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HIV Education Case Studies

*A Review of Community Based HIV Prevention Programs
Funded by the United States Conference of Mayors*

Education and Service Coordination for Asymptomatic HIV-infected Women and Injection Drug Users.

*CODAC Behavioral Health Services – Tucson
Congreso de Latino Unidos – Philadelphia
Health Crisis Network – Miami
Long Beach AIDS Network – Long Beach*

144123

U.S. Department of Justice
National Institute of Justice



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The United States Conference of Mayors

The United States Conference of Mayors is the official nonpartisan organization of cities with populations of 30,000 or more. There are over 1000 such cities in the country today, each represented in the Conference of Mayors by its chief elected official, the Mayor. The U.S. Conference of Mayors is in its second half-century of service to the Mayors and the citizens of America's principal cities.

William J. Althaus
President
Mayor of York

J. Thomas Cochran
Executive Director

Purpose of Publication

Since 1984, the U.S. Conference of Mayors, in cooperation with the U.S. Centers for Disease Control and Prevention (CDC), has provided HIV/AIDS education and information to localities. USCM has awarded \$4.96 million in prevention grants to 143 CBOs. These grants include \$4.21 million in funding to 135 CBOs to conduct HIV/AIDS education to persons at risk for HIV infection. USCM also provided \$755,000 to eight CBOs to carry out HIV/AIDS education and service coordination programs for persons with HIV infection. In 1993, USCM awarded \$1 million under the new Collaborative HIV/AIDS Prevention Grants Program to five local health departments and five CBOs. Under the new program, funds are awarded to conduct needs assessments to determine local HIV/AIDS prevention needs and capacities or for the improvement and expansion of HIV prevention programs for hard-to-access populations.

This publication is the sixth in a series of case studies, which have featured twelve USCM grantees, documenting the efforts of CBOs funded by USCM that have responded to the HIV epidemic with effective community-based education programs.

USCM HIV Case Studies

- #1 Teen Teatro, Avance Human Services (Los Angeles), August 1989
- #2 Focus Groups: Process for Developing HIV Education Materials, BEBASHI (Philadelphia), Health Watch (New York City), April 1990
- #3 Women & AIDS, Montgomery AIDS Outreach (Montgomery), Planned Parenthood SE VA, (Hampton/Newport News), Empowerment Program Services (Denver), Nevada AIDS Foundation (Reno), Women's Network/Mujeres Unidas (New York City), May 1991
- #4 Reaching HIV+ Clients, The Phoenix Shanti Group, May 1992
- #5 Reaching Youth in High Risk Situations, Sasha Bruce Youthwork, Inc. (Washington), Gay and Lesbian Adolescent Social Services (West Hollywood), Indianapolis Youth Group (Indianapolis) September 1992
- #6 Prevention and Service Coordination for Asymptomatic HIV-infected Women and Injecting Drug Users, CODAC Behavioral Health Services (Tucson), Congreso de Latinos Unidos (Philadelphia), Health Crisis Network (Miami), Long Beach AIDS Network (Long Beach), June 1993

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This case study was written and produced by Paula M. Jones, Senior Staff Associate and edited by Ellen Tynan, Staff Associate III. It is based on USCM's grant monitoring experience with the projects including records of site visits and follow-up telephone interviews with project staff, and activity reports collected by Jeffrey Menzer, former ESC Program Manager. Publication lay out by Peter Wiant, DC desktop publisher.

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USCM's HIV Education and Service Coordination Grants

In late 1989, USCM initiated, with funds from the U.S. Centers for Disease Control and Prevention (CDC), the HIV Education and Service Coordination (ESC) Grants Program, which over the course of the next two years provided eight grants totaling \$755,000. Grants made under the program were to community-based, nonprofit organizations to develop and implement projects to provide early care services to persons with HIV infection. The services provided by funded organizations include individualized risk-reduction education and service coordination (i.e., case management) to access medical and other supportive services.

The goals of the ESC program were: 1) to enhance the capabilities of community-based organizations to provide risk-reduction education and service coordination for persons with HIV infection, their partners and their families; and 2) to develop models of effective risk-reduction education and service coordination which may be replicated in other localities for persons with HIV infection. A unique element of the ESC program was the requirement that grantees utilize ten percent of their funds for program evaluation.

In December 1990, USCM released a Request for Proposals (RFP) for the second round of ESC grants with priority target populations of injecting drug users (IDU) and women with HIV infection. Four programs were selected for funding from over seventy proposals received. Funded during round two were:

- CODAC Behavioral Health Services, a substance abuse treatment agency in Tucson, Arizona;
- Congreso de Latinos Unidos, Inc. (Congreso), a substance abuse and AIDS prevention agency serving Puerto Ricans and other Latinos in Philadelphia, Pennsylvania;
- Health Crisis Network (HCN), a community-based AIDS service organization in Miami, Florida, and
- Long Beach AIDS Network (LBAN), an AIDS service organization in Long Beach, California.

CODAC and Congreso targeted HIV-infected injecting drug users and HCN and LBAN targeted HIV-infected women.

Serving hard to reach populations presented a challenge to all the grantees—especially in the recruitment and retention of clients. All programs found that subgroups existed within their target population and that it was difficult to provide services that accommodated the needs of all subgroups. Additionally, all four organizations found that the needs of many of their clients were so profound that they were outside the realm of what the organization could provide. The organizations experienced serious delays in providing some services (e.g., drug treatment) and found it was impossible to meet the needs of some clients due to poverty, ongoing substance abuse, or lack of an outside support network.

The following document consists of case profiles of the four programs funded by USCM. The profiles discuss agency background, program design, program goals and objectives, staffing, implementation, and program evaluation as well as barriers experienced in accessing and serving clients. The lessons learned by these four organizations, as they sought to serve HIV-infected IDUs and women, can help other organizations in their efforts to serve these target populations.

ESC Program Grantees (Round 1)

Community Health Project, New York City
C.U.R.A., Inc., Newark

Minority AIDS Project, Los Angeles
Operation Concern, San Francisco

New Connections: Building Linkages for Clients and Service Providers

As a long-time service provider to IDUs in Tucson Arizona, the CODAC Behavioral Health Services was familiar with many of the needs of this target population. CODAC was also familiar with some of the barriers drug treatment providers experience when addressing HIV issues or providing services to HIV-infected individuals. In addition to proposing to provide case management and risk reduction counseling to HIV infected IDUs, CODAC's New Connections program contained a significant training component for Tucson-based service providers with ties to the target population. CODAC hoped the training would result in an enhanced referral network and increased sensitivity to the needs of the target population. By improving the quality of services available to this hard-to-reach target population, CODAC believed that client retention would be improved and opportunities to provide risk reduction counseling increased.

Agency Background

CODAC was established in 1970 to create a network of treatment and prevention programs. From 1972 to 1980, CODAC was funded by the National Institute on Drug Abuse (NIDA) to serve as an umbrella organization for drug abuse treatment and prevention programs in the county. In 1983, CODAC expanded its scope to address a broader range of behavioral health problems with treatment, prevention and education programs.

CODAC's services include: outpatient drug abuse therapy tailored to such populations as emotionally disturbed children, adolescents, women, and individuals involved in the criminal justice system; medical and psychosocial therapies for the treatment of opiate addiction; a prevention program targeting preschool through sixth grade children which includes teacher training and workshops for parents; treatment and case management services to pregnant women with a history of drug or alcohol use; a demonstration program providing extensive assistance to families of preschool-age children in high-risk situations. In 1987, CODAC integrated specific HIV risk reduction/prevention education into all programs.

