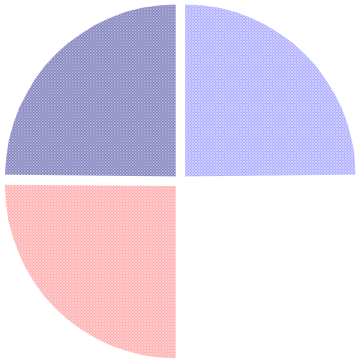

The Los Angeles Family AIDS Network (LAFAN)
2003 HIV/AIDS CARE NEEDS ASSESSMENT

Prepared for
The Los Angeles Family AIDS Network (LAFAN)

August 2003

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GOAL OF NEEDS ASSESSMENT

The goals of the needs assessment are to provide information to LAFAN in assessing its past efforts and anticipating future needs, gaps, and barriers in HIV/AIDS care for women, infants, children, youth, and families. The conclusions reached will guide LAFAN in establishing its program/funding priorities for 2004-2007.

BACKGROUND

Title IV Legislation

Ryan White CARE Act Title IV programs specifically address the needs of women, infants, children, youth, and families. Title IV supports programs that:

- Target gaps in services in the Title IV service area.
- Work to bring HIV-positive women, infants, children, and youth who are not in-care into care.
- Increase access to clinical trials and research.
- Increase access to research for women, infants, children, youth, and families infected or affected by HIV/AIDS.

Title IV programs must create an infrastructure that consists of a network of medical and social service providers, who collaborate and provide services that are comprehensive, family centered, coordinated, and culturally appropriate. Services that can be reimbursed under Title IV include the full range of outpatient and support services, including psychosocial support, case management, logistical support, and coordination.

CARE Act funds are to be used as a "payer of last resort"; that is HIV-infected and affected individuals can have no other way to obtain or have a service reimbursed. Typically this means that persons accessing Title IV are near or below the federal poverty level.

Epidemiology – Women, Families and Children Living with HIV/AIDS in Los Angeles

<u>Infants, Children, Adolescents, and Young Adults</u>

Because not all person living with HIV and AIDS have been tested, there is no precise estimate of the number of children (under 13 years old), adolescents (age 13-19), and young adults (age 20-24) living with HIV and AIDS. The HIV Epidemiology Program estimates that at the end of 2002 there were an estimated 1,449 infants, children and adolescents (age 0-19) living with HIV/AIDS in Los Angeles County (LAC). There may be as many as 4,000 young adults from 20 to 24 living with HIV/AIDS, of whom the vast majority are HIV-positive without progressing to AIDS.

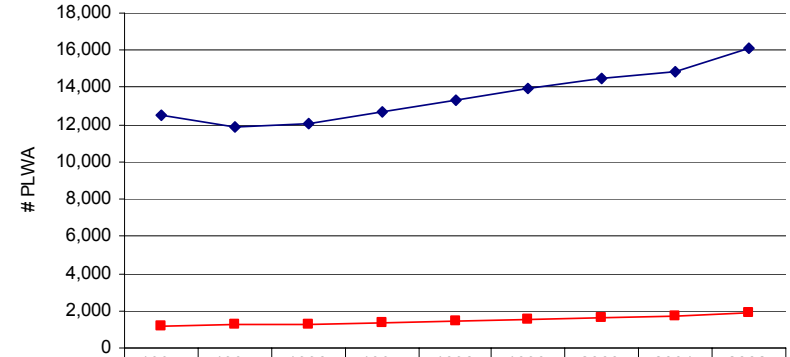
According to the 2003 Pediatric Spectrum of HIV Disease (PSD)[1] Report, since June, 1982, there have been 714 HIV perinatal cases of HIV. They are further classified as AIDS (316), HIV – non-AIDS (283), and Indeterminate (115)[2]. At the end of 2001 there were 342 infants and children under 13 years old alive and in-care (291 infected and 51 and "indeterminate"). Forty-nine (49) of these 342 were under 1-year old. Of these 342 children, Children's Hospital of Los Angeles saw the largest number (119), followed by Los Angeles County University of California Medical Center (77), University of California Los Angeles Medical Center (41), and Long Beach Memorial Miller's Children Hospital (35).

Women-of-Childbearing Age

In 2003, the County HIV Epidemiology Program estimated that there were just over 6,000 women of childbearing age (WCBA) living with HIV/AIDS[3]. In the 2002 LAC Needs Assessment, 67% of WCBA reported living with children.[4]

Because AIDS is a reportable disease there are accurate statistics on women living with AIDS, and only estimates of women living with HIV. Typically, however, the demographic trends found in living AIDS cases mirror the profile of PLWH. There is a marked increase of women living with AIDS. As seen in Figure 1, since 1994 the number of women living with AIDS has increased over 60%, and during 2002 the number of women living with AIDS increased by about 12%.

Figure 1 Yearly Trend of PLWA



	1994	1995	1996	1997	1998	1999	2000	2001	2002
Male	12,469	11,900	12,079	12,671	13,350	13,976	14,460	14,854	16,074
Female	1,184	1,223	1,277	1,378	1,437	1,518	1,614	1,693	1,897

[1] The Pediatric Spectrum of HIV Disease (PSD) project is part of the national PSD project sponsored by the CDC. It has collected data on pediatric HIV exposure in LAC since 1988. See "The Prevention of Perinatal HIV Transmission in LAC: Where we are in 2002", by Toni Federick, Laurene Mascola, et. al., Los Angeles County Department of Health Services (on-line at www.lapublichealth.org/acd/pediatric.htm).

[2] "Indeterminate" status refers to pediatric cases whose mothers were infected but the child's HIV status remains unknown.

[3] HIV/AIDS Comprehensive Plan, August 2002, based on estimates from HIV Epidemiology Program, County of LA Public Health Programs.

[4] The sample for the Needs Assessment Survey over-represents PLWH/A in Ryan White reimbursed services.

Based on PLWA at the end of 2002 there are large differences by race and region for women, adolescents, children and infants. Notably, the data below is for AIDS only through the end of 2002. Given decreased mortality, it is likely that in 2003 there are more women, and they are more likely to be in communities of color.

As shown in Figure 2, there are slightly more Latina than African American women living with AIDS. Given their proportions in the population, African American women are disproportionately more likely to be living with AIDS.

As shown in Figure 3, like all PLWH/A, women are more likely to be in the Metro, South Bay, South, and San Fernando Valley SPAs with just under 75% of all women represented in these four SPAs. However, women living with HIV are present in all SPAs.

