	0.0%	0.0%	0.0%	1.8%

8. CARE NEEDS, UNMET NEEDS, GAPS, & SERVICES DELIVERY BARRIERS

Service Categorization

The 2003 Needs Assessment survey was responded to by 213 PLWH/A. The survey over-represented women and Latinos, but otherwise is relatively close to the profile of people living with HIV/AIDS in Long Beach. As was done as part of the LA EMA 2002 Needs Assessment, consumers were asked to rank their awareness of need, demand, and utilization for 33 services. Table 8-1 below shows the services included in the 2003 Consumer Survey (see Attachment 2). In general, this is the most current and complete estimate of stated need by PLWH/A.

Table 8-1 Needs Assessment Survey Services (2003)

MEDICAL CARE	**CASE MANAGEMENT**
Outpatient medical care	Medical case management
Medical care by a specialist	Case manager
Nutritional supplements	Employment assistance
Dental care	
Home health care	**HOUSING**
Hospice Services (In-home and residential)	Housing information services
Complementary care	Rental subsidy
Medication reimbursement	“Independent” housing
Assistance paying health insurance premiums	Residential housing/ group home
	Emergency/ transitional housing
TRANSPORTATION	
Van transportation	**FOOD**
Taxi/bus vouchers	Food pantry/ food bank
	Food vouchers
MENTAL HEALTH &	
SUBSTANCE ABUSE SERVICES	**OTHER SERVICES**
Residential mental health services	Prevention information and education
Individual or groups mental health therapy	Emergency financial assistance
Peer counseling	Legal services
Outpatient substance abuse treatment/counseling	Adult day care
24 hr residential substance abuse counseling	Day care
Detox and / or methadone maintenance	

Most Needed Services

For each of the 33 service categories shown in Table 8-1 PLWH/A were asked if they "needed the service in the past year" (see Q. 38 in the 2003 Needs Assessment Survey).

Top Rated Service Needs

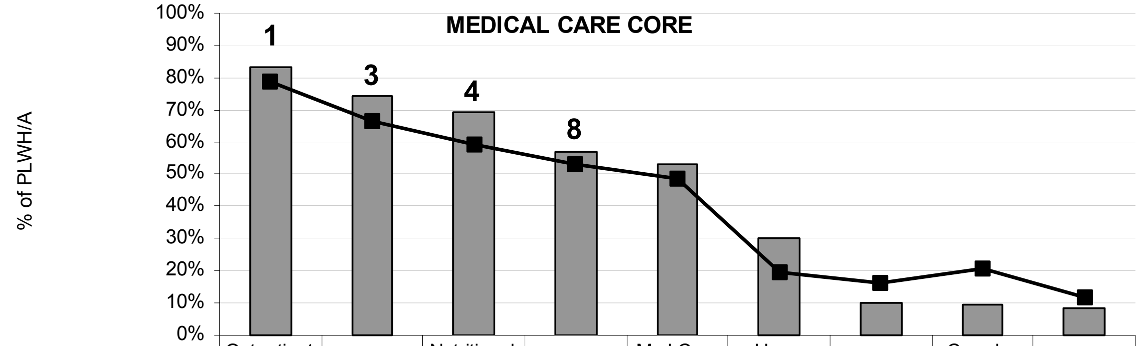
The graph is presented by the seven major service categories in Table 8-1. Within the major categories, services are ranked by the percentage of PLWH/A who report they needed the service in the past year. The numbers on top of some bars represent the ranking of the top ten service categories, regardless of their category. The solid line in the graphs indicates the percentage of PLWH/A from LAC who say they need the service.

Figure 8-1 shows that:

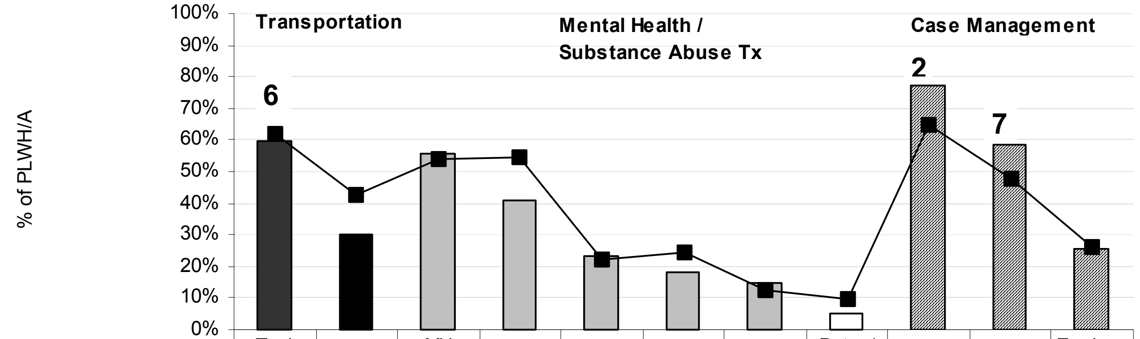
- Outpatient medical care (83%) and case management (78%) are the services that PLWH/A in Long Beach perceive they need the most.
- Overall PLWH/A in Long Beach and LAC rank services similarly, although the rank orders within category differ. A slightly larger percentage of Long Beach PLWH/A tend to say they need case management and medical services, while those in LAC are more likely to report a need for wrap around services.
- Four of the top ten most need 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%). In LA County, PLWH/A also ranked outpatient medical care as their number one need.
- Dental care was ranked the third highest need in Long Beach and second highest need in LAC.
- Case management was ranked second in Long Beach and fourth in LAC.
- Medical case management (58%) was ranked seventh in Long Beach but was not named among the most needed services in LAC.
- Taxi vouchers and bus tokens are the sixth most needed service for PLWH/A in Long Beach while LAC PLWH/A ranked this service fifth.
- Independent housing was ranked as the fifth most needed service by PLWH/A in Long Beach, with 61% of the PLWH/A reporting needing the service in the past year. This is similar to the 61% who ranked it as their sixth most important need in LAC.
- After independent housing, over 50% of Long Beach PLWH/A say they need housing information, and over 40% need rental subsidies.
- Two out of the three food services are among the top ten service needs of PWLH/A in Long Beach. More than 55% of the PLWH/A feel they need food pantry services and food vouchers. PLWH/A in LA County ranked food services higher than PLWH/A in Long Beach, with food pantry services being their third most import need and food vouchers being the seventh ranked need.

- Although mental health and substance abuse services are not ranked among the top services needed by PLWH/A in Long Beach (or LAC), over half or the participants said they needed mental health group or individual counseling. Substance abuse treatment and counseling services tend to be among the lowest ranked services by PLWH/A in Long Beach with less than one quarter of the PLWH/A stating they needed the service in the past year.
- Emergency financial assistance is the highest ranked service among the “other service” category with close to half of the PLWH/A reporting it as a need in the past year. However it did not make the top ten service needs in either LAC.
- Adult day care and children’s day care are the lowest ranked service need.

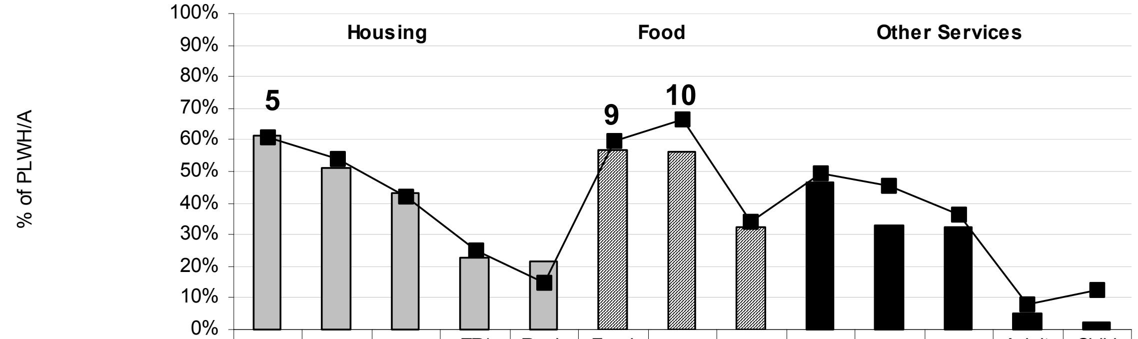
Figure 8-1 Ranked Service Needs



	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%

Top-Rated Service Needs – Qualitative Comments

Medical Care

A Latina IDU feels that there needs to be a better system of specialized HIV care. She feels that there is a need for a better way to remind patients of their appointments and making one location for all HIV-services. She says, *"I think, it's like, so many people are infected and it's just one hospital…with many people. I think if you go to a place that specializes in that, I think it would be better. Sometimes the appointments, I forget my appointments…I forget sometimes what year I was born...so many drugs that I've used...I forget my appointments. They don't really send me the appointments when...or they don't give me a call to tell me."*

A substance using Native American woman talks about her need to switch medical care provider. She says "*I recently switched my care over to the [name of agency], because it was meeting the needs that my other care program could not meet. My other planning, it wasn't that the doctor was no good or that the nurses were no good, but that the referral system took so damn long I was afraid I was going to die before I got treated..."*

Another substance using female also explains this by saying *"only because it's a county clinic it's caught up in all that county crap. The doctors…the new doctor they have is very good, he respects all his patients, but like everything else he's stuck in that county…"*

Dental Care

An Anglo male in discussing his need for dental care says, *"I've been looking for a good dental program…just going on six months. Social security has a dental program, but it does not cover the kind of dental I need. The other agency that I was told…they had it. One that's called [name of agency] but I haven't been able to find an office..."*

Transportation

Transportation services are critical for PLWH/A to be able to access care. An Anglo MSM discusses his frustration with the existing transportation provider. He says, *"Transportation using [name of agency] is horrible!! They are always late and long waits on phone to set up rides."*

Housing

An Anglo MSM expresses the needs for housing, particularly Section 8 housing. He says, *"For our services, they got to do something with Section 8 housing. In LA at one time, their housing authority had what was called the Fast Track program, which was strictly for HIV positive people, which they had even stopped. But Long Beach, the Section 8 housing, just the registration to get in the lottery has been closed for over five years. I can't even register and there is no housing for HIV positive people."*

Qualitative responses were also obtained from open-ended survey responses. In expressing his need for housing an African American MSM writes in his survey, *"I personally would like to see more housing available for HIV positive people and more housing available through the City of Long Beach and more assistance for utilities."*

Prevention Information

While some PLWH/A have lived with HIV for many years, there is still a perceived need for prevention education. An MSM of color talks about the need to continue to teach others. He says, *"...we need groups that give us more information to be able to give other people guidance in a more professional manner then just handing out a bunch of pills or this and that. We need discussions to teach us how to teach other people."*

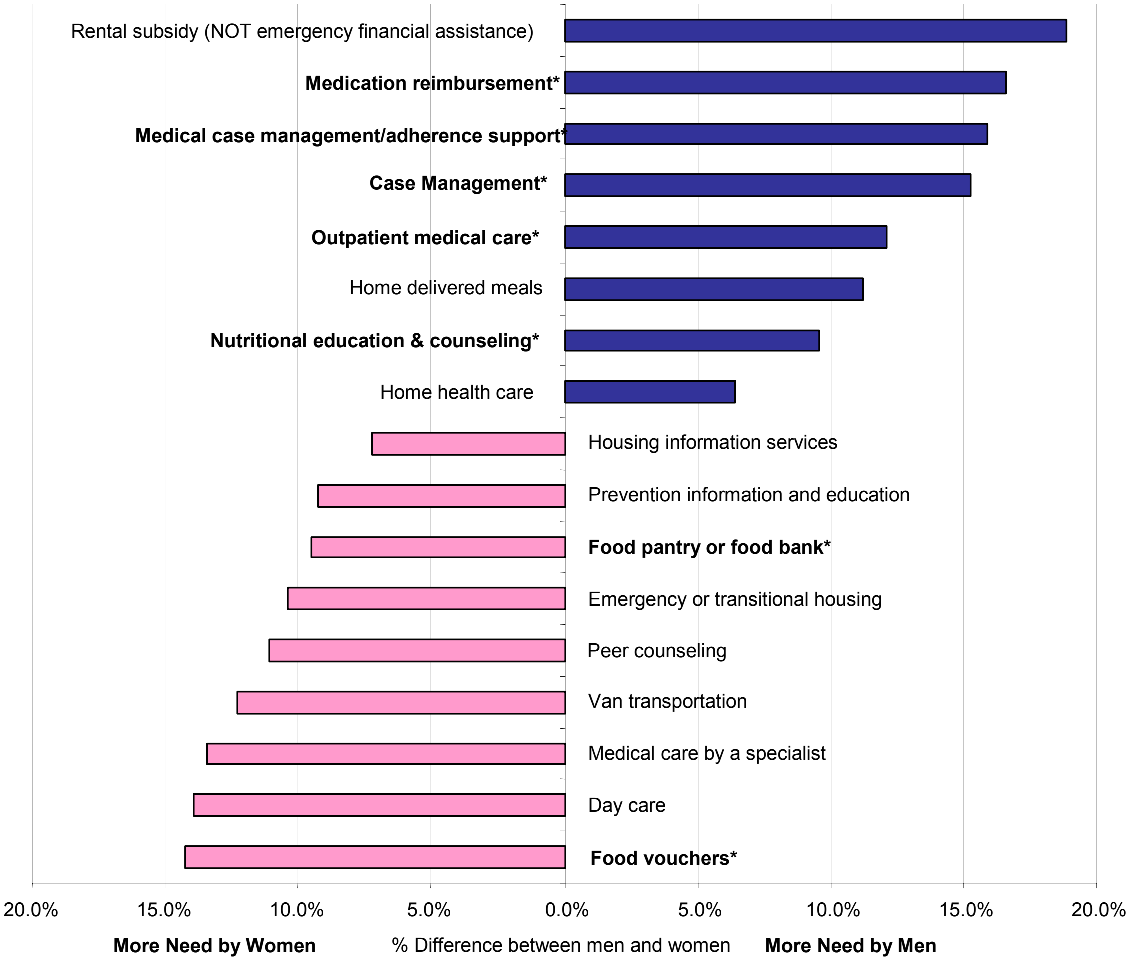
Top Service Needs: Gender Differences

Although the top three needs for women and men are the same – outpatient care, case management, and dental care -- the 2003 Needs Assessment Survey indicates large differences in need by gender (see Figure 8-2).

- The largest differences between men and women are the expressed need by men for medication reimbursement and rent subsidy. This is probably because women are more likely to be insured or receive other benefits outside/beyond of the Ryan White CARE Act.
- Women report higher need than men for wrap around services particularly food and day care, but also for van transportation, peer counseling, emergency transitional housing, prevention information and housing information.
- Women indicate a greater need for medical specialists.
- Men indicate a higher need than women for medical, medication reimbursement, and case management services.

Figure 8-2 Service Needs Differences by Gender

Bold are top ten overall needs



Gender differences – Qualitative Comments

Food Vouchers

Consistent with the quantitative findings an IDU African American woman discussed her need for food vouchers. She says, "*The Food-for-less Food vouchers and stuff; they have gotten very tight with that. I'm on a budget, too, light, gas, rent, cable. I mean, hell, every time you ask them for a damned voucher they always say we don't have it you know, and the other guy come out with $50.*"

Nutrition Education and Counseling

Men express a greater need for nutrition and wellness programs. An Anglo heterosexual male would like greater access to programs. He says, *"More body mind experience workshops are needed; example: nutrition-vitamins, exercise-wellness classes."*

Day care

An Anglo 25 yr old woman diagnosed in 1997 talks about her need for childcare as follows, "*The only reason I put her in childcare is because I know the people there. They go to my church and I don't have to worry about them mistreating her. They've been friends with my family for years and they cut her childcare…They said it's 'cause other families let their kids go five days a week and charging them three days.*"

Prevention Information

An Anglo heterosexual woman feels that there is a need for more social marketing campaigns like "HIV stops with me", that is geared to women. In her opinion, "*These types of advertising create a sense of "normalcy" to being HIV+ and makes a strong impact on the positive community by reducing stigma.*"

Peer Counseling

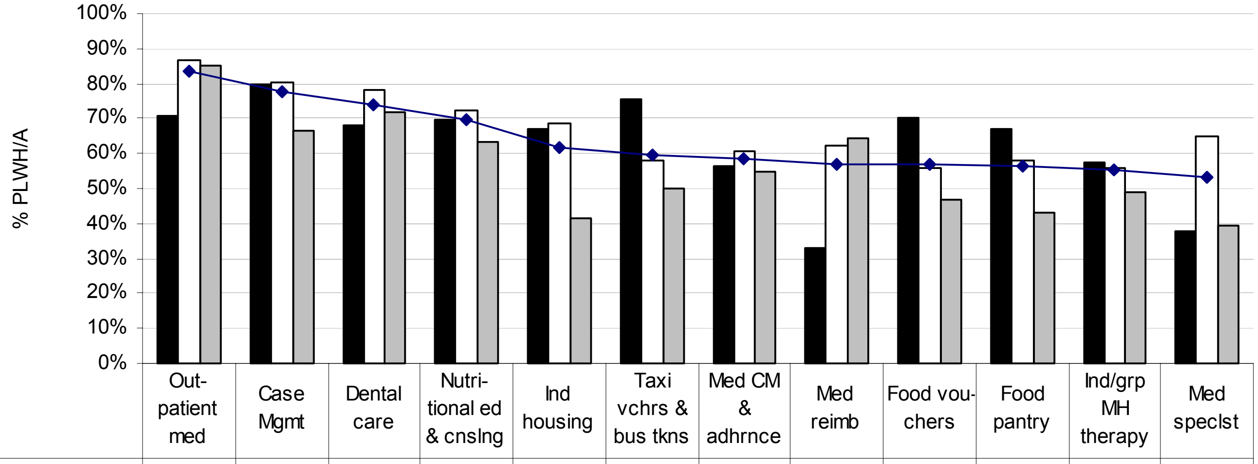
An Anglo heterosexual woman describes some of the different issues she's faced with services. She writes in her survey, *"Budget cuts, services not as compassionate, doctors and people assume you are making problems up, afraid of loosing Medical, SSI and SSDI are horrible to work through, no housing or bill benefits for those who work or are not bellow poverty level, no hetero-support groups, too much emphasis is on gay community, not enough services in LBC too far in LA."*

Top Service Needs: Ethnic/Racial Differences

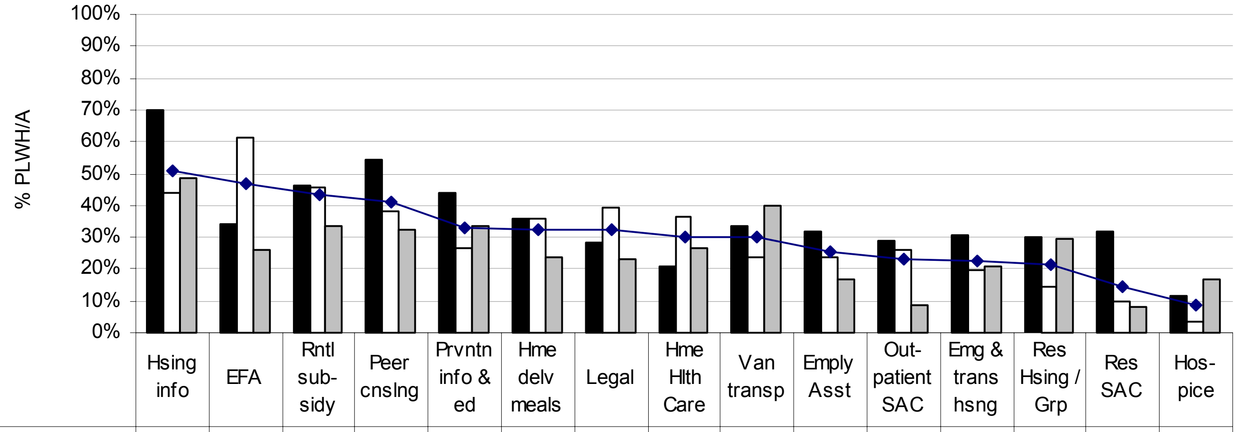
Figure 8-3 shows the ethnic/racial differences among the services, ranked by the needs of the total population of PLWH/A. In general, Anglos and Latinos report higher needs for medical services, while African Americans report higher needs for food, housing, and transportation services. These expressed needs may reflect the lower socio-economic status of the communities of color in which basic needs such as food and shelter are most important.

- The top three expressed needs for African American PLWH/A are case management (80%), taxi and bus tokens (75%), and outpatient medical care tied with food vouchers (71%).
- African Americans report a substantially higher need than Anglos or Latinos for taxi vouchers and bus tokens, food vouchers and food pantry, housing information, peer counseling, prevention information, emergency and transitional housing, and residential substance abuse services.
- The top three needs of Anglos living with HIV/AIDS are outpatient medical care (87%), case management (81%), and dental care (78%). Anglos also state a substantially higher need for medical specialists, emergency financial assistance, legal and home health care.
- Anglos and African Americans tend to report higher needs for case management, nutritional education, independent housing, food pantry, and rental subsidies than Latinos.
- Latinos' top three needs mirror those of Anglos with a shift in rank among the top three services. They are medical care (85%), dental care (72%), and case management (67%).
- Latinos tend to report greater needs for medication reimbursement, van transportation, assistance paying insurance premiums and day care services than Anglos or African Americans.
- In general Latinos indicate a lower need for all services. This likely reason is that have lower expectations and the perception of lack of eligibility.

Figure 8-3 Top Service Needs by Ethnicity



	Out-patient med	Case Mgmt	Dental care	Nutri-tional ed & cnslng	Ind housing	Taxi vchrs & bus tkns	Med CM & adhrnce	Med reimb	Food vou-chers	Food pantry	Ind/grp MH therapy	Med speclst
■ African Am	70.6%	80.0%	68.2%	69.6%	66.8%	75.4%	56.5%	33.1%	70.5%	67.2%	57.5%	37.6%
□ Anglo	86.9%	80.5%	77.9%	72.4%	68.6%	57.9%	60.9%	62.4%	55.7%	57.8%	55.9%	64.7%
▨ Latino	85.1%	66.6%	71.9%	63.2%	41.5%	50.2%	54.6%	64.5%	46.6%	42.8%	48.9%	39.3%
◆ TOTAL	83.3%	77.5%	74.1%	69.5%	61.4%	59.4%	58.4%	57.0%	56.8%	56.4%	55.5%	53.0%



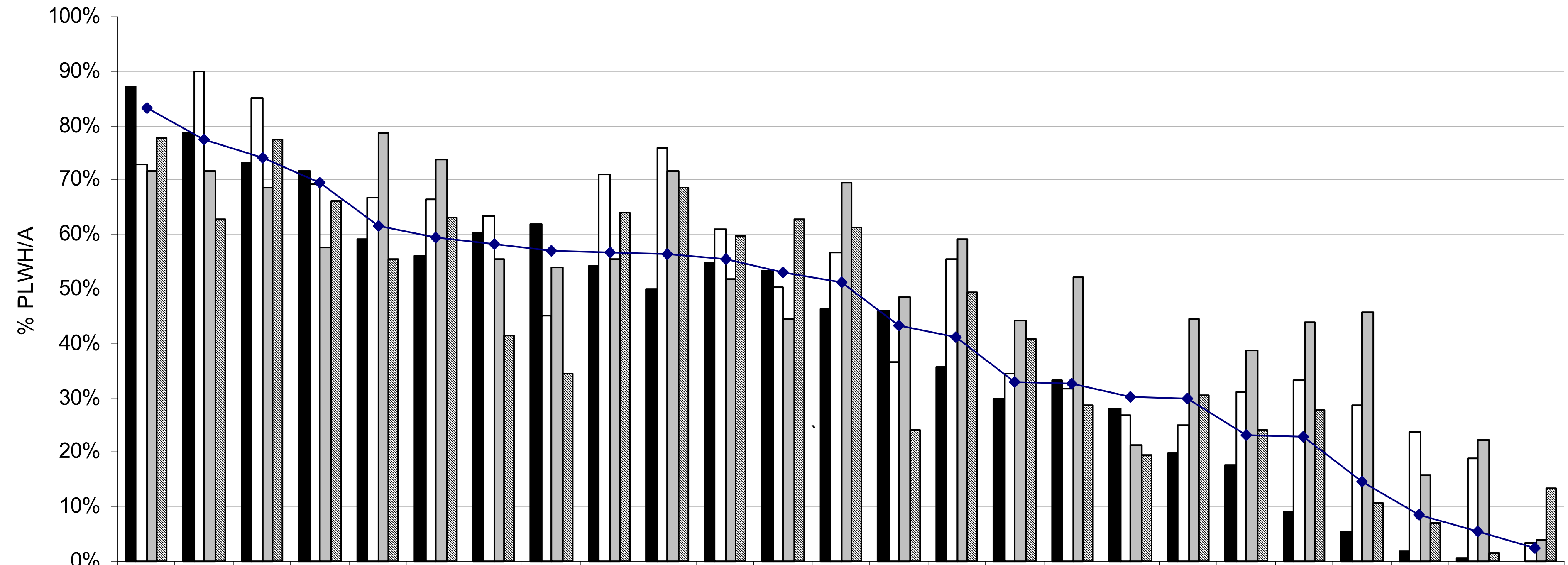
	Hsing info	EFA	Rntl sub-sidy	Peer cnslng	Prvntn info & ed	Hme delv meals	Legal	Hme Hlth Care	Van transp	Emply Asst	Out-patient SAC	Emg & trans hsng	Res Hsing / Grp	Res SAC	Hos-pice
■ African Am	70.0%	34.2%	46.2%	54.3%	44.1%	36.0%	28.0%	21.0%	33.4%	31.9%	28.6%	30.8%	29.8%	31.8%	11.4%
□ Anglo	43.7%	61.4%	45.5%	38.3%	26.7%	35.7%	39.1%	36.6%	23.8%	23.8%	26.2%	19.7%	14.7%	9.9%	3.3%
▨ Latino	48.5%	25.9%	33.8%	32.5%	33.3%	23.8%	22.9%	26.6%	40.1%	17.0%	8.7%	20.7%	29.3%	7.9%	17.0%
◆ TOTAL	51.2%	46.7%	43.4%	41.1%	32.9%	32.5%	32.2%	30.2%	29.9%	25.4%	23.1%	22.7%	21.6%	14.7%	8.4%

Top Service Needs: Risk Group Differences

Figure 8-4 on the following page shows the risk group differences among the top ranked services. Overall, IDUs and MSM/IDU appear to have a greater need for a large number of wrap around services than other risk groups.

- The top three needs for MSM PLWH/A are medical care (87%), case management (79%), and dental care (73%), with the highest need of any risk group for outpatient care and medication reimbursement. MSM express a lower need for the remaining services than other risk groups.
- MSM/IDU report higher needs than other PLWH/A for 21 out of the 33 services. Their top three needs are case management (90%), dental care (85%), and food pantry (76%).
- Overall, IDU PLWH/A express high need for services. Their expressed need for 12 out of 33 services is more than 10% higher than the average need reported by other PLWH/A. Their top need is independent housing (79%), which is the fifth ranked service among all PLWH/A (61%). They are also state a greater need for housing information (70%) than other risk groups.
- The 2nd most important need for IDUs is taxi vouchers (74%) followed by case management, food pantry, and outpatient medical care (all tied at 72%).
- While the absolute need is relatively low, IDUs report a greater need for all substance programs than other risk groups.
- Notably, IDUs report the lowest need for outpatient medical care than any of the other risk groups.
- The top needs for heterosexual PLWH/A are medical care and dental care (both at 78%), followed by food pantry (69%) and nutritional education and counseling (66%). They have a higher need for medical care specialists probably due to the higher proportion of women represented among heterosexuals. Overall, heterosexuals report the lowest needs. This may be because the majority are women who may go outside of the Ryan White Care system for services.

Figure 8-4 Top Service Needs by Risk Group



	Out-patient med	Case Mgmt	Dental care	Nutritional ed & cnslng	Ind housing	Taxi vchrs & bus tkns	Med CM & adhrnce	Med reimb	Food vouchers	Food pantry	Ind/grp MH therapy	Med speclst	Hsing info	Rntl subsidy	Peer cnslng	Prvntn info & ed	Hme delv meals	Hme Hlth Care	Van transp	Out-patient SAC	Emg & trans hsng	Res SAC	Hospice	Detox /meth matnce	Day care
■ MSM	87.2%	78.7%	73.2%	71.7%	59.0%	56.0%	60.3%	61.7%	54.2%	50.1%	54.9%	53.4%	46.4%	45.9%	35.8%	30.0%	33.2%	28.2%	19.8%	17.7%	9.1%	5.6%	1.7%	0.7%	
□ MSM IDU	72.8%	89.9%	85.0%	69.1%	66.9%	66.4%	63.5%	45.1%	70.9%	75.8%	60.9%	50.4%	56.8%	36.6%	55.5%	34.4%	31.7%	26.9%	25.1%	31.0%	33.1%	28.7%	23.8%	19.0%	3.5%
■ IDU	71.5%	71.8%	68.7%	57.7%	78.6%	73.9%	55.5%	54.0%	55.4%	71.6%	51.8%	44.5%	69.5%	48.4%	59.0%	44.2%	52.0%	21.2%	44.5%	38.7%	43.8%	45.6%	15.9%	22.3%	3.9%
▨ Hetero	77.8%	62.9%	77.5%	66.1%	55.4%	63.2%	41.6%	34.4%	63.9%	68.7%	59.9%	62.7%	61.3%	24.2%	49.4%	40.8%	28.7%	19.4%	30.5%	24.1%	27.7%	10.6%	6.9%	1.4%	13.5%
◆ TOTAL	83.3%	77.5%	74.1%	69.5%	61.4%	59.4%	58.4%	57.0%	56.8%	56.4%	55.5%	53.0%	51.2%	43.4%	41.1%	32.9%	32.5%	30.2%	29.9%	23.1%	22.7%	14.7%	8.4%	5.4%	2.4%

Risk Group Differences – Qualitative Comments

As the epidemic shifts to different populations, PLWH/A are aware of the changing needs of their peers. An Anglo MSM expresses this as follows, "*They miss the boat as far as being inclusive, as in this is everybody's problem. 'Cause people still think its IV drug users and gay men. You know, they need to see women. They need to see kids."*

Housing Services

Housing is a concern for everyone. However, substance users face other challenges. An Anglo IDU male explains, *"My concern is housing. What am I gonna do about housing? Where am I gonna be? Being taken away from my support system, being taken out of that and moving to Bellflower or moving to where ever they made me move to due to Section 8 or whatever was it's really, really kind of frightening. The transition from the drug program to the street was really frightening. How can I do this, I have no idea. And I used drugs for 24 years; I was homeless. I knew nothing else but dope…my problem is this thing about housing and support unit should be addressed a little earlier than just a couple months before you leave."*

Similarly for an Anglo IDU male, "*My only problem with services has been in housing. Since having to leave my job and being on disability, I can't afford the housing that I live in."*

Substance Abuse Treatment and Counseling

Substance abuse treatment and counseling are among the lowest ranked services, however, for the 47% of the PLWH/A who are currently using substances, substance abuse programs are still important. For example, an African American woman tells her story, "*I wanted to kill the person I was infected by. I was infected by heterosexual relationship; I had a relationship for 11 years. By just not paying attention is how I got infected. But I have no symptoms. I never took medicine. Undetectable. Been like that for almost six years...Just doing what I need to do...'Cause I know if I get involve in any alcohol or drugs it's over. I'm gonna die. So I just stay focused."*

Service Gaps

Need, Demand, and Utilization of Services

Needs assessment participants indicated whether they had asked for each of the 33 services in the past year, and whether they received the service. (See question 38, Attachment 2). As shown in Figure 8-5, expressed need, reported demand (asking for a service) and reported utilization (receiving a service) follow a similar, but not identical pattern. The difference between the percentage reporting a perceived need for a service and asking for that services, and asking for service and receiving it indicate two types of gaps in services.