Tucson AIDS Project (TAP) provided case management services for the New Connections program. TAP, an AIDS service organization established in 1985, provides services to persons with HIV/AIDS and their families and educational outreach to the greater community.

Proposed Program

The New Connections program featured community networking, service coordination and direct case management, and risk reduction counseling for HIV-infected injecting drug users, their partners and their families. To create a supportive network within the community, CODAC proposed to conduct a series of training sessions for personnel at drug treatment facilities. The training would serve to increase staff

knowledge and understanding of HIV and the relationship between HIV and injection drug use. In turn, trained service providers would serve as the first link with potential clients, utilizing their increased knowledge and sensitivity to HIV-related issues to increase the likelihood of clients seeking services. In order to build linkages within the community and increase the sensitivity among the staffs of organizations making up the referral network, CODAC proposed to convene a conference of agencies providing substance abuse and HIV support services. The conference would provide training for drug treatment providers and AIDS service providers and increase familiarity with community resources.

To reduce barriers to accessing the program, New Connections leased a van so that case management and support services could be provided to clients in their homes, and at hospitals, drug treatment agencies

Program Staff

CODAC
Project Coordinator (.75 FTE)
Counselor/Trainer (.5 FTE)
Program Assistant (.5 FTE)

Tucson AIDS Project
Case Management Specialist (1 FTE)
Prevention Services Director

Budget

CODAC	
Project Budget	\$99,078
Expenditures	\$99,078
Tucson AIDS Project	
Project Budget	\$34,362
Expenditures	\$34,362

and other locations in the community. Both CODAC and TAP, based on past experience, identified the lack of transportation as one of the most significant barriers to providing services to the target population. The van would also allow the case manager, a TAP staff member stationed at the CODAC offices, to make referrals to other community services and coordinate transportation for the client.

The risk reduction component of the program consisted of ten one-hour individual counseling sessions and five two-hour group counseling, skill-building and support sessions. Issues addressed during the sessions included: basic HIV/AIDS information, risk reduction techniques, sexuality/sexual behavior issues, disease progression issues, coping with stress and fear, acknowledging grief, and overcoming isolation. Counseling was also available to couples. The group sessions alternated between structured and open topics and included exercises in communication building, problem solving, and other coping skills. The New Connections program proposed to make risk-reduction counseling and services available to all clients regardless of drug use or treatment status.

HIV Training for Drug Treatment Counselors

Prior to the New Connections program, CODAC staff had observed that clients needed to reach a level of acceptance concerning their HIV status before they could address their chemical dependency problem. According to staff, the continuum of HIV disease (HIV diagnosis, development of symptoms, early intervention, AIDS diagnosis) require the counselor frequently to refocus the treatment plan and to be sensitive to the changing needs of clients.

Prior to designing the curriculum for drug treatment personnel, CODAC surveyed the staff of fifteen local service providers to assess their interest in, and knowledge of, HIV. Service providers were also interviewed by phone to determine the most effective format for the training and to provide more information on the case management services offered by CODAC under the new program. The surveys indicated that service providers preferred training sessions to be limited to three hours, to allow more staff to attend without disrupting the operation of the agency. By the conclusion of the program period, 20 training sessions had been conducted at ten agencies, reaching 114 staff.

CODAC compiled a manual from existing resources and worked very closely with the University of Arizona AIDS Education Project in designing the training sessions. The topics covered included: basic AIDS 101

Tailoring Professional Education

Before beginning the professional training component, CODAC surveyed 15 drug treatment/counseling agencies to assess their interest in and knowledge of HIV. Follow-up phone calls concerning the survey provided an opportunity to introduce the New Connections Program. To make sure that the training was appropriate for a specific agency, CODAC staff met with the director or the clinical supervisor to discuss the curricula and the agency's needs. This allowed for tailored training sessions since units of the curricula could be delivered independently.

information; a discussion of counseling and testing; prevention and risk reduction information (both safer sex practices and needle cleaning techniques); misconceptions, dilemmas and strategies for providing services to HIV-infected individuals; and information on local resources. Training stressed the importance of confidentiality in providing services to HIV-infected individuals. According to CODAC, "The counseling agency must be perceived as a safe environment where client rights will be respected."

Participants received folders that included the training materials, listings of state and local HIV/AIDS resources, and articles on the connection between substance abuse and HIV/AIDS. A manual including information on AIDS epidemiology, HIV testing and counseling, risk reduction, and local resources was provided to participating agencies.

CODAC also organized a two day cross-training conference which brought together professionals from the fields of drug treatment, case management and HIV/AIDS organizations. Topics addressed at the conference included: incorporating primary and secondary HIV prevention into treatment planning; a facilitation model of case management; the challenges of case management, barriers and solutions; instruction for developing, presenting and evaluating a treatment plan.

Case Management Services

Program planners had assumed that homophobia on the part of the target population would cause them to

be reluctant to seek services from AIDS service providers. While initiating the program, it became apparent through feedback from clients that the avoidance resulted more from a lack of knowledge and experience with addiction treatment on the part of service providers. In an effort to make the target population more comfortable while accessing services, a case manager experienced in working with IDUs was hired and based at the CODAC offices. As an employee of TAP (a subcontractor with CODAC in the proposal), the case manager was linked to an established case management system and the resources available through TAP.

The availability of transportation was vital to the provision of services. Approximately 75 percent of the intakes of the New Connections program were conducted off-site in client homes or at other community organizations.

During intake, an assessment of client's drug use was conducted and risk reduction counseling was provided. Following intake, the case manager helped clients to access services by assisting in the completion of forms and providing transportation to appointments. Periodic follow-up was carried out by the case manager to assure that client needs were being met or to determine if the case management plan needed modification.

Based on TAP's experience in meeting the needs of HIV-infected clients, CODAC anticipated that, after transportation, help with housing, medical assistance and entitlements would be most frequently requested by New Connections clients. As anticipated, assistance with housing was requested by many clients (CODAC received 36 requests). Because of their history of substance abuse, according to CODAC, many clients had alienated family, friends and social service agencies. Without a system of support, they were highly dependent on CODAC to meet their needs. CODAC referred clients with housing needs to the People with AIDS Coalition of Tucson (PACT). PACT coordinated a housing service.

CODAC also experienced unexpected demands from non-targeted populations. The original proposal identified IDUs as the target population, but the case manager found that he was providing services to a broad range of substance (including alcohol) users. The target population was expanded beyond IDUs to any HIV-infected substance users since they all had addiction issues to address.

During the program period, case management services were provided to 76 HIV-infected clients (62 males and 14 females), with the case load remaining between 30-35 clients. At the time of intake, 14 clients were diagnosed with AIDS. The ethnic breakdown of clients was: 69 percent (52) White, 21 percent (14) Hispanics, nine percent (7) African Americans and one percent (1) Native American. Most of the clients were between 30 - 39 years old.

The following services were provided by CODAC during the project period:

Service	# of requests
Transportation	69
Primary Care	46
Housing/Shelter	36
Substance Abuse Treatment	34
Food/meal services	34
Benefits/entitlements assistance	32
Specialty Care	24
HIV counseling & testing	23

The original proposal identified IDUs as the target population, but the case manager found that he was providing services to a broad range of substance (including alcohol) users.

Other services requested included: legal services (15), mental health services (14), home nursing care (9), inpatient care (6), financial assistance (6), religious/pastoral care (3), and clinical trials (1). In all, CODAC provided 708.8

hours of case management services.

In response to a client satisfaction survey, case management services received a mean score of over four on a five point scale (five being "extremely satisfied").