Figure 2 PLWA by Gender (% of all PLWA)

As of end of 2002

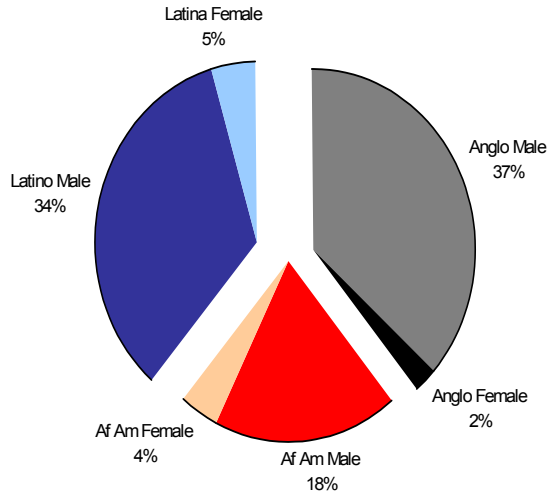
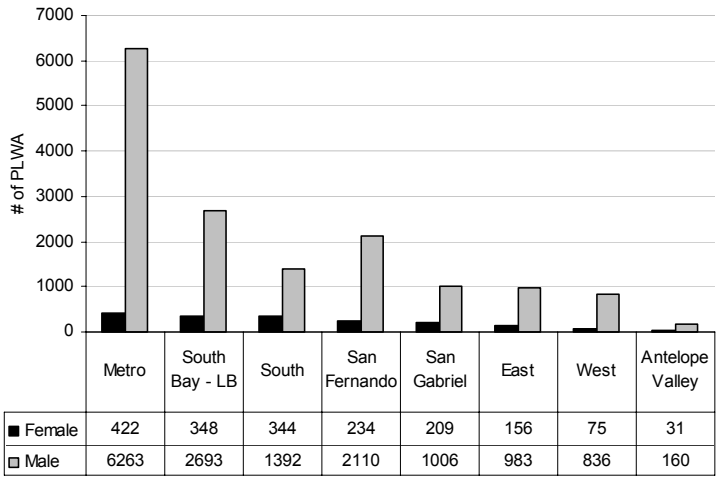


Figure 3 PLWA by SPA and Gender



	Metro	South Bay - LB	South	San Fernando	San Gabriel	East	West	Antelope Valley
Female	422	348	344	234	209	156	75	31
Male	6263	2693	1392	2110	1006	983	836	160

Age and Gender Patterns

There are different patterns of infection for different age groups. As shown in Table 1, for those 12 and under, the largest populations of those infected are among Latino males followed by Latinas and African American males. For those 13 to 19, Latinos (men and women) are the most likely to have AIDS followed by African American males. Among young adults (20-29), Latino men are, by far, the most likely to have AIDS, followed by African American males. Of the women, Latinas represent the largest group of PLWA.

Table 1 PLWA by Age and Gender

Age	0-12	13-19	20-29	30-39	40-49	50-59	60+
Af Am Male	24.4%	22.2%	13.7%	16.9%	18.5%	19.6%	16.0%
Af Am Female	13.3%	7.4%	6.0%	4.0%	3.7%	3.2%	3.1%
Ang Male	4.4%	3.7%	11.5%	26.5%	39.8%	45.0%	45.6%
Ang Female	0.0%	1.9%	2.2%	2.2%	1.8%	2.4%	2.4%
Latino Male	31.1%	33.3%	52.0%	42.5%	29.4%	23.5%	23.9%
Latina Female	24.4%	27.8%	10.5%	4.7%	3.5%	3.1%	5.9%
Total	97.8%	96.3%	95.9%	96.9%	96.8%	96.8%	96.9%

LAFAN

In Los Angeles, the Title IV Grantee is The Los Angeles Family AIDS Network (LAFAN), which is a program of Public Health Foundation Enterprises, Inc. (aka PHFE Management Solutions). All HIV/AIDS services are funded through contractual arrangements with providers, with the exception of three support groups (described under "funding"). LAFAN provides a range of services to enhance collaboration, networking and evaluation. LAFAN began in 1988 as a Pediatric AIDS Demonstration Project.

LAFAN's Community Advisory Board (CAB) meets bimonthly and has diversified its membership over this past year to include two Consumer Leadership Council (CLC) members and additional service providers representing non-LAFAN funded agencies.

Goals and Objectives

The mission of LAFAN is to coordinate a system of services for women, infants, children, youth and families infected and affected by HIV/AIDS in Los Angeles County.

Funding Priorities

In order for an organization to be a LAFAN subcontractor and receive funding from LAFAN, all proposed activities must be in accordance with Title IV program expectations. To receive Title IV funding in any area, HRSA/HAB expects that the following are addressed.

- Developing and supporting comprehensive care infrastructures that increase access to culturally competent, family centered, community-based, coordinated care including primary care for women, infants, children, youth and families.

- Involving consumers in personal care decisions and in planning, implementing and/or evaluating project activities.
- A commitment to the reduction of perinatal transmission.
- Identifying HIV-infected populations and linking these individuals to care.
- Services targeted at clients with histories of substance use.

Funding

In 2003-2004 LAFAN's Title IV allocation is $1,422,894, which is about half a percent of the estimated total funds available for HIV/AIDS care in Los Angeles County. The purpose of those funds is to fill identifiable gaps in services for women, families, infants and children. Given the small percentage of the overall funding, it is important that the funding decisions be made with the best available information.

In addition to Title IV funds, LAFAN also receives Ryan White Title I and II funds, and taking these into consideration provides a more complete profile of LAFAN services. Under Title II LAFAN receives about $36,000. Under Title I, for the 2003-2004 year, LAFAN receives $398,475. Like Title IV funds they are allocated to LAFAN salaries and expenses.

Of the approximately $1.4 million in Title IV funds, $829,112 (57%) are appropriated to direct services through subcontracts. About 31% is allocated to LAFAN headquarters staff, including the project director, Associate Director of Clinical Services, Data Manager, Fiscal Liaison, Consumer Community Liaison, Office Coordinator, and Quality Management Coordinator. About 8% of the Title IV budget is for administrative and communication expenses, including rent (3%), equipment and data support (1.3%), communication (1%), and consumer related expenses (.6%).

Of the almost $400,000 in Title I funds, about $335,956 (84%) are allocated to direct services, with about 10% for headquarters personnel and 5% for operating expenses.

The $36,000 Title II funds pay for five support group meetings each month conducted at LAFAN for grandparents, women (two meetings), and family networks (2 meetings). This is the only direct service provided by LAFAN.

Based on an RFP process for Title IV funds, in 2001 LAFAN currently has subcontracts with over 20 social service and medical outpatient providers in Los Angeles County. Each receive between $10,000 and $130,000 a year to provide services that include community case management, medical social work, mental health services, preventing perinatal transmission and identifying HIV-positive youth and integrating them into care.

