



## **EXECUTIVE SUMMARY**

# **THE LOS ANGELES FAMILY AIDS NETWORK (LAFAN) 2003 HIV/AIDS CARE NEEDS ASSESSMENT<sup>1</sup>**

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## INTRODUCTION

This is a summary of the more comprehensive 2003 LAFAN Needs Assessment. The needs assessment had two goals:

1. Assess LAFAN's past efforts and anticipate future needs, gaps, and barriers in HIV/AIDS care for women, infants, children, youth, and families.
2. Guide LAFAN in establishing its program/funding priorities for 2004-2007.

The next section presents the recommendations that were developed based on the needs assessment. Following the recommendations is a summary of the needs assessment, which provides background information.

## 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 Los Angeles County 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 focuses 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 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 to 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 of 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 that are targeted to the specific



needs of women should be offered. 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 that 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 outcomes 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.

## **BACKGROUND**

### **Title IV Legislation**

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

Because CARE Act funds are to be used as a "payer of last resort", most persons accessing Title IV are near or below the federal poverty level.

### **Epidemiology**

#### Infants, Children, Adolescents, and Young Adults

The HIV Epidemiology Program estimates that at the end of 2002 there were an estimated 1,449 infants, children and adolescents (ages 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.<sup>2</sup>

According to the 2003 Pediatric Spectrum of HIV Disease (PSD)<sup>3</sup> 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)<sup>4</sup>. 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"). 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<sup>5</sup>. In the 2002 LAC Needs Assessment, 67% of WCBA reported living with children.<sup>6</sup>

Because AIDS is a reportable disease, there are accurate statistics on women living with AIDS,

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<sup>2</sup> While AIDS cases are based on the HIV/AIDS Reporting System (HARS), HIV is estimated because it was not a reportable disease.

<sup>3</sup> 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](http://www.lapublichealth.org/acd/pediatric.htm)).

<sup>4</sup> "Indeterminate" status refers to pediatric cases whose mothers were infected but the child's HIV status remains unknown.

<sup>5</sup> HIV/AIDS Comprehensive Plan, August 2002, based on estimates from HIV Epidemiology Program, County of LA Public Health Programs.

<sup>6</sup> The sample for the Needs Assessment Survey over-represents PLWH/A in Ryan White reimbursed services.

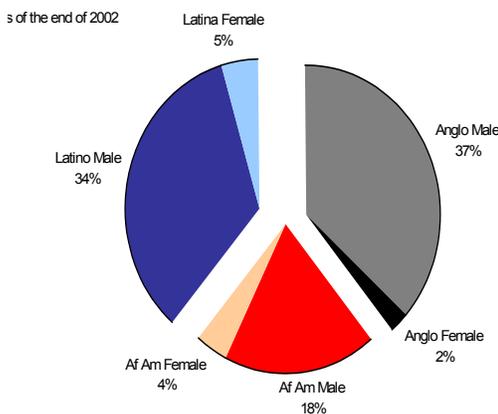


and only estimates of women living with HIV. Typically, the demographic trends found in living AIDS cases mirror the profile of PLWH. There has been a marked increase of women living with AIDS. Since 1994 the number of women living with AIDS has increased over 60%, and during 2002 the number of women living with AIDS increased by about 12%.

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.

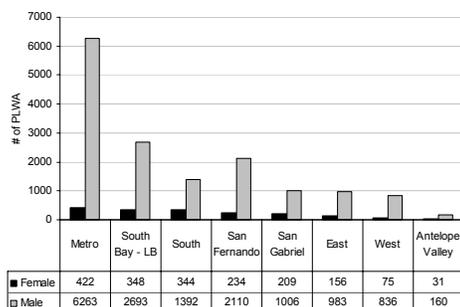
As shown in Figure 1, there are slightly more Latina than African American women living with AIDS. Given their proportions in the population, African American women are disproportionately more likely to be living with AIDS.

**Figure 1 PLWA by Gender (% of all PLWA)\***



As shown in Figure 2, 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 3four SPAs.

**Figure 2 PLWA by SPA and Gender**



### Age and Gender Patterns

There are different patterns of infection for different age groups. 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.

### **LAFAN**

In Los Angeles, the Title IV Grantee is The Los Angeles Family AIDS Network (LAFAN). All HIV/AIDS services are funded through contractual arrangements with providers, with the exception of three support groups, and LAFAN provides a range of services to enhance collaboration, networking and evaluation.

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.

### 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. In addition to Title IV funds, LAFAN also receives \$398,475 from Ryan White Title I and \$36,000 from Title II.

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, the Associate Director of Clinical Services, the Data Manager, the Fiscal Liaison, the Consumer Community Liaison, the Office Coordinator, and the Quality Management Coordinator. About 8% of the Title IV budget is for administrative and communication expenses.