Counseling Services

Forty-eight clients received group or individual counseling during the program period. The CODAC counselor provided 169.75 units (a unit is equivalent to one hour of face-to-face contact) of individual counseling, 362.5 units of group counseling and 10.5 units of family counseling. Each client was offered individual or group counseling services at intake. Family members and partners could be included in individual counseling sessions and referrals to outside support groups were also available to family members and partners. Clients were not required to participate in group or individual counseling in order to receive case management services.

The counseling component of New Connections focused on issues of substance abuse, psychosocial ad-

justment to HIV infection, disease progression and secondary risk-reduction education. Group sessions alternated between structured and open topics. Exercises during these sessions were designed to improve communication, problem solving and other coping skills.

In designing the program, CODAC planned that counseling sessions would be provided until a client could be placed in drug treatment (34 referrals to drug treatment were made during the project period). The counselor found that some clients preferred to continue attending counseling sessions after they had begun drug treatment. According to the counselor, "Their requests were based on their perception that many treatment facilities lacked knowledge and understanding of HIV disease and its progression. Clients stated that they felt more support from a counselor who was HIV/AIDS knowledgeable and who understood their fears."

The counselor kept notes for both group and individual sessions. After ninety days the counselor assessed and revised the treatment plan. Behavior change was also reported in the counselors notes.

Measuring Behavior Change

During the fourth month of the program, CODAC began utilizing self-administered risk assessments to measure client behavior change. It was decided to administer the risk assessment only to clients receiving counseling, because clients that only received case management services would not be receiving ongoing risk reduction information. Due to client attrition, CODAC was not able to collect sufficient follow-up information to measure the impact of risk reduction counseling.

Conclusion

In their final report to USCM, CODAC conclude:

"When we think of HIV/AIDS prevention, we need to be conscious that there exists a correlation between HIV/AIDS and substance abuse. The two areas must be thought of and dealt with as one. Substance abuse treatment must be available if we expect this population to integrate low risk behaviors. It will be through addressing the dual issue—HIV/AIDS and substance abuse—that control over the epidemic may be possible."

CODAC believes that the New Connections Program's combination of direct services for HIV-infected substance abusers and education for service providers has created a necessary foundation for meeting the growing needs within the community.

New Connections Counseling Program

Individual Sessions (10)

Dealing with a Diagnosis of HIV Infection

Understanding HIV/AIDS
Facing your emotions (psychosocial adjustment)
HIV: a manageable disease

HIV and Relationships

Sex in the age of HIV
Safer sex skills

Medical Issues

HIV: a manageable disease
Choosing a physician
Medical facts about HIV/AIDS
Alternative therapies

Substance Abuse

Addiction issues and HIV
Steps to cleaning works (needle, syringes, cotton)
Community Resources

Health Issues

Nutrition
Relaxation, stress reduction, and lifestyle change
Emotional, mental and spiritual health

Groups Sessions (5)

Establishing a Support Network

Family, friends and significant others
Community Service

Substance Abuse and HIV

Addiction issues and HIV
Steps to cleaning works

Sexuality and Relationships

Sex and HIV
Safer Sex Skills

"Confianza" and "Familiarismo" Help Congreso Reach IDUs

In their proposal for Project Life Line/Proyecto Linea De Vida, Congreso de Latinos Unidos proposed to provide risk reduction education and service coordination to HIV-infected injecting drug users and their sex and needle-sharing partners. When they tried to reach the target population, staff experienced difficulty reaching active drug users. It appeared to staff that many were too involved in their addiction to take advantage of available services. Though they continued street outreach to active drug users as planned, because of the lack of responsiveness to the program by the original target population, Congreso switched their emphasis to coordinating service for individuals in, or considering entering, recovery programs.

Agency Background

Congreso de Latinos Unidos is a nonprofit, multi-service agency established in 1977. Congreso offers a variety of programs in both Spanish and English, including: employment services, youth drug prevention services, outpatient drug and alcohol services, services to children and their families, crisis intervention services, crisis intervention for youth on court probation, adolescent drug and alcohol services, child abuse prevention services, AIDS education and outreach services, HIV counseling and testing services, and HIV case management and support services.

Proposed Program: Project Life Line/Proyecto Linea De Vida

In designing the program, Congreso looked to several studies which indicated that positive peer support, increasing treatment options, and emphasizing the positive aspects of safer sex could lead to the reduction of high risk behaviors. Throughout the development of the program, Congreso placed importance on designing an intervention sensitive to the culture of the target population.

Utilizing the information from the studies and experience in drug treatment, Congreso developed a two-pronged approach for providing HIV risk reduction and case management services to HIV-infected asymptomatic Puerto Rican/Latino IDUs and their sex and needle-sharing partners. The proposal presented the program as incorporating "social networking prevention sessions and a peer support program, which take into consideration cultural and behavioral characteristics that facilitate relationships like the extended kinship network to reinforce efforts in adopting safer sexual practices, discouraging I.V. needle sharing, resisting drug use relapse pressures, managing the fear of AIDS, and accessing needed services."

Congreso proposed to provide intensive bilingual/bicultural risk reduction education, case management, and service coordination services to 60 HIV seropositive

asymptomatic Puerto Rican/Latino IDUs and 300 sex and needle-sharing partners. Congreso proposed to measure its success in promoting safer sex and needle using practices among clients by tracking increases in condom use and decreases in needle sharing. By the end of the project period, Congreso anticipated that clients would report using condoms and not sharing needles at least 70 percent of the time, as a result of the HIV risk reduction education and counseling.

Congreso employed an external evaluator to analyze client data collected by the networking team through pre-tests of knowledge, attitudes, and behaviors, and compiled by staff during service coordination and counseling sessions. The evaluator was also responsible for providing quantitative and qualitative assessments of program progress in accordance with established goals and objectives.

A Strategy to Reach the Target Population

Congreso proposed to employ a "social networking team" comprised of Congreso staff experienced in working with the target population and four trained peer volunteers (HIV seropositive asymptomatic recovering IDUs). Congreso believed the team's success depended on its ability to establish "confianza" and

Program Staff

Clinical service coordinator/case manager
(1 FTE)
Case manager (1 FTE)
Educator/Group Facilitator (.5 FTE)

Budget

Program Budget	\$95,075
Expenditures	\$80,834

"familiarismo" (trust) with the target population by approaching them on their own terms in familiar environments. While canvassing areas where the target population congregated (bars, homeless shelters, low-income housing projects, abandoned houses, alleys, and prisons) the team members provided information on HIV/AIDS, sexually transmitted diseases (STDs), and advice on how to negotiate and enter the drug treatment system.

Risk Reduction/Recruitment Activities

In the original proposal, active drug users were to be targeted by the outreach team. According to Congreso, "several difficulties were encountered due to the constant non-compliance and disruptive behavior of those actively using drugs." The attention span of active drug users also made it difficult to provide them with risk reduction information. Because of this unexpected difficulty, Congreso shifted the project's emphasis to individuals already in recovery or those seriously considering entering a drug treatment program.

To provide HIV risk reduction information to the newly identified target population, Congreso directed outreach activities to facilities in contact with these individuals such as non-regulated religious-based residential drug and alcohol programs, hospital detoxification programs, and correctional facilities. Risk reduction sessions were also held at the facilities already serving the target population: detox units, outpatient drug treatment centers, and correctional facilities. Congreso used activities, such as softball games, to attract the target population to the program.