Table 2 is a list of currently funded agencies, the amount and funded category from both Title IV and Title I. Notably, all medical providers are required to bill third-party payers including MediCal and California Children's Services (CCS) in order to be eligible for Title IV funding.

Table 2 Agencies and Services Funded with LAFAN Title IV and Title I

PROVIDER *Regular Print = Title IV ***Italicized print = Title I*	**DESCRIPTION** +Subtotals include agency overhead and will be greater than cumulative amounts shown for each subservice.	**$**	**SERVICE**
AIDS Project Los Angeles (APLA)		**$53,568+**	
Mental Health provider*	Funds provide ongoing individual, family and group psychotherapy for 20 clients.	$28,080	MH
Peer Advocate	Funds provide peer support, education and information to 20 women, including how to access medical interventions and clinical trials. Balance of salary paid by agency.	$10,333	Peer
Case Manager	Funds provide case manager to coordinate referrals with childcare vendors.	$5,034	CM (In-Home Care)
In-Home Childcare Program (200 hours x $20 per hour)	Funds provide in-home childcare services to allow women to access outpatient medical appointments and other support services.	$4,000	Childcare
Food and Supplies for Support Groups	Funds supply therapy supplies and nutritional incentives for support group services facilitated by mental health coordinator.	$1,252	MH
AIDS Service Center (ASC)		**$90,952**	
Peer Advocate	Funds provide staff providing peer support, education and information to 20 HIV-positive women and their families.	$33,320	Peer
Clinical Supervisor	Funds provide clinical supervision to peer advocate and oversight of LAFAN Title IV subcontract.	$3,273	MH
Mileage Funds	Provides mileage for home visits conducted by peer advocate.	$1,200	MH
Teen Support Group Facilitator	Consultant facilitates support group for7HIV-positive adolescents.	$4,800	MH
*Family case manager***	*Funds support salary for a family case manager.*	*$44,100*	*CM*
AltaMed Health Services		**$72,975**	
Medical Social Work Associate	Funds provide outpatient paraprofessional support and referrals to community agencies. Serves 30 women and families.	$37,440	CM
Mental Health Service Provider	Funds provide mental health services to 25 infants, children, youth and families including psychosocial assessment, crisis intervention, and ongoing counseling.	$22,301	MH
Nutritional Incentives for Support Groups ($200 x 24) groups per year)	Funds provide refreshments for Latino support group targeting monolingual Spanish-speaking families.	$4,800	MH
Logistical Support for Support Groups ($75 x 24 groups per year)	Funds provide logistical support for ongoing Latino support group targeting monolingual Spanish-speaking families.	$1,800	MH
Bienestar		**$42,786**	
Youth Case Manager	Funds provide case management services to 1o HIV-positive youth and coordination of referrals to youth-competent medical providers.	$16,886	CM
Youth Mental Health Provider	Funds provide counseling and support for 5 HIV-positive youth and their families.	$18,011	MH

PROVIDER *Regular Print = Title IV ***Italicized print* = *Title I*	DESCRIPTION +Subtotals include agency overhead and will be greater than cumulative amounts shown for each subservice.	$	SERVICE
Other Program Costs	Funds provide translation of patient education materials ($1,500) printing and duplicating ($1,500), and telephone/fax/e-mail expense ($1,000).	$4,000	HERR
Children's Hospital Los Angeles-Adolescent Medicine		**$78,601**	
Mental Health Provider	Funds provide mental health services to 15 youth, including psychosocial assessment, crisis intervention and offer information related to clinical trials as part of interdisciplinary team.	$10,437	MH
Psychologist	Funds provide co-facilitator for support group for HIV-positive youth.	$8,941	MH
Program Coordinator	Program Coordinator provides oversight to LAFAN Title IV subcontract.	$1,359	Admin
Supplies/food	Funds provide food and supplies for ongoing teen support group.	$1,000	MH
Group Expenses	Transportation for support group participants.	$4,500	Trans
Minority AIDS Initiative	Includes funding for 2 program coordinators ($5,201), mental health provider ($1,187), case manager ($28,257), fringe ($5,789), other costs ($4,785) for mileage, meeting supplies, office supplies, transportation and computer lease).	$45,219	CM
Children's Hospital Los Angeles-Pediatrics		**$58,617**	
Medical Social Worker	Funds provide outpatient medical social work services to 20 children and families, including psychosocial assessment, crisis intervention and provision of information related to clinical trials as part of interdisciplinary team.	$24,594	CM
Social Work Associate	Funds provide outpatient paraprofessional support and referrals to community services for 20 children and families.	$12,816	CM
Neuropsychologist	Funds provide developmental assessments for 15 infants and children and coordination with hospital multidisciplinary team to address cognitive issues and develop treatment plans.	$12,340	MH
LAFAN Medical Director	Funds provide oversight of the medical components of LAFAN, review standards of care to assure that state-of-the art HIV care is provided by all medical providers in the LAFAN network, and assist in the development of Title IV reports.	$3,339	Admin
Other Expenses	Emergency food vouchers for clients.	$470	Food
LAC Maternal/Child Clinic		**$134,675**	
Social Work Associate	Funds provide outpatient paraprofessional support and referrals to community services for 20 women and children.	$16,764	CM
Neuropsychologist (Mental Health Services	Funds provide developmental assessments for 30 infants and children and mental health services for women and youth.	$45,740	MH
Transportation	Funds provide 37 taxi rides (approximately $25 per trip) for support groups.	$927	Transp
Clinical Supervision	Funds provide individual supervision ($1,248) and group supervision ($480) for Social Work Associate.	$1,728	MH