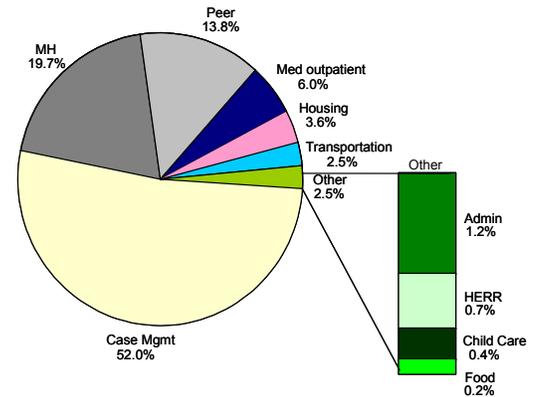
Of the almost \$400,000 in Title I funds, about 84% is allocated to direct services, 10% to headquarters personnel, and 5% to operating expenses.

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 2002 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. A complete list of providers and programs funded can be found in the full report, found on-line at [www.PCHhealth.org](http://www.PCHhealth.org). A copy can also be requested from LAFAN.

As shown in Figure 3, of the current funded categories, case management receives the most funds from LAFAN. Mental health and peer support follow with lower levels of funding. While not proportionately high, there has been some emphasis on funding transportation after Title I cuts in that service category, and a reported gap between the demand and utilization of transportation to medical services.

**Figure 3 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 of 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 connect 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

In 2002 LAFAN reported that Title IV funds were used to provide services to 1,385 clients, of whom 80% were HIV-infected and 90% were from communities of color. Sixty-two percent (62%) were female. From 2000 to 2002, the total number of clients served in LA under Title IV remained fairly constant but there was a 37% increase in the number of HIV-positive clients served. An analysis of the age and sex of LAFAN clients from 2000 to 2002 indicates that:

- The number of adults (over age 25) increased 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 female consumers has increased, children have significantly decreased, and young adults have remained fairly constant.
- In 2003, LAFAN projects that an estimated 1,450 clients will be served.

## PROVIDER AND CONSUMER FEEDBACK

### Methodology

Focus groups, key informant interviews, and surveys 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. Populations interviewed included consumers (including youth), medical and mental health providers, peer advocates, case managers, administrators, and funders. Greater details on the methodology can be found in the full needs assessment report (on-line at [www.PCHealth.org](http://www.PCHealth.org)).

The data collected in this needs assessment is qualitative and the sample is not generalizable to

all clients served under Title IV. The data over-represents women and Latinos. Most of the key informant interviews were with doctors and health care workers, and Latinos are over-represented in the consumer key informant interviews.

In addition, 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.

## Findings

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 better coordinates care 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 referrals 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 maintaining confidentiality is 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). 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.

Providers did not perceive LAFAN requirement as onerous, however some providers noted that IMACS was not user-friendly. Several providers did mention the need to improve CCS reimbursement mechanisms and better collaboration between MediCal and Ryan White-funded services.

### 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 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).

The geographic areas mentioned that needed the greatest improved services were SPAs with the largest number of PLWH/A, particularly those in 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

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 ranked high in the survey. In the LAC Needs Assessment Report, mental health services are requested significantly more by women than men.

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. They also noted bilingual services were needed, particularly in mental health. A few mentioned grief and loss counseling. There was some discussion about the need for enhanced prevention and outreach. Services for victims of domestic violence, although not a Ryan White 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 LAC 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. The top perceived needs are medical visits (86%),



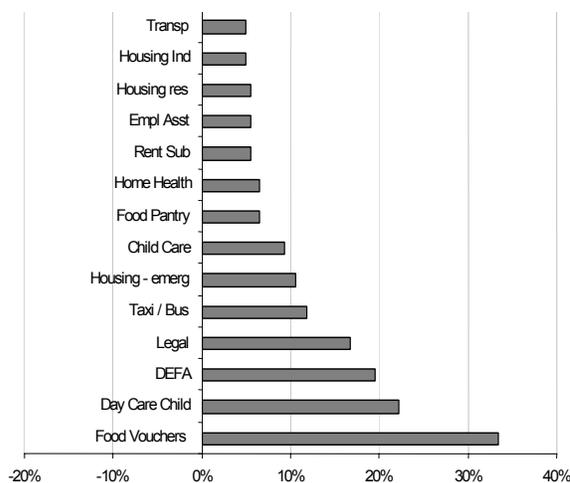
education and information (85%), emergency financial assistance (84%), and taxi vouchers and bus passes (80%). Support from PLWH/A (79%), food services (vouchers 76%, pantry 75%, and nutritional supplements 73%) were also cited as important needs. More than 60% of those responding to the questionnaire noted as important case management, medical specialists, dental, medical reimbursement, and legal services. 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.

As shown in Figure 4, some services had substantial gaps between what consumers asked for and what they reported receiving. The top gaps, where at least 10% more consumers asked for a service than received it, included:

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

**Figure 4 Ask-Receive Service Gaps**



### Comparison to LAC Needs Assessment

The Title IV Participants in the LAFAN Needs Assessment had quite similar needs to those interviewed in the 2002 LAC Needs Assessment. Both groups noted medical services as their greatest need. Top needs included food pantry, transportation, and peer counseling, individual housing and housing information. However, LAFAN 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.

### Barriers

Barriers are directly related to the socio-economic status of the PLWH/A, and there is a lack of resources when clients are poor.

- Latinos and African Americans mentioned discrimination as a barrier to obtaining services.
- Providers noted 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.
- Communities of color were more likely to mention transportation, particularly lack of access to vouchers.
- Latinas noted difficulty finding childcare when going to appointments.