- First, the difference between what services are needed and what services are asked for (“need-ask gap”) indicates a gap between what PLWH/A believe they need and their expectation of receiving a service. PLWH/A may not ask because they know or perceive that they are ineligible, feel that they have no access, or do not know who to ask for in order to obtain the service. These barriers are explored later in the report.
- Second, the difference between what is asked for and what is received, “unmet demand”, reflects the misperception of the consumer about their eligibility for a service and/or the system’s lack of capacity to provide requested services.

These differences are shown in Figure 8-6. By analyzing Figure 8-5 with Figure 8-6 the gaps can be identified for the services with the greatest perceived needed. Overall, the demand for services tends to follow reported need, however, the need-ask gap is rather high with more than a quarter of the services having a difference of 10% or more. Services with a large unmet need (expressed need minus reported demand) are independent housing (13%), legal services (13%), food vouchers, rental subsidy, dental care, and nutritional education (all at 12%).

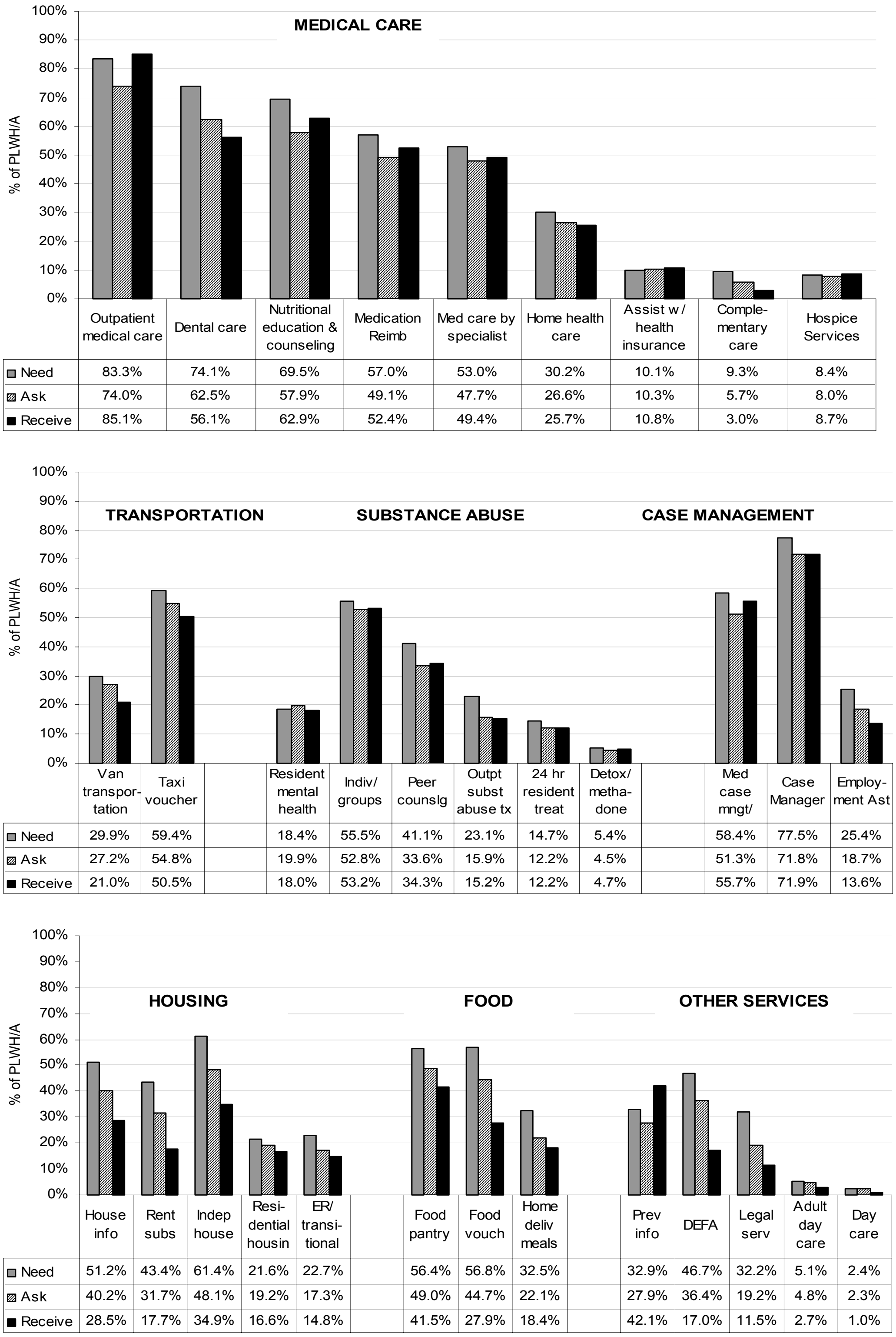
The greatest ask-perceived gap is for emergency financial assistance, food vouchers, rental subsidies, independent housing, and housing information.

- Outpatient Medical Care, the service with the greatest perceived need, is asked for somewhat less that it is needed, probably because it is provided without explicitly asking for it. This is consistent with utilization being even higher than demand. Also, perhaps indicative of improved health status, PLWH/A don’t feel the need to be monitored as often as is the protocol. PLWH/A also feel they are receiving far more prevention information than they need. This suggests that information has to be targeted with meaningful messages to PLWH/A. General messages or highly redundant messages are likely to lose their value.
- Housing services, including independent housing, rent subsidies, and housing information, have fairly high perceived need. They also have the highest “need-ask” and “ask-receive” gaps, with independent housing have the largest “need-ask” gap. As is clear by the survey and focus group responses the demand for quality housing far exceeds the systems capacity to provide it.
- Food vouchers and food pantry are the ninth and tenth most need services. Food vouchers have the next to the largest “need-ask” and “ask-receive” gaps, with over 15% of those who ask for them not receiving them, and about 12% needing them and not asking for them. Although home delivered meals are needed by considerably fewer PLWH/A, there is a

considerable “need-ask” gap. This may be due to the awareness PLWH/A have that they would not be eligible for the service. With 97% of the sample living 300% below poverty levels, PLWH/A struggle to make ends meet and put food on their table. In focus group discussion, PLWH/A emphatically discuss the perceived increase in shortage of food banks.

- Nutritional counseling, medical case management, medication reimbursement, and medical specialists are often received at the care provider, and they follow the same pattern. All are received more than asked for, but there is a greater perceived need than reported demand.
- Nutritional education and counseling has one of the largest “need-ask” gaps.
- Dental care has a moderate “need-ask” gap. There is a smaller but significant “ask-received” gap.
- PLWH/A report needing the other medical services considerably less and there are few gaps in these medical services. More person need than report receiving complementary care, but sample sizes are not large enough to confirm this trend.
- Case Management, the service with the second highest reported need, has a small “need-ask” gap with just over 5% more PLWH/A needing it than asking for it. There is no “ask-received” gap.
- Taxi vouchers and bus tokens have the sixth highest need. While gaps exist they are relatively low, with fewer than 4% saying they ask for it and don’t receive it. Based on focus groups, many of those receiving the service, may not find it adequate. There is a slightly larger ask-receive gap for van transportation.
- Even substance users do not rank mental health and substance abuse counseling among the most needed services. However, more PLWH/A perceive a need than ask for substance abuse services than ask for it, but there is just a small reported gap between those who ask for it and receive it.
- In terms of ask-receive gaps, the largest gap is in emergency financial assistance. Almost 20% of the PLWH/A report asking but not receiving it. Just fewer than 10% say they need it but don’t ask for it.
- Legal services have just over 30% of PLWH/A saying they need it, and have a relatively large “need-ask” gap suggesting that people don’t feel they are eligible or don’t know who to ask for services.
- The small gaps reported in services – particularly those in the core primary care system show that the care system is addressing important needs of PLWH/A.

Figure 8-5 Consumer Need, Demand, & Utilization

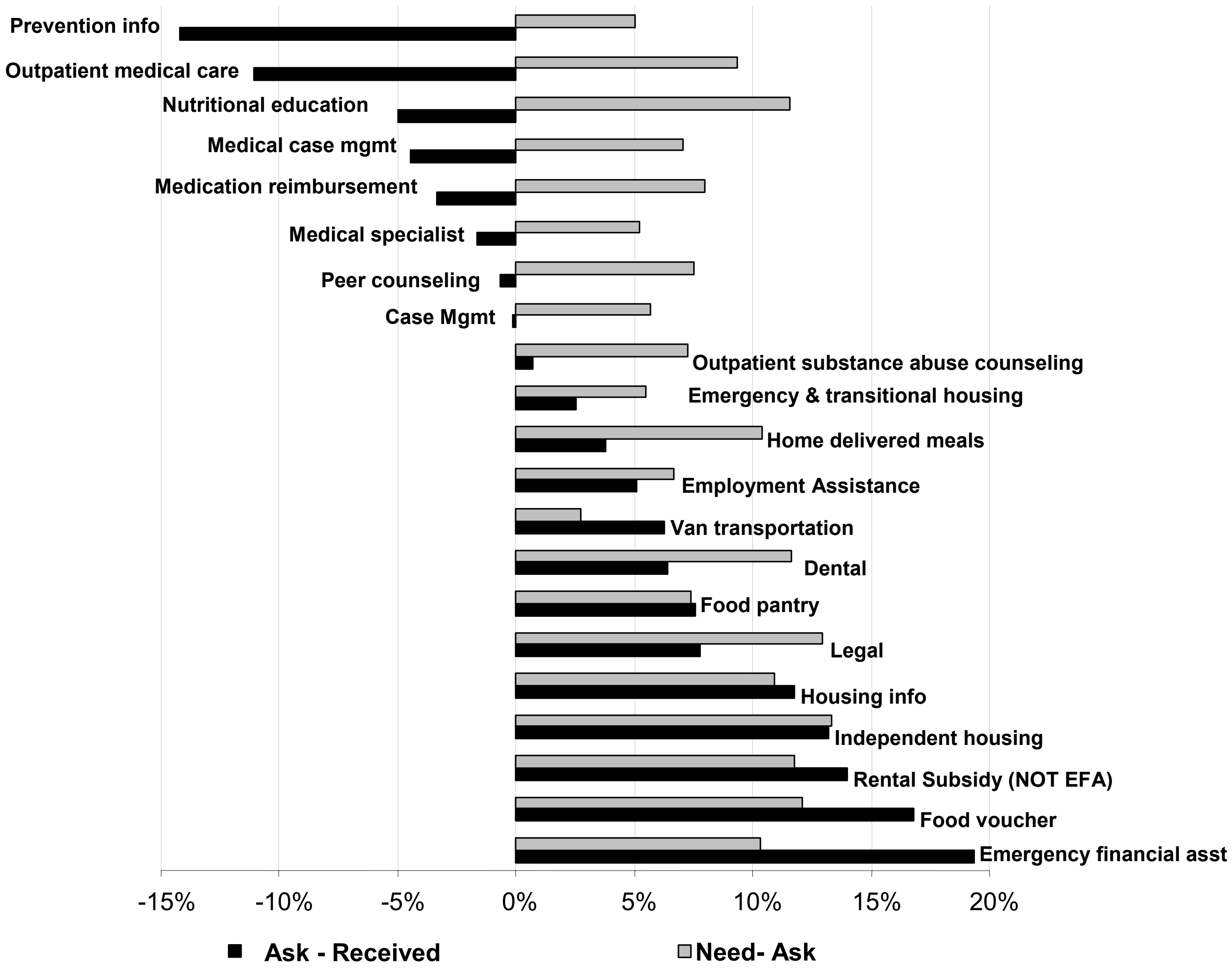


	Outpatient medical care	Dental care	Nutritional education & counseling	Medication Reimb	Med care by specialist	Home health care	Assist w / health insurance	Comple-mentary care	Hospice Services
□ Need	83.3%	74.1%	69.5%	57.0%	53.0%	30.2%	10.1%	9.3%	8.4%
▨ Ask	74.0%	62.5%	57.9%	49.1%	47.7%	26.6%	10.3%	5.7%	8.0%
■ Receive	85.1%	56.1%	62.9%	52.4%	49.4%	25.7%	10.8%	3.0%	8.7%

	Van transpor-tation	Taxi voucher		Resident mental health	Indiv/ groups	Peer counslg	Outpt subst abuse tx	24 hr resident treat	Detox/ metha-done		Med case mngt/	Case Manager	Employ-ment Ast
□ Need	29.9%	59.4%		18.4%	55.5%	41.1%	23.1%	14.7%	5.4%		58.4%	77.5%	25.4%
▨ Ask	27.2%	54.8%		19.9%	52.8%	33.6%	15.9%	12.2%	4.5%		51.3%	71.8%	18.7%
■ Receive	21.0%	50.5%		18.0%	53.2%	34.3%	15.2%	12.2%	4.7%		55.7%	71.9%	13.6%

	House info	Rent subs	Indep house	Resi-dential housin	ER/ transi-tional		Food pantry	Food vouch	Home deliv meals		Prev info	DEFA	Legal serv	Adult day care	Day care
□ Need	51.2%	43.4%	61.4%	21.6%	22.7%		56.4%	56.8%	32.5%		32.9%	46.7%	32.2%	5.1%	2.4%
▨ Ask	40.2%	31.7%	48.1%	19.2%	17.3%		49.0%	44.7%	22.1%		27.9%	36.4%	19.2%	4.8%	2.3%
■ Receive	28.5%	17.7%	34.9%	16.6%	14.8%		41.5%	27.9%	18.4%		42.1%	17.0%	11.5%	2.7%	1.0%

Figure 8-6 Service Gaps



Service Delivery Barriers

The PLWH/A participating in the survey were asked about barriers to care services in question 39 of the survey (see Attachment 2). They were asked to rank 30 different potential problems. First they indicated whether they were a problem or not, then, if it was a problem, rated it on a scale ranging from “not a problem” to a “very big problem.” These barriers were not “linked” to a particular service category. As shown in Table 8-2, the thirty potential problems can be classified into the more general categories of “organizational”, “structural”, or “individual” 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 knowledge and well-being barriers. For the overall category of individual barriers, it is similar to LAC, although as shown later, there are some specific items that are different.
- 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. Structural “access” barriers have to do with lack of transportation, access to specialists or lack of family-oriented services. These are mentioned less frequently than “rules and regulations” but still about 26% of PLWH/A registered they had a problem with these types of barriers. Notably PLWH/A has fewer problems and barriers with structural problems than all PLWH/A in LAC.
- 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. On average, more than 35% of the sample reported experiencing this type of barrier. 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.

Table 8-2 Types of Barriers

1=Very small, 2=Small, 3=Moderate, 4=Big, 5=Very big **STRUCTURAL**	**% WITH PROBLEM**	**% WITH BIG PROBLEM**	**AVERAGE BARRIER SCORE**
Rules and Regulations			
1. The amount of time I had to wait to get an appointment or to see someone.	56.6%	39.6%	3.0
2. My ability to find my way through the system.	50.0%	34.9%	2.9
3. There was too much paperwork or red tape.	42.0%	40.6%	3.2
4. My lack of, or inadequate, insurance coverage.	39.3%	44.3%	3.4
5. I was not eligible for the service.	46.0%	43.4%	3.2
6. There are too many rules and regulations.	42.2%	38.7%	3.0
7. I can't afford one or more of the services.	44.6%	30.7%	2.9
Access			
8. No transportation.	32.9%	38.4%	3.0
9. There was no specialist to provide the care I needed.	35.7%	19.6%	2.3
10. I have been denied or have been afraid to seek services due to a criminal justice matter	26.2%	26.0%	2.6
11. No childcare.	15.2%	30.0%	2.3
12. I have been terminated or suspended from seeking services.	21.3%	17.2%	2.0
ORGANIZATIONAL			
Provider Sensitivity			
13. Sensitivity of the organization and person providing services to me regarding my issues and concerns.	46.5%	32.7%	3.0
14. The organization providing the service made me feel like a number.	40.5%	31.2%	3.0
15. Discrimination I experienced by the persons or organization providing the services.	40.1%	22.8%	2.7
16. The people providing services to me are not helpful.	33.5%	25.4%	2.5
17. Fear of my HIV or AIDS status being found out by others – lack of confidentiality.	37.1%	40.4%	3.0
18. Fear that I would be reported to immigration or other authorities.	14.6%	44.1%	2.9
Provider Expertise			
19. Experience or expertise of the person providing services to me.	46.7%	26.2%	2.9
20. The organization did not provide the right referrals to the services I needed.	38.0%	21.0%	2.5
21. I do not get along with the people providing services.	31.6%	17.0%	2.2
INDIVIDUAL			
Knowledge			
22. Not knowing that service or treatment was available to me	55.2%	45.5%	3.5
23. Not knowing location of the services.	60.8%	36.8%	3.1
24. Not knowing who to ask for help.	56.2%	46.7%	3.2
25. Not knowing what medical services I need to treat my HIV infection or AIDS.	46.6%	24.7%	2.5
26. Not understanding instructions for obtaining service or treatment	46.0%	28.3%	2.8
27. My ability to communicate or interact with the service provider.	32.5%	30.0%	2.9
Well-Being			
28. My physical health has not allowed me to get to the place where the service is provided	52.6%	31.2%	2.8
29. My state of mind or mental ability to deal with treatment.	60.0%	34.9%	2.9
30. I not believe HIV/AIDS is a problem for me that requires assistance (denial)	51.2%	29.6%	2.8

Figure 8-7 graphs the three types of barriers. The bar represents the proportion of PLWH/A who say each item asked is a barrier. The line shows the size of a barrier, ranging from a very small barrier to a very big barrier. For example, for structural barriers, between 50 and 60% report that waiting for an appointment is a barriers. On a five-point scale, the size of the barrier is moderate.

Individual Barriers

Starting with the individual “knowledge” barriers the bottom of Figure 8-7:

- Between 55% and 60% of the PLWH/A say they have had a problem in not knowing where to go for services, knowing who to ask to get services, and not knowing about the appropriate treatments. Over 40% said that they did not know the medical services and did not understand the instructions for the medication. While high, a smaller percentage of PLWH/A had “knowledge” barriers than PLWH/A in LAC.
- The size of the barriers ranged from moderate to big for ‘not knowing about treatments’ and small to moderate for ‘understanding instructions’. While fewer Long Beach PLWH/A had problems than PLWH/A in the LA EMA, those that did had bigger problems.
- ‘Well-being’ individual barriers are particularly high considering participants are reflecting on their own disabilities. Surprisingly, 60% of the sample say that their own state of mind or mental ability to deal have prevented them from getting services. This would most probably be connected to medical care. More than half of the PLWH/A also felt that their own sense of denial was a barrier when seeking services. For those naming these ‘well-being’ barriers, they were moderate barriers. Fewer PLWH/A names these barriers than PLWH/A in LAC, and those naming them had about the same level of problem with them.

Structural Barriers

The top of Figure 8-7 shows the different structural barriers.

- Among the ‘rules and regulations’ structural barriers, over 45% think that there are structural problems that prevent or inhibit them from getting a service but they rate the problems to be moderate. This compares to about 50% of the PLWH/A in LAC naming ‘rules and regulations’ barriers.
- The largest problems faced by PLWH/A appear to be 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%).
- While less than 40% of PLWH/A reported lack of or inadequate insurance coverage as a barrier, those who mentioned it rated it as a moderate to high barrier – higher than any other barrier in mentioned.
- These rules and regulations barriers were much smaller than PLWH/A in LAC, but those with barrier in Long Beach rated them as bigger than PLWH/A in LAC.
- Relatively few PLWH/A in Long Beach named “access” to care as a problem. The largest access barrier was a lack of access to a specialist (36%). Thirty-three percent (33%) felt that not having transportation was a problem. Only transportation was a moderate barrier, while the other access barriers were considered small barriers. Proportionately more PLWH/A had access barriers in LAC, particularly transportation barriers.

Organizational Barriers

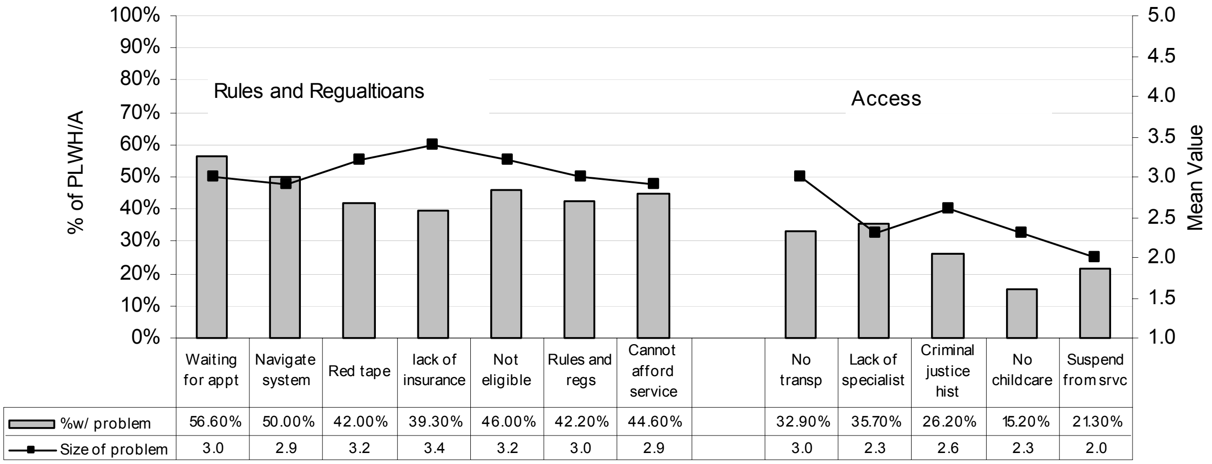
In Figure 8-7, organizational barriers were ranked lowest by PLWH/A in Long Beach, suggesting that actions by service providers are not the main reasons PLWH/A do not access care. Still:

- Among 'provider sensitivity' organizational barriers, 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. Fifteen percent of PLWH/A report the fear of being reported to authorities as a problem. This is a greater problem among PLWH/A who are born outside the U.S., with up to 50% of the Mexico born and 35% of the South and Central America PLWH/A expressing this concern. Recently incarcerated PLWH/A (20%) also had this concern. These barriers were rated as a moderate.
- Among 'provider expertise' organizational barriers, 47% say the lack of experience or expertise of the person providing services can be a problem. Based on feedback from consumers, this may be due to high staff turnover over in case management programs. About a third felt referrals were a problem, and for them it was a small to moderate problem.
- As with individual and structural barriers, proportionately fewer Long Beach PLWH/A named organizational barrier than PLWH/A.

Figure 8-7 Barriers to Services

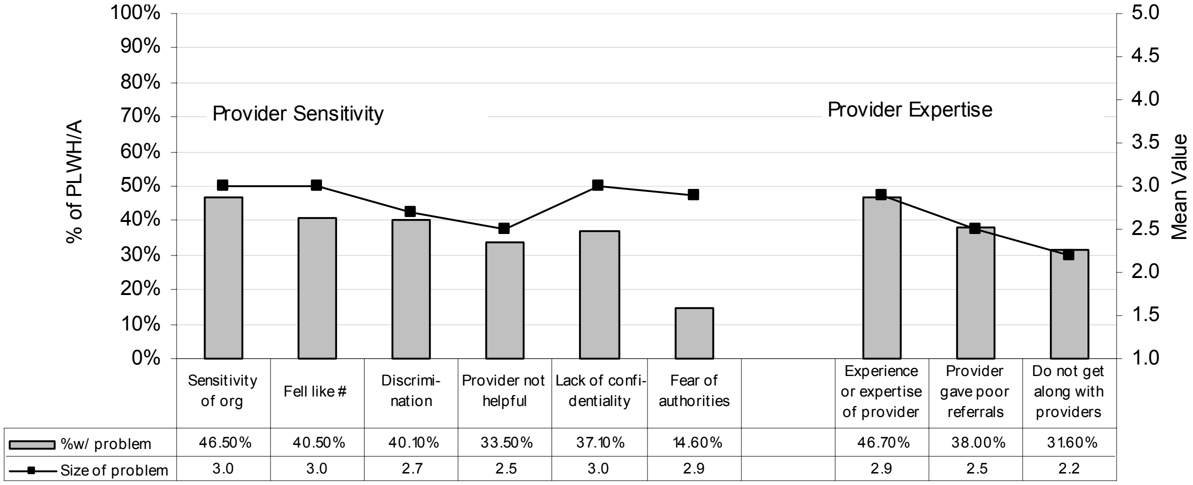
1=Very small, 2=Small, 3=Moderate, 4=Big, 5=Very big

Structural



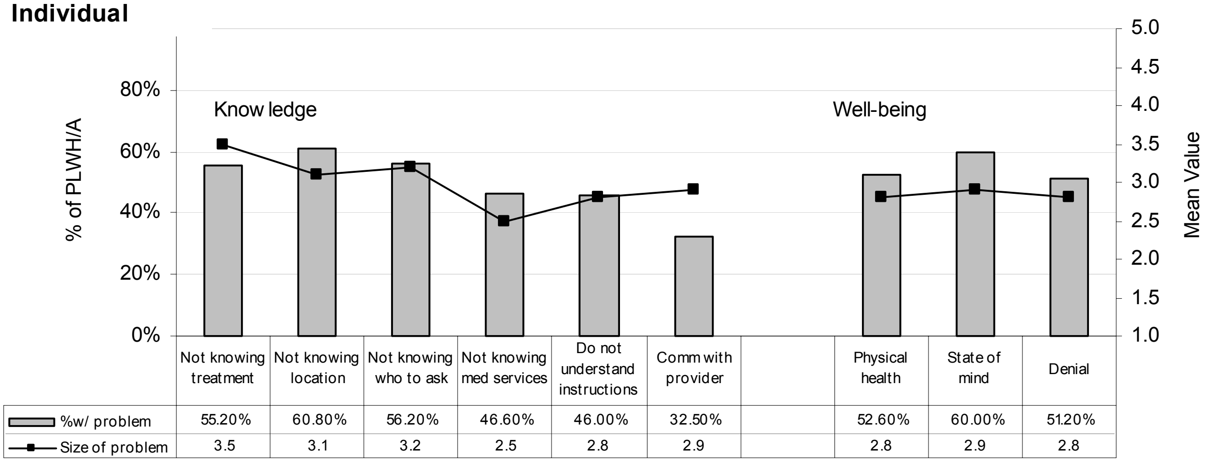
	Waiting for appt	Navigate system	Red tape	lack of insurance	Not eligible	Rules and regs	Cannot afford service		No transp	Lack of specialist	Criminal justice hist	No childcare	Suspend from srvc
▭ %w/ problem	56.60%	50.00%	42.00%	39.30%	46.00%	42.20%	44.60%		32.90%	35.70%	26.20%	15.20%	21.30%
—■— Size of problem	3.0	2.9	3.2	3.4	3.2	3.0	2.9		3.0	2.3	2.6	2.3	2.0

Organizational



	Sensitivity of org	Fell like #	Discrimi-nation	Provider not helpful	Lack of confi-dentiality	Fear of authorities		Experience or expertise of provider	Provider gave poor referrals	Do not get along with providers
▭ %w/ problem	46.50%	40.50%	40.10%	33.50%	37.10%	14.60%		46.70%	38.00%	31.60%
—■— Size of problem	3.0	3.0	2.7	2.5	3.0	2.9		2.9	2.5	2.2

Individual



	Not knowing treatment	Not knowing location	Not knowing who to ask	Not knowing med services	Do not understand instructions	Comm with provider		Physical health	State of mind	Denial
▭ %w/ problem	55.20%	60.80%	56.20%	46.60%	46.00%	32.50%		52.60%	60.00%	51.20%
—■— Size of problem	3.5	3.1	3.2	2.5	2.8	2.9		2.8	2.9	2.8

Service Delivery Barriers- Qualitative Comments

The following focus group and open-ended comments from surveys highlight the various challenges that PLWH/A face in trying to access HIV care. The quotes are presented in the three barrier dimensions discussed above: 1) structural, 2) organizational, and 3) individual barriers.

Some of the overall structural barriers discussed were the perception of lack of services. A heterosexual Latina conveys this sentiment as follows, "*I also think that there is much missing… For example, those that use ADAP do not have regular access to the eye doctor…The support groups for families have disappeared and the conferences for doctors to determine the new advances are lacking or sporadic. I hope they don't cancel the services because many people would die and there would be an increase in orphan children."*

Another heterosexual Latina feels that budget cuts have had an impact on her life. She says, "*I've seen them go through a lot of changes, as my needs have grown throughout the years, I find that [the agency] has also grown. I don't know if it's the budget or but I'm not getting things that I really need to help me survive...It's a limited budget and it's really difficult...And when I asked for their help [she trails off]...the food banks out there are not that much, and I'm grateful for what they have too. You know, I don't want to complain because I'm grateful for everything that they've done."*

In addition it is evident from the following comments, more specific structural factors, such as eligibility criteria, rules and regulations, and the amount of paper work required to access care present significant barriers for PLWH/A.