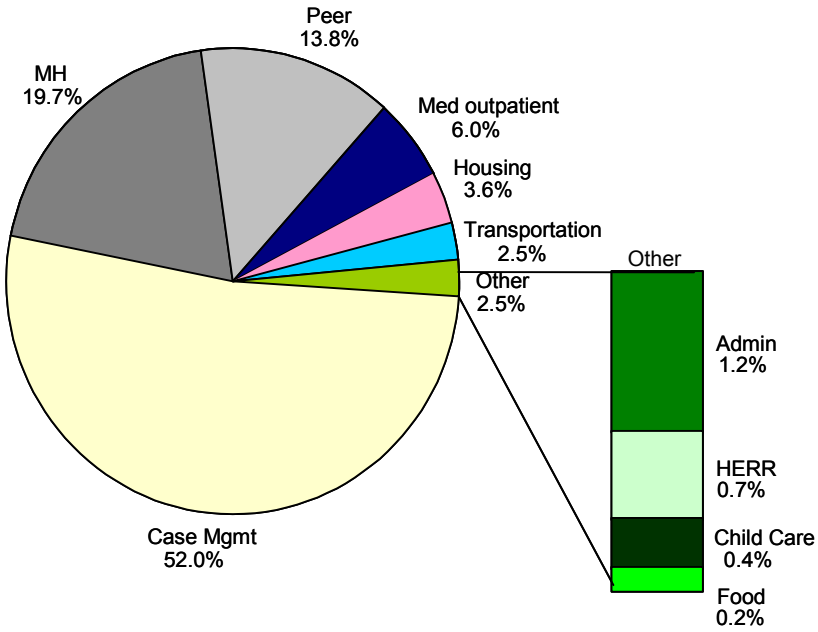
PROVIDER *Regular Print = Title IV ***Italicized print = Title I*	DESCRIPTION +Subtotals include agency overhead and will be greater than cumulative amounts shown for each subservice.	$	SERVICE
Family Case Management	*Funds part of two salaries for family case managers.*	*$63,000*	*CM*
Miller Children's Hospital		**$102,166**	
	Funds provide outpatient medical social work services to 20 women, children and families, including psychosocial assessment, crisis intervention and provision of information related to clinical trials.	$14,426	CM
Primary Care (Medical Services)	Funds provide care for up to 13 uninsured infected adult patients seen monthly – up to 104 patient hours at approximately $154 per visit, covering physician fees, facility fee, supplies and pharmacy.	$16,016	Med Outpatient
Laboratory Test Expense	Funds provide necessary laboratory tests for 13 uninsured infected adult patients monthly.	$2,270	Med Outpatient
Nurse Facilitation/Family Case Manager	*Funds partial salaries for two positions: a social working and nurse.*	*$65,430*	*CM*
Northeast Valley Health Corporation		**$43, 357**	
Social Work Assistant	Funds provide outpatient paraprofessional support and referrals to community services for 20 women, children and families.	$22,651	CM
Mental Health Provider	Funds provide mental health services to 8 children, youth and families (monthly), including psychosocial assessment, crisis intervention and ongoing counseling.	$17,334	MH
Transportation	Provide transportation for clients for medical and other appointments (674 round trip taxi rides averaging $50 each).	$3,372	Transp
South Bay Family Health Center		**$7,920**	
Transportation	Funds provide transportation services to women and families receiving case management to get to medical appointments (158 round trip taxi rides averaging $50 each).	$7,200	Transp
Spectrum/Drew University		**$39,823**	
Peer Advocate	Funds provide peer support, education and information to 20 women, including information on accessing medical interventions and clinical trials.	$33,344	Peer Support
Supplies	Funds provide educational materials and emergency food vouchers for clients.	$1,400	Food
Transportation	Funds cover transportation services to women receiving case management to get to medical appointments (30 roundtrip taxi rides averaging $50 each).	$1,459	Transp
Tarzana Treatment Center		**$107,940**	
Outreach Program Housing Specialist	Housing Specialist provides case management related to housing issues to 15 post-incarcerated women.	$19,723	Housing
Case Manager	Case manager provides services to 15 women (the majority of whom have been released from correctional facilities) to secure medical care and other support services.	$21,132	CM

PROVIDER *Regular Print = Title IV ***Italicized print = Title I*	DESCRIPTION +Subtotals include agency overhead and will be greater than cumulative amounts shown for each subservice.	$	SERVICE
Other Program Costs	Educational Materials ($480). Funds used to purchase HIV/AIDS materials for client distribution. Emergency Housing ($15,000). Funds used to purchase vouchers for local motels for HIV-positive post-incarcerated women. Transportation ($2,155). Funds cover costs of taxis and bus tokens for women being released from prison to enhance their ability to access ongoing medical care and support services. Communications ($450). Funds cover costs of telephones and e-mail.	$18,085	Housing Transp Materials
Case Manager	*Funding family case manager at the Catalyst Foundation and support family case manager at Tarzana Treatment Center.*	*$43,106*	*CM*
T.H.E. Clinic		**$60,660**	
Mental Health Consultant	Provides mental health services for 15 women in individual and group modalities (392 hours @ $50 per hour).	$19,600	MH
Family Case Manager	*Funds part of a salary for a family case manager at T.H.E.*	*$39,100*	*CM*
UCLA CARE Center		**$35,004**	
Peer Advocate	Funds provide peer support, education and information to 10 women, including how to access clinical trials, as appropriate.	$35,004	Peer
UCLA Maternal/Child Clinic		**$68,208**	
Nurse Facilitator	Funds provide clinical oversight for clients served on primary care subcontract (below).	$2,000	Med Outpatient
Primary Care	Funds provide medical care to 6 adolescents no longer covered by CCS program ($236 x 6 patients x 5 visits per year and cover physician fees, lab, and pharmacy expenses).	$7,080	Med Outpatient
Medical Social Worker & Nurse Facilitator	*Fund family social worker and nurse facilitator primarily for links to clinical trials.*	*58,220*	*CM*
UCLA/Harbor Medical Center		**$40,306**	
Neuropsychologist	Funds provide developmental assessment to address cognitive issues in HIV-positive children. Balance of salary paid by agency.	$2,844	MH
Medical Social Work Associate	Funds provide outpatient paraprofessional support and referrals to community services for 20 women and children.	$32,000	Med outpatient
Mileage meetings and make home visits to clients	Funds provided for medical social work associate to attend required LAFAN meetings.	$405	Admin

Title IV- and Title I-Funded Categories

As shown in Figure 4, of the current funded categories, case management receives the most funds from LAFAN. Mental health services and peer support follow with lower levels of funding. While not proportionately large amounts, there has been some emphasis on funding transportation after Title I cuts in that service category with a greater perceived gap in transportation to medical services.

Figure 4 Funded Categories of Services



Behind these broad categories are specific activities that LAFAN funded to fill gaps in the continuum of HIV/AIDS care. These services included:

- Providing increased support services, including case management and mental health, using a family-centered approach.
- Utilizing medical case management to ensure that families remain in care and to update treatment plans.
- Encouraging case conferencing with women who have multiple providers and/or services to include a multi-disciplinary approach.
- Providing medical care in community clinics, such as T.H.E., Alta Med, and North East Valley Health Corporation.
- Following-up for infants of HIV-positive women including proper referrals.
- Providing information on treatment options and clinical trials.
- Supplementing services funded under the Minority AIDS Initiative, to identify HIV-positive youth and connecting them to primary care.
- Reaching out to youth through health fairs.
- Providing links to residential substance abuse housing.

- Encouraging community participation and self-help through peer programs.
- Encouraging partner agencies to utilize consumers of the Title IV target population as paid staff.
- Providing funding for wrap-around services with the goal of helping clients obtain access to care (transportation, childcare).