A series of four sessions, conducted at the facilities, provided comprehensive HIV prevention information, encouraged the development of positive peer relationships, reinforced the cultural concept of "confianza" and assisted the target population in reducing behaviors that may lead to HIV infection (e.g., sharing needles and unprotected sex). Topics addressed during the sessions included: what is AIDS, HIV, and the immune system?; how the immune system works; alcohol, substance abuse and the immune system; the importance of monitoring T4 cells; HIV/STD transmission and prevention; and progression to AIDS (a workshop which covered opportunistic infections, adjusting to prevention methods with HIV seropositive partners, enhancing communication with partners, living with HIV, treating HIV, how to provide support for partners, how to access services).

In addition to the outreach and risk reduction sessions, Congreso initiated a peer support program as part of

Project Life Line. Trained volunteers provided intensive risk reduction education sessions to the target population. Peer support groups, co-facilitated by the educator/counselor and a peer volunteer, consisted of at least five former or active drug users and their sex and/or needle-sharing partners. According to Congreso, "the role-play exercises and discussions with HIV-infected individuals have proven to be quite effective in helping participants understand the implications of HIV infection and how to begin thinking about ways of protection."

The peer support groups emphasized the development of "positive peer pressure" as a means to influence behavior change. Participants in the sessions became role models for their active drug using friends and partners. Many participants in the peer support program went on to receive further training and became "buddies" to other drug users. Some remained in the program after they left the drug treatment program from which they were recruited.

Despite the changed focus of its outreach, Congreso continued to provide risk-reduction information to active injection drug users. The team went to "crack houses" and street corners to provide drug users with information on HIV counseling/testing services, substance abuse treatment and other support services on a regular, ongoing basis.

Service Linkage

The other component of Project Life Line linked clients to services. These services included: anonymous/confidential HIV counseling and testing, outpatient drug and alcohol treatment, hospitals, health care centers and other treatment services. A priority of the program was to link clients with early intervention services and develop weekly, monthly and quarterly service coordination goals. Congreso anticipated a 30:1 client to case manager ratio throughout the program.

Clients were recruited through street outreach, at peer education sessions, and by referral from Congreso's other services and other organizations. Project Life Line case management services included: one-on-one HIV risk reduction information; psychosocial counseling; nutritional counseling; support groups; and direct access through referral to appropriate early intervention, medical, and drug treatment services. Both case managers hired by Congreso had educational and professional experience in substance abuse and mental health treatment.

At intake, prospective clients received information on

the range of services available and on their rights as clients. The case manager then administered a baseline risk assessment questionnaire, collected demographic information, obtained consent for services, carried out a needs assessment, and, with the client, developed a long- and short-term service plan. HIV risk-reduction education and materials (condoms and bleach) were provided to clients by case managers and the effectiveness of these efforts was measured through monthly risk assessment questionnaires.

Following intake, case managers worked closely with the client for the first 15 to 30 days to meet immediate needs. Service plans were revised by the client and the case manager on both a weekly and monthly basis to insure that progress was being made toward accomplishing the established goals and objectives. The case managers arranged access to other organizations by making appointments and providing transportation and Spanish/English translation.

Case managers conducted follow-up by phone or during office and home visits to determine if clients were adhering to the treatment plan. If clients were unable to keep appointments, the case managers assisted them in rescheduling. All contacts between case manager and client were recorded in confidential client files. Client files were reviewed monthly by the case manager and the clinical service coordinator to assure that client needs were being met.

Experiences From the Program

Both drug treatment and HIV counseling and testing were high priorities for clients. Case managers worked closely with Congreso's outpatient drug and alcohol program staff (coordinating admittance to detox and assisting in treatment intake) and HIV counseling and testing staff to assure easy access for clients. Case managers also assisted in locating other service providers when Congreso's drug treatment services were full. Case managers cited the lack of accessible drug treatment and the shortage of medical doctors serving Latinos as significant barriers to meeting the needs of clients.

One particular difficulty with the case management

component was encountered early in the program. Case managers noticed that the clients had trouble distinguishing between the services provided by case managers and those provided by drug and alcohol counselors, since the clients had not had experience with case management before. The case managers worked to clarify their role by emphasizing the HIV-related support and resources they could and could not provide to clients.

Case managers noticed that the clients had trouble distinguishing between the services provided by case managers and those provided by drug and alcohol counselors, since the clients had not had experience with case management before.

The case managers also noted that as relationships and "confianza" developed, clients expressed more needs and requested greater support. Clients consistently identified nutritional training as a significant need. Staff noted, "due to the fact that the large majority of project participants are seriously eco-

nomically disadvantaged, proper nutrition is often not possible, causing many to fail in health and begin to experience symptoms earlier than they should."

Clients Served

During the project period, a total of 318 Puerto Rican/Latino IDUs (not infected with HIV) and their sexual partners and 59 HIV-infected IDUs and their sex partners participated in the four-part risk-reduction intervention, social networking interventions, and one-on-one peer discussions. The 59 HIV-infected IDUs were provided intensive case management and service coordination services. Seven of the clients receiving case management services were women. Forty-two percent (25) of the clients were between 30-39 years old and forty-two percent were between 40-49 years old. Fourteen percent (18) were in their twenties and 2 percent (1) was fifty or older.

Behavior Change Reported

Congreso tracked client self-reported behavior change on a monthly basis throughout the program. A follow-up survey was conducted one month after the completion of the USCM project period. Clients were asked to report on condom use, instances of sex in exchange for drugs or money, needle sharing habits, and use of health and HIV testing services. A report provided by Congreso of the results from the monthly risk assessment is on the following page.

Behavior Change Data Provided by Congreso

Congreso De Latinos Unidos, Inc.
USCM Project
Monthly Risk Assessment
HIVab+ Asymptomatic Puerto Rican/Latino Injecting Drug Users
December, 1991 - July, 1992

	Dec.	Jan.	Feb.	Mar.	Apr.	May	June	July	% of Change
	(Baseline)								
1a. Percentage of clients who reported having had sex with a person using a condom.	33%	30%	50%	55%	52%	70%	75%	77%	44%
b. Percentage of clients who reported having had sex with more than one person using a condom.	76%	85%	78%	88%	88%	86%	89%	90%	16%
c. Percentage of clients who reported not having had sex with one or more persons without using or using a condom for exchange of money or drugs.	92%	92%	92%	88%	94%	95%	96%	96%	4%
d. Clients who reported not sharing needles.	61%	57%	78%	66%	84%	83%	85%	85%	24%
2. Percentage of clients who reported have gone to a clinic or hospital for a general check-up..	50%	61%	64%	68%	64%	77%	79%	74%	24%
3. Percentage of clients who reported have gone to a clinic or hospital for a check-up for a general disease (STD).	16%	23%	28%	38%	44%	50%	50%	58%	42%
4. Percentage of clients who have gone to a clinic, hospital or testing site to get tested for HIV (AIDS)	16%	23%	15%	13%	13%	15%	12%	22%	6%

Risk Assessment
Risk Reduction Education Sessions
Puerto Rican/Latino Injecting Drug Users and Sexual Partners

	Dec. (Baseline)	July (End of Project)	% of Change	August (Follow-up)	% of Change
1a. Percentage of clients who reported having had sex with a person using a condom.	20%	66%	46%	61%	-5%
b. Percentage of clients who reported having had sex with more than one person using a condom.	42%	81%	39%	70%	-11%
c. Percentage of clients who reported not having had sex with one or more persons without using or using a condom for exchange of money or drugs.	58%	69%	11%	71%	2%
d. Clients who reported not sharing needles.	38%	78%	40%	75%	-3%
2. Percentage of clients who reported have gone to a clinic or hospital for a general check-up.	15%	52%	37%	39%	-13%
3. Percentage of clients who reported have gone to a clinic or hospital for a check-up for a general disease (STD).	16%	45%	29%	37%	-8%
4. Percentage of clients who have gone to a clinic, hospital or testing site to get tested for HIV (AIDS).	20%	32%	12%	43%	11%

HCN "Out-Stations" Staff to Reach Women

Based on reports from other local service providers that HIV-infected women in Miami faced significant barriers to services and consequently received services much later than HIV-infected men, Health Crisis Network (HCN) developed a program to meet the needs of these women. Since the target population was not receiving services, HCN assumed that many women had not received HIV risk-reduction information. To meet both the pressing need for direct services and reduce further spread of HIV, HCN proposed to provide case management and HIV risk-reduction counseling at five community agencies where HIV-infected women might seek services. HCN hoped that the case management services would attract and retain women within the program and allow staff to provide individual and group HIV risk-reduction counseling to reduce program participants' high risk activities.