Structural: Eligibility Rules

An African American female expresses her frustration with the reasons for her ineligibility for SSI. She says, *"I don't understand [why] you must have AIDS to get SSI, not with HIV. The people in the information center and some doctors say that you must be sicker. I will and can't ever understand that. I don't even want to think about it because it's not right. I'm dying right now."*

An African American heterosexual female has also been denied services because of the eligibility criteria. She discusses the irony of her situation, *"Its funny about what you all hear, I was working and they told me because I was working and I did not appear to have a need that I did not need childcare and I had to fight to get it. By the time I got it, it was like, well now I don't need it."*

Structural: Red Tape

An Anglo MSM has to go through many hoops before anyone even talks to him. He says *"I rent from a relative and with just getting SSI there's just not enough money to deal with a bank account so I just pay cash for rent and utilities. But now, I don't get HOPWA because I have to have documentation for at least two months by a canceled check. So I gotta go out and get a* *bank account and deal with all of this while looking for an agency that has been providing these services all this time. Suddenly I have to provide two months of documentation or they won't even talk to me."*

Structural: Insurance

A Latino MSM had insurance problems, saying *"I believe insurance should be more encouraging to people because I used to have [name of insurance] and they denied me every AIDS medication there was out there for the reason that I didn't have the coverage. So I had to find, shop around for another insurance because they didn't want any pre-existing diagnosis or condition. So there's still a lot of ignorance with the insurance company."*

Structural: Rules and Regulations

A heterosexual African American female says, *"I will go see my doctor regularly but I have a primary. No one else can control my life and that really pisses off my HIV clinic and say they hold on to the vouchers, they are known for that. If you don't follow through on something, they will hold on to that. [Name of agency] is known for doing that, its something they do it constantly. They require you go get pap smears on a monthly basis or else they don't give you the voucher. Well, you see, I get my pap smears, but I go to my primary [doctor]. Now they're getting better."*

Access: Childcare

For a heterosexual Latina the lack of childcare presents a barrier. She says, *"I have a grandson and sometimes I can't do things because I don't have nobody to take care of my grandson."*

Access: Criminal Justice

Some participants feel that their past experience with the criminal justice system affects their ability to access care. Two focus participants discussed how they were denied services. An Anglo MSM/IDU says, *"It's funny 'cause they took blood samples and I'm sure [the medical care in the jail] must have picked up that I was HIV positive, but they didn't segregate me from anybody else. I've been coming here for a number of years, and a few years ago when I got put in jail for about ten months, my treatment stopped."*

A heterosexual Latina describes one of the problems with continuity of care once you've been in jail. She says, *"I used to be in jail for a month and then go out so at one time I did the test but I went out the next month so I never got the results for HIV or AIDS."*

Organizational: Sensitivity

A lack of sensitivity in various forms was expressed during the focus groups and in the survey. An Anglo MSM writes in his survey, *"I feel that our HIV and AIDS services are adequate but I also feel sometimes we are viewed as just being HIV+, when there are other issues that go* *untreated. I guess I'm saying I don't want to walk into a service provider and just be HIV+. I would like to be treated with a more "total health" attitude, like symptoms other than from HIV+ related: i.e. prostrate, cancer, etc."*

An Anglo IDU female has a similar criticism of her drug treatment facility. She says, *"as soon as they see you at the treatment center they think that you're court ordered, and they send you back on your way. They think you're trying to get out of it. They think you need to be hospitalized and they charged you $2,000 to take your blood. I brought in blood work from the week before, and they looked at it and charged me $2,000 dollars for the visit and they sent me home because they thought I wanted to be in the hospital because I didn't want to be in treatment. Why put myself in treatment? People at the center, they don't understand. They're not fully educated."* She continues, *"I'd rather be in a treatment center that has only HIV workers. That's what I want because nobody understands. I have diarrhea every five or ten minutes and when they clean up the bathroom they close up the bathrooms and the foods they give you are going to cause you ten times more diarrhea and you can't be picky about the food... and I don't have a lot of problems with the food...I want to be where there is a place where they're working on it and hopefully there is a place...*"

Organizational: Confidentiality

A lack of confidentiality tended to be a problem with various groups. A heterosexual African American female says, *"When you go to [name of agency] and use something there, [other people] automatically know what you're there for. People on the streets see you going, they know what the building; they know what you're there for. It would be really nice if there was some way, some way we can go some place else. I realize that's living in a fairy tale world, but I'm sure there's someone else is thinking about it. It would be wonderful if we could make it more confidential. Keep your privacy. There's a lot of things I will not attend because I know when I walk in through the door my privacy is out the window."*

An African American IDU woman also discusses her fear of lack of confidentiality. She says, *"I didn't go to the support groups, I don't do none of that because people that I was out there getting high with…I didn't want them knowing that I was HIV positive. My neighbors…you know what I'm saying? And that's what's hurting me. It's hurting me because I haven't been in the groups, but...And when I first got diagnosed, I was like that too, I didn't give a fuck...somebody gave it to me, so I was out there...I went crazy!"*

The fear of loss of confidentiality does not only apply to other peers learning your HIV status but it also applies to potential conflicts of interest and repercussions a consumer may have to face when filling a grievance. She cautions about how to go about filling a complaint against an agency as follows, *"[Name of agency] is a great place, but if you have a complaint against an agency, you can take your time, god forgiving, and find out who is on their board of commission because you give them all your information and then they will tell you there is a conflict of interest so you have to be careful when you're reporting an agency that is doing something wrong. You make sure that someone from that agency is not on that board. Make sure"*

Organizational: Providers Unhelpful

An Anglo MSM feels that his case manager is less than helpful. He says, *"My medical care has been superior…my problem has been with case management. I feel I have had to drag things out of my caseworker to get help."*

A heterosexual female API expresses her frustration with the carelessness of her provider by writing, *"My previous case manager just conveniently lost my file every year for three years every time I tried to apply for HOPWA."*

Organizational: Getting Along with Provider

A heterosexual Latina says that although her care in general is great, **"***the social worker lacks people skills. We butts head many time."*

Individual: Knowledge

A Latino IDU male feels that not enough information is made available to PLWH/A to informed consumers. He explains, *"Deciding where I can go to get services or where I can get taken care of for my HIV point of view. I think it'd be better if they just give me a list of places in the Long Beach area, and then let me go and talk to different people and different places and make a decision. The place I go to, I don't know anything about. Now I'm going to [name of agency] and I don't know what to expect from them or how far. I know how to deal with [names of agencies], but I don't know anything about this one, and when I came to the office there wasn't like okay you can check out these ten places, AIDS organizations, and this one do medical...Nobody told me that stuff and I couldn't find a written pamphlet to tell me where these places were. There's all these organizations that service to HIV positive people, but I don't know what they do or how to find them."*

Individual: Denial

An African American MSM had to face his own denial and societal pressures before being able to seek care. He says*,"[I] was scared to go to a doctor, fear of the stereotype. As a pastor I couldn't tell my church, had to leave my church. I'm living with this. Because for me because I'm positive and have AIDS, I can now be bold now to a certain degree."*

Individual: State of mind

A heterosexual African American female is of the opinion *"When you're on drugs or, the crack-heads and junkies…people don't even think about that. They're not in their right state of mind and then you don't care, you know you're HIV positive but ain't nobody gonna say they're HIV positive.*"

Providers' Perception of Barriers to Care

Barriers to care were rated by twelve providers on the Provider Information Form. The providers were asked to rate 23 factors that could affect consumers' ability to access services. They were asked to indicate the effect that they thought each factor would have on the level of access to services by rating each item on a scale from 1 to 5, where (1) would mean that the factor would greatly reduce consumer's ability to access services, (2) somewhat reduce, (3) have no effect, (4) somewhat increase, and (5) would greatly increase consumer's ability to access services.

Table 8-3 shows how providers rated each of the factors. The factors that providers feel would have the greatest affect in improving access to care are mostly dependent on organizational factors including funding and staff training. From the providers' perspective these include finding qualified staff, increase funding, retaining qualified staff, providers' ability to talk about sexual and drug using behaviors, training staff on cultural diversity issues, and knowing where to refer clients for other services. Thirty-eight percent (38%) of consumers also feel that being provided the proper referrals presents a small to moderate barrier for them to access care.

Providers also feel that addressing consumers' denial, the amount of paperwork needed to obtain services, and consumer transportation needs are important concerns to address in order to increase access. Consumers tend to agree, with over half of consumers rating denial as a small to moderate barrier, and 42% of consumers rating red tape as a big to moderate barrier. On the other hand, consumers rank transportation as a lower priority with less than one third of consumers reporting transportation as a problem, and they feel that lack of transportation represents a small to moderate barrier.

For providers, factors that reduce consumers' ability to access care are perceived to be individually based as well as structurally. For instance, the factors that would have the greatest impact reducing access to care include loss of contact, consumers not knowing what services are available, and lack of childcare. Like providers, consumers feel that not knowing what services are available to them is a significant barrier to care. More than half of consumers rate this among their top barriers and feel that this would be a moderate to big barrier. However, while providers feel that not having childcare available at service sites would somewhat reduce consumer access, this affects less than 16% of the consumers, who rate this as a small to moderate barrier.

Moreover, providers and consumers also disagree on other 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.
Also, providers feel that the consumers' ability to follow instructions somewhat reduces access, 46% of consumers feel this is a small to moderate barrier. 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 face this as a moderate to big barrier.

Providers and consumers tended to agree on the impact of several barriers. Both say that fear of lack of confidentiality reduces access to care. Both agree that language is not a major barrier.

Table 8-3 Top Barriers to Care from Providers' Perspective (N=9)

Factor Affecting Access	Average Score
Finding/training qualified staff, volunteers, subcontractors	4.8
Increase funding for the service.	4.7
Retaining qualified staff, volunteers, subcontractors	4.3
Providers' ability to talk about sexual and drug using practices	4.2
Training staff on cultural diversity issues	4.2
Knowing where to refer a client for another service	3.9
PLWH/A's transportation needs	3.9
Public campaigns regarding prevention needs of PLWH/A	3.9
Addressing organizational issues or infrastructure development	3.9
The amount of red tape and paperwork needed to be filled out to get the service	3.6
Current hours of operation	3.2
Changing location or physical limitations of the building/office space	3.2
Rules and regulations regarding HIV reporting and partner notification	3.1
Consumers thinking they are not being affected by HIV (denial)	3.1
Long waiting list for services (i.e. high demand)	2.6
Poor coordination among the organizations and programs providing services	2.3
Consumers ability to follow instructions	2.3
The cost of the service to the consumer (i.e. insufficient insurance coverage)	2.3
Clients' concern that other people would see them when they went to the program (fear of loss of confidentiality)	2.2
Not being able to communicate in the consumer's language	2.1
Having no childcare available at service site	2.0
Consumers not knowing what services are available	1.9
Loss of contact with client (e.g. no phone, no return visit)	1.4

9. PREVENTION NEEDS, UNMET NEEDS, GAPS, & SERVICES DELIVERY BARRIERS

The Continuum of Prevention Services shown in Figure 2-1 outlines the different types of programs and outcomes that must be achieved for a successful HIV prevention effort. One part of that effort is prevention programs targeting HIV infected individuals – "prevention-for-positives."

Understanding the size of HIV positive population that is placing others at risk of HIV infection, and the magnitudes of that risk is useful for estimating the needed capacity for prevention-for-positive services. This section also discusses their perceived needs and barriers to prevention services.

The different behaviors, attitudes, and beliefs discussed below may all be part of developing a strategy to avoid HIV infection. From the focus groups, it was clear that many individuals have a fairly complex set of criteria for their own protection – some based in truth and others in myth. For example, one white MSM depends on disclosure and condom use. He says, "*First of all just disclosing your status -- that's number one [and] I always do [that]. Even when I meet people who I think I'm gonna date, I tell them right up front I'm HIV because if they're the type that gets freak out by it, I'd just get them out of the way because that will waste my time continuing anything and they behave that way. So that's one way. Another way is I always use a condom, but I tell them to use a condom and if they don't that's up to them because I'm not gonna make someone do something they don't want to do you know. If they're HIV positive or if I think they might have something else, I use a condom. I don't usually do anything without a condom, without protection.*"

Another MSM says, "*It's a little less nerve wrecking having sex with someone who's HIV positive. The preliminaries usually don't involve using a condom. When it gets down to the main event, they're always there. But I'm a little less nerve wrecked. To be with someone who's negative that impedes...there's always that fear that something could happen. With a positive person it's already happened. Yes, there's re-infection and that's certainly to be considered but it's not like you're going to infect them and destroy their life. Should somebody get carried away or something happens…I use a condom when the moment is there.*"

For IDUs and sex workers, there is often a fairly complex strategy. While this IDU sex worker based her strategy on a false belief in the effectiveness of washing, she explains says, *"When I was out there working. The oral [sex], I would use antiseptic before [oral sex]. I give them the option [vaginal sex with] the condom or the oral [sex]. If they didn't want to come with the oral, I would use antiseptic...the blue stuff. Do the oral, spit it out, gargle with the Listerine again, put hand sanitizer spray on their, you know, spray, hand cleanser and a little towelette, a complimentary towelette. That's for the oral. For the intercourse, of course, [I use a]* condom. *For the boyfriend or the other significant, we don't do anything. Nothing. We don't share needles.*

These quotes, and quotes like them, are good reminders that adopting and maintaining prevention behaviors is a complex activity based on correct information, personal sense of efficacy, having access to condoms or clean needles, negotiating with a partner, and being in a state of mind, or having the habit, of using safer practices.

Defining the at risk population among HIV positives

Not all HIV positive individuals place others at risk for HIV. HIV positive persons at risk for transmitting HIV to others have to engage in unprotected sex with HIV negative persons or share unclean needles with other intravenous drug users. Those who abstain from sex and needles, have a monogamous HIV positive partner, or always use condoms with their regular and/or casual are not likely to infect others.

Number of Partners

A little over a third of PLWH/A in Long Beach say they have no sexual partners and another third say they are monogamous. Both categories tend to be low risk for transmitting HIV through sex. However, nearly 20% of those PLWH/A who are currently sexually active, report having "serial monogamous relationships", and this was particularly true of the MSM and MSM/IDU risk groups and among the racial subpopulations of Anglos and Latinos. Others may not continue to be abstinent, so there is some continued risk for those who say they abstinent or monogamous.

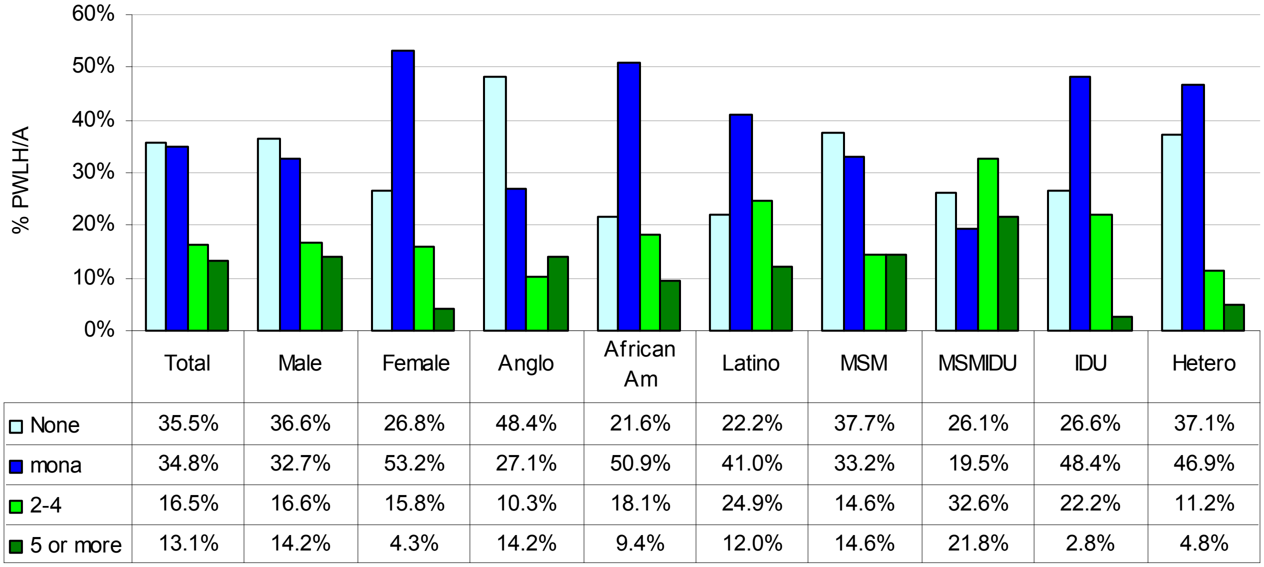
An example of how PLWH/A can move from monogamy to multiple partners was told by this 45-year-old MSM. He said, "*I was in a serial monogamous for years. This is the longest I've ever been single and right now I'm a bigger slut than I've ever been in my life and it's unbelievable. I don't know how I'm at 45 years old and have the energy to do as much as I do but you know… it happens.*"

Over 16% of PLWH/A say they have 2 to 4 partners and 13% say they have over 5 partners. Provided these individuals have sex with negative persons, they are far more likely to transmit HIV.

Figure 9-1 displays the number of sexual partners by different demographic subpopulations.

- Anglos are more likely to be abstinent.
- Men, of all risk groups, are more likely than women to report multiple partners. Among the different risk groups, MSM/IDU stand out as much more likely to have multiple partners. IDUs are also more likely to have multiple partners than most other populations who risk transmitting HIV.
- African Americans and females (of whom a majority are African Americans living with HIV and AIDS) are more likely to report being monogamous.
- While a large percentage of Latinos report being monogamous, they are also more likely than other ethnic groups to report more than one partner.

Figure 9-1 Number of Partners



	Total	Male	Female	Anglo	African Am	Latino	MSM	MSMIDU	IDU	Hetero
☐ None	35.5%	36.6%	26.8%	48.4%	21.6%	22.2%	37.7%	26.1%	26.6%	37.1%
■ mona	34.8%	32.7%	53.2%	27.1%	50.9%	41.0%	33.2%	19.5%	48.4%	46.9%
🟩 2-4	16.5%	16.6%	15.8%	10.3%	18.1%	24.9%	14.6%	32.6%	22.2%	11.2%
■ 5 or more	13.1%	14.2%	4.3%	14.2%	9.4%	12.0%	14.6%	21.8%	2.8%	4.8%

In a follow-up question, where PLWH/A were asked to describe the type of sexual partnering they had in the last year, about a third of the participants said they had multiple sexual partners last year, with 9% being in an open relationship, 3% saying they were in an relationships that their main partner did not know about, and 17% reporting some type of serial monogamy. Those engaging in serial monogamy cut across all risk and ethnic populations, and younger PLWH/A tend to engage in serial monogamy more than older PLWH/A.

The increase in infection rates among women is troubling. In addition to transmission from IDUs to their sexual partner, they may be infected by their bisexual partner. As one of the focus group participants noted, *"I think regarding minorities -- and this is the case with Latinos as well as African-Americans-- is that there are a larger percentage of [these] men who consider themselves straight but engage in sexual activities with other men. And like these [other] gentlemen [in the group] have indicated it's passed on to their women. I mean it doesn't take a rocket scientist to figure out how AIDS became a disease predominantly [among] white gay man and then black gay men and then somehow so-called straight black men and straight black women became infected. There's a reason why it's happened in minority communities because there's a larger percentage of men who consider themselves straight who interact with other men sexually.*

An African American male explained some of his logic for having sex with men, although he would prefer sex with a woman. He said, *"I can't have sex with the females as much as I would like to because I want a relationship and want understanding and usually when it does occur with a female then ...she's going to throw it back in your face like you might get into an argument and she'll say a thing like, hey you know I'm risking my life for you and that's a really hurting thing and I had that happen in a relationship and therefore [I have] more of a tendency to go towards a male that has it because if you don't go through that mentally, you don't have that problem."*

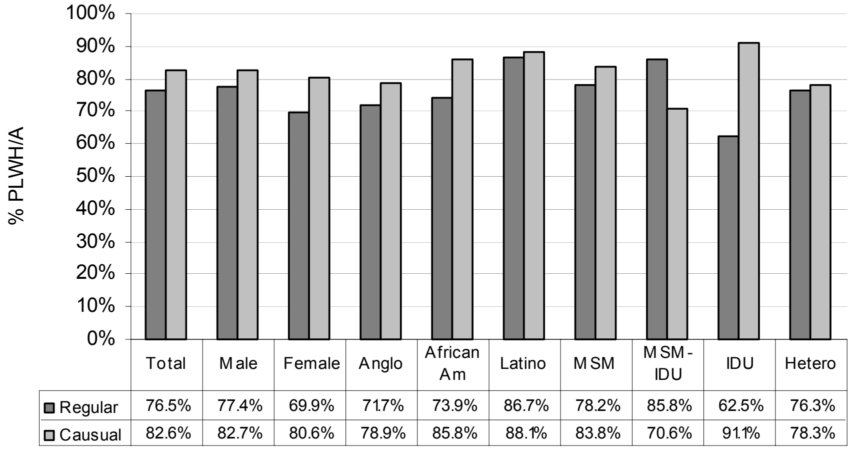
Designing programs that are culturally sensitive to the “Down-Low (DL)” subculture among African American men who have sex with men and women is one important aspect of addressing subpopulations with effective prevention messages. A Latino male added, “A*s a matter of fact, my best friend. He's married. He's bisexual. He has a lot of sex with men. He still goes to his wife and has sex. And I'm very angry that he, I told him you know what, you're damaging yourself and your wife and your family. And I told him that I'm very afraid that your wife is very sick right now because I've seen her lose weight drastically. And I try to talk to her, take her to a doctor but she won't listen. Because she's one of those women, she will listen to her husband no matter what. That angers me because, even though there's prevention and workshops, men won't go. They don't want to get knowledge about it.”*

Condom Use

The risk of infection is mitigated by condom use, and several questions were asked in the survey about condom use (see questions 43 – 45, Attachment 2). When reading reported condom use figures, note that they may be inflated, because using condoms are a “socially desirable” response – that is, respondents may feel that it is the “right” answer. However, when analysis is shown below among those who say they don’t use condoms, it is very likely that they are telling the truth and comparisons between users and nonusers of condoms are likely to be accurate. Furthermore, the level of condom use and patterns of condom use are consistent with past findings in this area.

As seen in Figure 9-2, when asked to say how often those with a regular partners or casual partners used a condom, about three-quarters (77%) of the PLWH/A said they used it most of the time with a regular partners and over 80% with a casual partner. Women and IDUs are significantly less likely to use a condom all of the time or most of the time with a regular partner than men. MSM/IDUs are much less likely to use a condom all or some of the time with casual partners, while IDUs are more likely to use a condom all or some of the time with a casual partner.

Figure 9-2 Condom Use



	Total	Male	Female	Anglo	African Am	Latino	MSM	MSM-IDU	IDU	Hetero
■ Regular	76.5%	77.4%	69.9%	71.7%	73.9%	86.7%	78.2%	85.8%	62.5%	76.3%
□ Causual	82.6%	82.7%	80.6%	78.9%	85.8%	88.1%	83.8%	70.6%	91.1%	78.3%

Sharing Needles

Of the 18% of those who report injecting substances not prescribed by a physician, about 13% say they shared needles in the past year. While the sample is small, an analysis of that group shows that they are more likely to be in the IDU and MSM/IDU risk groups, and among Anglos.

Estimating Number at Risk

Based on the survey, about a third (34%) report that they are at risk for at transmitting HIV to a negative or partner of unknown status. That is, about a third report have sex with a regular partner who is HIV negative but not always using a condom, casual partners without always using condoms, or sharing needles.

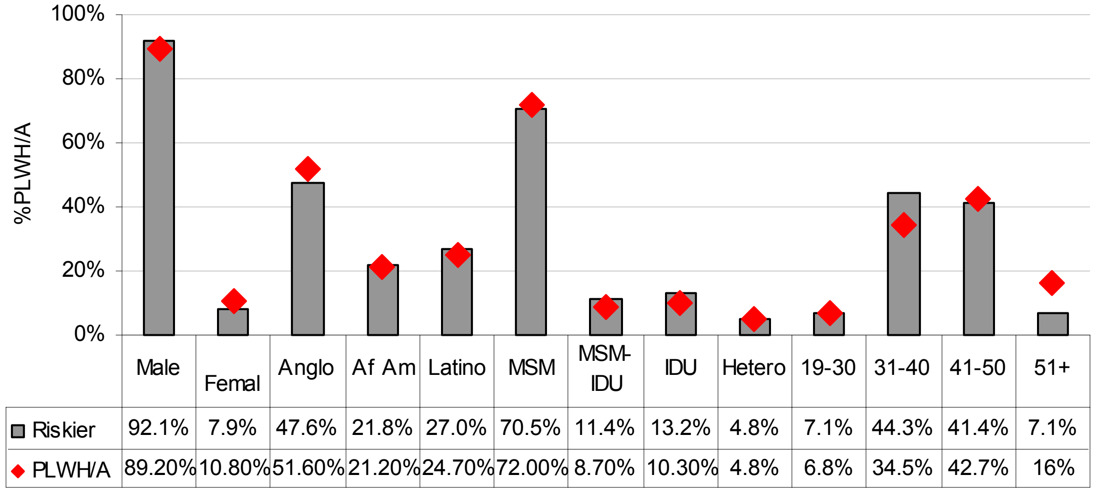
As shown in Figure 9-3, the unfortunate news is that there is no single population that disproportionately engages in behavior that is likely to transmit HIV. In looking at this figure, if the triangle is within the gray bar, that population is more likely to engage in riskier behavior. Males, African Americans, Latinos MSM/IDUs, and heterosexuals are slightly more likely to engage in riskier behavior. Only those in the age group 31-40 are significantly more likely to engage in riskier behavior, while over 51 are less likely to engage in behaviors that are likely to transmit HIV infection.

In terms of the number of individuals who are most likely to transmit infection, Because MSM make up about 70% of all PLWH/A in Long Beach, HIV negative partners of MSM living with HIV and AIDS are, by far, at the greatest risk of becoming infected unless partners practice safer sex. Within this population African American and Latino gay men are a bit more likely to engage in riskier behavior and the consequences will be some increase in gay men of color who become infected.

The data indicate that MSM/IDUs, who makes up about 10% of the population, are particularly high-risk, having both more partners and using condoms less frequently with causal partners. As a consequence, this group of substance using MSM are much more likely to transmit HIV. Also, Latinos report a high number of multiple partners, and they may be a greater risk of infection in the community than their low incidence of HIV suggests.

Given the largely disproportionate infection rates among African Americans in Long Beach and LAC, much higher risk behavior is expected. However based on self-reported data, African Americans engage in slightly riskier behavior, but the increase is not dramatic.

Figure 9-3 Profile of PLWH/A with Greater Risk of Transmitting HIV



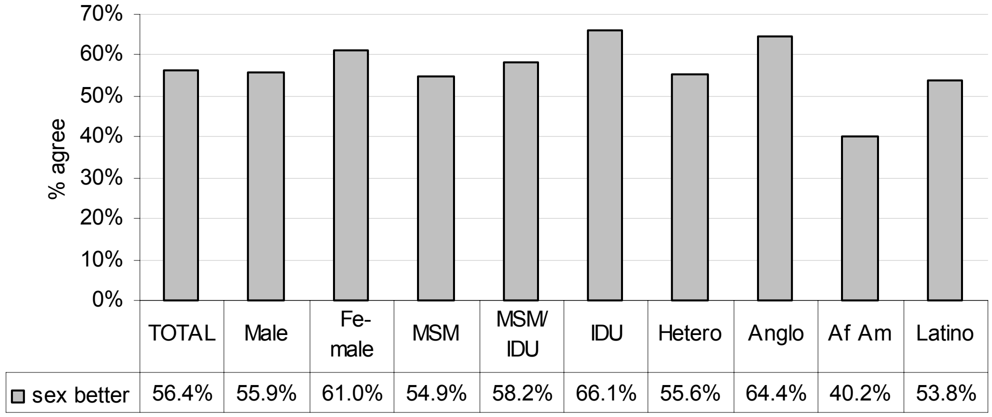
	Male	Femal	Anglo	Af Am	Latino	MSM	MSM-IDU	IDU	Hetero	19-30	31-40	41-50	51+
■ Riskier	92.1%	7.9%	47.6%	21.8%	27.0%	70.5%	11.4%	13.2%	4.8%	7.1%	44.3%	41.4%	7.1%
◆ PLWH/A	89.20%	10.80%	51.60%	21.20%	24.70%	72.00%	8.70%	10.30%	4.8%	6.8%	34.5%	42.7%	16%

Attitudes Toward Condoms

The vast majority of participants with multiple partners say the use condoms at frequently. One of the biggest hurdles in prevention campaigns is to create a general acceptance of condoms. There is clear evidence that they are at least accepted in Long Beach. Over three-quarters say that having sex with a condom is "real" sex.

Still, the starting assumption for any persuasive message on increasing condom use is that a large majority says sex is better without using a condom. As shown in Figure 9-4, over half of the PLWH/A agreed that sex without a condom was better. Females, IDUs, Anglos, and Latinos were more likely to say sex was better using a condom than other key target populations.

Figure 9-4 Attitudes Toward Condoms



	TOTAL	Male	Fe-male	MSM	MSM/ IDU	IDU	Hetero	Anglo	Af Am	Latino
□ sex better	56.4%	55.9%	61.0%	54.9%	58.2%	66.1%	55.6%	64.4%	40.2%	53.8%

Obstacles to Using Condoms

There is a core – most likely about a quarter to a third of PLWH/A who are unlikely to use condoms, and converting irregular and non-frequent condom users to frequent users face substantial barriers. About a quarter of the PLWH/A say they wanted to have children and therefore would not use a condom. For them, condom use is really not an option, and there should be counseling about HIV and pregnancy. For example in a focus group, a Latina said, "*I want to get married and I want to have kids. And sometimes I don't seem to get it, you know? How I'm gonna have a baby because I have heard of negative babies and I think he knows already and I wouldn't protect myself but I just, I'm just anxious to have another baby. I have a little girl and she's 12. She's negative. But I want to have a little boy.*"

Also about a quarter of all PLWH/A surveyed say that their partner insists on sex without using a condom (23%), and, their barrier is attitudinal. In the focus groups women of color noted the difficulty in bringing up condoms with their partner. One female noted, "*Please don't take this if I say it wrong, but in African American community, in the Latino community and in the Asian community, condom use is not something that the women can talk to their men about doing.*"

Drug Use and Condom Use

The relationship between drug use and unsafe sex is clear from the data. On average, about 17% of those surveyed report that they are usually high on alcohol and/or drugs with they have sex. Yet, for IDUs it is nearly 40% and for MSM/IDUs it is nearly 36%. African Americans (27%) are also more likely than other ethnic populations to be high on drugs and/or alcohol when they have sex.

Among PLWH/A who use drugs, over a third (35%) says that when they are "turned on", putting on a condom ruins the moment. Far more MSM/IDU report condoms ruin the moment when they are high (42%) and heterosexuals and Latinos are also more likely to say condoms ruin the moment.

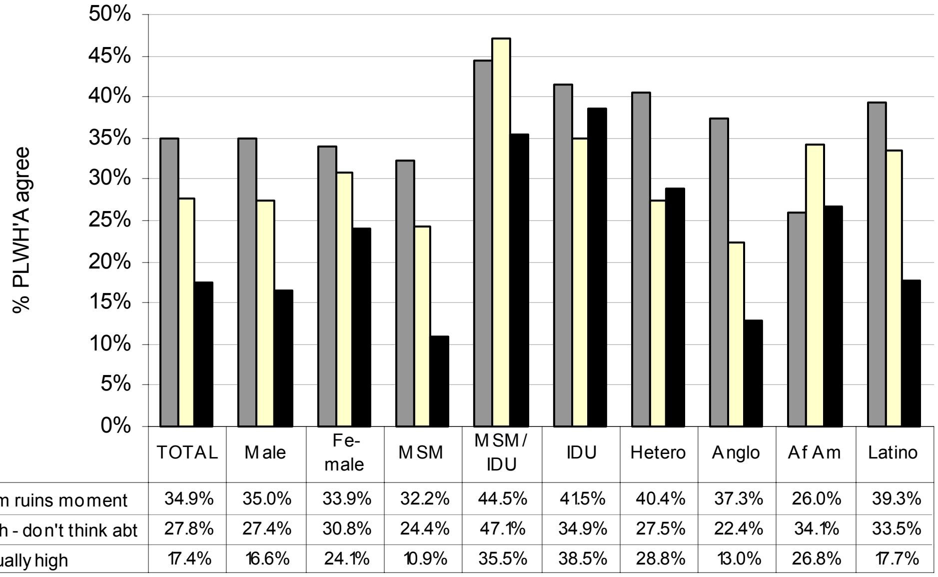
The participants in focus groups often mentioned the impact of drugs on unsafe behaviors. One Latino noted, "*they're either intoxicated or they're high as a kite. They don't acknowledge what is present. Even if you try to alert them what's gonna happen, they don't care because they're machismo ego gets in the way and so they're gonna have their way regardless.*" Another MSM of color noted, "*a lot of the times it is unprotected and it is on the spur of the moment and it is with regard to under the influence…*"

A Latina said, "*I know for a fact [that I was infected] through heterosexual contact, unprotected sex. I kind of attribute it to being too much in the influence of alcohol to insist on using a condom at that particular time.*"

Given that 40% say that condom use is not a habit for them, it is not surprising that over a quarter of the PLWH/A who were interviewed say that when they are high they don't think about using a condom. Nearly half of the MSM/IDU say they don't think about it, and IDUs and

African Americans and Latinos are more likely to say they don't think about using a condom when they are high. An African American explains, *"A lot of time I can say it comes from drug use. 'Cause I have personally been out there and cried, told the person I'm HIV positive, when they take a hit they whip that little thing out; they don't give a damn when they're at risk. You can tell them you have AIDS but when they take a hit..."*

Figure 9-5 Drug Use and Condom Use

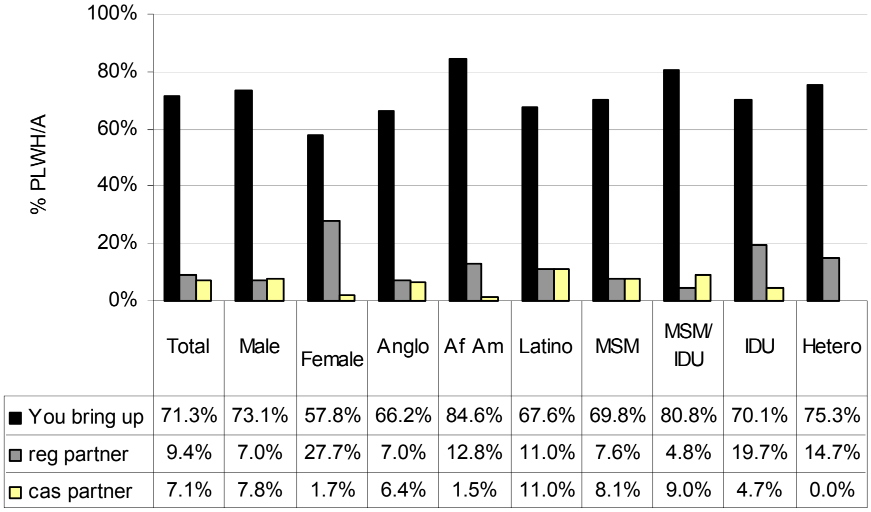


	TOTAL	Male	Fe-male	MSM	MSM / IDU	IDU	Hetero	Anglo	Af Am	Latino
▨ cdm ruins moment	34.9%	35.0%	33.9%	32.2%	44.5%	41.5%	40.4%	37.3%	26.0%	39.3%
☐ high - don't think abt	27.8%	27.4%	30.8%	24.4%	47.1%	34.9%	27.5%	22.4%	34.1%	33.5%
■ usually high	17.4%	16.6%	24.1%	10.9%	35.5%	38.5%	28.8%	13.0%	26.8%	17.7%

Communication Strategies

From past studies on condom use, if one partner suggests using a condom there is a much greater chance it will be used. For all of those interviewed, 71% say that they bring up condom use. Sixteen percent (16%) say their regular or casual partner brings it up. Twelve percent (12%) say that nobody brings it up. If condoms are brought up by anyone, over 90% of the participants say they use them. If it is not brought up, about 87% say they <u>never</u> use them. (While sample sized are small for this analysis, the differences are large and statistically significant.)