QUALITY MANAGEMENT

In 2003, additional Title IV funding was granted to hire a Quality Management Coordinator. At that time, a Quality Improvement Committee was established to develop key outcome indicators for the primary funded service categories, case management, medical social work, mental health, nursing and neuropsychology. Referral tracking forms and client satisfaction surveys are being implemented for case management, medical social work and peer advocacy. Results should answer key questions about the efficacy of the funded services.

TITLE IV CLIENT PROFILE

Nationally, from 1999 to 2000 the number of people served through all Title IV programs increased 18 percent. Title IV provided services to 53,051 clients, 54 percent of whom were HIV-infected. In 2000, of the clients with known race/ethnicity, nationally, the majority (88 percent) were minorities. Of clients age 13 and older, 78 percent were female, most of which reported exposure to HIV through heterosexual contact.

In comparison, in 2000 in Los Angeles, Title IV provided services to 1,445 clients and 56% of the Title IV clients were infected. There is a trend to treat more HIV-positive individuals; by 2002, 80% of the LA Title IV clients were infected. In LA, in 2002, 90% of the clients treated under Title IV were from communities of color. 62% of clients in 2002 were female. From 2000 to 2002, the total number of clients served in LA under Title IV remained fairly constant but there was a dramatic adjustment in treating PLWH/A with the number of HIV-positive clients increasing from 811 to 1113 (37%).

LAFAN Client Profile

A profile of LAFAN clients is shown in Table 3.

Table 3 Profiles of LAFAN Title IV Clients 2002

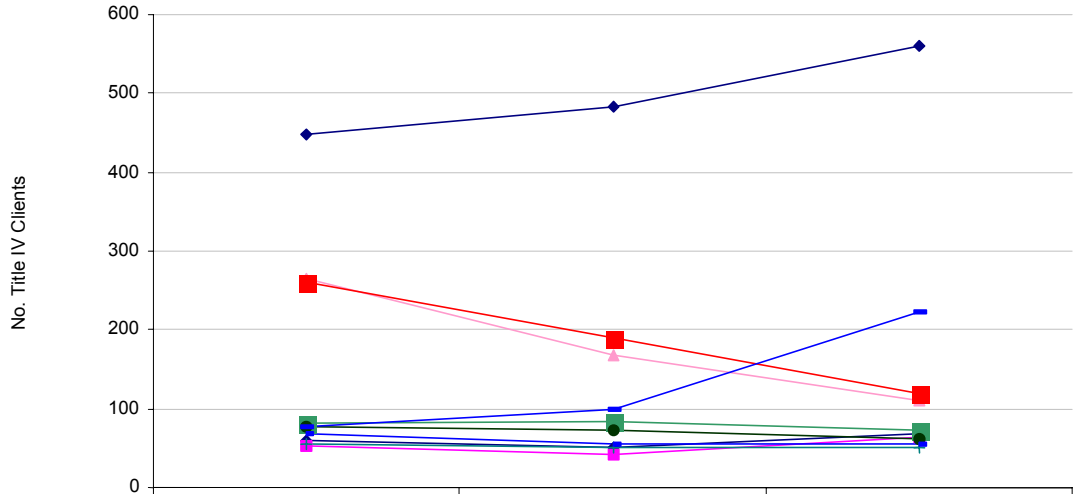
Client Characteristics	Number	%
Total	1385	100%
Gender**		
Male	523	38%
Female	862	62%
Race-Ethnicity		
Anglo (Non-Latino)	146	10%
African American/Black (Non-Latino)	452	33%
Latino	742	54%
Asian Pacific Islander	27	2%
American Indian/Alaska Native, Other / Unknown	18	1%
Age-Gender and Pregnant Women		
Infants (<2 years old)	131	9%
Children (2-12 years old)	230	17%
Adolescents (13-19 years old)	132	10%
Young Adults (20-24 years old)	86	6%
Pregnant Women	88	6%
Women (25 and older)	495	36%
Men (25 and older)	223	16%

An analysis of the age and sex of LAFAN clients from 2000 to 2002 is shown in Figure 5, and the trend from 2000 through 2002 indicates that:

- LAFAN subcontractors have also served an increasing number of adults (over age 25) during 2002, increasing from 36% in 2000 to 57% in 2002.
- Women represent the largest number of adults (561), but the largest growth in clients is among men (who are male caregivers).
- The number of infant males and females has increased, children have significantly decreased, and young adult have remained fairly constant.
- In 2003, LAFAN projects that an estimated 1,450 clients will be served.

Figure 5 Age and Sex Profile of LAFAN Clients

Infants=0-23 mo., children=2-12, youth=13-19, young adults 20-24, adults = 25+



	2000	2001	2002
Infant males	60	51	68
Infant females	54	42	63
Children males	264	167	110
Children females	260	190	120
Youth males	82	83	73
Youth females	78	73	61
Young adult males	55	51	51
Young adult females	68	56	55
Adult males	77	99	223
Adult females	447	484	561

NEEDS ASSESSMENT

Methodology

Qualitative Primary Information

Sampling and Recruiting

Quantitative and qualitative methods were employed for the needs assessment. Primary data collection from providers and consumers of services was obtained through eight focus groups and 19 key informant interviews conducted from June through August 2003. A focus group outline (Attachment 1) and key informant guide (Attachment 2) was used to guide the discussions.

Consumer participants were recruited through the LAFAN network partner agencies for input from the LAFAN target population with appropriate diversity in gender, age and ethnicity. Provider participants were recruited from within the LAFAN network and other entities, including the Commission on HIV Health Services (Planning Council) and the Los Angeles County Mental Health Task Force.

The key informant interviews represent 7 agencies and the focus groups represent 16 agencies.

Professional moderators, LAFAN network partners, and a graduate student intern conducted the focus groups and key informant interviews. Details on the focus groups and key informant interviews are shown in Table 4.

Table 4 Key Informant Interviews and Focus Group Profile

Provider Focus Groups	
Mental Health Providers	6 attendees
Medical Social Workers	9 attendees
Peer Advocates and Case Managers	10 attendees
Mixed (Clinical and Administration staff)	6 attendees
Title III Providers	4 attendees
Consumer Focus Groups	
HIV-positive Youth	4 males, (3 African Am, 1 Latino), 2 females, (Latina, African Am)
Consumers Leadership Council (CLC) Consumers	5 females, (3 African Am, 2 Latinas)
Women Alive Consumers (monolingual Spanish)	12 Females, (Latinas)
Key Informant (provider, consumer, funder)	
Consumers	3 males (Latino) 5 females (2 Latina, 2 Anglo, 1 Af Am)
Physicians	7
Other providers	3
Funders	1

In addition to the discussion, focus groups participants were given a paper-and-pencil list of services, which measured need, demand, and utilization (Attachment 3).