HCN's program hinged on "out-stationing" staff within other agencies that served racial/ethnic minority women. Racial/ethnic minorities comprised the majority of HIV-infected women in the Miami area. While HCN was eventually successful in reaching and providing services to the target populations, the initial difficulties encountered by the agency in building relationships with collaborating agencies demonstrate the challenges and potential barriers to carrying out collaborative HIV early intervention programs.

Agency Background

HCN is a non-profit, community-based AIDS service organization which provides counseling and support services, public information, and education in Miami, Florida. Started by volunteers in 1983, HCN's mission is to provide and help secure care with dignity for HIV-infected individuals, to promote healthy lifestyles, and to provide referrals to HIV-related services in the Miami area.

Services provided by HCN at the time of the grant application included:

- An information and referral hotline for English and Spanish speakers and the hearing-impaired;
- Support Groups and individual and family counseling in English and Spanish addressing women's issues, chemical dependency, basic HIV education, care-partners, and sexual identity concerns;
- Financial assistance and transportation for clients on a limited basis;
- Training on HIV-related issues for health care workers, drug treatment providers, and teachers, and
- Outreach activities in substance abuse treatment facilities, bars, jails, shelters, migrant labor camps, housing projects, local colleges and universities, elementary, junior and high schools, and business and professional groups.

Proposed Program

HCN proposed providing case management and coun-

seling services to two hundred HIV seropositive minority women living in Miami. The program was developed at the request of "front-line" medical and social service providers who had observed that women frequently did not have access to, or failed to seek out, services until the later stages of the HIV disease. Services would be provided to the target population by out-stationing HCN staff on a rotating basis at established community-based facilities.

Miami had an extremely high prevalence of AIDS among women—with minority women especially hard hit. It had also been observed that women tended to seek help much later in the disease process than men. Out-stationing staff appeared to be the most effective way to reach women who might not otherwise have access to HCN's facility or who were reluctant to seek services from an identified AIDS organization.

Also part of the proposed services were support groups designed to provide prevention information and focus on the learning and adoption of empowering behaviors. HCN planned six to eight week sessions. Staff believed that clients would be more likely to commit to attending sessions with a set start and ending as opposed to ongoing or open sessions. HIV/chemical dependency support groups, running for thirteen weeks, would also be available to the clients.

Program Staff

Counselor (1 FTE)
Case Manager (1 FTE)

Budget

Program Budget	\$84,455
Expenditures	\$81,063

To evaluate the success of the program in achieving identified goals and objectives, HCN proposed to collect client demographic information, information on types and units of services provided, and client adherence with treatment plans. HCN would also adminis-

ter brief knowledge and behavioral assessments at the beginning of, and three months into, a client's participation in the program. Client files would be monitored to assure the quality of the services provided.

Actual Program Implemented

Barriers to Developing an Out-Station Program

Prior to submission of the proposal to USCM, HCN had working relationships and referral agreements with numerous community service providers. The proposal included letters of agreement delineating responsibilities for the out-station program with four identified organizations. The organizations that HCN had selected were: a Dade County Public Health Unit in Miami Beach (serving many Hispanic clients); a shelter for homeless women; a youth and family development center; and a primary care center.

As HCN initiated the out-station component of the program following the award of the USCM grant, several unexpected barriers arose. When HCN approached the identified service providers for space in which to conduct counseling sessions and support groups, only one of the four providers identified in the proposal (the shelter for homeless women) allowed HCN access to their clients. The other service providers either had no space available for HCN staff, or management was not supportive of the project. In developing the program, HCN had relied heavily on input from "frontline" medical and social service staff who, while aware of the need for such a program, were not in a position to negotiate for their organizations. After HCN had been awarded the grant, earnest discussions began with agency administrators. It became apparent that, despite the need for counseling and case management services targeting women, other organizational concerns, such as facility remodeling and organizational restructuring, made management unwilling to collaborate. HCN staff noted that, "if we had this to do over, we would change our way of selecting potential out-stations so that we focused on sites where decision-makers were willing to publicly admit they could provide better services in partnership with another agency."

Because HCN had to identify new out-station sites and forge collaborative relationships with these organizations, the provision of services to clients was delayed. The additional three sites that were identified were: Stanley Myers Primary Health Center, North Dade Health Center, and

Coconut Grove Family Health Center.

The month-long orientation and training for new staff included: reading literature on HIV/AIDS, addiction, and special populations; orientation to existing HCN staff and their specific responsibilities; interviews with relevant service providers; and instruction in HCN's service documentation procedure.

Serving the Underserved

Services were initiated at the Salvation Army Shelter for Women, while efforts to identify additional out-station sites continued.

HCN reached potential clients by acquainting on-site personnel with the project, posting English and Spanish fliers in the facility, and through word of mouth among clients. Occasionally, referrals came through other service providers, such as visiting nurses. Women wishing to receive services approached the counselor

Staff: Key to Serving Target Population

Staff consisted of a case manager and a counselor working together to develop individual treatment plans for clients. The case manager was responsible for coordinating referrals and services with outside agencies while the counselor monitored the clients emotional and social needs.

Because of the diverse nature of the target population, it was important to hire culturally sensitive staff who would be accepted by the clients. HCN hired as counselor a Cuban-American with an M.S. in Clinical Psychology and experience in serving low-income populations, and a Haitian-American with HIV-related experience for the position of case manager. In the final report to USCM, the project manager noted, "experience with the target population proved to be extremely useful. Previous experience with HIV spectrum disease would be a close second."

or case manager directly or were referred by on-site medical or social service personnel. Intake was carried out immediately if office space was available at the facility.

Program intake consisted of an interview to collect standard demographic and contact information; assess the client's emotional state; determine the strength of her support system and financial situation; assess her current health status and access to care; and inquire about drug/alcohol use and mental health history. Also during the interview, the counselor administered a pre-test to determine the clients' level of HIV knowledge upon entering the program. An introduction to the program's risk-reduction activities followed the pre-test. If the counselor determined during the interview that the client was in need of case management services, an appointment was made with the case manager.

Case Management Services Meet Range of Needs

The case manager helped clients negotiate the complex bureaucracies necessary to receive Social Security: homecare services under the Project AIDS Care Medicaid Waiver; medical services and medications; emergency assistance for housing and food; and many other services. Self empowerment was an important element of HCN's provision of case management. Referrals were made by the case manager and clients pursued the referrals to the extent of their ability. Follow-up determined if clients had gained access to necessary services. During the project, meetings between the case manager and clients occurred mainly at the HCN office, but also at out-stations, hospitals, and clients' homes. For all HCN clients, transportation was arranged when necessary, either by providing rides in the agency's van or by covering taxi fare.