Figure 9-6 Who Brings Up Using Condoms

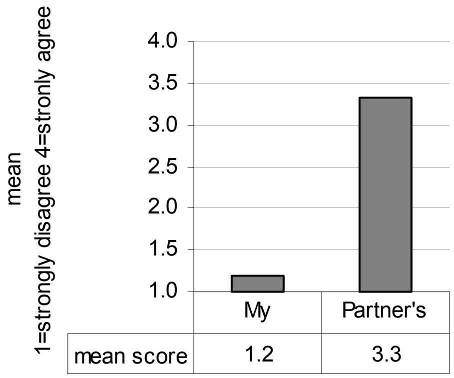


	Total	Male	Female	Anglo	Af Am	Latino	MSM	MSM/ IDU	IDU	Hetero
■ You bring up	71.3%	73.1%	57.8%	66.2%	84.6%	67.6%	69.8%	80.8%	70.1%	75.3%
▨ reg partner	9.4%	7.0%	27.7%	7.0%	12.8%	11.0%	7.6%	4.8%	19.7%	14.7%
□ cas partner	7.1%	7.8%	1.7%	6.4%	1.5%	11.0%	8.1%	9.0%	4.7%	0.0%

As shown in Figure 9-6, women are much less likely to bring up using a condom than men. This suggests an intervention that emphasizes the importance of partners -- men or women -- introducing condoms without the stigma of “blaming” or “accusing” the other partner of infidelity. While only 13% of all PLWH/A agree that their partners will interpret the request to use a condom as an indication of being unfaithful, about a quarter of the women, Latinos, and heterosexuals hold this belief. Consequently, programs could confront this problem by emphasizing that individuals could have become infected as much as a decade ago and that condom use does not mean that their partners currently have other sexual relationships.

The reasons for not bringing up condom use may be that PLWH/A feel it is the responsibility of the person they are having sex with to protect themselves, and not their responsibility to inform their partners. As shown in Figure 9-7, participants of the survey strongly disagree that it is their responsibility to inform their partner that they are positive. Females, heterosexuals, and Latinos are more likely to feel it is the responsibility of partners to protect themselves.

Figure 9-7 Who's Responsibility to Use Condom



As participants in the focus groups report, however, it is not always that clear-cut. There are two steps: 1) disclosing and then 2) use of the condom. For example, this MSM says, "*You're a negative person and they're having sex with you and you're honest if you disclose then that's really their problem. Me, personally, I'm not gonna let that rest on my head. And say for instance I was having sex with someone who was HIV positive and they re-infected me with a different strand and I got sick, I would be really pissed off if I were stupid enough not to use protection."*

An African American women is adamant about her responsibility to herself, *"I will not take that extra responsibility [of protecting my partner]. You think it's irresponsible on my part but I'm not doing it. [He's] not my kid…I feel as long as I'm protecting myself from [him], that's good enough."*

Still, 65% report that they disclose their HIV positive status to their sexual partners before having sex with them. While this may be an overstated due to social desirability, there is a clear pattern where Latinos (55%) and MSM/IDUs (50%) say they are much less likely to tell their partners their positive status. Still many people of color take their responsibility seriously. For example, an African American woman who said in a focus group, "*I think one thing you can do is to pay attention to what you're doing... the person who is positive needs to be responsible.*"

This confirms a fairly frequent theme in the focus groups expressed by this MSM who said, *"To me, I'm not letting HIV run my life but I'm not gonna take on the burden myself of being responsible for the whole world. My responsibility is to protect myself and the other person as far as what I do."* Of course behavior is not always consistent. An Anglo MSM notes, "*I've never had a tweeker ask me to put on a condom. That was always on me. My safety has always been in my court and I was up for the challenge. But a couple of the times I wasn't. I didn't ask for status or anything like that. And I'm not proud of it but that's the way it is when you're on drugs."*

IDU and non-IDU drug users are much less likely to disclose their needle-sharing partner their status. About 43% say they never tell their partner their status. African American IDUs are more likely than other ethnic populations not to tell their status. One reason may be the culture of sharing needles. As one Anglo IDU notes, "*You want to be part of the person, you know, so you go and use the same needle to be closer to the person.*"

Couples

The data suggest that discordant couples continue to be at-risk. Just under half of the sample says they have a regular partner. Of those about half say they their partner is negative or they don't know their HIV status.

While half of those who are in discordant couples say they never have anal or vaginal sex, about 40% say that they agree not to use a condom during anal and vaginal intercourse. About half do not agree to have safer sex outside the relationship.

Clearly many couples in discordant relationships have negotiated a level of safer behavior that they feel is effective. However, the survey indicates that there is still a considerable gap between the self-commitment to have safer sex – about 70% of the sample – and the reported sexual behavior. Effective prevention programs encouraging partner negotiation and awareness may help fill this gap.

Awareness, Need, Utilization, and Satisfaction with Prevention Services

Participants in the survey noted their awareness, perceived need, utilization, and satisfaction for fourteen prevention services. For each service they were asked:

- Do you know if this service is available to you? (Awareness)
- Do you currently need this service? (Need)
- Do you use this service? (Utilization)
- Did this service you receive meet your need? (Satisfaction)

Current Need

Figure 9-8 ranks prevention services by reported awareness, perceived need, utilizations, and satisfaction. For subgroup information see Attachment 9.

Figure 9-8 is ordered by reported current need, and indicates that:

- Community forums or meetings where they provide their input into prevention programs is needed by the 33% of PLWH/A and is the service with the greatest perceived need. Latinos are much less interested in community forums than other key subpopulations. The most interested are MSM/IDU, recently incarcerated, and homeless.
- Next, with 29% report needing support groups where you talk with others about HIV prevention. The greatest interest is among women and heterosexual (large overlap in these two groups) and MSM/IDUs. Among special populations there is greater interest among recently incarcerated and homeless.

- Third, 26% of PLWH/A report needing group education where experts provide information about how to prevent the spread of HIV. Females and heterosexuals again express considerably greater need than other subpopulations. Also HIV (not AIDS) symptomatic individuals express a greater interest in group education sessions.
- HIV testing is needed by about 24% of PLWH/A. In contrast, almost three-quarters of those out-of-care for over 6 month say they need testing – by far their highest perceived need. This suggesting a high level of denial among those out-of-care. Thirty five percent (35%) of those recently incarcerated say they need testing, and this may be denial or disbelief in the correction system. To a lesser degree, males say they need it slightly more than females, and African Americans less than other ethnic populations.
- About 23% of PLWH/A report they currently need prevention outreach from workers in the community. Latinos are significantly less likely to say they need it, while those out-of-care, homeless, and recently incarcerated are much more likely to say they need outreach.
- Twenty-three percent of PLWH/A say they currently need Internet and web-based information about HIV or AIDS. MSM/IDU are significantly more likely to say they need it than other populations. IDUs and Latinos say they need it the least.
- Free condoms in bars are requested by about 20% of PLWH/A. Not surprisingly, females say they need it significantly less than males. MSM/IDUs say they need it the most – a good thing given their high-risk behaviors. IDUs and heterosexuals, however, say they need it significantly less than other risk groups.
- Hotlines, church sermons, and events at places or worship, partner notification, and distribution of bleach kits each were reported needs by between 9% and 20% of PLWH/A. For these services with lower perceived need, MSM/IDU and Heterosexuals tend to have greater need. Females are more likely than males to say they need events at religious institutions. Recently incarcerated report a lower level of need for these services.

<u>Utilizations</u>

As seen in Figure 9-8, utilization is related to need, but there are differences among those prevention services that are needed by most.

- Testing, the services with the 4th highest current need (24%), is used by over 30% of PLWH/A.
- Support groups, the prevention service with the second highest current need (29%) is utilized by about 26% of PLWH/A.
- Community forums, the prevention service with the greatest need (34%), is utilized by about a quarter of the PLWH/A.
- Individual counseling is the service with the 7th largest number of PLWH/A saying they need it (22%). Like testing, however, more persons say they use it than report currently needing it.
- Group education, Internet, free condoms, and hotlines are utilized by between 10% and 16% of PLWH/A.
- Bleach-kits, partner notification, and church sermons are utilized by fewer than 6% of PLWH/A.

Awareness

The line in Figure 9-8 represents awareness, and it indicates that the percent of survey participants that report being aware of prevention service is two to three times their current need. It shows that seven out of the ten prevention services are known by over two-thirds of PLWH/A. Fewer PLWH/A are aware of free condom, hotline, church venues, partner notification, and bleach-kits.

There are a number of systematic groups with lower awareness that should be addressed in prevention planning.

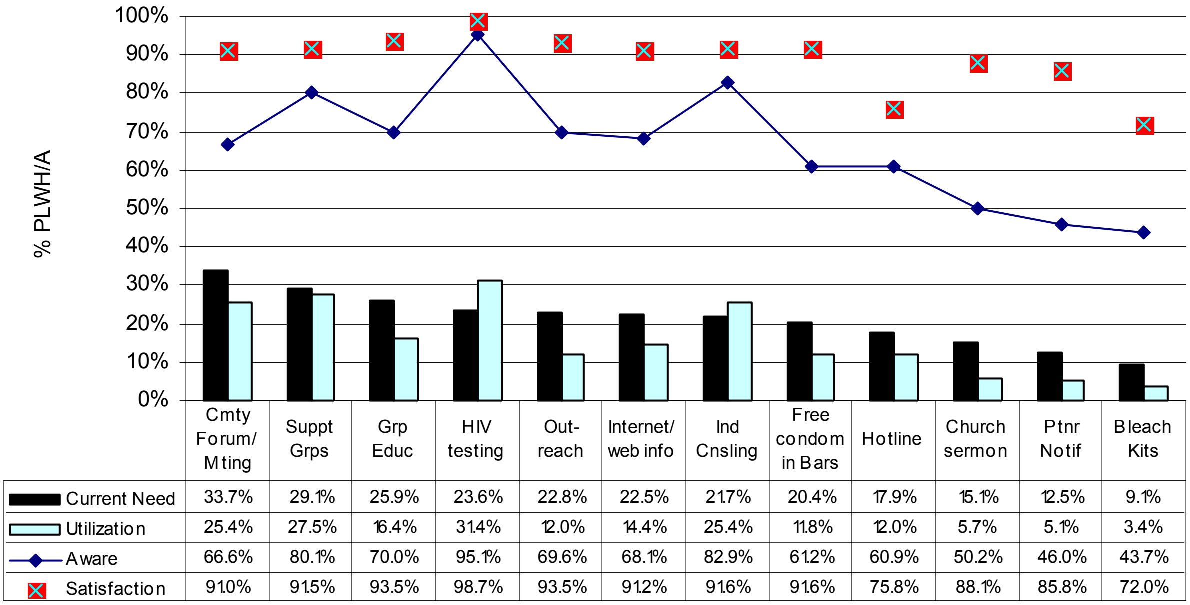
- Latinos and those out-of-care for 6 months or more have a generally lower awareness of all prevention programs, with the exception of testing for those out-of-care.
- There is a much higher awareness of women than men for group educational and partner notification. These programs are equally applicable to men and programs can be designed to increase their awareness.
- Those diagnosed with AIDS have much higher awareness of support groups, forums, and hotlines.

There appears to be a functional relationship between awareness and need. For example, men are more aware of free condom distribution at clubs –but men are also more likely to go to venues where condom distribution is an effective strategy. At the same time, there is a large gap between the awareness of Anglos (72%), African Americans (60%), and Latinos (45%). This difference is sustained even among only men in each of these ethnic populations.

Another functional relationship is between awareness for bleach kits and needle exchange. Awareness is much higher among IDUs for bleach kits (65%) and recently incarcerated (64%) than other subpopulations. Similarly IDUs (47%), MSM/IDUs (42%), and recently incarcerated (49%) are much more aware of needle exchange services than other subpopulations.

In terms of taking advantage of awareness in planning programs, African Americans have a much greater awareness of HIV/AIDS prevention events at churches.

Figure 9-8 Prevention Services Awareness, Need, Utilization, and Satisfaction



	Cmty Forum/ Mting	Suppt Grps	Grp Educ	HIV testing	Out-reach	Internet/ web info	Ind Cnsling	Free condom in Bars	Hotline	Church sermon	Ptnr Notif	Bleach Kits
■ Current Need	33.7%	29.1%	25.9%	23.6%	22.8%	22.5%	21.7%	20.4%	17.9%	15.1%	12.5%	9.1%
▭ Utilization	25.4%	27.5%	16.4%	31.4%	12.0%	14.4%	25.4%	11.8%	12.0%	5.7%	5.1%	3.4%
◆ Aware	66.6%	80.1%	70.0%	95.1%	69.6%	68.1%	82.9%	61.2%	60.9%	50.2%	46.0%	43.7%
☒ Satisfaction	91.0%	91.5%	93.5%	98.7%	93.5%	91.2%	91.6%	91.6%	75.8%	88.1%	85.8%	72.0%

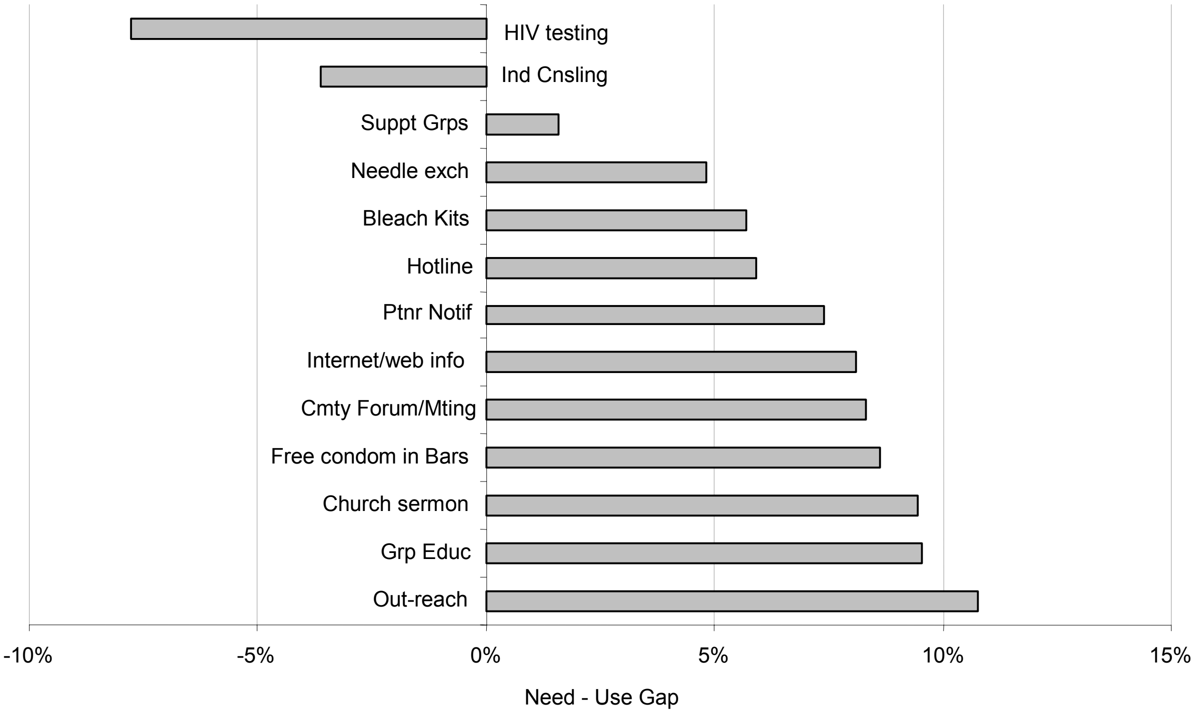
Satisfaction

The top boxes in Figure 9-8 reflect the high level of satisfaction PLWH/A report for prevention services. For all of the services that are most needed, over 90% of PLWH/A are satisfied. The hotline (76% satisfied) and distribution of bleach kits (72% satisfied) are the services, which were rated lowest.

Gaps

The difference between perceived need and the percentage of PLWH/A who receive a prevention service represents a need-receive gap. As shown in Figure 9-9, the gaps are small. No service has a gap larger than 10%. The largest gap is for outreach where 10% more PLWH/A perceive a need than say they receive the service. The services where there are small but significant gaps includes group education, prevention at religious institutions, and free condoms in bars.

Figure 9-9 Prevention Service Gaps



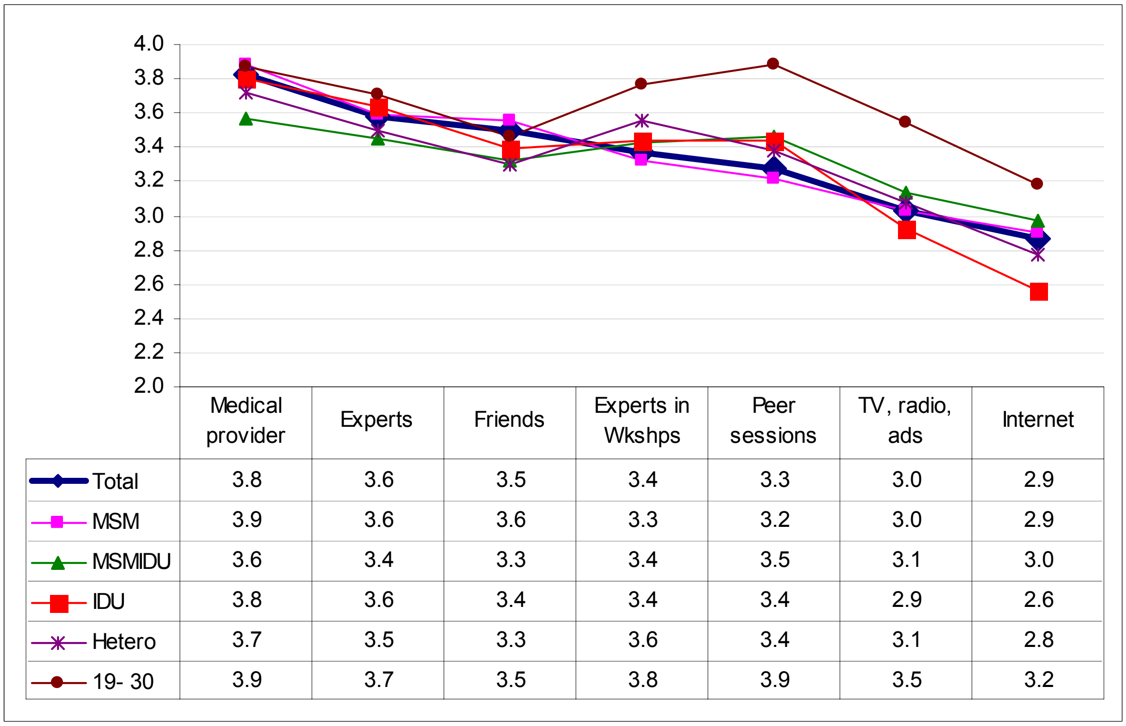
Best Sources of Information

When PLWH/A were asked to rate the importance of sources of information, as seen in Figure 9-10, there is a large degree of consensus. Generally, medical providers and experts are rated highest, suggesting that for most subpopulation one of the best places and sources of prevention information is at the provider of health care. Trained prevention counselors have an opportunity to work with PLWH/A during their medical visits provided it is accompanies by consistent monitoring and programmatic interventions that are appropriate. After providers, friends play a critical role in providing information. In addition, social networks and peer reinforcement of prevention behaviors can be critical for those having difficulty maintaining prevention behaviors.

Among adolescents and young adults there may be other equally effective sources of information. They rate their peers as just as important as their medical providers. Clearly peer views and peer pressure are important to young PLWH/A. They also consider mass media and Internet information as much more important than any other target populations.

Figure 9-10 Sources of Prevention Information

4=very important, 3=somewhat important, 2=not very important, 1=not important at all



	Medical provider	Experts	Friends	Experts in Wkshps	Peer sessions	TV, radio, ads	Internet
◆ Total	3.8	3.6	3.5	3.4	3.3	3.0	2.9
■ MSM	3.9	3.6	3.6	3.3	3.2	3.0	2.9
▲ MSMIDU	3.6	3.4	3.3	3.4	3.5	3.1	3.0
■ IDU	3.8	3.6	3.4	3.4	3.4	2.9	2.6
✳ Hetero	3.7	3.5	3.3	3.6	3.4	3.1	2.8
● 19- 30	3.9	3.7	3.5	3.8	3.9	3.5	3.2

Barriers to Prevention Programs

Participants in the survey were asked to rate thirteen problems related to accessing prevention services. Each participant in the survey indicated whether the barrier presented was a problem, and, if it was, how seriously it affected him or her. Figure 9-11 shows the barriers by the all the persons surveyed and by risk group. The line represents the rankings of all PLWH/A. The bars represent different risk groups. Also note that the last line of the table under the chart provides a mean of how serious PLWH/A consider each problem. Figure 9-12 and Figure 9-13 show the rankings of the barriers by gender and ethnicity. The rating for all PLWH/A and risk groups is shown in Attachment 10. These figures reveal:

- Overall, females and heterosexuals (groups that overlap) report having more problems than other populations.
- Based on a statistical method that finds patterns in data[3], the two major dimensions among these thirteen barriers: 1) problems caused by a feeling of lack of confidentiality, discrimination or being treated badly and 2) problems that are related to access such as transportation, or knowledge about programs.
- About 42%, the largest number of PLWH/A mentioning any single barrier, say that they have a problem with programs not being available at the time that is convenient for them. MSM/IDU, and heterosexuals and females are more likely to name this barrier to prevention

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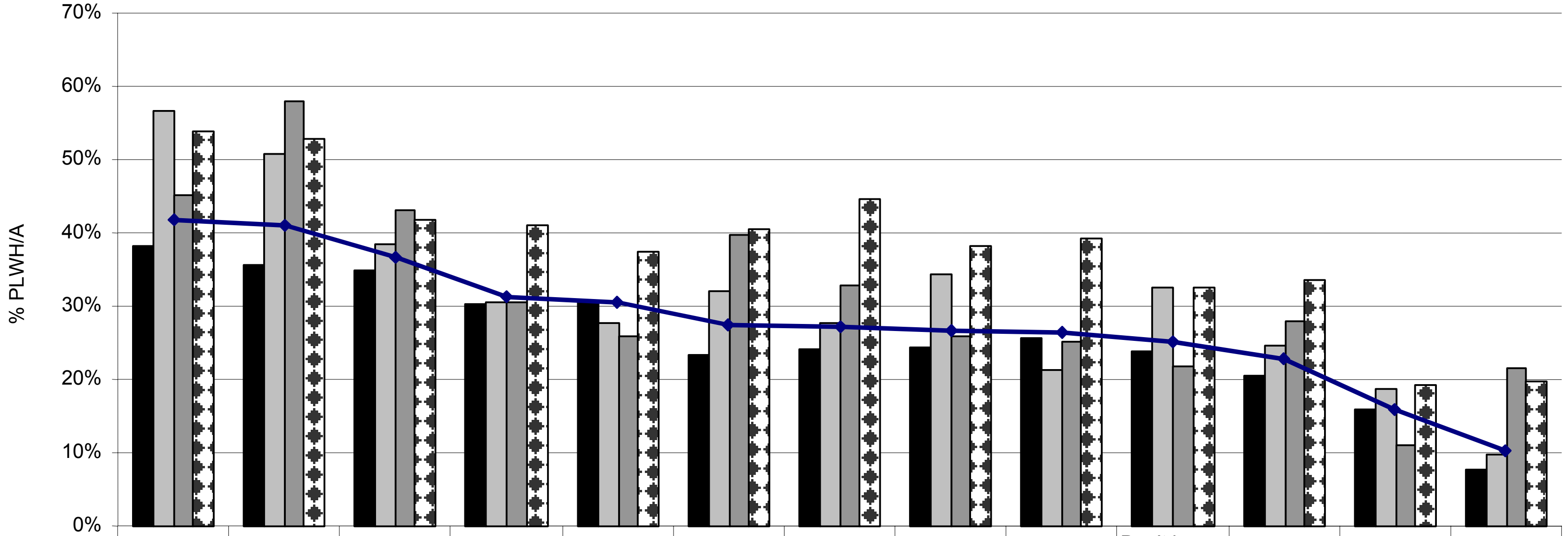
[3] Factor Analysis, with varimax rotation, using pearson correlations as input.

services. For those identifying this problem, it is considered a small to moderate problem, but it is a greater problem of Latinos.

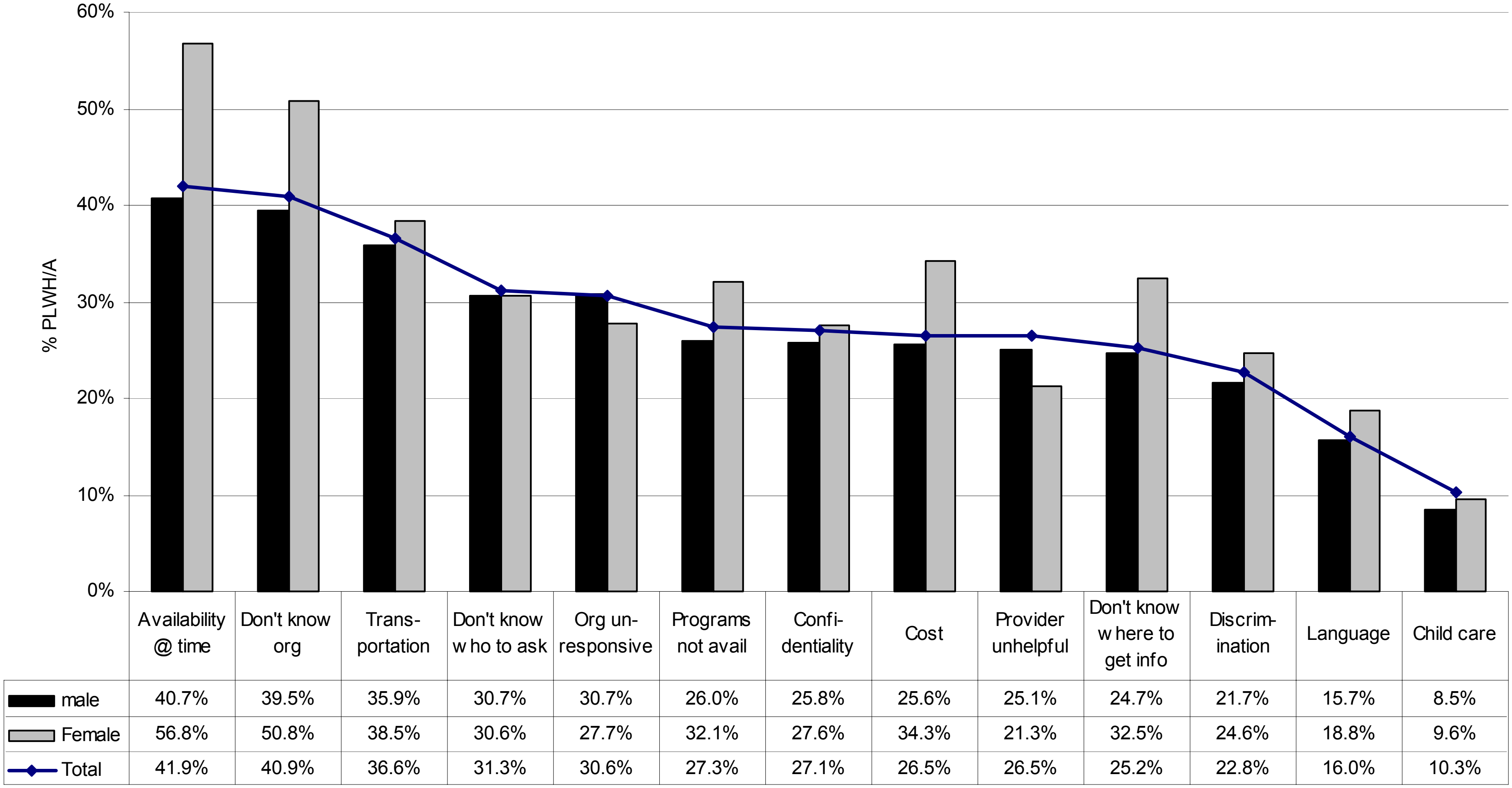
- About 41% of PLWH/A say that a problem in receiving prevention services is that they do not know what organizations provide the services they need. African Americans, females, and IDUs are particularly likely to note this problem. For those having this problem, it is a moderate problem, with Latinos, saying it is a moderate to large problem.
- About 37% say lack of transportation is a barrier to receiving prevention services, and it is among the top problems noted by PLWH/A. African Americans note it slightly more than other ethnic groups. For those citing lack of transportation, overall it is a small to moderate problem, but women say it is a moderate problem.
- About 31% of the PLWH/A say they don't know who to ask in an organization to get prevention services. Latinos and heterosexuals are significantly more likely to say they don't know whom to ask, although they say it is a small problem.
- Between 25% and 30% of the PLWH/A say that their provider is unresponsive, programs are unavailable, fear others will find out about their status, feel the cost is too great, their provider is unhelpful, and don't know where to get information. Heterosexuals are more likely to say these barriers are a problem than other populations.
- Females are more likely to say the programs are not available and costs are barriers. And MSM/IDU and females are more likely to say that they don't know where to get information. African Americans are more likely to say that provider response is a barrier. Latinos say confidentiality is a great barrier. For everyone, these problems are small to moderate, but confidentiality is a moderate barrier for IDUs, heterosexuals, and African Americans.
- The smallest number of PLWH/A – under 23% say that discrimination, language, and child care are problems in obtaining prevention services. More African Americans say discrimination is a problem, but for those Latinos who have problem with discrimination it is a bigger problem. Latinos are more likely to say that language and childcare are problems. For those naming these problems, discrimination is a relatively small problem, while language is a moderate problem.