Analysis and Data Entry

After the focus group, moderators summarized the groups using the focus group outlines as a guide. For key informant interviews, a report guide was completed to assist in analysis (Attachment 4). The moderators completed a summary of each group. Twenty-two needs assessment grids were completed by focus group participants and the data was entered at LAFAN and analyzed in PCH offices using SPSS, a statistical analysis programs.

Note that this is qualitative data and the sample is not generalizable to all clients served under Title IV. The consumer data over-represents women and Latinos. Doctors and health care workers represent most of the key informant interviews for providers and Latinos and Latinas are over-represented in the consumer key informant interviews.

Secondary Information

In addition to the primary data, epidemiological data from HARS, and utilization data from IMACS was analyzed to determine client profiles. Existing status reports were incorporated into the text, and Needs Assessment data collected for the 2002-2003 Needs Assessment Report in Los Angeles and 2003 Needs Assessment Report in Long Beach were analyzed for the HIV care needs of women and children.

Primary Data Collection

Key Informants and Focus Groups

Several different findings and recommendations were suggested in the key informant and focus group sessions.

Models of Care

There was considerable discussion about a "one-stop model" that is interdisciplinary, family-centered, and provided better coordination between the medical team and support services. The practicality of this approach is unclear, however, due to the number of university/hospital-based Title IV programs that provide care on referral from "user-friendly" community-based organizations. This sentiment does capture the frustration some clients and providers express with the case management that has little cross-agency coordination, and further emphasizes the need to increase case conferencing and sharing of case information.

A model of neighborhood clinics was also discussed. While a number of women and adolescents mentioned that they would like more accessible services, traveling in search of higher quality services or to maintain confidentiality appears to be a much higher priority.

Sources of Funding

As shown above, Title IV provides a very small percentage of funding for care and treatment services. There are several sources of funding for medical care for children, women, and adolescents such as California Children's Services (CCS), Department of Health Services, Access for Women and Mothers (AIM), Health Families Program (HFP), and the Major Risk Health Insurance Program (MRHIP). For employers there is PacAdvantage, which provides affordable coverage. Several university-based physicians note they rely on research dollars to fund services. To have an impact on filling gaps it is necessary that the Title IV funds be used where there is a demonstrated need and there is evidence of effective treatment and services.

Systems and Reporting

Providers state that shared medical records could help in coordinating treatment, but that there are no automated systems that make that possible. Coordination is done at the case conference level.

Several providers did mention the need to improve CCS reimbursement mechanisms and better collaboration between MediCal and Ryan White-funded services.

Providers did not perceive LAFAN requirement as onerous, unlike OAPP (Title I). However some providers noted that IMACS was not user-friendly.

Populations and geographic locations

Some populations were singled out as particularly under-served. They included:

- Adolescents in general with emphasis on youth of color.
- Women in general and particularly women without children, the homeless population, Latinas and African American women.
- Lower economic Latino and African American families.
- Older caregivers.
- Women and adolescents who do not know their HIV status (particularly prevalent in South Central LA).

Geographic areas needing improved services were SPAs with the largest number of PLWH/A and where HIV had the greatest impact of HIV on communities of color – the population where women are most likely to be represented. Areas noted include:

- South Bay and Long Beach (SPA 8), which has the fastest growing epidemic.
- South Central Los Angeles (SPA 6).
- East (SPA 7) with the highest proportion of Latinos.
- Metro area (SPA 4), which has the largest number of PLWH/A, including women and families.

- San Fernando Valley (SPA 2) which has the largest proportion of Anglo women of any area.

Current Service Needs

The service needs mentioned cover nearly all the available services. There was a fair level of consensus by provider and consumers that medical care, including mental health services, and case management were important. Key wrap-around services included transportation, housing, and food.

Medical providers were more likely than consumers to note the need to place mothers and adolescents in clinical trials, substance abuse services and reproductive counseling. A few providers emphasized the need for health treatment education and outreach.

Although mental health services were not mentioned often by participants, it is noted as a high need in the survey. In the LAC Needs Assessment Report, mental health services are requested significantly more by women than men. At the same time women often feel that existing mental health services are more focused on issues confronting MSM.

Substance abuse services received low priority rankings from consumers in this assessment and in the more general LA needs assessment. This reflects the relatively low number of individuals in LAC infected through IDU, and the reluctance of substance users to enter drug treatment. However, among those women who are substance users, there is strong evidence that it is related to unstable housing, poorer nutrition, and poorer care for dependents. Clearly targeted substance abuse treatment for substance abusers must remain in the mix of services offered.

Not surprisingly, non-medical providers were more likely to note wrap-around service needs such as food, housing, and transportation than primary medical providers. Notably non-medical providers also noted the need for OB/GYN services that were generally not mentioned by medical providers. Bilingual services were also noted as needs, particularly in mental health. A few mentioned grief and loss counseling as needs. There was some discussion about the need for enhanced prevention and outreach. Services for victims of domestic violence, although not a funded service category, were frequently cited as a need.

There was some disagreement about the overall need for dental services. Providers generally did not perceive a great need, but consumers – particularly in the overall LA needs assessment, ranked dental services among their top needs.

Consumers tended to focus their comments on service needs to where they saw gaps in services. They mentioned transportation (gas cards and vouchers), childcare bilingual services, food, and housing.

Survey Responses

Although only 22 consumers completed the questionnaire, their overall needs correspond with all the key informant and focus group information. As shown in Figure 6, the top perceived needs (solid line) are medical visits (86%), education and information (85%), emergency financial assistance (84%), and taxi vouchers and bus passes (80%). Support from PLWH/A (79%), food services (vouchers -76%, pantry -75%, and nutritional supplements - 73%) were also cited as important needs. More than 60% of those responding to the questionnaire noted case management, medical specialists, dental, medical reimbursement, and legal services as important. Notably, just over half said they needed transportation and individual mental health.

In general the percentage of participants in the survey said they needed services more than they asked for them. This was not the case for information and risk reduction, and independent housing.