HIV risk-reduction activities were carried out by the counselor through individual, family and group sessions. After intake, the counselor and client jointly developed a treatment plan. The counselor monitored the client's progress in adhering to the treatment plan and the plan was revised with client input every 90 days.

Individual counseling centered on assisting clients to cope with their emotional responses to HIV. The counselor attempted to establish a rapport with clients so that, according to HCN staff, "they feel safe expressing their fear, anger, hurt and weakness, as well as their hopes and dreams." Some of the issues addressed in individual counseling included: how to tell family members/significant other about HIV infec-

tion, dealing with rejection, and preparing oneself and one's children for eventual disability and death.

Psychoeducational techniques were utilized in HIV risk-reduction group sessions. Sessions ran for eight weeks with each meeting lasting three hours. Participants tended to react emotionally to many of the topics discussed and their responses were "processed" at the following session. According to HCN, "the group counseling provided a supportive atmosphere in which women could discover that they were not alone, share their common experiences, and work together on coping with HIV-related illness."

The following topics were covered during the eight week counseling session:

Week 1: Introductions

- Sharing awareness of HIV status
- Trust building
- Who to tell—partners, family, children, friends
- What does HIV mean to me personally?

Week 2: HIV Terminology

- HIV and the immune system
- Transmission, reinfection, safer sex
- HIV spectrum—symptoms, definitions
- Opportunistic infections, T-cell counts, TB tests

Week 3: Treatments

- Medications, side effects, research protocols
- Alternative treatments
- Holistic treatment—nutrition, vitamins, rest, exercise, stress management, relaxation, meditation, self-healing groups, imaging, affirmations.

Week 4: Drugs of Abuse and the Immune System

- Effects of alcohol/drugs on illness progression
- Dealing with a substance abuse problem
- Developing support networks—A.A., N.A., etc.

Week 5: Feelings

- Dealing with discrimination, ignorance, prejudice
- Avoiding isolation, anxiety, depression
- Coping with fear, anger, painful change, guilt/shame
- Coping strategies
- Changing behavior

- Week 6: Relationships: Partners, Family, Friends
- Sex and intimacy
 - Communication and negotiation skills
 - Assertiveness training
 - Dealing with partners' feelings about safer sex

- Week 7: Bureaucracy 101—How to get the help you need
- Planning to make changes to make your life work
 - Finding good primary care
 - Finding financial assistance and adequate housing
 - Obtaining SSI/SSAD, Medicare/Medicaid, AFDC, Food Stamps
 - Meeting nutritional needs
 - Legal considerations, insurance

- Week 8: How Do I Feel
- How do I feel now?
 - Sharing realities, fantasies and concerns
 - Closure, continuing options, moving on

The counselor used the following methods to convey HIV risk-reduction information: lectures, discussions, condom demonstrations, and role playing. Participants seemed most receptive to the condom demonstration, according to HCN staff.

Experiences from the Program

During the project period, HCN identified the following as barriers to serving clients:

- Members of the target population were not aware of what services were available and how to access them.
- Members of the target population were afraid to know their HIV serostatus.
- Members of the target population were afraid that receiving services would result in neighbors and friends discovering their HIV serostatus.

Clients, especially Haitian women, were extremely concerned about confidentiality and being identified as HIV infected. In three instances, Haitian women did not want to meet with the Haitian case manager because they did not want any Haitian to know of their HIV serostatus for fear that others in the close-knit Haitian community would find out.

In other instances, the counselor was effective in developing support networks for clients and, by working

with members of the support network, was able to provide HIV risk-reduction information to a greater number of people. In one case, the counselor reached ten family members of a client, and succeeded in strengthening the client's support network and providing HIV risk-reduction information to individuals who may not have come into contact with HCN personnel. The client, who was too sick to leave her home, was referred to HCN by a visiting nurse.

The counselor convinced the client's mother and sister that HIV could not be transmitted through casual contact and that family members should be allowed to visit. The client eventually requested that the counselor provide HIV risk-reduction information to the entire family, especially her teenage children, niece and nephew.

Clients Served

During the eleven months that HCN provided services under the USCM grant, 66 clients were served—64 HIV-infected women and 2 family members/care-partners. Services (outside of the case management and counseling program) were provided to 22 family members. Of the women served, 62 percent were African-American, including Haitians; 21 percent were Hispanic; and 17 percent were white or other. One percent (1) of the clients were 13-19 years old. Thirty percent (20) were in their twenties, 38 percent (25) were in their thirties, 26 percent (17) were in their forties and five percent were fifty years old or over. Thirty-nine percent (25) of the clients were diagnosed with AIDS.

Heterosexual transmission was reported by 72 percent of the clients and three percent reported same-sex sexual behavior. Fifty-one percent of the participants enrolled in the program within six months of their diagnosis, 46 percent enrolled more than a year after diagnosis and 23 percent more than three years after becoming aware of their HIV status. Of the clients enrolled in the program, 51 were retained until the end of the project period.

HCN reported that it provided 827 total service units: 86 health education (risk reduction and health promotion); 269 counseling; 350 case management; and 122 outreach, of various kinds. During the project, 409 referrals were made. Of these referrals, 29 percent were for benefits or entitlements, 19 percent for food services and 18 percent for transportation. The remaining 34 percent of the referrals were spread over twelve other categories including dental care and legal services.

In the original proposal, HCN anticipated providing

counseling and case management services to 200 women. HCN attributed the lower enrollment to the difficulty experienced in establishing the out-station sites.

Behavior Change Reported

HCN reported that participants experienced an increase of 12 percent, from 77 percent to 89 percent, on the pre- and post test of HIV-related knowledge. HCN reported that by the end of the project period the following had occurred:

- The percentage of participants reporting that they never used condoms or latex barriers decreased from 50 percent to 20 percent.
- Participants reported reducing the number of sex partners.
- Twenty percent reported reduced drug use, especially in combination with sex.
- Roughly half reported improved self-care including better nutrition, taking vitamins, adherence to treatment regimens, better attendance of medical appointments, and more exercise.

Conclusions

The needs of the women targeted by the project went far beyond the services HCN was able to provide and many, such as low income, family violence, and the effects of discrimination, existed prior to their infection with HIV. By linking women to desperately needed services, HCN was able to access this hard to reach population and further assist the women by providing counseling and risk reduction services.

HCN reported that the project was instrumental in improving communication between AIDS and non-AIDS service providers. While HCN experienced difficulties in gaining access to some service providers in the community, the out-station concept proved to be an effective way of accessing and serving hard to reach HIV-infected women. Based on its experiences, HCN strongly recommends that organizations considering a similar model obtain formal commitments from collaborating organizations prior to start-up of the project specifying space available for project activities, access to client files, storage space for educational materials, and access to phones and copiers.

HCN Provides Advice on Out-Stationing

- Before the project starts, get signed commitments from any person or agency whose cooperation is essential to the project's success.
- It is possible to emphasize an agency's strengths while remaining open to new ways of doing things. For example, HCN sets high standards for its clinical staff in terms of required experience and training, quality of counseling, and documentation. The project met these same standards while operating in four host sites.
- Outreach to as many other providers as possible. One never knows where new resources, new allies and clients who need one's services may be, or what political changes will reassign allies to places where they can no longer help. Share resources and findings liberally.

—Taken from the HCN Final Report to USCM

LBAN Strengthens Service Network Through WomanKind Program

During the project period, there was a 90 percent increase in women diagnosed with AIDS in Long Beach. By establishing the WomanKind program, Long Beach AIDS Network (LBAN) created a framework within the community to address these increasing needs. Combining training for professionals serving women at risk and direct services for HIV-infected women, WomanKind began to sensitize the community to the needs of HIV-infected women and encourage referral to its newly established services.