Figure 9-11 Risk Group



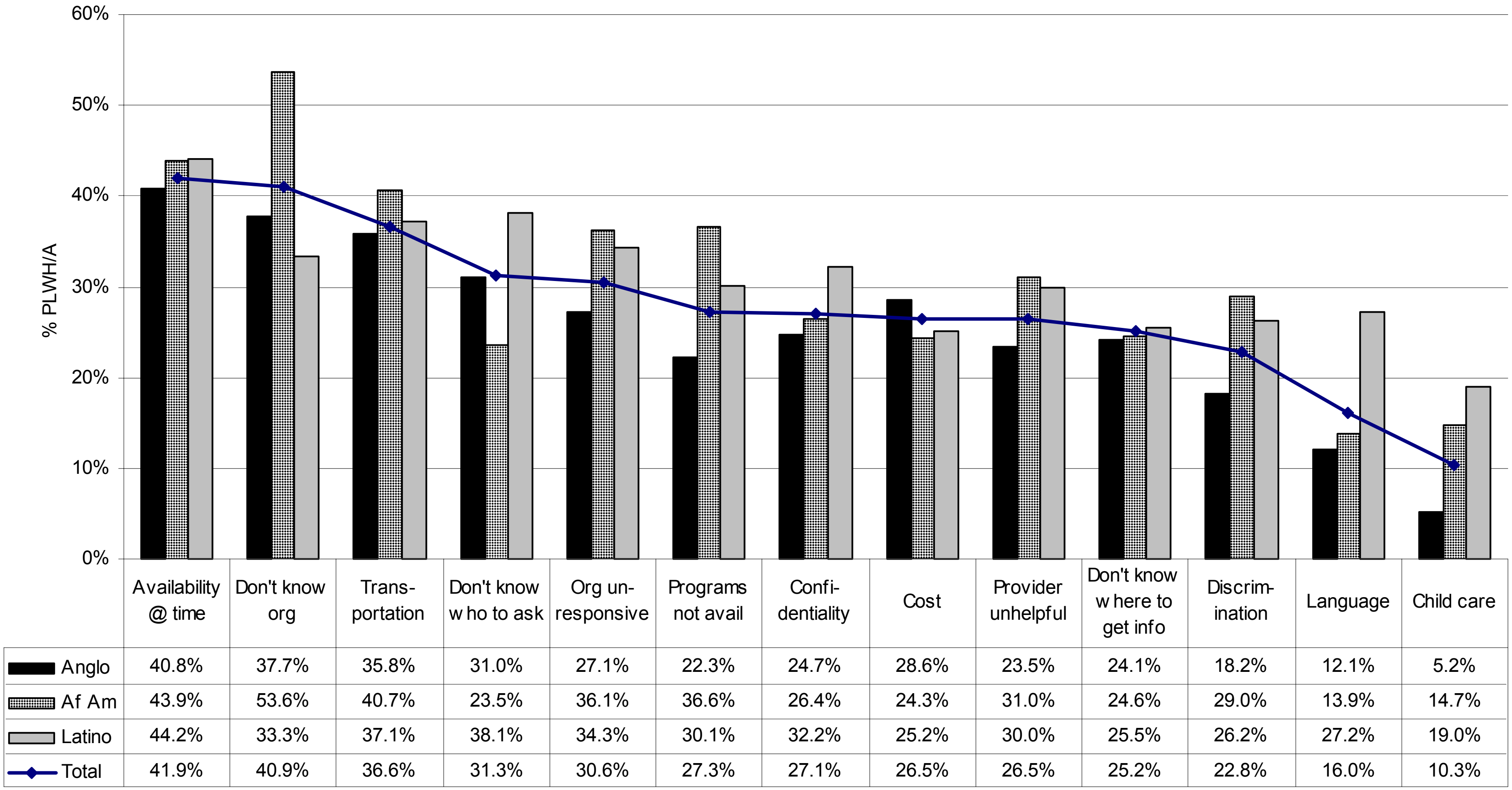
	Availability @ time	Don't know org	Trans-portation	Don't know who to ask	Org un-responsive	Programs not avail	Confi-dentiality	Cost	Provider unhelpful	Don't know where to get info	Discrim-ination	Language	Child care
■ MSM	38.2%	35.8%	34.7%	30.2%	30.8%	23.3%	24.1%	24.3%	25.8%	23.8%	20.6%	16.0%	7.6%
▭ MSM/IDU	56.8%	50.8%	38.5%	30.6%	27.7%	32.1%	27.6%	34.3%	21.3%	32.5%	24.6%	18.8%	9.6%
▨ IDU	45.0%	58.1%	43.2%	30.6%	25.9%	39.8%	32.7%	25.9%	25.1%	21.9%	27.9%	10.9%	21.5%
▦ Hetero	53.8%	52.9%	41.9%	40.9%	37.4%	40.6%	44.5%	38.3%	39.4%	32.6%	33.5%	19.2%	19.8%
◆ Total	41.9%	40.9%	36.6%	31.3%	30.6%	27.3%	27.1%	26.5%	26.5%	25.2%	22.8%	16.0%	10.3%
● Problem	1.7	1.8	1.8	1.8	1.8	1.6	1.7	1.8	1.8	1.8	1.6	2.0	1.9

Figure 9-12 Barriers to Prevention Services by Gender



	Availability @ time	Don't know org	Trans-portation	Don't know w ho to ask	Org un-responsive	Programs not avail	Confi-dentiality	Cost	Provider unhelpful	Don't know w here to get info	Discrim-ination	Language	Child care
■ male	40.7%	39.5%	35.9%	30.7%	30.7%	26.0%	25.8%	25.6%	25.1%	24.7%	21.7%	15.7%	8.5%
▨ Female	56.8%	50.8%	38.5%	30.6%	27.7%	32.1%	27.6%	34.3%	21.3%	32.5%	24.6%	18.8%	9.6%
◆ Total	41.9%	40.9%	36.6%	31.3%	30.6%	27.3%	27.1%	26.5%	26.5%	25.2%	22.8%	16.0%	10.3%

Figure 9-13 Barriers to Prevention Services by Ethnicity



	Availability @ time	Don't know org	Trans-portation	Don't know who to ask	Org un-responsive	Programs not avail	Confi-dentiality	Cost	Provider unhelpful	Don't know where to get info	Discrim-ination	Language	Child care
■ Anglo	40.8%	37.7%	35.8%	31.0%	27.1%	22.3%	24.7%	28.6%	23.5%	24.1%	18.2%	12.1%	5.2%
▨ Af Am	43.9%	53.6%	40.7%	23.5%	36.1%	36.6%	26.4%	24.3%	31.0%	24.6%	29.0%	13.9%	14.7%
░ Latino	44.2%	33.3%	37.1%	38.1%	34.3%	30.1%	32.2%	25.2%	30.0%	25.5%	26.2%	27.2%	19.0%
◆ Total	41.9%	40.9%	36.6%	31.3%	30.6%	27.3%	27.1%	26.5%	26.5%	25.2%	22.8%	16.0%	10.3%

Provider Information

To determine the current availability of prevention-for-positives programs, providers completed a provider information form. As noted in Section 3, Provider Information Form, the response rate was low – 12 out 58 – but those responding were among the largest providers of prevention services in Long Beach. Given the small response rate, the following information may not be representative of all providers serving Long Beach PLWH/A.

In general the information from discussions and the information form indicate that programs for prevention-for-positives are in their infancy. Most revolve around discussion and counseling, but few involve partners, and none use any kind of consistent follow-up or outcomes based programming. There is no special staff training for programs and any accepted protocols or curriculum. This is an area that requires substantial development.

Prevention For PLWH/A

As shown in Table 9-1, of the providers that responded to the survey, the most prevalent prevention service targeted to HIV positive individuals is counseling (67%) followed closely by support groups (58%), monitoring of HIV status (50%), adherence programs (50%), and behavior modification sessions (50%). Very few providers offer hotline/chat lines, partner notification, or prevention case management. Agencies also mentioned mental health treatment and educational information on safer sex habits as program informing PLWH/A about prevention. Two agencies included peer programs where HIV positive peers intervene, counsel, or provide support.

Table 9-1 Prevention-for-Positives Services

Prevention Service for Positive Individuals	# of agencies	Percent of agencies
Counseling	8	66.7%
Support Groups	7	58.3%
Adherence Programs	6	50.0%
Behavior Modification Sessions	6	50.0%
Monitor HIV status	6	50.0%
Safer behavior Workshop	5	41.7%
Newsletters	5	41.7%
Prevention Case Management	3	25.0%
Partner Notification	2	16.7%
Hotline/ Chat line	1	8.3%

Most of the agencies indicated that programs are for both men and women. About a quarter said their services were for men only. A few agencies noted they provided prevention services targeted to transgenders infected with HIV.

When agencies described their services they were more likely to note that the services were for communities of color, and particularly MSM of color. Few agencies mentioned having programs that particularly targeted heterosexuals or IDUs. This reinforces the large percentage of IDUs and heterosexuals who report problems accessing programs or finding the programs useful.

The services offered roughly correspond to consumer demand, where support groups and education were the most needed services. Several of the agencies that responded to the questions noted that they reached fairly large number of individuals in their prevention-for-positives programs. Of the six agencies that reported face-to-face sessions, most said they reached over 100 people. Of the four that said they did phone, they contacted between 200 and 500 PLWH/A. Group settings accommodated 11 to 1000 persons.

While these figures come for a small number of the total providers, if they hold true to all prevention-for-positives programs, it indicates that there is room for more personalized and ongoing programs that target those most at risk for transmitting HIV.

Prevention for Partners

Very few agencies that completed a provider information form offer any kind of prevention to partners. Only one agency mentioned partners' workshops, and two reported a program where they attempt to obtain partner agreements. There were expectedly fewer people reached in group settings, and much more face-to-face and phone communication.

This area appears to be a service that could be expanded with considerable impact on the infection rates.

Outreach to Positive Populations

Addressing a need identified by consumers, several of the agencies report outreach to high-risk populations (see Table 9-2), particularly services for drug users. However, it is rare that the program have specific prevention material for HIV positive persons. Most outreach efforts are targeted to groups rather than individuals.

Table 9-2 Prevention-for-positive: Outreach programs

Prevention Outreach for Positive Individuals	# of agencies	Percent of agencies
Access to Substance Abusers	7	58.3%
STD test	7	58.3%
TB test	7	58.3%
12-step/ abstinence	7	58.3%
Neonatal Clinic	3	25.0%
Family Planning	3	25.0%

10. OUT-OF-CARE PLWH/A

PLWH/A with History of Being Out-of-care

For the purpose of this report, 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 PLWH/A report a history of being out-of-care with 11 currently not having seen a doctor in more than 12 months.

Table 10-1 presents the age, gender, racial/ethnic, and risk group distribution for the PLWH/A with a history of being out-of-care. It indicates that:

- The majority of PLWH/A out-of-care are between 31 and 50 years of age. Yet, a substantial number of the out-of-care are over the age of 50. Five out of the 11 PLWH/A who are currently out-of-care are over 50 years of age. As PLWH/A live longer, the older population may face different challenges in accessing care.
- Similar to the overall sample, out-of-care PLWH/A are much more likely to be males. However, a greater proportion of women (15%) have a history of being out-of-care than are found in the overall sample (11%).
- Nearly half of the out-of-care are Anglos, which perhaps reflects their longer history managing their HIV. However, five out of the currently out-of-care are Latinos accounting for about 44% of those who currently have not seen a doctor in over 12 months.
- MSM are far more likely than PLWH/A from other risk groups to go periods of 12 months or longer without seeing a doctor. This again may reflect their longer history with HIV but the high percentage of MSM who are currently out-of-care may also suggest that the present system of care is not appropriately meeting their needs. This is perhaps a greater concern for MSM of color. While not shown in the table, 44% of the MSM currently out-of-care are Latino and an additional 18% are African American.

In addition, not shown in the table is that:

- More than 40% of the out-of-care have less than a high school education, compared to about 28% of the overall sample of PLWH/A.
- The proportion of out-of-care and in-care that are employed is about the same. However, a significant greater proportion of the 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 seeking employment.
- More than half (59%) of the out-of-care report an annual income of less than $8,600, with 85% of the currently out-of-care earning less than $8,600 annually.
- Surprisingly, PLWH/A with a history of being out-of-care (83%) are more likely than other PLWH/A to have health insurance (80%). However, the currently out-of-care are less likely (58%) to have insurance than other PLWH/A.

Table 10-1 PLWH/A with a History of Out-of-care: Demographic Profile

	History of Out-of-care		Currently Out-of-care*	
	N=53	%	N=11	%
AGE GROUP				
19- 30	1	2.5%	0	3.0%
31-40	19	37.6%	4	36.2%
41-50	18	36.7%	2	15.3%
51+	11	23.2%	5	45.6%
Gender				
Female	8	15.0%	1	6.6%
Male	45	85.0%	10	93.4%
RACE/ETHNICITY				
African American/Black	12	22.5%	2	21.3%
Anglo/White	26	49.0%	4	33.9%
Latino	14	26.7%	5	44.3%
API and Other	1	1.8%	0	0.5%
RISK GROUP				
MSM	33	62.1%	10	93.4%
MSM/IDU	6	11.9%	0	0.0%
IDU	7	13.8%	0	0.5%
Hetero	6	12.2%	1	6.1%

*Due to the small sample size the percentages reported may not be reliable.

Stage of Infection

The out-of-care PLWH/A (69%) are more likely than other PLWH/A (62%) to have been told that their infection has progressed to AIDS. However, currently out-of-care are not any different than other PLWH/A in regards to stage of infection.

More than one third (36%) of the currently out-of-care have known their HIV status for less than six years and 67% report having symptoms. Those with a past history of being out-of-care (43%) are more likely to have had HIV for longer than 12 years, and a majority (62%) report having symptoms. In addition, a much higher proportion of the out-of-care (53%) than all other PLWH/A (25%) report current t-cell counts below 350 cells/uL. The lower t-cell counts and the presence of symptoms is alarming and suggests that the care system is not meeting the needs of almost 25% of the PLWH/A in the 2003 Needs Assessment who have interrupted or suspended their medial care treatment.

The out-of-care are more likely than all PLWH/A to say that their physical health is less than good, with 75% of the currently out-of-care saying their health is fair or poor, and 65% of the PLWH/A with a history of being out-of-care saying their health is fair or poor.

On the other hand, the currently out-of-care report better emotional health, with about 80% saying their emotional is good to excellent. Those with a history of being out-of-care do not differ from other PLWH/A in regards to their assessment of their current emotional health; however, they are more likely than other PLWH/A to report an improvement in emotional health.

Medication Adherence

Over 60% of the out-of-care PLWH/A report currently taking anti-retroviral medications and/or protease inhibitors, and 76% of the currently out-of-care report taking medications. However, out-of-care PLWH/A have a difficult time adhering to their medications with 59% of those with a history of out-of-care skipping their medications and 82% of the currently out-of-care not taking their medications as prescribed. One currently out-of-care and 8 PLWH/A with a history of out-of-care have stopped taking their medications.

Table 10-2 shows the top five reasons that the out-of-care PLWH/A report for not taking their medications as prescribed. For out-of-care PLWH/A, similarly to all PLWH/A, forgetting to take the medications is the first reason they do not adhere to their medication regimen.

Table 10-2 Top Reasons for Skipping Medications

Top Reasons	N=	Percent
Forgot	18	42.7%
Side effects	13	29.8%
Just did not want to take them	10	23.3%
Ran out of medications	9	22.2%
Difficult schedule	9	20.4%

Co-Morbidities

The out-of-care have about the same incidence of hepatitis in the last year as all PLWH/A. However, 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.

Overall, out-of-care PLWH/A (62%) are less likely to report a history of mental illness than other PLWH/A (65%). However, out-of-care PLWH/A are more likely than other PLWH/A to report some level of dementia. The out-of-care are slightly less likely to report anxiety (42%) and depression (58%) compared to 46% of other PLWH/A who report anxiety and 61% who report depression – although sample sizes are too small to say this with certainty.

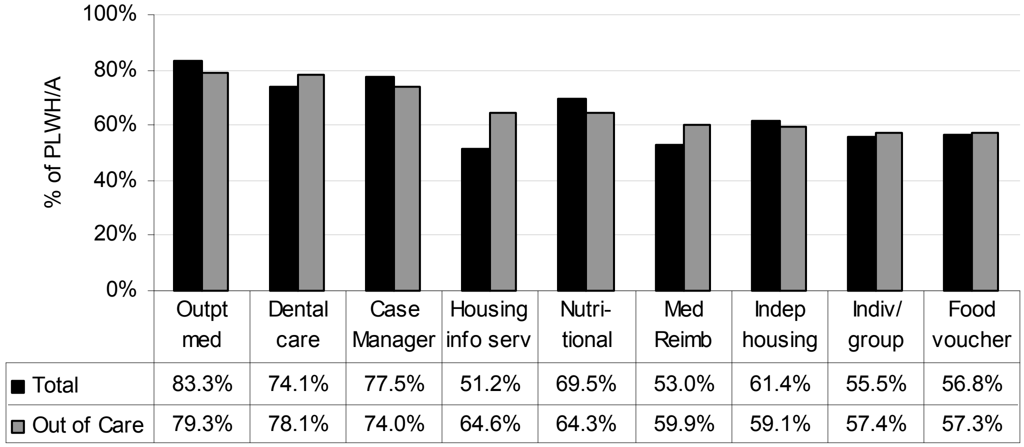
PLWH/A who are out-of-care are more likely than other PLWH/A to currently use substances. Alcohol is the most common substance used by all PLWH/A, but PLWH/A with a history of being out-of-care (60%) are far more likely than other PLWH/A to have used it in the past year.

Besides alcohol, the top substances used by out-of-care PLWH/A are marijuana (34%), crystal meth (20%), poppers (14%), and crack/cocaine (12%).

Top Service Need

Figure 10-1 shows the top 10 service needs for the out-of-care PLWH/A compared to the total sample of PLWH/A. Overall, the out-of-care tended to have similar rankings for service needs as all PLWH/A. Housing information services, and medication reimbursement are more important for the out-of-care than for other PLWH//A.

Figure 10-1 Top Service Needs for Out-of-care PLWH/A



	Outpt med	Dental care	Case Manager	Housing info serv	Nutri-tional	Med Reimb	Indep housing	Indiv/ group	Food voucher
■ Total	83.3%	74.1%	77.5%	51.2%	69.5%	53.0%	61.4%	55.5%	56.8%
▨ Out of Care	79.3%	78.1%	74.0%	64.6%	64.3%	59.9%	59.1%	57.4%	57.3%

Barriers

Using a five point scale where “1” indicates a very small problem in seeking care and a “5” represents a big problem, participants were asked to rate 30 items in terms of the level of difficulty they represented for them when trying to access care. Table 10-3 shows the top ten reasons along with the average score indicating how important a barrier each of the items represented for them for out-of-care PLWH/A as well as for the general sample of 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 feels 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. For other PLWH/A this did not represent as big a problem with 60% reporting it as a barrier and an average barrier score of 2.9, less than a moderate problem.

The out-of-care rate 20 out 30 barriers higher than other PLWH/A. The exceptions and the biggest differences in ratings include navigating the system, fear of lack of confidentiality and being terminated or suspended from services. These three barriers represent a much greater concern for PLWH/A in care than those out-of-care.

Table 10-3 Reasons for Not Seeking Care

REASON	% With Problem		Average Score 5=very big 1=very small	
	Out-of-care	Total	Out-of-care	Total
State of mind	78.6%	60.0%	3.2	2.9
Not knowing that service/treatment was avail	74.4%	55.2%	3.3	3.5
Physical health	72.9%	52.6%	3.1	2.8
Not knowing location of service	72.3%	60.8%	2.9	3.1
Not knowing who to ask for help	71.9%	56.2%	3.2	3.2
Wait for an appointment	66.9%	56.6%	3.0	3.0
Not understanding instructions	62.7%	46.0%	2.8	2.8
Denial	60.9%	51.2%	3.5	2.8
Not knowing needed med service	59.9%	46.6%	3.0	2.5
Experience or expertise of provider	56.8%	46.7%	2.7	2.9

Qualitative Comments

While it was difficult to recruit PLWH/A who are currently out-of-care, several focus group participants had experienced periods of time when they were unconnected to care. As shown by the quantitative data, the PLWH/A tend to be out-of-care because of individual barriers they face. For instance, an African American IDU Female says, *“The main reason I didn't go to the doctor is because I was on drugs and I didn't want the doctor to know I was on drugs. See I didn't know what the doctor was going to do if he found out I was on drug.*

Another IDU African American female attributes her delayed care to fear of lack of confidentiality and her own drug use. She says, *“I didn't go to the support groups, I don't do none of that because people that I was out there getting high with…I didn't want them knowing that I was HIV positive. My neighbors…you know what I'm saying? And that's what's hurting me. It's hurting me because I haven't been in the groups, but...And when I first got diagnosed, I was like that, too. I didn't give a fuck...somebody gave it to me, so I was out there...I went crazy!”*

Some might stop because of adherence issues like this African American substance using female who recalls, *“Because of the liver and kidney… I have problems with taking meds. I stopped treatment because I stopped taking my meds. I did have treatment when I found out that I was positive. I got treated. Then six to eights months, I stopped. I mean I stopped taking my medications. I told my doctor I wasn't taking my medications and I stopped going to the doctor.”*

Yet, others face structural barriers that limit their access to care. A heterosexual Anglo woman shared her situation as follows, *“I'm very dissatisfied with the fact I haven't seen a doctor in 3 years and the problems I’m having with my health insurance Health Net-Medical and services trying to get medical care.”*

Prevention and 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 them than their partner. In fact, almost half disagree with the statement that sex is better without using a condom, in contrast to just over a third of all PLWH/A.

There is a sense that those out-of-care believe they can design their own prevention. For example they are much more likely than all PLWH/A to say they know when their partner is infected with HIV, and they are more likely to pay attention to the status of their partner when having sex. They are more likely to have made a commitment to themselves to only have safer sex.

At the same time they are heavier party drug users, and over 30% say they aggress that hen they are high on drugs they don't think much about transmission of HIV infection to others. Still, they are less likely than all PLWH/A to report that they are high on alcohol or drugs when they have sex.

Prevention Needs of the Out-of-Care and Gaps in Prevention Services

Those currently out-of-care report a greater than average need for HIV testing, outreach, Internet services, individual counseling, free condom distribution. As noted above, about three-quarter report a need for testing, suggesting that there is a high degree of denial among this population. There is no need-utilized gap for HIV testing. Among those who have a history of out-of-care, there is a greater need for partner notification, individual counseling, but not outreach work or Internet accessed information.

Next, half of the currently-out-of-care say they need individual counseling, and 31% need Internet services and outreach (32%). Both these services are higher than among PLWH/A. 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.

11. SUMMARY AND CONCLUSION

Continuum of HIV/AIDS Services (CHS)

A Continuum of HIV/AIDS Services (CHS) is presented that targets services to appropriate populations and suggests outcomes.

This Needs Assessment has developed a comprehensive continuum of HIV/AIDS services (CHS) that includes services that increase public awareness, target HIV negative populations of high-risk, and HIV positive persons and partners that engage in behaviors that transmit HIV infection. The continuum also includes technical assistance for providers and administrative tasks for the grantee, including assessment and evaluation.

There is an explicit link between the CHS and Continuum of Care.

The report suggests how the CHS links to the overall continuum of care (COC) for HIV services, and how this link has to be further developed for a comprehensive continuum of prevention and care services.

Using epidemiological, survey, and focus group data, this report presents the care and prevention needs for PLWH/A.

The analysis of epidemiological, survey, and focus group data highlights the care and prevention service needs of PLWH/A in Long Beach. (This Needs Assessment does not address t prevention services for the general and high-risk HIV negative populations.)

Methodology

Secondary data: HARS, IMACS.

Survey of 213 PLWH/A with over samples of hard-to-reach populations.

Five focus groups.

Provider survey.

PCH analyzed secondary data, collected and analyzed a consumer survey of 213 PLWH/A, and conducted and analyzed five focus groups of selected at-risk populations. Over samples of women, Latinos, and IDUs were achieved to permit reliable subpopulation analysis, and are weighted back to their proportion when referring to the overall impact of the epidemic. API and “other” ethnic groups were not sampled in sufficient numbers to provide meaningful analysis. In addition, PCH assisted the Long Beach Department of Health in designing and collecting provider information on prevention-for-positive programs.

Epidemiological Estimates and Trends

The 4,926 PLWH/A in Long Beach represent 11% of PLWH/A in LAC.

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.

The number of PLWA has increased 18% between

Primarily due to lower mortality rates, since 1997 the number of

1997 and 2002.

PLWA has increased 18% in the Los Angeles County (LAC) EMA, about 24% in SPA 8, and 30% in Long Beach. While PLWA in Long Beach accounted for about 9% of all PLWA in the EMA in 1997, by 2002 they represented about 11% of all PLWA.

73% of PLWH/A are MSM, and this has remained fairly constant.

58% Anglo, 24% Latino, 15% African American. Latinos and African Americans are increasing.

In Long Beach, MSM (including MSM/IDU) represent about 73% of the PLWH/A. Fifty-eight percent (58%) are Anglo, 24% are Latino, 15% are African American, and three percent are other ethnicities. The percentage of MSM living with HIV and AIDS has remained fairly consistent for several years, although the newly infected MSM are now more likely to be African American and Latino.

165 IDUs and 175 MSM/IDU and represent about 10% of PLWA. They are disproportionately represented by African Americans.

Among people living with AIDS in 2002, there were about 165 IDUs in Long Beach, and 175 MSM/IDUs. Since 1997 the percentage of IDUs living with HIV and AIDS has remained constant at between 9% and 10%. 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.

The percentage of heterosexuals living with AIDS has increased slightly from 5% of PLWH/A in 1997 to 7% in 2002. They are much more likely to be people of color. More than 70% are women.

There are 138 heterosexuals living with AIDS in Long Beach, and the proportion of heterosexuals (non-IDU) living with AIDS has increased slightly from just over 5% in 1997 to 7% at the end of 2002. While heterosexuals represent a small proportion of PLWH/A in Long Beach, since 1997 their numbers have increased 80%, and heterosexuals 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 American. More than 70% of the heterosexuals are women.

In terms of planning services, there are over twice as many Anglos living with HIV and AIDS in Long Beach than any other ethnic populations.

However, compared to the general population Anglos and African Americans are disproportionately represented while Latinos are under-represented.

There are over twice as many Anglos living with HIV and AIDS in Long Beach than other ethnic populations. Among PLWA, Anglos represent 52%, Latinos 25% and African Americans 20%. 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. While Anglos living with AIDS have increased 24% between 1997 and 2002, during this period there has been a 57% increase in Latinos living with AIDS While no estimates are available, based on HIV testing data, the proportions of living HIV cases are likely to have higher percentages of Latinos and African Americans.

Virtually all PLWH/A in the sample live under 300% of the FLP. 70% of the

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

Over 80% of PLWH/A don't work. Over 60% of the asymptomatic PLWH/A report not working.

Eighty-two percent (82%) of PLWH/A do not work. Symptomatic PLWH/A are much more likely not to work than asymptomatic PLWH/A. Somewhat surprising is that asymptomatic PLWH are less likely to work (68%) than asymptomatic PLWA (60%). Latinos are morel likely than African Americans or Anglos to report working. This may be because they are less likely to be eligible for Medi-Cal and Medicare benefits.

PLWH/A are getting older. The majority are over 40; over 10% are 55 and older.

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

MSM/IDU and IDUs account for about 20% of PLWH/A, and they are the heaviest drug users. MSM/IDU tend to use "party drugs". Poppers are used primarily among MSM.

IDUs and MSM/IDUs account for nearly 20% of the PLWH/A and they continue to be the highest current drug users in Long Beach. A majority use alcohol and over a third use marijuana, crack/cocaine, and crystal meth. Poppers are much more likely to be used by MSM/IDUs and MSM.

MSM/IDUs are likely to be Anglo while IDUs are more likely to be African American.

While MSM/IDUs are more likely to be Anglo, IDUs are more likely to be African American and heterosexuals, and IDUs are more likely to use crystal-meth and heroin than other risk groups.

Behavior that transmits HIV is highly related to drug abuse. Reduce drug abuse and reduce new infections.

The association between behaviors that transmit HIV and substance abuse is so high that any impact on the use of "hard" or "party" drugs is 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.

Homelessness

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. Those who have accessed care more recently are more likely to be homeless than those with a longer history of care. Fifty-three percent (53%) of African Americans and 64% of IDUs report a history of transitional housing, and a very high 66% of those who have been recently incarcerated report being homeless in the past two years.

STDs

Over 40% of PLWH/A report having had hepatitis. Nearly 60% of the IDUs report having had Hep C.

Hepatitis A, B, and C are the most frequently reported STDs among PLWH/A in Long Beach, and they are highly related to drug use. 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.

A statewide trend of increased infection among young gay men, particularly among communities of color, is confirmed by the recent syphilis outbreak – particularly among MSM/IDUs.

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 report by MSM/IDU (8%). This confirms a statewide trend of increased infection among young gay men, particularly among communities of color.

Mental Illness

65% of PLWH/A report having a treatable mental illness – including depression and anxiety.

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.

Over 44% of PLWH/A report a history of serious mental illness.

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.

Over 60% of PLWH/A report some depression.

Depression is the most frequently diagnosed mental illness reported by PLWH/A (61%). It tends to be highest among MSM/IDUs (74%) and IDU (67%) PLWH/A. Latinos (48%) report a lower incidence of depression than other ethnicities.

Those out-of-care report less anxiety than those in

Nearly one half of PLWH/A (46%) report a diagnosis of anxiety in care.

the past two years. Heterosexuals (34%) and Latinos (33%) are less likely to have received a diagnosis of anxiety than any of the other race and risk groups. PLWH/A who have been out-of-care for more than six months (18%) and asymptomatic PLWH (36%) tend to report the lowest incidence of anxiety.

Outcomes

Deaths

Death or case-fatality rates have been declining since 1997. There is no significant difference between African Americans and Anglos. Latinos have the lowest rates, but this may represent problems in tracking.

In Long Beach case-fatality rates (deaths among a cohort of those in care) have fallen since 1997. They are comparable to LAC from 1997 to 2000, but seem to be significantly lower in 2000; (this requires further investigation as it may be a reporting error). However since 2001 they have leveled out at about 8%. African Americans and Anglos have had about the same rate since 1997. Latinos have had the lowest rate– but this rate may reflect the difficulty in tracking Latinos in the care system.

Progression to AIDS has significantly declined since 1997. However LAC has a steeper decline than Long Beach.

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%.

The number of new AIDS cases has dropped by risk group. Again, the drop is not as steep as that in LAC, with MSM continuing to account for the vast majority of new AIDS cases.

With a higher rate of progression to AIDS, the proportion of Long Beach AIDS cases in LAC is increasing.

The impact of the lower rate of decline means that the proportion of AIDS cases in Long Beach is increasing, up from 11% in 1997 to 15% in 2001.

Medication

36% of PLWH and 85% of PLWA report taking antiviral medication and/or protease inhibitors

As expected, there is a strong linear 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.

However, men are much more likely to take medication than women, and heterosexuals and homeless PLWH/A are also much less likely to take medication. This suggests that increased medication to control HIV may be indicated for these populations.

Adherence

A relatively large 49% of PLWH/A report having stopped taking their medication.

Forty-nine percent (49%) of PLWH/A in Long Beach report having stopped taking their medication in the past —14% with the advice of their doctor. Women have more difficulty adhering to their medical regimen and are more likely to have stopped taking their medication. PLWH who are symptomatic are more likely to stop taking their medication.