Some service had substantial gaps between what consumers asked for and what they reported receiving. Figure 7 shows that the top gaps where there was difference of over 10%, that is at least 10% more consumers asked for a service than received it. They included:

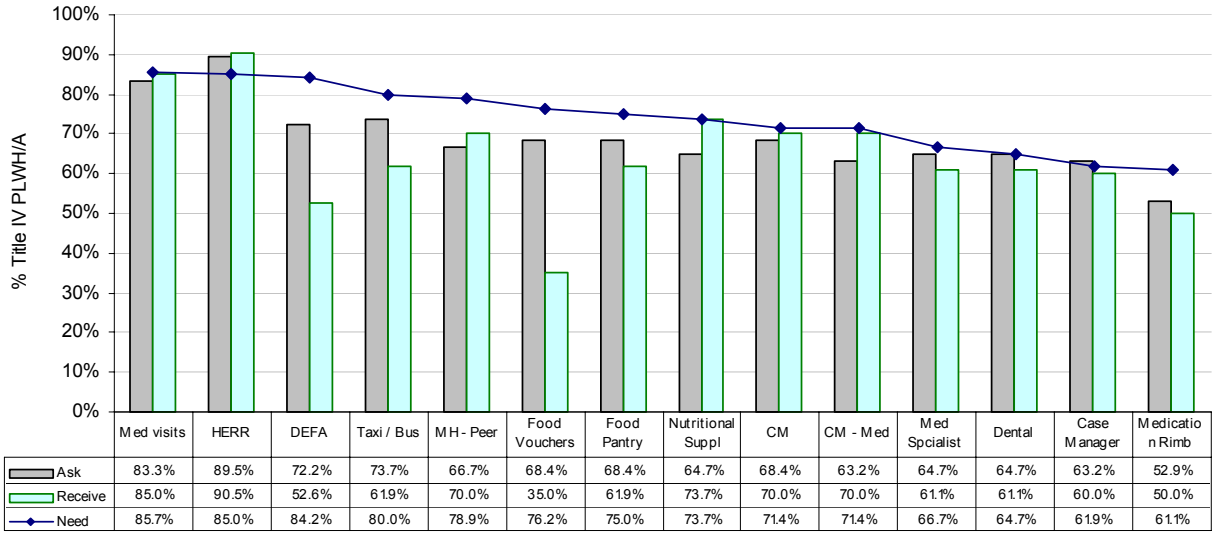
- Food vouchers
- Childcare
- Emergency financial assistance
- Legal services
- Taxi vouchers and bus passes
- Emergency housing

Notably, more consumers said they received case management and nutritional supplementary services than asked for them. This indicates that these services are provided even when consumers to do not explicitly ask for them, and suggest that there is adequate capacity for these critical services.

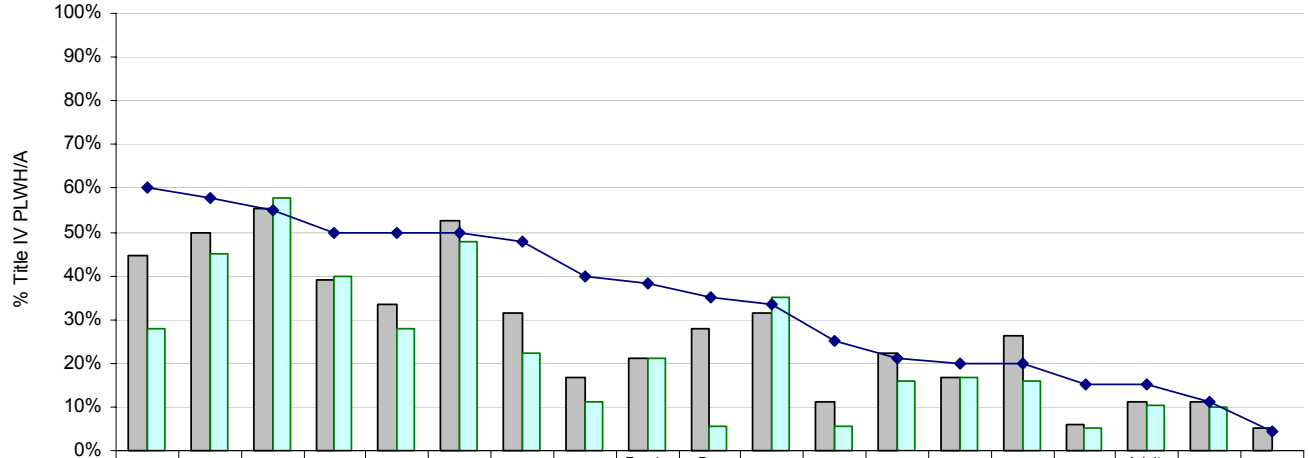
Comparison to LA Needs Assessment

In comparison to the 2002 Los Angeles EMA Needs Assessment, the Title IV participants in the survey had quite similar needs. Both groups noted Medical Services as their greatest need. In the top needs of both were food pantry, and transportation, and peer counseling. Both noted individual housing and housing information as top needs. Title IV survey participants were much more likely to mention education and information than women participating in the LAC survey. The LAC women, as a whole, were much more likely to mention dental care and somewhat more likely to mention case management.

Figure 6 Need, Demand, and Utilization of Services

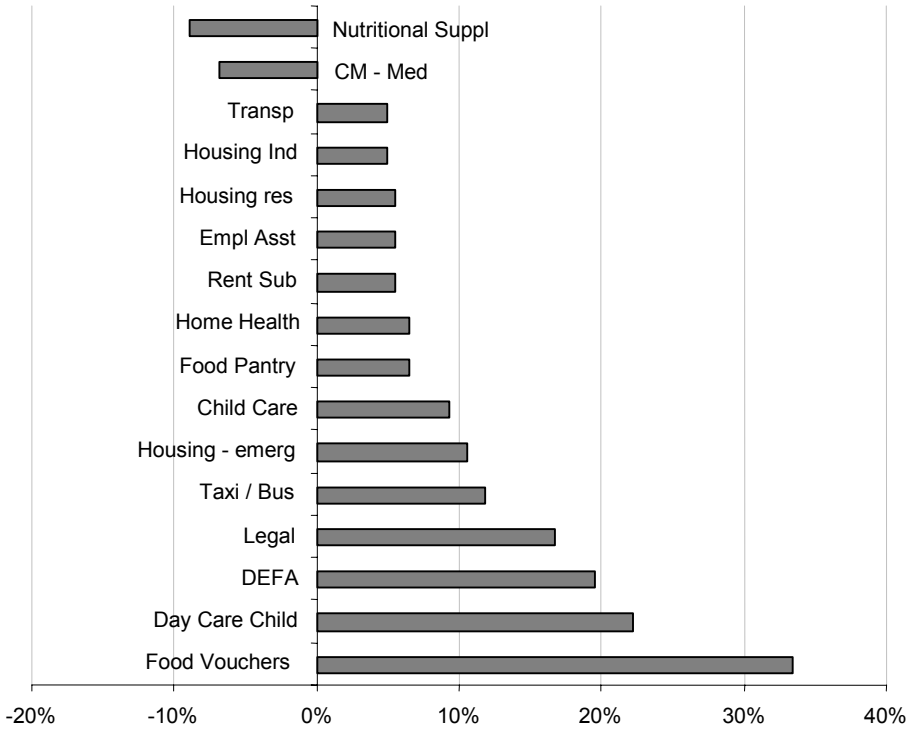


	Med visits	HERR	DEFA	Taxi / Bus	MH - Peer	Food Vouchers	Food Pantry	Nutritional Suppl	CM	CM - Med	Med Spcialist	Dental	Case Manager	Medication Rimb
Ask	83.3%	89.5%	72.2%	73.7%	66.7%	68.4%	68.4%	64.7%	68.4%	63.2%	64.7%	64.7%	63.2%	52.9%
Receive	85.0%	90.5%	52.6%	61.9%	70.0%	35.0%	61.9%	73.7%	70.0%	70.0%	61.1%	61.1%	60.0%	50.0%
Need	85.7%	85.0%	84.2%	80.0%	78.9%	76.2%	75.0%	73.7%	71.4%	71.4%	66.7%	64.7%	61.9%	61.1%