Due to the lack of services targeting women, LBAN anticipated providing services to all women with HIV. Early in the program it became apparent that the target population had diverse needs, depending on their circumstances, and that a single program could not meet the needs of all women. As with other hard-to-reach populations, the many problems confronting HIV-infected women created barriers to serving those most in need. Even though it was not able to reach and serve all women with HIV, WomanKind was successful in making woman-specific services available in the community and is now exploring ways to serve segments of the population that are more difficult-to-reach.

About the Agency

When formed in 1987 by the Long Beach Department of Health and Human Services, LBAN's role was to coordinate AIDS services in the city. LBAN became a nonprofit organization in 1989 with a mission to "improve AIDS services by being an agency for AIDS agencies" Services include: quarterly half- and full-day AIDS Education Community Forums; monthly lunch meetings for service providers to exchange information and network; an AIDS Education Committee and Direct Service Committee which allow local AIDS organizations to coordinate activities; a Cultural Diversity Training Program to increase awareness of the impact of cultural factors on AIDS service provision; an AIDS Volunteer Training Program; a buddy program; the Long Beach AIDS Community Demonstration Project (a CDC-funded community research program to implement and evaluate a prevention program targeting male and female injection drug users, female sex partners and female prostitutes); an AIDS Paycheck Insert Program which designs and distrib-

utes flyers with HIV risk and anonymous test site information (in both Spanish and English) for employers to place in paycheck envelopes; and the AIDS Walk Long Beach, an annual event that raises money for local agencies.

Proposed Program

The stated purpose of the USCM-funded program was to "develop, implement, and evaluate a model community-wide program of women's HIV-service coordination that incorporates transmission-prevention activities throughout and produces significant success in risk reduction in HIV-positive and high risk women." The program was viewed as a major opportunity to increase cooperation among local service providers and enhance service coordination for HIV-infected women.

Specifically, LBAN proposed to: reduce or eliminate high-risk behaviors of HIV-infected women in order to prevent further transmission; promote skill development through the introduction of prevention techniques during case management services; and improve HIV-infected women's access to prevention, health care and social services by encouraging cooperation among agencies and coordinating needed services.

To fulfill these objectives, LBAN initiated support groups for HIV-infected women and their families and/or significant others, a volunteer peer support program, case management services, and training for agencies on incorporating health education/risk reduction services with existing services.

To ensure that progress was being made toward accomplishing objectives, LBAN contracted with an out-

Program Staff

Project Coordinator (.5 FTE)
Client Advocate (1 FTE)
Client Advocate (1 FTE)
Clerk Typist (.25 FTE)

Budget

Program Budget	\$99,135
Expenditures	\$99,135

side specialist to design and carry out program evaluation. Surveys to measure client self-reported behavior change and satisfaction with WomanKind services, as well as demographic information and self-reported risk behaviors, were developed and administered at intake, during the course of the project period, and at the end of the grant period. Project staff documented client contacts and attendance at in-service training programs provided to other programs.

WomanKind also conducted a community needs assessment to document unmet prevention, social service and health-care needs of HIV-infected women. Both service providers and HIV-infected women and their families were surveyed to determine their views concerning the availability of services and their needs.

Program Activities

Community Assessment and Networking: Laying the Groundwork for Service Coordination

WomanKind conducted a survey of service providers, HIV-infected women, and their families to determine the prevention, social service and medical needs of women with HIV. Local service providers were very responsive to the survey. However, it was more difficult to reach HIV-infected women. The original plan was to send surveys to doctors and medical facilities serving HIV-infected women, but LBAN decided to administer the survey to clients during intake instead of identifying respondents prior to their involvement in the WomanKind program. LBAN also experienced difficulty in reaching the families of HIV-infected women because many of the women had not disclosed their illness to family members or were widowed, divorced or separated. Upon completion of the needs assessment, LBAN presented the findings of the survey to the Direct Service Committee, a group of local

service providers convened by LBAN, so the group could discuss filling the identified service gaps.

In addition to networking with local agencies to familiarize them with the program and build a referral network, WomanKind planned a series of educational forums targeting service providers. The first event was an all-day conference entitled "Health, Women and HIV." The conference addressed such topics as: signs and symptoms of HIV disease in women, issues affecting women with HIV, and techniques for conducting successful HIV risk-reduction education. The chief of obstetrics at a local hospital addressed the medical aspects of HIV in women. Continuing Education Credits (CEUs) were offered to encourage professionals to attend. Over 95 participants, including nurses, social workers, educators, and counselors, attended the conference and an additional 51 people were placed on a waiting list.

To further build communication and networking among service providers, WomanKind initiated Synergy, a monthly meeting for case managers. Initial meetings were devoted to presentations by community professionals. Later, a case conference format was adopted in which problem cases were discussed in an effort to improve treatment plans.

Staffing

During the project period, the WomanKind staff consisted of a half-time program coordinator responsible for recruiting and training staff and volunteers, networking with community organizations, participating in material development and overseeing the project on a daily basis. One full-time and a part-time case manager/client advocate were responsible for facilitating support groups, providing advocacy and case management services. The program also employed a part-time administrative assistant. Consultants were hired to carry out program evaluation and to conduct case management supervision sessions once a month.

Getting the Word Out

In order to promote all aspects of the program, WomanKind staff networked with community organizations. The staff informed the organizations of the services offered through WomanKind and encouraged them to refer their clients to the program. Flyers were also posted in these organizations, and articles announcing the program ran in many local papers.

Psychoeducational Support Groups: Building on Past Experience

The first support group for women in the Long Beach area had been organized by LBAN in 1988. WomanKind

Group Rules

- Information shared is confidential
- You may not ask anyone how they contracted HIV
- Questions may be asked at any time
- Respect the views of others
- You must have HIV disease to participate
- You do not have to share personal information to be part of the group

staff sought to utilize the lessons learned from this earlier effort to make the support group sessions more responsive to the needs of HIV-infected women. In coordinating the original support group, LBAN experienced a variety of problems, including: the poor health of the participants; lack of child care and transportation; and the reluctance of some women to participate in groups with "drug-users, prostitutes, and criminals." In designing and scheduling the WomanKind support group meetings, LBAN tried to be as responsive as possible to the needs of the client population.

Weekly meetings were held from 5:00 p.m. to 7:00 p.m. on Thursdays. The first fifteen minutes of the meeting were devoted to informal socializing to allow the women to begin to develop their own support networks and a "comfort level" with other participants. The risk reduction component of the program followed. WomanKind staff developed twenty educational modules for use at the support groups. Each twenty-minute module focused on health issues incorporating experiential learning techniques to maintain participant interest and enhance the learning process. Topics included AIDS 101, risk reduction and needles, risk reduction and safer sex, perinatal transmission, human sexuality, HIV prevalence and symptoms, death and dying, new developments in HIV (increase in incidence, affected populations), living with HIV and AIDS, setting goals, building self-esteem, co-dependency, assertiveness training, and accessing community services. The final four modules were based on participant requests and consisted of videos and guest speakers. Education sessions were followed by a twenty-minute question-and-answer period.

The reaction of the women to the HIV risk-reduction segment was unexpected. According to LBAN reports, "each time risk-reduction material was pre-

sented in group, all the women stated that they were never going to have sex again so why bother to learn about 'safe sex'." The group facilitator encouraged the women to listen anyway. All of the women attending the group had acquired HIV through sexual transmission and were unreceptive and indifferent to HIV risk-reduction information relating to injection drug use. WomanKind staff decided that the best strategy was to provide this information on an individual basis during case management sessions.