African Americans and MSM/IDU have the most difficulty adhering to their medication.

African Americans and MSM/IDU have greater difficulty in adhering to their medication than other ethnic populations and risk groups.

Forgetting to take the medication, side effects, and not wanting to take the medication are the main reasons for lack of adherence.

The two primary reasons for not adhering to a medication regimen are: 1) 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.

Physical and Mental Health

Over 60% of PLWH/A say they are in better physical health now than when they first sought treatment. Three-quarters feel the same or better.

While there is no trend data, it would be expected that a successful continuum of care would improve or maintain the physical and emotional health of PLWH/A. 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%), however only about 15% report their current health as excellent.

Those who are symptomatic are more likely to do worse compared to LAC.

On a more negative note, almost 60% of those who are HIV positive and symptomatic report physical health as the same (29%) or worse (29%) compared to when they first sought treatment. Given their symptomatic status, it is not surprising that they have the least stable physical health, but, compared to LAC, they report significantly worse physical health.

About half of PLWH/A say their emotional health is better than when they first sought treatment.

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%).

PLWH/A in LAC report better emotional health than those in Long Beach.

In contrast to their physical health, those who are HIV positive and symptomatic report the greatest improvement in their emotional health, with 58% reporting better emotional health than when they were first diagnosed with HIV. Still, compared to LAC, a significantly greater proportion of PLWA in LAC report that their emotional health is better (61%) than those in Long Beach (46%).

Particularly among PLWH/A who are symptomatic, there is room to improve their physical and emotional health status.

This data suggest that the system is producing positive physical and mental health outcomes for the majority of PLWH/A, but particularly among the HIV positive who are symptomatic, there is considerable room for improvement.

Access to Services

Insurance

80%of PLWH/A in Long Beach report having some form of insurance. This is much higher than PLWH/A in LAC.

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. One indicator of the success of the system is that far more PLWA (90%) report insurance, than those who are HIV positive and asymptomatic (53%)

86% report either Medi-Cal or Medicare. 22% report both Medi-Cal and Medicare and 11% report private insurance.

Latinos are less likely to have Medicare.

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. Latinos are the least insured ethnic population, with the largest difference in Medicare coverage.

MSM/IDU have some of the greatest needs and are most likely to be insured.

MSM/IDU – a risk group that consistently has greater needs – is also more likely to have insurance than other risk groups.

Disability

Because AIDS is considered a disability, those with AIDS are much more likely to be on disability.

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 supplementary income. There is a much higher rate of PLWH/A on SSDI in Long Beach than in LAC.

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. In contrast, 22% of LAC PLWH/A report receiving SSDI.

About a third of PLWH/A receive SSI. 21% receive housing subsidies. While SSI is mostly received by communities of color, housing subsidies are more likely among Anglos, men, and IDUs.

Indicative of the low income of PLWH/A, close to one-third (31%) report receiving SSI and 21% report receiving housing subsidies. Men and women are equally likely to receive SSI. However, MSM/IDU, IDUs, and African Americans are more likely to receive SSI than other ethnic or risk groups. This pattern does not hold true for rental subsidies. Men are more likely than women to receive rental supplements; Anglos are more likely to receive rent subsidies than other ethnic populations; and IDUs are more likely to receive rental subsidies than other risk groups.

Less than 1% report receiving direct financial assistance.

Less than one percent of the PLWH/A report receiving direct emergency financial assistance (DEFA) usually used for utilities, rent, or emergency medical treatment. This compares to 2.4% in LAC, and both are lower than in most other EMAs.

Few receive food stamps –African American women and MSM are more likely than other risk groups to receive them.

Surprisingly, only 12% report receiving food stamps and two percent report receiving TANF/CalWorks. Women (21%), African Americans (20%), and MSM (37%) are much more likely to receive food stamps than any other group

An estimated 6% receive some form of VA benefit.

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.

Top Needs

Each PLWH/A who participated in the survey was asked if they "needed the service in the past year."

Three top needs:
1. Outpatient medical care
2. Case management
3. Dental

The top two services that PLWH/A in Long Beach perceive they need the most are outpatient medical care (83%) and case management (78%).

Overall the PLWH/A in Long Beach and LAC rank services similarly. 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.

4 out of top 10 needs are in the core medical services. Men tended to report more need than women.

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%). In LAC, PLWH/A also ranked outpatient medical care as their number one need. Men tend to report a greater need for these services than women.

Case management was ranked second in Long Beach and fourth in LAC. Dental care was ranked third in Long Beach and second most important in LAC.

After medical care, PLWH/A said they needed housing, taxi vouchers, and bus tokens.

Independent housing was ranked the fifth most needed service by PLWH/A in Long Beach, with 61% of the PLWH/A reporting needing the service in the past year. This is similar to the 61% who ranked it as their sixth most important need in LAC. After independent housing, over 50% of Long Beach PLWH/A say they need housing information, and over 40% need rental subsidies.

Along with independent housing, over half say they need housing information and rental subsidies.

Taxi vouchers and bus tokens are the sixth most needed service for PLWH/A in Long Beach while LAC PLWH/A ranked this service fifth. Medical case management (58%) was ranked seventh in Long Beach but was not named among the most needed services in LAC.

Food, while ranked by PLWH/A among the top ten services, rank them lower than the PLWH/A in LAC.

Two out of the three food services are among the top ten service needs of PLWH/A in Long Beach. More than 55% of the PLWH/A feel they need food pantry services and food vouchers. LAC PLWH/A ranked food services higher than Long Beach PLWH/A, with food pantry services being their third most important need and food vouchers being the seventh ranked need. Women report needing food services more than men.

Over 50% of PLWH/A in

Although mental health and substance abuse services are not ranked

Long Beach say they need mental health services.

Perceived need for substance abuse services, even among IDUs, is relatively low.

among the top services needed by PLWH/A in Long Beach (or LAC), over half of the participants said they need mental health group or individual counseling. Substance abuse treatment and counseling services tend to be among the lowest ranked services by PLWH/A in Long Beach with less than one quarter of the PLWH/A stating they needed the service in the past year.

About half of PLWH/A say they need emergency financial assistance.

Emergency financial assistance is the highest ranked service among the "other service" category with close to half of the PLWH/A reporting it as a need in the past year. However it did not make the top ten service needs in LAC either.

Adult day care and children's day care are the lowest ranked service needs.

African Americans have a higher need for wrap around services, information services, and substance abuse treatment.

In Long Beach, African Americans report a substantially higher need than Anglos or Latinos for taxi vouchers and bus tokens, food vouchers and food pantry, housing information, peer counseling, prevention information, emergency and transitional housing, and residential substance abuse services.

Anglos and African Americans tend to report higher needs for case management, nutritional education, independent housing, food pantry, and rental subsidies than Latinos.

Latinos report a greater need for medication reimbursement, and transportation.

Although Latinos report less need for services than other ethnic groups, Latinos tend to report greater needs for medication reimbursement, van transportation, assistance paying insurance premiums and day care services than Anglos or African Americans.

MSM/IDUs have the greatest number of service needs.

MSM/IDU report higher needs than other PLWH/A for 21 out of the 33 services. The top three needs for MSM/IDU are case management (90%), dental care (85%), and food pantry (76%), and a much greater proportion of MSM/IDU than any other PLWH/A feel that these are services they need.

The top need of IDUs is independent housing, other housing services, and transportation.

The top need for IDUs is independent housing (79%), which is the fifth ranked service among all PLWH/A (61%). They also state a greater need for housing information (70%) than other risk groups. The second most important need for IDUs is taxi vouchers (74%) followed by case management, food pantry, and outpatient medical care (all tied at 72%).

Overall, heterosexuals report the lowest needs. This may be because the majority are women who may be getting their services elsewhere, outside of the Ryan White Care system.

Gaps

If PLWH/A need, but don't ask for a service it may reflect lack of knowledge about where to go or a belief of ineligibility.

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 largest need-ask gaps are for independent housing, legal services, and food vouchers.

The need-ask gap is rather high with more than a quarter of the services having a difference of 10% or more. Services with a large unmet need (expressed need minus reported demand) are independent housing (13%), legal services (13%), food vouchers, rental subsidy, dental care, and nutritional education (all at 12%).

PLWH/A sometimes ask for, but do not receive a service. The largest ask-receive gaps are for financial assistance, food vouchers, and rental assistance.

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

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, which can be classified into the more general categories of "organizational", "structural", or "individual" barriers.

Problems Faced

The biggest barriers to accessing services are lack of knowledge and the PLWH/A's own limitations.

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.

While fewer PLWH/A in Long Beach mentioned barriers, for those that did, they were larger barriers than PLWH/A in LAC.

The size of the individual barriers ranged from moderate to big for "not knowing about treatments" and small to moderate for "not understanding instructions". While fewer Long Beach PLWH/A had problems, those that did, had bigger problems than those in LAC.

46% of PLWH/A say they have structural constraints, including rules and regulations and red tape.

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. Notably PLWH/A in Long Beach have fewer barriers with structural problems than PLWH/A in LAC.

The second largest structural problem is the amount of waiting to get an appointment and seeing the provider.

The largest structural problems faced by PLWH/A appear to be 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 said they had problems seeing a specialist and 33% had problems with transportation – a large number but not as large as in LAC.

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.

About 47% of PLWH/A report lack of sensitivity on the part of the providers.

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.

40% noted problems related to provider expertise.

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

Providers noted problems with recruiting and retaining qualified staff.

The factors that providers feel would have the greatest affect in improving access to care are dependent on organizational factors

They note they have some restrictions on talking about sexual and drug use behavior.

They noted a need for training on cultural diversity issues.

including funding and staff training. From the providers' perspective these include 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 said they have to address the denial of PLWH/A, reduce paperwork, and improve transportation.

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.

Waiting time and cost barriers are perceived as much higher by PLWH/A than providers.

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.

Both providers and consumers rate issues related to confidentiality and language as relatively minor barriers.

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.

Prevention Summary and Conclusions

About a third of the PLWH/A in Long Beach report that they are at risk for transmitting HIV to a partner of negative or unknown status.

About a third of the PLWH/A in Long Beach report that they are at risk for transmitting HIV to a partner of negative or unknown status. They report having sex with a regular or casual partner who is HIV negative without always using condoms or sharing needles.

Targeting PLWH/A for Prevention

There is no single demographic group that

From a prevention perspective, it would be ideal if all of those who can be targeted for prevention-for-positives.

practice unsafe behaviors were of one demographic type or lived in one area and thus could be efficiently targeted with effective prevention services. Unfortunately, those engaged in behaviors that can transmit HIV infection are not concentrated among any single subpopulation. Males, African Americans, Latinos, MSM/IDU, and heterosexuals are slightly more likely to engage in riskier behavior, but not remarkably more than Anglos, females, and MSM.

Because MSM make up the vast majority of PLWH/A in Long Beach, even with moderately risky behavior, they are the population most likely to spread HIV.

In addition, *proportions* of populations engaging in unsafe behavior do not translate into numbers of new infections. Even though MSM are not engaging in proportionately riskier behaviors, they represent the vast majority of PLWH/A in Long Beach with the largest number of individuals engaging in unsafe behaviors who could transmit HIV. Based on this, MSM should be one focus of prevention-for-positive efforts.

MSM/IDUs – of every ethnicity engage in behaviors that are very likely to transmit infection.

Of all populations that can be targeted, MSM/IDUs and MSM who use “party-drugs” appear to engage in both sexual and drug use behaviors that place negative populations at the greatest risk of infection. MSM/IDU are about 9% of all PLWH/A, but MSM who use drugs make up a far greater proportion of PLWH/A. Consequently MSM/IDUs and MSM who use party drugs should be another focus of prevention-for-positive programs.

African American men and women should be a primary target for prevention-for-positives programs.

Based on the epidemiology and relatively high incidence of unprotected sex by African American men and the disproportionate number of African American women among PLWH/A, both should be targeted for prevention-for-positive programs.

African American men are disproportionately represented among bisexuals, heterosexuals, and drug users. Given the variety of sexual partners, it is not surprising they have had the largest crossover from same-sex and drug users to the general heterosexual population. They report much higher than average unsafe behaviors, and there is a “down-low” (bisexual) subculture that should be a focus of prevention efforts.

Women are less likely to engage in risky behavior than men.

The epidemiology strongly suggests that women are at increased risk of HIV infection. Although women currently represent between 11% and 15% of the epidemic their numbers are increasing. The epidemiology strongly suggests that African American women are at high risk of infection by their partners who were infected through same-sex or drug use.

Women who abuse drugs are at a relatively high risk of transmitting HIV infection.

While men are the likely targets because they say they are more likely to bring up the condom than women, there is a significant need for programs that provide strategies for women to bring up the subject of safer practices. Although women report more condom use and fewer partners than men, a subpopulation of women who are drug users also engage in risky behavior particularly when they exchange sex for drugs or money.

Based on reported behavior Latinos may be on the threshold of expanded infection rates. Prevention-for-positive programs can provide a necessary prophylaxis for increasing infection rates.

Although current infection rates are lower among Latinos than other ethnic populations, the reported behavior of Latinos living with HIV presents a precarious scenario for HIV transmission. Latinos, particularly men, appear to engage in as much risky behaviors as other high-risk populations. Combined with lower awareness and less utilization of prevention programs, the likely consequence is a growing epidemic among Latinos, particularly Latino MSM. Effective prevention-for-positives will reduce the likelihood of a major increase in Latino infections.

PLWH/A who are under 40 engage in significantly more unsafe behavior. They overlap considerably with infected party drug users and prevention strategies should address their needs.

While young persons living with HIV are far fewer than middle and older persons living with HIV and AIDS, they are much more likely to engage in risky behavior, and therefore should be another target of prevention-for-positives. PLWH/A between the ages of 31 and 40 are significantly more likely to engage in riskier behavior than those older. Those over 51 are considerably less likely to engage in behaviors that transmit HIV infection.

Strategies that maximize fertilization and minimize infection should be developed for partners who desire children.

One constraint on condom use is that up to a quarter of PLWH/A say they would like children and therefore will not use a condom. To minimize the likelihood of infection, methods should be developed for partners that allow fertilization but minimize the risk to the uninfected mother.

Top populations for interventions are based on epidemiology and behavior. Young adults in each targeted population tend to engage in higher risk behaviors.

Based on the likelihood of infecting others, a rank order of populations that should be targeted for prevention-for-positive are:

- MSM – particularly party drug using MSM and MSM of color.
- Drug abusers – men and women.
- African Americans.
- Latino men.
- Couples desiring children.

Among these populations PLWH/A under 40 are much more likely to engage in high-risk behaviors and young adults in these subpopulations should be a focus of prevention efforts.

Specifying Outcomes

Develop explicit prevention outcomes.

The most desirable outcome for prevention-for-positive programs is the reduction in HIV infection among populations that receive interventions. Intermediate outcomes include:

- Increased use of condoms and clean needles.
- Increased commitment to safer sex.
- Increased acceptance of responsibility of introducing safer behaviors to partners.
- Increased agreement among partners to engage in safer behaviors.
- Increased requests that condoms or clean needles are used.
- Increased abstinence of illicit drug use.
- Increased adherence to drug regimen.

Programs Development

Develop innovative programs that can achieve those outcomes.

Innovative programs that achieve these specific outcomes could have a significant impact on lowering infection rates.

Adopting and maintaining safer behaviors is a complex process involving awareness, beliefs, attitudes, negotiation skills, and commitment.

In developing a comprehensive approach to prevention-for-positives the complexity of adopting and maintaining safer behavior is important. The decision to adopt and maintain safer sex or needle use first depends on the availability of the knowledge and commodities for safer behaviors and safer behaviors within the sexual or drug-using repertoire of one or both partners. Second it has to be consonant with attitudes and beliefs – or at least not the result of misperceptions and strong dislike of safer sexual and drug-use behaviors. Third, it has to be verbally or nonverbally negotiated with a partner. Fourth, partners have to be convinced of its efficacy. Fifth, it has to be a priority for PLWH/A.

Given the complexity of the process, models that have targeted specific populations for ongoing prevention-for-positive programs that monitor the client's behaviors stand the best chance of success. While one-time group education sessions may be a good way of conveying information, guidance in processing and changing behavior are better accomplished in multiple o on-going individual or small group sessions. Based on the provider information form, there are only a few agencies that have adopted small group, individual sessions, or prevention case management for PLWH/A.

Most persons accept the need to use condoms, but many don't accept the responsibility to initiate use.

Develop programs that have positives take more responsibility.

The data suggests that most persons accept the need to use condoms, even though many feel that sex is better without them. Still, many PLWH/A do not accept the responsibility of initiating condom use. An objective for prevention-for-positive programs is to change the norms so it becomes the exception <u>not</u> to use a condom. The shift in the expectations of partners will be from not using a condom to expecting that a condom will be used unless there is an explicit agreement not to use one.

Misperceptions about the efficacy of prevention have to be addressed.

Barriers to introducing condoms based on misperceptions can be addressed. For example, 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. Another misperception is that there are some persons who cannot become HIV positive for some genetic reason.

<u>Strategies can be developed to address these objectives.</u>

Target partners – regular and casual.

First partners, both regular and casual, should be the focus of prevention-for-positive programs. Participants reported that if condoms are brought up there is a large probability that they will be used. Consequently, an effective strategy to introduce condoms into the sexual discourse should be developed for targeted media, workshops, and counseling.

Prevention of HIV may be a less important motivator than enhanced status or acceptance by a partner.

While the prevention of HIV is one motive for safer behaviors, an equally persuasive message could be that engaging in safer behaviors increases your value in the eyes of your partner. Prevention messages have to assume that immediate gratification and self-esteem are major motivators for adopting and maintaining safer behaviors.

Key objective: Shift the sense of responsibility to use protection to PLWH/A – not their partner.

Disclosure is important but is not a substitute for behavior.

Second, an objective of prevention strategies should be developed to shift the sense of responsibility for using protection from the "other" person to the person living with HIV. Disclosure is part of that equation – and strategies for disclosure should be developed. However disclosure without taking the responsibility for safer behavior is less effective than visa versa. Consequently, PLWH/A must realize that disclosure is not a substitute for adopting safer behaviors.

Formalize HIV prevention-for-positives in abstinence programs.

Drug users, both IDU and non-injection drug users, face additional challenges. All different subpopulations note that getting high makes them more likely to engage in unsafe behavior. Effective abstinence programs will have a positive impact on infections, and clearly abstinence programs should have strong prevention-for-positive components.

Increase availability of needles and condoms through harm reduction.

Make prevention-for-positives as a formal part of those programs – the goal is to change the norm.

However, methadone and risk reduction programs directed at active users also need innovative and sustained prevention-for-positives programs. Clean needles and condoms have to be easily available. After that, an effective strategy could involve changing the norm of these groups to safer sex and drug use. That is, making safer behaviors the expected norm, not the exception. Being high need not be an excuse for not using a condom or sharing a needle.

Prevention has to be high on the agenda of PLWH/A.

“Not thinking about” safer behavior when high means that it is not on the top of their mind. Prevention programs that have drug users mentally rehearse safer behaviors can set the stage for greater adoption of those behaviors.

Emphasize the negative aspects of managing HIV/AIDS.

Another more general prevention-for-positives objective could be to emphasize the seriousness of the infection. Several PLWH/A in focus groups noted that advertisements of medication and other treatments have tended to show how drugs can normalize life, without emphasizing the side effects, cost, and symptoms of HIV. They suggest countering these images with the reality of the impact of HIV as a very serious chronic illness that requires substantial effort and expense to control, and often results in serious physical and mental health disabilities.

Consumer Perception of Needed Prevention Services

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.

Overall, 57% of PLWH/A in Long Beach say they have enough or too much prevention information, while 43% say they need more information. However, a majority of women (54%), African Americans (56%), IDUs (60%), and MSM/IDU (62%) say they need more information.

Providing forums for consumers fills a need and encourages

About a third of the consumers say they want more input into the process through community forums, and this can be a successful involvement and buy-in.

Increased participation by Latinos will be difficult to achieve, but important.

strategy for improving consumer input and increasing involvement – a main predictor of behavior change. The least likely to want input through community forums are Latinos, but they represent a community where involvement is most needed. There is a moderate gap between stated need and utilization of community forums.

The need to focus on Latinos is further supported by their generally lower awareness of all prevention programs.

Support groups for prevention-for-positives is the most frequently provided services and among the most frequently asked for.

About 30% say they want support groups. Women and MSM/IDUs say they would like groups the most, and these are two populations where support groups could be used effectively. Women often report feeling isolated and have difficulty contacting others like themselves. Exchanging and reinforcing beliefs about efficacy and partner negotiation may prove effective. Based on the provider information forms, counseling and support groups are the most provided services for PLWH/A, and it is not surprising that there is a small gap between stated need and utilization of support groups.

Support groups among MSM drug users meets a demand and could be effective.

MSM/IDUs are among the most likely population to spread HIV, and therefore support groups to encourage them to recognize and change their behaviors may be an effective strategy.

Expert session are demanded but not often provided.

Over a quarter report needing group education where experts provide information about how to prevent the spread of HIV. Females say they need them more than men. Less than half the providers say they offered any safer behavior workshops, and lack of availability may be the reason group education by experts has the second largest need-utilization gap.

Over 75% of those out-of-care say they need testing. This indicates a high level of denial that must be addressed.

About 24% of PLWH/A report needing HIV testing. Remarkably for those out-of-care over 75% report needing testing. Note, however, that the sample size is small, and the finding may be unreliable. Nonetheless, if true, it strongly suggests that one reason for being out-of-care is denial.

Outreach to Latinos is most needed and least requested. Demand has to be built.

Recently incarcerated PLWH/A are also much more likely to say they need testing (35%) and may feel that they are being deceived by the correction system. Clearly, testing should be encouraged for these selected populations. For others, there is no evidence of gap betweens stated need and utilization.

There is a perceived need among homeless and

Less than a quarter of PLWH/A (23%) say they need outreach and recently incarcerated populations and providers have indicated some programs are available.

Latinos -- who probably need it the most – say they need it the least. Agencies appropriately target substance abusers for outreach. Still, outreach has the largest need-utilization gap, particularly among the more disenfranchised homeless and recently incarcerated.

Web-based services are an effective way to reach adolescents and young adults.

Web-based services have a limited but important audience. MSM/IDU say they need it the most, and this is probably an excellent way to reach this sexually active HIV positive population, but only one agency runs or collaborates in a chatroom or hotline. Similarly, free condom distribution at venues where MSM congregate is most likely to prove effective among MSM/IDU and MSM drug users.

For African Americans and females the development of prevention-for-positive programs at faith-based institutions should be a priority.

It is likely that church-based prevention programs are underutilized and may be an effective way to reach African Americans and particularly female African American and Latina populations. An inventory of church-related programs should be developed, and it seems likely that faith based programs could play a more significant role in prevention-for-positives.

Where prevention-for-positive services can be part of a more general array of health services, the important issue of confidentiality could be addressed.

Although most agencies completing a provider information form noted that they target prevention-for-positive programs to communities of color, there are several barriers to accessing prevention among HIV positives. Many women, African Americans, heterosexuals, and Latinos say confidentiality is a relatively big barrier. Showing the importance of prevention to their community, and raising it on the public agenda can diminish that barrier. Also, access for communities of color is further complicated by not knowing who to ask for services.

Convenient times and locations for prevention-for-positives programs will greatly improve attendance.

The data is clear that a major barrier is the timing of the prevention activities. They are often not available to PLWH/A when they can access them. This combined with transportation, particularly for African Americans, makes prevention-for-positives programs difficult to access.

At this point, knowledge and awareness about prevention-for-positives programs remains a substantial barrier.

Knowledge about prevention-for-positives programs continues to be a barrier. Over 40% of PLWH/A say they don't know who provides prevention-for-positive programs. Thirty-one percent (31%) say they don't know whom to ask about prevention-for-positive programs. Again, Latinos and women are more likely to say they don't know whom to ask.

Who Best Conveys Prevention Messages to PLWH/A?

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.)

Generally, medical providers and experts are rated highest, suggesting that for most subpopulations one of the best places and sources of prevention information is at the provider of health care. Trained prevention counselors have an opportunity to work with PLWH/A during their medical visits by providing appropriate programmatic interventions.

Friends play a critical role in providing information and, more importantly, in providing social support for sustained prevention activity.

After providers, friends play a critical role in providing information. In addition, social networks and peer reinforcement of prevention behaviors can be critical for those having difficulty maintaining prevention behaviors.

For adolescents and young adults, peer and mass media are considered as important as medial providers. Peer pressure and acceptance is one of the most important motivators.

Among adolescents and young adults there may be other equally effective sources of information. They rate their peers just as important as their medical providers. Clearly peer views and peer pressure is important. They also consider mass media and Internet information as much more important than any other target population of PLWH/A.

Out-of-Care

Demographic Profile

Out-of-care is defined as having gone a period of 12 or longer without seeing a doctor. About a quarter of the survey participants have been out-of-care, with about 5% saying they are currently out-of-care.

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 a history of being out-of-care with 11 (5%) currently not having seen a doctor in more than 12 months.

In the sample Latinos, women, and older PLWH/A are more likely to be out-of-care. Over 60% are MSM of color.

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.

Those out-of-care are less likely to be insured.

Those currently out of care are less likely to be insured, but there is no difference in insurance status among those with a history of being out-of-care.

Those out-of-care are more likely to be looking for work.

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 physical health of those out-of-care is worse than other PLWH/A, but their emotional health is better.

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.

Overall, out-of-care seem to have higher need for determining their own needs and medication regimen.

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.

Medication Adherence

Those out-of-care have greater medication adherence problems.

Out-of-care PLWH/A are equally as likely as those in care to have taken medication. However, out-of-care PLWH/A have a difficult time adhering to their medications with 59% of those with a history of out-of-care skipping their medications and 82% of the currently out-of-care not taking their medications as prescribed.

For out-of-care PLWH/A, similar to all PLWH/A, forgetting to take the medications is the first reason they do not adhere to their medication regimen, followed by side effects. Third, is "just not wanting to take them."

Co-Morbidities

Based on STDs, those out of care appear more likely to engage in unsafe sexual behavior.

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.

Those out-of-care appear to use "party" drugs more than other PLWH/A.

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.

The out-of-care are slightly less likely to report anxiety (42%) and depression (58%) compared to 46% of other PLWH/A who report anxiety and 61% who report depression.

Service Needs and Barriers

The out-of-care report a greater need for housing and medication reimbursement than in-care PLWH/A.

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.

The out-of-care report more and higher barriers to accessing care. Most are individual barriers such as lack of knowledge, or their own state of mind.

The top organizational barrier is waiting for an appointment.

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

Over a quarter of the out-of-care engage in high-risk behavior that places others at risk of HIV infection.

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. In fact, almost half disagree with the statement that sex is better without using a condom, in contrast to just over a third of all PLWH/A.

Out-of-care are aware of their behavior, and have made a self-commitment to reduce it. That is counter-balanced by their greater drug use and lack of self-control while high on drugs.

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.

Out-of-care report a greater need for testing – noting some degree of denial.

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

The out-of-care have a greater than average need for individual counseling, Internet information services, and outreach. Outreach has the largest gap need-receive gap.

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.

Overall Summary

PLWH/A in Long Beach are similar to PLWH/A in LAC.

The Long Beach Needs Assessment confirms that the community of PLWH/A in Long Beach has many of the same epidemiological trends and needs of all PLWH/A in LAC. There are, however, notable differences.

PLWH/A in Long Beach share positive outcomes of the care systems.

One concern is their more rapid progression to AIDS than in LAC.

They share with LAC the outcomes of lower infection rates, lower mortality, and lower progression form HIV to AIDS. However, in 2001 Long Beach appeared to have significantly lower mortality rate than LAC. At the same time, there were proportionately more people progressing from HIV to AIDS than in LAC.

The vast majority of PLWH/A say their physical health has improved. However, their emotional health has not shown the same level of improvement.

Like LAC the many PLWH/A showed improved physical and mental health status. However, Long Beach showed slightly better outcomes on physical health, but worse outcomes on emotional health than LAC.

The epidemiological profile in Long Beach is relatively stable among risk groups and gender. There are an increasing number of infected people of color.

The profile of the HIV epidemic in Long Beach is relatively stable. The proportion of MSM, about three quarters, and IDUs – just fewer than 10%, have remained constant. There is a slight increase in heterosexuals. The racial profile has shifted slightly to more people of color, particularly Hispanics, but disproportionately African Americans.

MSM/IDU and IDUs each represent about 10% of the epidemic. However their profile is significantly different. MSM/IDUs tend to be more Anglo and much heavier party-drug users. They are more likely to be out-of-care, have greater barriers to care, and be much more likely to transmit HIV infection to others.

There are three sub-populations in the epidemic.

1. Mature epidemic – gay, largely white, MSM. More medical needs. Greater gap in dental care.

Like LAC, the epidemic might be divided into three main groups. First are those that have been infected for several years, the "mature epidemic", largely consisting of MSM, mostly Anglo. They are older, have greater medical needs, and less need for wrap around services.

2. Those more newly infected, majority communities of color. More wrap around service needs. Greater family and substance abuse needs.

The second epidemic is among the more currently infected. The majority is among communities of color. The increase in number of Hispanics living with HIV and AIDS is large, but proportionate to their increase in the overall population. There are fewer African Americans, but they far exceed their representation in the general population.

This second epidemic reports the greats gaps in services – mostly housing, food, and transportation.

These more newly infected are poorer, less insured (although they have a higher insurance rate than in LAC), and in much greater need of wrap around services.

The Latinos living with HIV and AIDS are more likely to be MSM, and they have, as a group, lower expectations of the care system. While placing less stress on the system, they also create much greater challenges in bringing them into care and sustaining care.

3. Emerging sexually active substance users. Younger, HIV/AIDS lower priority. Engage in behaviors that are more likely to transmit infections.

The third emerging epidemic is among younger sexually active, men. Mostly gay, they are the core of the MSM/IDU groups. They stand out because of their high needs, larger gaps in service. They are much more likely than the previous two groups to engage in behaviors that place others at risk of infection.

Long Beach is doing a good job of placing eligible persons into insurance, with 80% saying they have some type of insurance. This will be of continued high importance as the stress on Ryan White funds being used as a funding of less resort will become greater.

Knowledge of services and providers remain a large barrier for PLWH/A.

The biggest barriers to care – especially among the more newly infected and the MSM/IDUs -- is a lack of knowledge, suggesting the need for an accessible resource guide.

Co-pays are perceived as major barriers to

Future changes in the system that may implement co-pays –even accessing care.

minor ones – will be significant barriers to accessing care for PLWH/A.

Efficient prevention-for-positive programs will only target those individuals at risk of transmitting infection.

Regarding prevention-for positives, not all PLWH/A need prevention-for-positive programs. Those not engaging in behaviors that have a risk of infecting others need not be targeted. However, maybe a third of those living with HIV/AIDS should be targeted.

Knowledge remains a barrier.

Increasing the awareness and knowledge of prevention-for-positive programs remains an urgent task. It cannot be done until an overall model is developed and accepted.

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.

While several models of behavior change and sustaining safer behaviors exist, they have not systematically been incorporated into a citywide prevention-for-positives effort. Integrating prevention services into care services provides a logical distribution channel, but messages have to be tailored to the needs of specific populations. Peer support and peer pressure are key to maintaining safer behaviors.

Prevention has to be on the agenda of PLWH/A. Public awareness and group efforts raise the awareness of prevention.

Key to the success of the program is raising the importance of prevention and placing it on the agenda of PLWH/A. A seismic shift has taken place with the acceptance of condoms. Now an equal shift has to take place with HIV positive persons taking responsibility for infecting others.

Effective prevention is individualized, monitored and culturally appropriate.