	Legal	Transp	MH Ind/Grp	Housing info	Rent Sub	Housing Ind	Child Care	Empl Asst	Food - Home Del	Day Care Child	MH Res	Housing res	Home Health	Insurance Asst	Housing - emerg	Hospice	Adult Day Care	Comple	SA- Res
Ask	44.4%	50.0%	55.6%	38.9%	33.3%	52.6%	31.6%	16.7%	21.1%	27.8%	31.6%	11.1%	22.2%	16.7%	26.3%	5.9%	11.1%	11.1%	5.3%
Receive	27.8%	45.0%	57.9%	40.0%	27.8%	47.6%	22.2%	11.1%	21.1%	5.6%	35.0%	5.6%	15.8%	16.7%	15.8%	5.3%	10.5%	10.0%	0.0%
Need	60.0%	57.9%	55.0%	50.0%	50.0%	50.0%	47.6%	40.0%	38.1%	35.0%	33.3%	25.0%	21.1%	20.0%	20.0%	15.0%	15.0%	11.1%	4.5%

Figure 7 Ask-Receive Service Gaps



Barriers

Barriers are directly related to the socio-economic status of the PLWH/A. There is a lack of resources when clients are poor. Providers said they did not have resources to fund positions for direct client services. Latinos and African Americans mentioned discrimination.

Providers noted that denial as a particularly big problem for Latinos and African Americans.

Both consumers and providers noted that there was no comprehensive consumer-friendly guide to HIV and AIDS care services.

Reporting requirements and red tape were noted as a burden, and some providers mentioned that payments by OAPP were too slow with insufficient administrative allowance.

On the questionnaire completed by those in focus groups – and they are heavily weighted toward the Latino populations, a number of barriers were noted and a few themes emerged. For transportation, lack of access to vouchers was consistently noted. Also difficulty finding childcare when going to appointments was mentioned several times.

RECOMMENDATIONS

One purpose of this needs assessment is to highlight the perceived needs of providers and consumers and combine them with findings from the overall LAC 2002 HIV/AIDS Needs Assessment, epidemiological trends, and financial analysis of the continuum of HIV care.

From a procedural viewpoint, it is recommended that LAFAN focus on larger grants that have an opportunity to show a demonstrated impact. Thus the level of the grants should be greater and the number of grantees reduced. While there is no formula to set a minimum funding level, $40,000 is a suggested minimum based on discussion with LAFAN and consultants.

The following are service recommendations. They are in no particular order of priority.

- From the evidence presented, it is clear that women and families, who tend to be newer to the epidemic than other risk groups, are also least knowledgeable about their eligibility for benefits. Women are more likely to delay their own care as they focus primarily on the needs of their families. Consequently, case management is a continuing LAFAN program priority. Case managers should be knowledgeable about the full continuum of care as well as non-Ryan White programs for insurance, housing, food, emergency financial assistance, and transportation.
- Infected women, particularly in communities of color, are more likely to cite confidentiality as a barrier. They are more likely to talk and seek assistance from people like themselves and there is a need for case managers who are culturally aware of the needs of these women.
- Food ranks among the greatest needs and has one of the largest gaps in care services for women, adolescents, and families. However, it is well documented that federal food programs are not well utilized by persons living with HIV/AIDS. Food vouchers and aggregate meals may assist women and families maintain a nutritional diet and they should be used as funding as last resort. Given the many other food programs available to women and families, case managers must be aware of and provide linkages to non-Ryan White food subsidy programs (e.g. Health Start, WIC, food stamps). Nutritional counseling can help sustain balanced diets. Using Ryan White in emergencies and stabilizing nutritional needs should be a high priority outcome.
- Transportation continues to be a need for women, adolescents, and families. Better coordination of transportation with medical and case management appointments would allow women to access services more efficiently. Efforts to educate consumers on the existing transportation alternatives and supplementing the existing system with a feeder system of vans may increase access to care and treatment for women.
- Housing and rent / utility assistance are among the top needs of all PLWH/A, and particularly women with families. There is limited subsidized housing that accommodates families that is safe from violence and drug use. Programs that provide emergency housing and link women to stable and permanent housing would enable women to attend to their care and treatment needs.

- Consumers mention childcare as a need, however in-home childcare services have not been well utilized. The County of Los Angeles, utilizing Title I funding, will be providing "drop off" childcare at local childcare agencies. The outcomes of greater utilization and higher rates of accessing services should be monitored as well as the quality of childcare.
- Mental health services, particularly for the newly infected, who often delay or have inconsistent patterns of care, are indicated for women and adolescents. Additional mental health services should be offered that are targeted to the specific needs of women. Among adolescents there is a need for peer support and family counseling to overcome issues of denial.
- Women are less likely to adhere to their medication. Adherence programs targeted to women and families would be useful in assuring women maintain their treatment regimen and don't develop drug resistant strains of HIV.
- Many of the women noted an unpredictable but severe need for housing, medication, or care in cases of emergencies. Developing protocols to efficiently provide emergency financial assistance would be helpful in meeting this need.
- For the growing number of Latinas and non-English speaking women with HIV and AIDS, greater access to bilingual services could improve access to care and greater comprehension and access to public benefits.
- Continued efforts to increase linkages and case conferencing would assist in providing more coordinated and efficient care. As new systems are introduced that allow sharing information they should be adopted by Title IV providers.
- Title IV should continue to expect that providers will measure the quality and outcome of their programs. Standard quality protocols and outcomes should be specified and measured.
- Last, the needs assessment indicated that the system has sufficient capacity for outpatient care and there are sufficient funds through Ryan White and other programs to meet the needs of women, adolescents, and families. Consequently, requests for outpatient medical care have to demonstrate a severe need before being considered.

ATTACHMENTS

Attachment 1 Focus Group Outline

Attachment 2 Key Informant Guide

Attachment 3 Service Assessment Grid

Attachment 4 Key Informant Report Guide