After the educational session, forty-five minutes were devoted to the emotional support segment of the session which consisted of a facilitated group discussion. The final fifteen minutes were devoted to informal socializing.

Target Population Slow to Respond

The first support group meeting was held on August 1, 1991 with two women in attendance. During the first month, 23 women contacted LBAN for information on the support group and attendance ranged from two to four women (a total of six women attended in the first

month.) According to LBAN staff, the greatest success during the first month of meetings was simply bringing the women together. "Most had never known another HIV-infected woman and were

consoled to discover infected women like themselves with similar backgrounds and lifestyles," reported LBAN.

As anticipated, the lack of transportation and child care prevented many potential participants from attending. At least half the women interested in attending experienced difficulties in arranging transportation. To allow more women to attend, LBAN recruited volunteers to provide transportation and child care. An unexpected barrier was that many women were reluctant to bring their children to the group meetings even when child care was provided because they were afraid their children would discover their HIV infection status—they had not yet disclosed it to their children. To make it easier for women with school age children, WomanKind began a second group that met on Tuesday mornings from 10:00 a.m. to 11:30 a.m. during the second quarter. This new time was also popular with women who were reluctant to travel at night for security reasons.

As the program period progressed, support group attendance fluctuated. (This may have been related to staff turn-over.) In order to encourage attendance,

WomanKind began to mail a monthly calendar of events to clients. Staff enlisted the help of regular participants by having them call and encourage women who had been absent to return. WomanKind also utilized an intern to make weekly calls reminding clients of the meetings.

Regular participants in the meeting suggested that in addition to the logistical barriers (transportation, child care, etc.), poor attendance might result for the following reasons: the meetings were held too frequently; the HIV-related focus was too narrow (they wanted to address other issues in addition to HIV); and the women were unwilling to discuss their HIV infection status. Some woman also reported feeling depressed after group meetings and attributed their feelings to seeing the health of other participants deteriorate and addressing topics such as symptoms of HIV and death and dying.

Client Advocacy and Case Management Services

Case management services, which included HIV risk-reduction education, supportive services, advocacy, benefits assistance and referrals to appropriate agencies, were also initiated in August 1991. LBAN developed a brochure to inform potential clients of services and also promoted the services through newspaper articles and announcements at other organizations serving the target population.

To provide additional assistance to clients in identifying and accessing services, the WomanKind program

produced two resource guides in the early stages of the project. A pocket/purse referral guide was developed to provide easily accessible information on local health and case management services available to HIV-infected women. The "Women's Resource Guide to HIV and other Services" provided more detailed information and listed public and private agencies, hotlines, support groups and community-based AIDS service organizations.

The WomanKind program was designed to offer "proactive" case management services. Case managers actively followed clients and provided services at hospitals, doctor's offices, homes, and even restaurants. During the first month, seven women received services and two women asked about case managers coming to their homes for intake.

Learning By Doing: Creating a Program Responsive to Client Needs

Although originally designed to take less than 60 minutes to administer, the first intake survey required from two to three hours. Clients were confused by some sections, especially those designed to measure mental health. The staff reported that the intake process overwhelmed many clients. According to staff, most women called about having a specific need met, but then became anxious and frustrated by the barrage of questions. Several women avoided further contact with the program after their initial contact. In order to address these problems and to avoid alienating potential clients, the intake process was modified so that the collection of baseline data was spread over several sessions to reduce the number of questions asked at any one time.

By the second quarter, WomanKind's caseload was up to 33 clients—including one heterosexual man and his at-risk wife. Other agencies began to refer married male clients to the program. Women with HIV-infected children were also referred, but often failed to access the program's services after referral. Staff suspected that the women were too overwhelmed caring for their children to seek services for themselves.

The WomanKind Program had a client retention rate of 59 percent. Client attrition was attributed to women leaving the area, incarceration, and the lack of services in Spanish. Sixteen percent of the clients died during the grant period. According to WomanKind staff, the women most likely to seek services on a continuing basis were middle-class women who were motivated to stay healthy.

The Challenge of Reaching Women: One Example

Early in the program, staff enrolled one client in a drug treatment center. This client disclosed that the day before she contacted WomanKind she had unprotected sex with six different men in exchange for drugs. The client was persuaded to seek treatment when staff informed her that resources, such as food, clothing, and shelter were available to her and she could access them in addition to drug treatment. According to WomanKind staff, women from the streets, like drug users and prostitutes, were occasionally referred to the program for support but the case managers were unable to provide continued support due to the transient nature of these women's lives.

Peer Support Program

The WomanKind Program also included a peer support component. Seven women who had become comfortable with their HIV infection status and seemed able to share their experiences with other women received eight hours of training which included setting limits, crisis referrals, risk reduction, basic AIDS education, and definitions of commonly used HIV-related terms. Upon completing their training, the peer counselors were available to be paired with women who were newly diagnosed or having trouble accepting their HIV infection status. The peer counselors could then provide support and assist these women in adopting and maintaining lower risk behaviors.

Few clients sought the services of the peer support counselors. WomanKind staff believed that this was due in part to clients preferring to establish their own support networks among the women they met during the social interaction at the support group meetings. Only two clients were eventually paired with peer counselors. One was paired with a patient in the hospital where she worked and the other was paired with a newly diagnosed woman experiencing hysteria. Both peer relationships were of limited duration.

Despite clients not utilizing the peer support program, LBAN considered it partially successful in that the women who participated in the training reported increased self-confidence and improved advocacy skills.

Family/Companion Program

The companion program for friends, significant others and family of clients consisted of a series of four workshops. The first workshop, "Everything You Want to Know about HIV but are Afraid to Ask," focused on issues concerning HIV. "Family Gatherings," the second workshop, addressed the important roles family members can play in the lives of people with HIV. Other scheduled topics included "Holiday Blues and HIV" and "New Year, New Start."

Despite efforts to publicize the workshops, including working in cooperation with the Los Angeles Pediatric AIDS Network and the child infectious disease and

immunology clinic at a local hospital, attendance at the sessions was low. LBAN staff believed one reason for low attendance was that many clients had yet to disclose their HIV serostatus to family members. Attendance varied from five to nine participants at the first three meetings. The final session was canceled due to low turnout at the previous meetings.

Project Results

LBAN focused evaluation efforts in determining client satisfaction with the WomanKind program. According to the project's final report, "the WomanKind program was rated very favorably by clients who remained in the program for three months or longer.

These women expressed high levels of overall satisfaction with program services and reported that the program had made a strong positive impact in their lives." Women who left the program were not surveyed. Services identified by clients as most helpful included support groups,

case management services, public benefits assistance, telephone follow-up, and home visits.

The report acknowledged that client reporting of satisfaction is subject to bias. The women surveyed were those who remained in the program and who might be reluctant to provide negative feedback for fear of jeopardizing the program or hurting the feelings of staff. LBAN reported that many of the women surveyed were more satisfied with the quality and range of services available at follow-up than they were at intake.

According to LBAN, the women who remained in the program, "...were better educated, more likely to live with a husband or boyfriend, less likely to be homeless, less likely to have been to prison, and less likely to be Hispanic." Staff experienced difficulty serving IDUs and prostitutes. These women reported feeling uncomfortable in group sessions and tended to seek services only when they were extremely ill, and then only remaining in the program until their immediate needs were met. Staff concluded that, "street outreach would be a desirable addition [to the program] to enable street women to feel more comfortable in accessing case management and support services."