Individualized monitoring of prevention behavior and appropriate interventions should be an objective. Appropriate interventions have to be culturally appropriate and address specific barriers to adopting and maintaining behaviors.

Out-of-care are a diverse group. One primary subpopulation of out-of-care overlaps with the third epidemics of young, sexually active, substance users.

Last, many out-of-care are not, as some would expect, those PLWH/A who are disenfranchised. Rather their reasons for being out-of-care range from having no insurance to feeling they don't need to be in care. This later group represents a significant number of the out-of-care. On the positive side they face less structural barriers to retuning to care. On the negative side, they seem to place less importance on their infection, and are among those that place others at significant risk for HIV infection.

This Needs Assessment has reviewed the consumer perception of care and prevention-for-positive services. Long Beach has shown that for those PLWH/A who seek core medical services, they are available. In the next phase of service delivery, the epidemiology and perceived needs suggest that services be targeted to the three major epidemics – “mature”, “emerging”, and “those abusing substances”. Unlike other services, prevention-for-positives has little overall coherence suggesting that the continuum of care has to be operationalized. The data strongly suggest emphasizing personal responsibility among PLWH/A and interpersonal and partner strategies to encourage and maintain behaviors that are less likely to transmit HIV infection.

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Attachment 2 2003 Needs Assessment Survey

CONSENT FORM
2003 LONG BEACH NEEDS ASSESSMENT

The Long Beach Department of Health and Human Services is conducting a needs assessment of HIV and AIDS services.

You have been invited to participate in filling out this survey and discussing your experiences, knowledge, and opinions about the service needs for people like yourself living with HIV/AIDS in this forum. This process assures that you have a voice in the planning for HIV and AIDS treatment services throughout the Long Beach. You will receive $20 in food vouchers for completing this survey.

This survey and forum are entirely confidential. This assurance of confidentiality means that no information about your participation can be obtained by anyone outside staff from PCH, the group hired to conduct the Needs Assessment. While we ask some questions about your background for the purpose of analysis, your name will never be linked to your answers and nobody working for any provider or from the Council will be able to link your comments to your name. The results of this Needs Assessment may be published, but your name will never be used in any report or publication.

Your consent is entirely voluntary and your decision to participate or not participate will have no effect on the care you are receiving or the relationships you have with providers and caregivers.

By signing below, you consent to complete the survey.

PARTICIPANT'S SIGNATURE: ____

PARTICIPANT'S NAME: ____

Address: ____

City __________________________CALIFORNIA Zip Code ________________

Telephone: __ __ __ - __ __ __ - __ __ __ __ Date: __ __/ __ __/ 2003

If you have any questions, please call Irene Hung at (800) 411-4399 x 25 or Teresa Ayala-Castillo at (562) 570-4331.

LONG BEACH NEEDS ASSESSMENT SURVEY OF PEOPLE LIVING WITH HIV AND AIDS

Sponsored by the Long Beach Department of Health and Human Services

INTRODUCTION

Thank you for agreeing to participate in this important survey. Completing this survey gives you a voice in the planning of HIV and AIDS prevention and treatment services throughout the community of Long Beach.

For each question below, circle or write in an answer. There are no right or wrong answers. Please take as much time as you need to answer each question based on your experiences. If you have any questions or need help reading the survey or interpreting the questions, please ask for assistance.

Your responses are completely confidential. Your name will never be linked to your answers.

Thank you in advance for completing this survey. Please complete the confidential ID below.

Confidential ID

We will be obtaining responses from many people living with HIV and AIDS over the next few weeks. Please create a confidential identifier which you will place on the top of every page of your survey so that nobody can ever see your name connected to your answers.

______	______	______ ______	______ ______	______
What is the *first* letter of your first name	**What is the *last* letter of your last name**	**What is the month of your birthday** **(For January through September use a leading "0" e.g. 01 for January)**	**What is the day of your birthday** **(For days 1 - 9 use a leading "0" e.g. 01)**	**What is the first letter of your mother's first name? (If you don't know, list the first letter of your father's first name)**

(01=Jan, 02=Feb, 03=Mar, 04=Apr, 05=May, 06=June, 07=July, 08=Aug, 09=Sept, 10=Oct, 11=Nov, 12=Dec)

Please copy the confidential ID you have created to the top right of each page of the survey.

Confidential ID: ____ ____ ____ ____ ____ ____ ____

1. Are you currently **(Circle number next to the answer)**

HIV+ with disabling symptoms	1	
HIV+ with no symptoms	2	
HIV negative......................	3 →	**Please see the interviewer.**

2. When were you born?................. __ __/__ __ __ __ **Mo. Year.**

3. Are you…

Male	1
Female	2
Transgender - Male to female (MTF)	3
Transgender - Female to male (FTM)	4

4. What do you consider your ethnic background?

African American (Black)	1
Other non-Hispanic Black.....................	2
Latino/Hispanic	3
Asian Pacific Islander (API)	4
Native American	5
White/Caucasian (non Hispanic)	6
Mixed Race **(Specify)** ___________________	7
Other **(Specify)** __________________________	8

5. Do you consider yourself **(circle one)**

Heterosexual/Straight	1
Homosexual - Gay male.......................	2
Homosexual - Lesbian	3
Bisexual..	4
Other **(Specify)** ________________________	5

6. What is the highest level of education you completed?

Grade school or less	1
Some high school................................	2
Graduated high school/GED/trade school	3
Some college/2 year college degree...........	4
Completed 4 year college	5
Graduate level or professional study	6

GO TO QUESTION 7 AT TOP OF NEXT COLUMN

7. What is the zip code and city and/or neighborhood where you live?

___ ___ ___ ___ ___ **Zip** ______________________ **City and/or Neighborhood**

8 Where do you currently live? **(Circle one)**

In an apartment/house I own	1
In an apartment/house I rent	2
At my parent's/relative's apt. /house	3
Living/crashing with someone & not paying rent...	4
Single Room Occupancy (SRO)	5
In a "supportive living" /assisted living facility	7
In a group home or residence including residential drug therapy.......................	8
In a half-way house or transitional housing...	9
Skilled Nursing Home	10
Homeless (on the street/in car)	11
Homeless shelter	12
Jail or correctional facility	13
Hospital / Institution	14
Residential Hospice/Nursing Facility...........	15
Other **(Specify)** _________________________	16

9. Is your living situation …? **(Circle 1 for "Yes" or 2 for "No" for each item)**

	Yes	No
Safe...	1	2
Habitable (clean and livable)	1	2
Stable	1	2

10. Do you.... **(Circle 1 for "Yes" or 2 for "No" for each item)**

	Yes	No
Live alone	1	2
Live with other adults **(write how many)** ..	___ #	2
Live with your children **(write how many)**	___ #	2

GO TO Q 11 AT BOTTOM OF PAGE

11. Over the last two (2) years, how long (total time) have you lived in each of the places listed below?

(Circle one answer for each of the items below)	Never	Less than a month	1-3 months	4 months to 1 yr.	More than 1 yr.
In a half-way house or transitional housing	1	2	3	4	5
In a treatment facility (drug or psychiatric)	1	2	3	4	5
Homeless (on the street/in car).........................	1	2	3	4	5
Homeless shelter	1	2	3	4	5
Jail or correctional facility...............................	1	2	3	4	5
Other **(Specify)** _______________________________	1	2	3	4	5

12. What best describes your current job (work) situation? **(Circle one)**

Employed full-time (33-40 hours a week)........	1
Employed part-time (less than 33 hours a week)	2
Not working – looking for work	3
Not working – student /homemaker /other	4
Not working – not looking for work	5
Retired...	6
Other **(Specify)** ____________________	7

13. What is your reported estimated **yearly** income from all sources and before taxes?

$0 to $ 8,600 (up to $716 a month)	1
$8,601 to $11,600 ($717 - $967 a month)........	2
$11,601 to $16,500 ($968 - $1375 a month).....	3
$16,501 to $23,200 ($1376 - $1933 a month)....	4
$23,201 to $26,000 ($1934 - $2167 a month)....	5
$26,001 to $35,000 ($2168 - $2917 a month)....	6
Greater than $35,001 ($2918 or more a month)	7

14. Which of the following benefits do you receive?

(Circle 1 for "Yes", 2 for "No" or 8 for "Don't Know")	Yes	No	Don't Know
Food stamps	1	2	8
Long term disability	1	2	8
Short term disability	1	2	8
Supplemental Security Income (SSI)	1	2	8
Public Health Service, Bureau of Indian Affairs (BIA)	1	2	8
State Disability Insurance (SDI) ...	1	2	8
Social Security Disability Insurance (SSDI)..................	1	2	8
Veteran's benefits (VA)	1	2	8
CHAMPUS (VA Assistance for non-military personnel)..............	1	2	8
Worker's compensation...........	1	2	8
Annuity/Life insurance payments	1	2	8
Retirement..........................	1	2	8
Rent supplement...................	1	2	8
Subsidized housing (HOPWA Subsidy, Section 8 certificate or Shelter Plus Care)............	1	2	8
General Assistance (GA)	1	2	8
Emergency Financial Assistance	1	2	8
WIC..................................	1	2	8
TANF/CalWORKS – formerly AFDC	1	2	8
Other **(Specify)** ______________	1	2	8
Not eligible for benefits	1	2	8

15. What kind of health insurance do you currently have?

(Circle 1 for "Yes" or 2 for "No" for each item)	Yes	No
Insurance through work	1	2
COBRA or OBRA (insurance through my last employer)	1	2
Private insurance, not through work	1	2
Medicaid or MediCal........................	1	2
Medicare	1	2
Other Insurance **(Specify)**_____________	1	2

16. IF NO TO ALL OF THE ITEMS IN Q.15, do you have any health insurance?

Yes **(Specify)** ____________________	1
No	2

17. What was the month and year that you first tested positive for HIV? __ __ **Mo.** __ __ __ __ **Year**

18. Where were you diagnosed as HIV positive?

____________________ **City** ____________________ **State**

19. What is the most likely way you were infected by HIV? **(Circle one)**

Having sex with a man............................	1
Having sex with a woman	2
Having sex with a transgender	3
Sharing needles....................................	4
Blood products/Transfusion (blood or tissue recipient)	5
Hemophilia	6
Acquired at birth	7
Other **(specify)**_________________________	8
Don't Know	9

20. Have you ever been told by your doctor, nurse, or other health care provider that you have AIDS?

Yes..	1
No	2

20a. IF DIAGNOSED WITH AIDS, When were you diagnosed with AIDS? __ __ **Mo.** __ __ __ __ **Year**

21. Has your T-Cell count ….?

(Circle 1 for "Yes", 2 for "No" or 8 for "Don't Know")	Yes	No	Don't Know
Ever dropped below 500 cells/UL	1	2	8
Ever dropped below 350 cells/UL	1	2	8
Ever dropped below 200 cells/UL	1	2	8
Now dropped below 350 cells/UL	1	2	8
Now dropped below 200 cells/UL	1	2	8

22. Has your viral load ….?

(Circle 1 for "Yes", 2 for "No" or 8 for "Don't Know")	Yes	No	Don't Know
Ever rose above 30,000 copies....	1	2	8
Ever rose above 10,000 copies....	1	2	8
Currently above 10,000 copies ...	1	2	8

23. In general, would you say that today your physical health is…

Excellent	4
Good	3
Fair	2
Poor	1

24. How would you rate your physical health now as compared to when you first sought treatment for your HIV infection?

Much better	5
A little better	4
About the same	3
A little worse	2
Much worse	1

25. In general, would you say that today your emotional health is…

Excellent	4
Good	3
Fair	2
Poor	1

26. How would you rate your emotional health now as compared to when you first sought treatment for your HIV infection?

Much better	5
A little better	4
About the same	3
A little worse	2
Much worse	1

27. Check the box if you have never seen a doctor or gone to a clinic since you were diagnosed with HIV. **(GO TO Q.34)** ☐

28. What was the date of the last visit you had with a doctor for your HIV infection **(ESTIMATE IF NECESSARY)**? __ __ **Mo.** _ _ _ _ **Year**

29. Since you found out you were HIV positive,

(Circle 1 or "Yes" or 2 for "No" for each item)	Yes	No
Has there ever been a period of time of more than a **year (12 months)** when you didn't see a doctor or go to a clinic	**1**	**2**
Has there ever been a period of time of more than **six months** when you didn't see a doctor or go to a clinic?....	**1**	**2**

30. If you stopped going to see a doctor, did you go back to see a doctor?

Yes	1	**(GO TO Q.31)**
No	2	**(GO TO Q.32)**

31. **IF YES TO Q.30**, What happened to make you seek medical care after not seeing a doctor or clinic professional for more than six months?

(Circle 1 or "Yes" or 2 for "No" for each item)	Yes	No
I got sicker	1	2
Change in my income	1	2
Change in my insurance status	1	2
Heard about new doctor / clinic	1	2
There was a change in my doctor's or clinic's attitudes	1	2
There were different drugs or treatments available	1	2
I had stable housing	1	2
Other **(specify)** ______________________	1	2

32. At any time in the last year, have you been diagnosed with any of the following diseases listed below?

(Circle 1 for "yes", 2 for "no" or 8 for "Don't Know)	Yes	No	Don't Know
Hepatitis A or B	1	2	8
Hepatitis C	1	2	8
Syphilis	1	2	8
Herpes (genital)	1	2	8
Gonorrhea	1	2	8
Chlamydia	1	2	8
Genital warts	1	2	8
Yeast infections	1	2	8
Other **(specify)** ________________	1	2	8

33. Are you taking any of the following?

(Circle 1 for “Yes”, 2 for “No” or 8 for DK)	Yes	No	Don’t Know
Antiretrovirals and/or protease inhibitors........................	1	2	8
Antibiotics (such as Bactrim) that fight off infections	1	2	8
Antifungal (such as Diflucan) that are for body rashes or thrush	1	2	8
Steroids which help you with your appetite or build weight	1	2	8
Antidepressants for depression or anxiety.......................	1	2	8
Herbal and/or other supplements....................	1	2	8

34. How often have you skipped taking your HIV/ AIDS medication as prescribed by your doctor?

Never / Have not skipped **(Go to Q. 36)**	1
Once or twice a month	2
Once or twice a week............................	3
More than twice a week	4
I have stopped taking my medicine............	5

35. If skipped or stopped taking your HIV/AIDS medication, why?

(Circle 1 for "Yes" or 2 for "No" for each item)	Yes	No
Side effects	1	2
Difficult schedule and requirements ...	1	2
Didn’t want others to see the medications	1	2
Didn’t understand the directions	1	2
Felt that medication didn’t work	1	2
Could not afford medication............	1	2
Forgot to take the medication..........	1	2
Ran out of medications	1	2
Hard to coordinate with food	1	2
Just did not want to take them	1	2
Homeless..................................	1	2
Medication made me feel good so I felt I didn’t need them anymore	1	2
My doctor advised me to stop taking my medications	1	2
Other **(specify)** ____________________	1	2

36. Since you were infected with HIV have you received mental health counseling or treatments?

Yes	1	→ **Go to Q. 36a**
No	2	→ **Skip to Q.37**

36a. Have you every received any of the following mental health counseling or treatments related to your HIV infection?

(Circle 1 for "Yes" or 2 for "No" for each item)	Yes	No
Inpatient (in a hospital at least overnight)	1	2
Individual counseling/therapy............	1	2
Group counseling/therapy	1	2
Medication for psychological or behavioral problems....................	1	2

37. At any time in the last two years have you been diagnosed with any of the following mental health problems?

(Circle 1 or "Yes" or 2 for "No" for each item)	Yes	No
Anxiety	1	2
Bipolar Disorder	1	2
Dementia.................................	1	2
Depression	1	2
Other **(specify)**__________________	1	2

GO QUESTION 38 TOP OF NEXT PAGE

38. For each of the services below:

1. Under column A, note if you *needed* the service in the past year. Circle "1"for yes or "2" for no.
2. Under column B, note whether you *asked* for this service this past year.
3. Under column C, note if you *received* this service this past year.

		A		B		C	
	For each service below…	**Have you *needed* this service this past year?**		**Have you *asked* for this service this past year?**		**Have you *received* this service this past year?**	
MEDICAL CARE		**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
1	Visits with a doctor, nurse, or assistant to take care of your on-going HIV treatment – Outpatient medical care.	1	2	1	2	1	2
2	Medical care by a specialist, including OB/GYN.	1	2	1	2	1	2
3	Nutritional supplements, education, and counseling.	1	2	1	2	1	2
4	Dental care.	1	2	1	2	1	2
5	Home health care from a nurse or aide.	1	2	1	2	1	2
6	Hospice Services (In-home and residential).	1	2	1	2	1	2
7	Complementary care – includes acupuncture and traditional Chinese medicine.	1	2	1	2	1	2
8	Medication programs including ADAP that provides assistance obtaining and paying for HIV/AIDS related drugs.	1	2	1	2	1	2
9	**IF YOU HAVE PRIVATE HEALTH INSURANCE**, assistance paying health insurance premiums.	1	2	1	2	1	2

TRANSPORTATION		**Need it**		**Ask for it**		**Receive it**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**
10	Van transportation to HIV/AIDS services.	1	2	1	2	1	2
11	Taxi vouchers or bus tokens.	1	2	1	2	1	2

MENTAL HEALTH & SUBSTANCE ABUSE SERVICES		**Need it**		**Ask for it**		**Receive it**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**
12	Residential mental health services.	1	2	1	2	1	2
13	Individual or groups mental health therapy or counseling sessions by a psychiatrist, psychologist, or social worker.	1	2	1	2	1	2
14	Peer counseling, support, or drop-in groups.	1	2	1	2	1	2
15	Outpatient substance abuse treatment or counseling.	1	2	1	2	1	2
16	24 hour-a-day residential substance abuse counseling.	1	2	1	2	1	2
17	Detox and / or methadone maintenance.	1	2	1	2	1	2

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		A		B		C	
	For each service below…	**Have you *needed* this service this past year?**		**Have you *asked* for this service this past year?**		**Have you *received* this service this past year?**	
CASE MANAGEMENT		**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
18	Medical case management and adherence support from a nurse or care provider.	1	2	1	2	1	2
19	Case Manager (not a doctor or nurse) who helps you obtain treatment, medications, financial assistance, and benefits and assures coordinated access to care.	1	2	1	2	1	2
20	Employment Assistance – vocational counseling and training.	1	2	1	2	1	2

HOUSING		**Need it**		**Ask for it**		**Receive it**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**
21	Housing information services – assistance in finding or getting housing.	1	2	1	2	1	2
22	Rental subsidy (NOT emergency financial assistance).	1	2	1	2	1	2
23	"Independent" housing provided through Section 8, HOPWA, or other state agency that has no on-site medical or case management.	1	2	1	2	1	2
24	Residential housing or group home where there is 24-hour support such as case management or nursing.	1	2	1	2	1	2
25	Emergency or transitional housing for those who are homeless and in need of immediate housing.	1	2	1	2	1	2

FOOD		**Need it**		**Ask for it**		**Receive it**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**
26	Food pantry or food bank.	1	2	1	2	1	2
27	Food vouchers.	1	2	1	2	1	2
28	Home delivered meals.	1	2	1	2	1	2

OTHER SERVICES		**Need it**		**Ask for it**		**Receive it**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**
29	Prevention information and education on how to prevent the spread of HIV.	1	2	1	2	1	2
30	Emergency financial assistance, usually to pay rent, utilities, food, and clothing.	1	2	1	2	1	2
31	Legal services – preparing wills or estate planning; assistance with evictions and housing discrimination.	1	2	1	2	1	2
32	Adult day care.	1	2	1	2	1	2
33	Day care for children during a caregiver's appointment for HIV/AIDS care.	1	2	1	2	1	2

39. Below is a list of problems that you may have had when trying to obtain or use HIV/AIDS services. Mark an X on the line beside each item to say how big a problem it has been for you. The line goes from a "very big" to a "very small" problem. A "very big" problem means that it stopped you from getting the service(s). A "moderate" problem means that you faced substantial problems but that you were able to get the service most of the time. A "very small" problem caused you minor concern and delays in obtaining the service(s). If you have not had the problem at all, circle "0".

Very Big = it stopped you from getting the service **Moderate = you faced substantial problems but were able to get the service** **Very Small = caused you minor concern and delays in obtaining the service**	**Very Big**	**Big**	**Mod-erate**	**Small**	**Very Small**	**Not a problem**
Example: The survey is difficult to complete					X	0
1. Not knowing that a service or treatment was available to me.						0
2. Not knowing a location of the service(s).						0
3. My physical health has not allowed me to get to the place where the service is provided.						0
4. I was (or am) in denial that HIV requires medical care.						0
5. Not knowing what medical services I need to treat my HIV infection or AIDS.						0
6. My state of mind or mental ability to deal with the treatment.						0
7. Not understanding the instructions for obtaining the service or treatment.						0

	Very Big	**Big**	**Mod-erate**	**Small**	**Very Small**	**Not a problem**
8. Not knowing who to ask for help.						0
9. Sensitivity of the organization and person providing services to me regarding my issues and concerns.						0
10. Discrimination I experienced by the persons or organization providing the services.						0
11. Experience or expertise of the person providing services to me.						0
12. The amount of time I had to wait to get an appointment or to see someone.						0
13. The organization providing the service made me feel like a number.						0
14. I do not get along with people providing services						0

39. (continued) Below is a list of problems that you may have had when trying to obtain or use HIV/AIDS services. Mark an X on the line beside each item to say how big a problem it has been for you. The line goes from a "very big" to a "very small" problem.

Very Big = it stopped you from getting the service **Moderate = you faced substantial problems but were able to get the service** **Very Small = caused you minor concern and delays in obtaining the service**	**Very Big**	**Big**	**Moderate**	**Small**	**Very Small**	**Not a problem**
15. I have been denied or have been afraid to seek services due to a criminal justice matter.	____|	______|	________|	_______|	______	0
16. My ability to communicate or interact with the service provider.	____|	______|	________|	_______|	______	0
17. The people providing services to me are not helpful.	____|	______|	________|	_______|	______	0
18. The organization did not provide the right referrals to the services I need.	____|	______|	________|	_______|	______	0
19. My ability to find my way through the system.	____|	______|	________|	_______|	______	0
20. There was no specialist who could provide the care I needed.	____|	______|	________|	_______|	______	0
21. Fear of my HIV or AIDS status being found out by others – lack of confidentiality.	____|	______|	________|	_______|	______	0

	Very Big	**Big**	**Moderate**	**Small**	**Very Small**	**Not a problem**
22. Fear that I would be reported to immigration or other authorities.	____|	______|	________|	_______|	______	0
23. No transportation.	____|	______|	________|	_______|	______	0
24. No childcare.	____|	______|	________|	_______|	______	0
25. I was not eligible for the service.	____|	______|	________|	_______|	______	0
26. There was too much paperwork or red tape.	____|	______|	________|	_______|	______	0
27. I can't afford one or more of the service.	____|	______|	________|	_______|	______	0
28. There are too many rules and regulations.	____|	______|	________|	_______|	______	0
29. My lack of, or inadequate, insurance coverage.	____|	______|	________|	_______|	______	0
30. I have been terminated or suspended from seeking services	____|	______|	________|	_______|	______	0
31. Other ________________________________	____|	______|	________|	_______|	______	0

39a. How do you protect others from becoming infected with HIV? **Write answer below**

40. How many sexual partners have you had in the past year? .... ______ Write #

41. How would you describe the type of sexual partnering you've had in the last year? **(circle only one)**

Monogamous (exclusive sexual relations with the same partner)	1
Open relationship (you and your partner agree to permit outside sexual relations)	2
In a relationship but have multiple partners without the knowledge of your main partner	3
Single relationship with multiple partners (more than 1 sexual relationship during the year) .	4
Did not have any sexual relationship in the past year **(CIRCLE RESPONSE AND SKIP TO Q. 46)**	5

42. Overall, I believe that my sexual behavior… **(circle only one)**

Has a high risk of transmitting HIV infection to my sexual partner	1
Has a moderate risk of transmitting HIV infection to my sexual partner..........................	2
Has a low risk of transmitting HIV infection to my sexual partner	3
Has no risk of transmitting HIV infection to my sexual partner.....................................	4
I am not sexually active	5

43. How often do you use a condom with your regular and casual partner(s) **(IF YOU DO NOT HAVE A REGULAR OR CASUAL PARTNER CIRCLE 9 for "Not applicable" AND GO TO QUESTION 46)**

Condom use with	**Every Time**	**Most of the Time**	**Some of the time**	**Rarely**	**Never**	**Not applicable**
Regular partner	5	4	3	2	1	9
Casual partners...........................	5	4	3	2	1	9

44. Who usually brings up the use of a condom when you have sexual intercourse?

Nobody – we never use a condom when having anal or vaginal intercourse ...	1
You bring up using a condom	2
My regular partner brings up using a condom	3
My casual partner brings up using a condom	4

IF YOU HAVE A REGULAR PARTNER ANSWER Q. 45 and 45a.

45. My regular partner is **(circle one)**		45a. **IF REGULAR PARTNER IS POSITIVE OR STATUS UNKNOWN:**		
HIV negative..............	1		**Yes**	**No**
HIV positive...............	2	We never have anal or vaginal intercourse.......	1	2
Don't Know	3	We never talk about the type of sex that we will have - it just happens	1	2
		For the two of us, we agree not to use a condom during anal and vaginal intercourse	1	2
		We agree to always have safer sex outside the relationship	1	2
		We never talk about the type of sex we have outside of our relationship	1	2

46. Below are some statements. Do you strongly agree, agree some, disagree some, or strongly disagree with each statement?

	Strongly Agree	**Agree Some**	**Disagree Some**	**Strongly Disagree**
a. It is my responsibility to inform my sexual partner(s) that I am HIV positive.	4	3	2	1
b. It is the responsibility of the person I am having sex with to protect themselves from HIV infection.	4	3	2	1
c. When I have unprotected sex with another HIV positive person, it presents no health risk for either of us.	4	3	2	1
d. Sex is better without using a condom.	4	3	2	1
e. When I am "turned on" putting on a condom ruins the moment.	4	3	2	1
f. I am not in the habit of using a condom when I have sex.	4	3	2	1
g. When I have sex I am usually high on alcohol and/or drugs.	4	3	2	1
h. When I am high on drugs I don't think much about transmission of HIV infection to others.	4	3	2	1
i. I know when my partner is infected with HIV.	4	3	2	1
j. I am embarrassed to suggest using a condom with a partner.	4	3	2	1
k. Sex with a condom isn't real sex.	4	3	2	1
l. Using a condom will be interpreted by my partner as me being unfaithful.	4	3	2	1
m. I want to have kids and condoms are a type of birth control.	4	3	2	1
n. Not using condoms or sharing needles is exciting -- it tempts fate.	4	3	2	1
o. My partner insists on having sex without using a condom.	4	3	2	1

47. How often do you do each of the following **(Circle the number which BEST fits your behavior)**				
	All the time	**Some of the time**	**Not frequently**	**Never**
a. I do not have sex with people who I know are infected with HIV, regardless of condom use.	4	3	2	1
b. I tell all my sexual partners my HIV status before I have sex with them.	4	3	2	1
c. I tell my HIV status to partners with whom I'm thinking of having a relationship, but not casual sex partners.	4	3	2	1
d. I only have sex with people of my own HIV status.	4	3	2	1
e. I don't pay much attention to HIV status when deciding to have sex with someone.	4	3	2	1
f. I am in control of whether or not I use protected sex.	4	3	2	1
g. I have made a commitment to myself to only have safe sex.	4	3	2	1
h. I have made a commitment to other people to only have safe sex.	4	3	2	1
IF YOU USE OR SHARE NEEDLES ANSWER I and K, IF NOT GO TO QUESTION 48				
i. I tell all my drug using partners my HIV status before I share needles with them.	4	3	2	1
j. I make the decision about whether or not to share needles.	4	3	2	1
k. I don't pay much attention to HIV status when sharing needles with my drug using partners.	4	3	2	1

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48. For each of the following types of prevention service:

1. Do you know that it is available to you personally?
2. Do you think you currently need each service?
3. About how often have you used the service?
4. IF YOU USED IT, Did the service meet your need?

For each item, go across the columns 1-4. Circle the number that corresponds to your response.	1. DO YOU KNOW IF THIS SERVICE IS AVAILABLE TO YOU?			2. DO YOU CURRENTLY NEED THIS SERVICE?		3. DO YOU USE THE SERVICE?	3a. IF USED, HOW OFTEN HAVE YOU USED EACH SERVICE?	4. DID THE SERVICE YOU RECEIVED MEET YOUR NEED?	
	Yes	No	Don't Know	Yes	No	Check	Write # times in last year	Yes	No
a. HIV testing	1	2	3	1	2	☐		1	**2**
b. Individual counseling about safe sex, HIV testing, safe needle use, or preventing HIV transmission.	1	2	3	1	2	☐		1	**2**
c. HIV prevention support groups where you talk with others about HIV prevention.	1	2	3	1	2	☐		1	**2**
d. Forum or community meeting about HIV where you provide your input into HIV/AIDS prevention programs.	1	2	3	1	2	☐		1	**2**
e. A hotline that provides information and answers questions about HIV.	1	2	3	1	2	☐		1	**2**
f. Post Exposure Prophylaxis, also known as PEP or the AIDS "morning after pill or therapy"?	1	2	3	1	2	☐		1	**2**
g. Group educational sessions where experts provide information about how to prevent the spread of HIV.	1	2	3	1	2	☐		1	**2**
h. Outreach work: Workers in the community who give people information on HIV infection and provide them counseling and referrals about safe sex, HIV testing, safe needle use, and preventing HIV transmission.	1	2	3	1	2	☐		1	**2**
i. A place where you can get bleach kits for cleaning used needles.	1	2	3	1	2	☐		1	**2**
j. A service that helps notify the partners of people infected with HIV or have STDs that they have been exposed.	1	2	3	1	2	☐		1	**2**
k. Sermons and events at churches, synagogues, mosques, and other places of worship that encourage safer sexual and drug use behaviors.	1	2	3	1	2	☐		1	**2**
l. Internet or web based information about HIV or AIDS.	1	2	3	1	2	☐		1	**2**
m. Bars or dance clubs where I can get free condoms.	1	2	3	1	2	☐		1	**2**
n. A place where I can exchange used needles for clean needles.	1	2	3	1	2	☐		1	**2**

49. Below is a list of things that can prevent people from getting information about HIV or receiving HIV prevention services. For each item, circle the number indicating how big a problem it is **for you**: a big problem for you, a moderate problem, a small problem, or no problem at all.

A "big problem" prevents you from obtaining services or information. A "moderate problem" is one that causes concern and delays getting services or information. A "small problem" causes minor concern and delay.

	Big Problem	Moderate Problem	Small Problem	No Problem
a. The HIV/AIDS prevention programs I need are not available.	4	3	2	1
b. I do not have transportation to get from my home to the place where the program is provided.	4	3	2	1
c. I do not know what organizations provide the information or programs that I need.	4	3	2	1
d. Programs are not available at the time that I can get them.	4	3	2	1
e. I cannot find programs in a language that I speak.	4	3	2	1
f. I do not know where to get information.	4	3	2	1
g. I have child care needs that prevent me from getting information.	4	3	2	1
h. I do not know who to ask for help.	4	3	2	1
i. The discrimination I felt from people providing information to me.	4	3	2	1
j. The people are not helpful who work at the organization (s) providing programs.	4	3	2	1
k. The cost is too great for information and programs.	4	3	2	1
l. The organization providing programs did not answer my questions.	4	3	2	1
m. I fear that someone I know will see me when I go get HIV or STD prevention services.	4	3	2	1

50. For you, how important are each of the following sources for HIV/AIDS information?

	Very important	Somewhat important	Not very important	Not important at all
a. Talking with experts in workshops/ group settings.	4	3	2	1
b. Talking with people like me in peer group sessions.	4	3	2	1
c. Television, radio, or billboard ads.	4	3	2	1
d. My doctor or medical provider	4	3	2	1
e. My friends	4	3	2	1
f. From experts	4	3	2	1
g. From internet, web, or on-line sources	4	3	2	1
h. Other (specify, then circle)	4	3	2	1

50a. Do you feel you **(Circle 1 for "Yes" or 2 for "No")**

Are getting too much information and too many services regarding HIV/AIDS prevention	1
Have enough information and services about HIV/AIDS	2
Need more information and services regarding HIV/AIDS prevention	3

51. During the past year, how often have you used any of the following substances?

	Not used in last year	Used in the past 6 months	Used less than once a month	Used at least once a month	Used once a week or more
Alcohol	1	2	3	4	5
Marijuana or hash	1	2	3	4	5
Crack / Cocaine	1	2	3	4	5
Heroin	1	2	3	4	5
Crystal Meth or Methamphetamines	1	2	3	4	5
Speedball	1	2	3	4	5
GHB (Gamma Hydroxybutyrate)	1	2	3	4	5
Poppers	1	2	3	4	5
Ecstasy (X)	1	2	3	4	5
Pills not prescribed by my doctor **(specify)**___________________	1	2	3	4	5
Other substances **(specify)** ___________	1	2	3	4	5

52. **IF YOU HAVE USED ANY SUBSTANCES**, Have you ever injected any substances not prescribed by a medical person?

Yes	1
No	2

53. **IF YOU HAVE INJECTED SUBSTANCES**, How many times have you shared needles with someone in the past year?

Write Number of times _______

54. Where were you born?

The United States **(IF BORN IN THE US, GO TO Q57 NEXT PAGE)**	1
Mexico	2
Puerto Rico or other US Territories	3
South and Central America	4
Asia	5
Other **(specify)** ____________________	6

55 **IF NOT BORN IN THE UNITED STATES**, in what year did you first come to the United States?

_______ **Year**

56. How would you describe your residency status in the United States?

Citizen	1
Have a visa (student, temp or permanent)	2
Have legal refugee or asylum status	3
Undocumented	4
Other **(specify)** ______________________	5

Confidential ID: ____ ____ ____ ____ ____ ____ ____

57. **(Optional)** Before we finish this survey, do you have any other comments about your satisfaction with the way you get HIV or AIDS related care or prevention services? **If not enough space, please continue your comments on the other side.**

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Interview End Time: ________________

Mode of transmission (Q18)

MSM	1
IDU	2
Heterosexual Transmission	3
MSM/IDU	4
Adult Hemophiliac/blood products	5
Don't Know (DK)	8

Race/Ethnicity (Q4)

White	1
African American	2
Hispanic/Latino	3
Asian/Pacific Islander	4
Native American/Alaskan Native	5
Mixed Race	6

Gender (Q3)

Man	1
Woman	2
Transgender	3

Interviewer Asst Initials ☐☐

Seq. Identifier ☐☐☐

SPA

SPA1	01	SPA4	04	SPA7	07
SPA2	02	SPA5	05	SPA8	08
SPA3	03	SPA6	06		

Attachment 3 Quota Sample Design

Risk Group	**MSM**	**IDU**		**Hetero**		**Total**	**Sample**
Sex	**Male**	**Male**	**Female**	**Male**	**Female**		**%**
Race							
Anglo	15	15	15	8	10	63	31.5%
African Am	15	15	10	8	15	63	31.5%
Latino	15	15	10	8	15	63	31.5%
API/ Other ethnicity	5	2	2	0	2	11	5.5%
Total (HIV+AIDS)	50	47	37	24	42	200	100%

Attachment 4 Focus Group Outline

FOCUS GROUP OUTLINE, PREVENTION-FOR-POSITIVES
Long Beach – February 2003

QUESTIONS/PROTOCOL	CONCEPT
SET UP GROUND RULES: PURPOSE, CONFIDENTIALITY, INCENTIVE, TAPING.	INTRO
1. Please introduce yourself – first name only --and tell the others in the group a little about yourself, including age, how did you get infected with HIV, do you have any children, and how long you have known that you have been HIV positive? How would you describe your current physical and emotional health? Have you had any symptoms or opportunistic infections related to your HIV infection (such as PCP--Pneumocystis carinii Pneumonia; or thrush)? *[Place in notes the gender and ethnicity of each participant.]*	Warm up, stage of infection
2. Since you have known about your HIV status, have you modified your behavior at all regarding risky behavior such as unprotected sexual intercourse or sharing needles with others? Why? (**PROBE FOR LOGICAL REASONS, REASONS RELATED TO INTERACTIONS WITH PARTNERS, PEER PRESSURE, AND OTHER REASONS)**	Change in behavior
3. Condom use can protect from transmitting HIV. Still most people who have sex do not use condoms all the time. If you don't use condoms all the time, why not?	Rationale for not using condoms
4. What do you think are the most likely routes of HIV infection in [NAME OF SUBGROUP]	Community transmission
5. Do you think you have enough information and understanding about HIV to avoid infecting others?	Need for information
6. What percent of [INSERT SPECIAL POP] do you think are infected with HIV? Almost all? Three quarters? Half? A quarter? Almost none?	Perception of risk
7. How important is it for you to prevent further the spread of HIV/AIDS relative to other problem?	Relative ranking of HIV as a priority
8. How many of you are sexually active (SHOW OF HANDS), and how many of you are in an ongoing relationship (SHOW OF HANDS)?	Risk
9. For those in an ongoing relationship, what is the HIV status of your partner? (NUMBER OF CORDANT AND DISCORDANT COUPLES)	Risk
10. Just a show of hands – how many of you are active substance users (SHOW OF HANDS), substance injectors (SHOW OF HANDS?) Have partners that are active users (SHOW OF HANDS)?	Risk
11. How many of you have shared needles in the past two years? (SHOW OF HANDS?) and how many of you have cleaned them (SHOW OF HANDS)? Or Exchanged needles (SHOW OF HANDS) Where?	Risk
12. What do you think the chances are of you infecting others? (**Probe for family connections**)	Self as a risk to others

QUESTIONS/PROTOCOL	**CONCEPT**
13. How important is the chance of re-infection to you? What do you think your chances are of getting re-infected?	Risk
HERE ARE A FEW QUESTIONS ABOUT PREVENTION SERVICES	
14. [Since becoming infected with HIV:] How do you get information about preventing transmission of HIV? Do you seek such information actively? (**ON INTERNET?; IN NEWSPAPERS? WORKSHOPS?**) Have you ever attended, participated in, or watched any type of HIV prevention program or event? What type? (**PROBE FOR COMMUNITY EVENTS**)	Top of mind participation in prevention events; info seeking
15. What types of prevention information do you get from your medical care providers– doctors, nurses, dentists, etc.? How about case managers? Mental health counselors? How about buddies?	Prevention from providers
16. Now, here is a list of different group services that have information [and programs [related to HIV prevention. We would like you to study the list for a few minutes and then tell us whether you are aware of them, if you have ever been to any of them or used their services, and what your impression is about the usefulness and quality of the service. Are there others that are not mentioned that you know about? What are the problems you have to not seeking group services?	Group/community service use and assessment
17. Here is a list of services where you go by yourself. Have you ever used them? How useful have they been? Are there any others we have not mentioned? What are the problems you have to not seeking individual services?	Individual service use and assessment
18. If you have attended such events, did you feel that the prevention information applied to you, as someone who is already HIV positive?	Appropriateness of content to positives
19. Here is a list of information sources where you can go to get information about prevention. Have you ever used them? Have they been useful? Are there any others?	Information sources and use
20. What has been the most important HIV-related prevention service that you have received?	Information sources and use
21. Here are two statements. Which do you think is more accurate: (1) I can control whether or not I infect others with HIV, or (2) I believe what will happen will happen and there is little I can do about infecting others with HIV.	Self-efficacy; locus of control
NOW I WOULD LIKE TO TALK ABOUT YOUR FEELINGS AND THOUGHTS REGARDING HIV TESTING	
22. Why did you go get tested for HIV? Did you go by yourself because you suspected you might be infected? Did you go because your partner asked you? Was it part of a treatment program? Was there some other reason? (**Probe for number of times**)	Testing: Why, when, and with whom
23. Did you get counseling before and after the HIV test? (Show of hands) How was the counseling before and after you got tested? What did they tell you? Were you satisfied?	Pre & post test counseling

QUESTIONS/PROTOCOL	**CONCEPT**
24. Why do you think people who are aware of the possibility of infecting others continue risky behavior? (**Probe for intimacy, economic need, and powerlessness….**)	Priority of personal and familial needs
NOW I WOULD LIKE TO TALK ABOUT WHO YOU TRUST TO GIVE YOU ADVICE ABOUT HIV AND AIDS	
25. Who do you trust the most to give advice about preventing HIV infection in your community? Who do you think others in your community trust? (Probe for friends, doctor, flyers, brochures, medical professionals, media, magazines, etc.)	Credibility of sources of info for prevention
26. Have you learned anything recently about preventing the spread of HIV and AIDS that you did not know before? What? From who?	
COMORBIDITIES	
27. Just a show of hands – how many of you are in recovery or currently using substances? *(Moderator verbalize response)* Do you receive any services for substance abuse? Where? Did your substance abuse provider ever refer you to other services, such as HIV, STD, or mental health?	Substance use [PCN]
28. Just a show of hands – how many of you have been tested for TB? How many have TB? *(Moderator verbalize response)*	TB; PCN
29. Just a show of hands – how many of you have been tested for STD? How many have STD? *(Moderator verbalize response)* Do you receive any services for STD? Where? Did your STD provider ever refer you to other services, such as HIV, substance abuse, or mental health?	STD; PCN
30. Just a show of hands – how many of you have ever needed mental health services for depression, anxiety, etc,? How many of you have used mental health services? *(Moderator verbalize response)* Do you receive any mental health services? Where? Did your mental health provider ever refer you to other services, such as HIV, STD, or substance abuse?	Mental health; PCN
31. What has been your experience with referrals from one service to another? Within the past few years, have you been referred from one agency to another? Did you act on the referral? (GET NAMES OF AGENCIES) If you did not act on the referral, why not?	Linkages [PCN]

Additional Needs

32. Is there anything else that you would like to tell us about getting or not getting information about how to stop the spread of HIV/AIDS?	Considered open end

ATTACHMENT 5 - 10 ARE IN A SEPARATE PDF FILE THAT ACCOMPANIES THIS REPORT

Attachment 5 2003 Survey - Demographics
Attachment 6 2003 Survey – Care Services Needed
Attachment 7 2003 Survey – Care Services Asked and Received
Attachment 8 Prevention Behaviors and Attitudes
Attachment 9 Prevention Awareness, Needs, Use, and Satisfaction
Attachment 10 Prevention Barriers

Attachment 11 Focus Group Coding Schema

INSTRUCTIONS

The attached coding sheet and codes are to be used in coding focus groups.

In the coding sheet the first eight columns describe the demographics of the participant:

- GROUP, the focus group that they participated in (Survey means that this is qualitative text that was written in the consumer survey by the participant);
- SEX, the gender of the participant;
- RACE, the race/ethnicity;
- AGE;
- GEO, geographic residence of the participant (urban or rural);
- RG, the risk group the participant is in;
- YR SERO, the year of the participant's Serostatus;
- PCH ID, the unique identified given to the participant to maintain their anonymity.

The next column is for the actual quote.

Once the quote is typed in, then it has to be coded for the service and barrier. Use the codes in the "code" worksheet. If there is more than one applicable code, separate the code by a comma.

Once this is done, we can sort using EXCEL by any of the categories, or we can enter it into a database for analysis.

Below is a small list of items that do come up in the focus groups and could be helpful in reviewing of the qualitative data. Please place any coding from this list in the Barrier column.

Disabilities	Disability
Drugs	Drugs
Fatalism	Fate
Homeless	Homeless
Jail	Jail
Prevention	Prevention
Rural	Rural
Side effects	Side
Phone	Phone
Church	Church
Services are good	DALLAS
Community Support	Community
Comparison to other cities	Compare

	Q46 Q47	Attitudinal Barrier	Barrier Code
	46a	It is my responsibility to inform my sexual partner (s) that I am HIV positive	Myresp
	46b	It is the responsibility of the person I am having sex with to protect themselves from HIV infection	Ptresp
	46c	When I have unprotected sex with another HIV positive person, it presents no health risk for either of us.	NoRisk
	46d	Sex is better without using a condom	Condom
	46e	When I am turned on putting on a condom ruins the moment	Moment
	46f	I am not in the habit of using a condom when I have sex	Habit
	46g	When I have sex I am usually high on alcohol and/or drugs.	Substances
	46h	When I am high on drugs I don't think much about transmission of HIV infection to others.	Drugs
	46i	I know that my partner is infected with HIV	Knowstat
	46j	I am too embarrassed to suggest using a condom with a partner.	Embarrass
	46k	Sex with a condom isn't sex	Condom
	46l	Using a condom will be interpreted by my partner as me being unfaithful	Fidelity
	46m	I want to have kids and it is a type of birth control	Kids
	46n	It is exciting – it tempts fate	Excite
	46o	My partners prefer not to use condoms	Condoms
	47a	I do not have sex with people who I know are infected with HIV, regardless of condom use.	NoSexHIV+
	47b	I tell my partners of my HIV status before I have sex with them.	Disclose
	47c	I tell my HIV status to partners with whom I'm thinking I of having a relationship with, but not casual sex partners.	DisRegPrt
	47d	I only have sex with people of my own HIV status	HIV+Sex
	47e	I don't pay much attention to HIV status when deciding to have sex with someone.	PayAttn
	47f	I am in control of whether or not I have protected sex	Control
	47g	I have made a commitment to myself to only have safe sex.	Safe Sex
	47h	I have made a commitment to other people to only have safe sex.	OtherSafe
	47i	I tell all my drug use partners my HIV status.	DisDrug
	47j	I make decisions about whether or not to share needles.	Needles
	47k	I don't pay much attention to HIV status when sharing needles with my drug using partners.	DrgPayAttn

	Q39	**Barriers**	**Barrier Code**
	39a	Not knowing the service or treatment was available to me	Know-srvcs
	39b	Not knowing a location of the service (s)	Know-loc
	39c	My physical health has not allowed me to get to the place where the services is provided	PH
	39d	I do not believe HIV or AIDS is a problem for me that requires assistance	Denial
	39e	Not knowing what medical services I need to treat my HIV infection or AIDS	Need
	39f	My state of mind or mental ability to deal with the treatment	MH
	39g	Not understanding the instructions for obtaining the service or treatment	Comp
	39i	Sensitivity of the org and person providing services to me regarding my issues and concerns	Sense-issues
	39j	Discrimination I experienced by the persons or org providing the service	Disc
	39k	Experience or expertise of the person providing services to me	Expert
	39l	The amount of time I had to wait to get an appointment or to see someone	Time
	39m	The org providing the service made me feel like a number	#
	39n	I do not get along with the people providing services	Along
	39o	I have been denied or have been afraid to seek services due to a criminal justice matter	Crime
	39p	My ability to communicate or interact with the service provider	Comm
	39q	The people providing services to me are not helpful	Helpful
	39r	The organization did not provide the right referrals to the services I need	Ref
	39s	My ability to find my way through the system	Ability
	39t	There was no specialist who could provide the care I needed	Spec
	39u	Fear of my HIV or AIDS status being found out by others-lack of confidentiality	Conf
	39v	Fear that I would be reported to immigration or other authorities	Reported
	39w	No transportation	Trans
	39x	No childcare	CC
	39y	I was not eligible for service	Eligible
	39z	There was too much paperwork or red tape	Red
	39aa	I can't afford one or more of the service	Cost
	39bb	There are too many rules and regulations	Rules
	39cc	My lack of, or inadequate, insurance coverage	Uninsured
	39dd	I have been terminated or suspended from seeking services	Term
	Q49		
	49a	The HIV prevention programs I need are not available	Available
	49b	I do not have transportation to get from my home to the place where the program is provided	Trans
	49d.	Programs are not available at the time that I can get them	Schedule
	49e.	I cannot get programs in a language that I speak	Language
	49f	I do not know where to get information	KnowInfo
	49g	I have child care needs that prevent me from getting information	CC
	49h	I do not know who to ask for help	KnowAsk
	49j	The people are not helpful who work at the org(s) running the program	Helpful
	49k	I cannot afford to pay for information and programs	Cost

Q38	Services	Service Code
1	Visits with a doctor, nurse, or assistant to take care of our on-going HIV treatment – Outpatient medical care	Test
2	Medical care by a specialist, including OB/GYN	OB/GYN
3	Nutritional supplements, education, and counseling	Nutrition
4	Dental care	Dental
5	Home health care from a nurse or aide	HHC
6	Hospice Services (In-home and residential)	HS
7	Complementary care – includes acupuncture and traditional Chinese medicine	Well
8	Medication programs including ADAP that provides assistance obtaining and paying for HIV/AIDS related drugs	Outreach
9	Assistance paying health insurance premiums	HealthIns
10	Van transportation to HIV/AIDS services	Trans
11	Taxi vouchers or bus tokens	Taxi
12	Residential mental health services	MH
13	Individual or groups mental health therapy or counseling sessions by a psychiatrist, psychologist, or social worker	MH
14	Peer counseling, support, or drop-in groups	Peer
15	Outpatient substance abuse treatment or counseling	SAT
16	24 hour-a-day residential substance abuse counseling	SAT
17	Detox and / or methadone maintenance	Detox
18	Medical case management and adherence support from a nurse or care provider	CM
19	Case Manager (not a doctor or nurse) who helps you obtain treatment, medications, financial assistance, and benefits and assures coordinated access to care.	CM
20	Employment Assistance – vocational counseling and training	Voc
21	Housing information services – assistance in finding or getting housing	Hsing
22	Rental subsidy (NOT emergency financial assistance)	Rent
23	“Independent” housing provided through Section 8, HOPWA, or other state agency that has no on-site medical or case management	HsingIndy
24	Residential housing or group home where there is 24 hour support such as case management or nursing	CongHsing
25	Emergency or transitional housing for those who are homeless and in need of immediate housing	HsingER
26	Food pantry or food bank	Food Bank
27	Food vouchers	Vouch
28	Home delivered meals	Meals
29	Prevention information and education on how to prevent the spread of HIV	Info
30	Emergency financial assistance, usually to pay rent, utilities, food, and clothing	DEFA
31	Legal services – preparing wills or estate planning; assistance with evictions and housing discrimination	Legal
32	Adult day care	ADC
33	Day care for children during a care givers appointment for HIV/AIDS care	CC

Q48	Prevention Services	Service Code
a.	HIV testing	Testing
b.	Individual counseling about safe sex, HIV testing, safe needle use, or preventing HIV transmission	Individual
c.	HIV prevention support groups where you talk with others about HIV prevention	Support
d.	Forum or community meeting about HIV where you provide your input into HIV/AIDS prevention programs	Council
e.	A hotline that provides information and answers question about HIV	Hotline
f.	Post Exposure Prophylaxis, also known as PEP or the AIDS "morning after pill or therapy"?	PEP
g.	Group educational sessions where experts provide information about how to prevent the spread of HIV	Educator
h.	Outreach work: Workers in the community who give people information on HIV infection and provide them counseling and referrals about safe sex, HIV testing, safe needle use, and preventing HIV transmission	Outreach
i.	A place where you can get bleach kits for cleaning used needles	Needle
j.	A service that helps notify the partners of people infected with HIV or have STDs that they have been exposed	ISDH
k.	Sermons and events at churches, synagogues, mosques, and other places of worship that encourage safer sexual and drug use behaviors	Religion/Church
l.	Internet or web based information about HIV or AIDS	Internet
m.	Bars or dance clubs where I can get free condoms	Bar
n.	A place where I can exchange used needles for clean needles	Exchange

	Supplements	**Code**
	Participation from people of color on HIV/AIDS education prevention	Involvmt
	The stigma that people with HIV/AIDS are all gay	Stigma
	Resources to educate people about HIV/AIDS prevention and services	EduRes
	Politics involve in HIV/AIDS agencies and services	Politics/Account
	People living with HIV/AIDS going out and educating the community	EduComm
	Lack of funding for HIV/AIDS agencies and services	Funding
	Difficulties with movement in housing location or transition period	Move
	Misinformation of HIV/AIDS issues	MisInfo
	Misrepresentation of HIV/AIDS victims in advertisements	MisAds
	Side effects of medications	Side
	Issues of homelessness as to barriers for HIV/AIDS services	Hmlss
	Misconceptions about HIV/AIDS and sex	MisCon
	Symptoms resulting from HIV/AIDS	Symptoms
	Issues with Medical or Medicare or Medicaid	Medi
	Religious taboos and/or discrimination within communities regarding HIV/AIDS	ReliTaboo/Dis
	Having to go through drug rehab or having drug or alcohol addiction as a barrier to services	Addict
	Time in jail as a barrier to services	Jail
	Should have mandatory HIV/AIDS testing	MandTest
	People don't want to get tested/think it doesn't affect them	Denial
	Fear of knowing HIV/AIDS results if tested	Fear
	How the media handle issues regarding to HIV/AIDS	Media
	High turn-over rate within the service provider or medical staff	Turn-over
	Problem maintaining medication or services at the correct level	Adherence
	Service not available or offer at sufficient level due to funding level or other constraints.	Available
	Not being represented ethnically, racially or in terms of sexual orientation	Rep
	Issue with the focus group or surveys	Focus
	Fatalism	Fate
	Services and/or provider are good	Good
	Prevention	Prevention
	Side Effects of medication/drugs	Side
	Quality of life as a barrier	QOL
	Being Promiscuous	Promiscuous
	Compare services to other cities	Compare
	Centralization or decentralization of services or provider as a barrier	Consol

Attachment 12 Provider Information Form

This provider form will be used to create an inventory of the existing prevention-for-positives services available to PLWH/A in the Long Beach area. Where information is filled in, please verify it. Please complete all relevant areas left blank.

SECTION I: AGENCY INFORMATION

SECTION I AGENCY INFORMATION

1. INITIALS OF PERSON COMPLETING FORM		**2. POSITION**
3. AGENCY NAME		**4. ALSO KNOWN AS**
5. STREET ADDRESS		Suite #
P.O. or other address information		Website
City	State CA	Zip

6. HEAD OF AGENCY		
Mr./Ms./Dr. First		Last
Title		
Telephone ( ) -	Fax ( ) -	Email

7. PERSON TO CONTACT ABOUT AGENCY		
Mr./Ms./Dr. First		Last
Title		
Telephone ( ) -	Fax ( ) -	Email

8. TYPE OF AGENCY (circle all that apply)			
All volunteer	☐	Governmental	☐
For-profit	☐	Non-profit –501c (3) or 501 (c) (4)	☐

In the next section please check off services you offer and provide a description of them.

The deadline for completing the form is **May 9, 2003**. Once you fill in the forms, please mail to: Teresa Ayala-Castillo, Long Beach Health Department, 2525 Grand Avenue Room 201, Long Beach, CA 90815.
Or fax to Teresa Ayala-Castillo: (562) 570-4374.

If you prefer to fill out the form on-line, please request via e-mail from Ms. Irene Hung at Irene@PCHealth.org. Once complete, it can be e-mailed back to her.

If you have any other questions or concerns regarding the Form, please do not hesitate to call Irene at (800) 411-4399 x 25.

SECTION II SERVICE INFORMATION

SECTION II LONG BEACH PROVIDER INFORMATION FORM SERVICES

1. PREVENTION TARGETED TO HIV POSITIVE INDIVIDUALS

Please check the box on the left column if this agency offers the service. In the space provided below, please add detail about the service.

☐ Provide adherence programs	☐ Prevention case management
☐ Offer support groups	☐ Provide partner notification
☐ Offer hotline or chat line	☐ Monitor HIV status
☐ Conduct behavioral modification sessions	☐ Counseling
☐ Provide safer behavior workshops (for sexual and substance use practices)	
☐ Circulate newsletters (with treatment and prevention updates)	

SERVICE DESCRIPTION: Please attach any program descriptions or evaluations to this form. For **each** service checked above note:

1. As complete a description of activities completed in 2002 and planned for 2003.

2. Target population by ethnicity, risk group, and sex.

3. Number of persons reached or using the service in 2002 including whether it as face-to-face, phone, or in group or individual setting.

Face-to-face: #
Phone: #
Group Setting: #
Individual Setting: #

Continue on back if not enough room

SECTION II SERVICE INFORMATION

SECTION II LONG BEACH PROVIDER INFORMATION FORM SERVICES

1b. PREVENTION TO PARTNERS

Please check the box on the left column if this agency offers the service. In the space provided below, please add detail about the service.

☐ Provide partner negotiation workshops	☐ Develop partner agreements
☐ Partner negotiation campaign	
☐ Other program targeted to partners of PLWH/A (*specify)*	

SERVICE DESCRIPTION: Please attach any program descriptions or evaluations to this form. For **each** service checked above note:

1. As complete a description of activities completed in 2002 and planned for 2003.

2. Target population by ethnicity, risk group, and sex.

3. Number of persons reached or using the service in 2002 including whether it was face-to-face, phone, or in group or individual setting.
Face-to-face: #
Phone: #
Group Setting: #
Individual Setting: #

Continue on back if not enough room

1c. OUTREACH TO HIV POSITIVE POPULATIONS

Please check the box on the left column if this agency offers the service. In the space provided below, please add detail about the service including..

☐ Health education and risk reduction	☐ Offer/refer to STD testing
☐ Operate a mobile Van	☐ Offer/refer to TB testing
☐ Exchange dirty needles	☐ Offer/refer to 12-step and other abstinence
☐ Distribute bleach kits	☐ Offer/refer to care at neonatal clinics
☐ Distribute condoms	☐ Offer/refer to family planning services
☐ Provide referrals to primary care	
☐ Conduct 1-1 contact with high –risk HIV positive individuals	
☐ Coordinate access to substance abuse treatment, detox, and methadone maintenance	

SERVICE DESCRIPTION: Please attach any program descriptions or evaluations to this form. For **each** service checked above note:

1. As complete a description of activities completed in 2002 and planned for 2003.

2. Target population by ethnicity, risk group, and sex.

3. Number of persons reached or using the service in 2002 including whether it was face-to-face, phone, or in group or individual setting.
Face-to-face: #
Phone: #
Group Setting: #
Individual Setting: #

Continue on back if not enough room

SECTION II LONG BEACH PROVIDER INFORMATION FORM SERVICES

SECTION II SERVICE INFORMATION

3. **Below are factors that can affect a PLWH/A's ability to access care. For each item below circle the number relative to the effect that you think each factor would have on the level of access to services. For instance do you think that "increase funding for the service" would greatly increase (5), somewhat increase (4), have no effect (3), somewhat reduce (2), or greatly reduce (1) the consumer's ability to access services.**

		Greatly Increase	**Somewhat Increase**	**No Effect**	**Somewhat Reduce**	**Greatly Reduce**
a.	Increase funding for the service.	5	4	3	2	1
b.	Finding/training qualified staff, volunteers, subcontractors	5	4	3	2	1
c.	Retaining qualified staff, volunteers, subcontractors	5	4	3	2	1
d.	Providers' ability to talk about sexual and drug using practices	5	4	3	2	1
e.	Training staff on cultural diversity issues	5	4	3	2	1
f.	Addressing organizational issues or infrastructure development ***(please specify***	5	4	3	2	1
g.	Rules and regulations regarding HIV reporting and partner notification	5	4	3	2	1
h.	Knowing where to refer a client for another service	5	4	3	2	1
i.	PLWH/A's transportation needs	5	4	3	2	1
j.	Consumers thinking they are not being affected by HIV (denial)	5	4	3	2	1
k.	The amount of red tape and paperwork needed to be filled out to get the service	5	4	3	2	1
l.	Having no childcare available at service site	5	4	3	2	1
m.	Poor coordination among the organizations and programs providing	5	4	3	2	1
n.	Consumers not knowing what services are available	5	4	3	2	1
o.	Consumers ability to follow instructions	5	4	3	2	1
p.	Loss of contact with client (e.g. no phone, no return visit)	5	4	3	2	1
q.	Current hours of operation	5	4	3	2	1
r.	The cost of the service to the consumer (i.e. insufficient insurance	5	4	3	2	1
s.	Long waiting list for services (i.e. high demand)	5	4	3	2	1
t.	Not being able to communicate in the consumer's language	5	4	3	2	1
u.	Clients' concern that other people would see them when they went to the program (fear of loss of confidentiality)	5	4	3	2	1
v.	Public campaigns regarding prevention needs of PLWH/A	5	4	3	2	1
w.	Changing location or physical limitations of the building/office space ***(please specify in Q. 3a)***	5	4	3	2	1
w.	Other **(Specify)** ____	5	4	3	2	1

3a. For the factors you have identified above as reducing consumers' access, what are you doing at the present time to address them? (***Please use an additional page of paper if necessary***)

Attachment 13 List of Providers contacted

Ryan-White Funded Providers
1* AIDS Service Center
2 Altamed Health Services
3* CSULB Center for Behavioral Research and Services
4* Being Alive
5 Catalyst Foundation
6* Charles Drew- Spectrum
7* CITY OF LONG BEACH - CASE MANAGEMENT, Tax, Ed, & Adv
8* CITY OF LONG BEACH – EIP
9* CITY OF PASADENA - ANDREW ESCAJEDA
10 CLINICA PARA LAS AMERICAS
11 COMMON GROUND (SANTA MONICA AIDS PROJECT)
12 EAST VALLEY COMMUNITY HEALTH CENTER
13 EL PROYECTO DEL BARRIO
14 GREATER LA COUNCIL ON DEAFNESS (GLAD)
15 H CLAUDE HUDSON C H C
16 HARBOR – UCLA MEDICAL CENTER (psychiatry)
17 L A GAY & LESBIAN CENTER (LAGLC)
18 LA FAMILY AIDS NTWK (LAFAN)
19 LAC & USC MEDICAL CENTER (SRANDER CLINIC-5P21)
20* LONG BEACH C H C (TOM KAY CLINIC)
21* MARTIN LUTHER KING (MLK)
22* MEMORIAL MILLER CHILDRENS HOSPITAL
23 MINORITY AIDS PROJECT
24 OLIVE VIEW MEDICAL CENTER
25 ONE IN LONG BEACH
26* PROJECT NEW HOPE (HOMESTEAD HOSPICE)
27 PROTOTYPES
28 SANTA MARIA HOUSE
29* SO CA ALCOHOL & DRUG PRO
30 SOUTHBAY FAMILY HEALTHCARE CENTER
31* ST MARY MEDICAL CENTER -(CM&OUTPATIENT)
32 SUBSTANCE ABUSE FNDN OF LB
33 T.H.E. CLINIC
34 WATTS HEALTHCARE
35* WHITTIER RIO-HONDO AIDS PROGRAMS (WRHAP)
36 WOMEN ALIVE

Other Providers
37 APLA Food Store
38 Atlantic Recovery Service
39 Flossy Lewis
40 Harbor Area Halfway House
41 HOPWA Agency
42 Interval House
43 La Clinica del Pueblo
44 Long Beach Mental health
45 Lutheran Social Services
46 Men's 12-Step
47 Mental Health Association
48* Padua House (Program of Project New Hope)
49 Redgate Memorial Recovery Center
50 Rescue Mission
51 Spiritual Truth Unity Fellowship
52 Transcultural Health Development
53 US Vet Initiative
54 VA Hospital
55 West County Medical
56 Western Health Clinic
57 Women to Women
58 Tarzana Treatment Center: Drug Treatment for Women
* Signifies response