PREVENTING AIDS
COMMUNITY-SCIENCE COLLABORATIONS

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Critical Collaborations in Serving High-Risk Women: The PHREDA Project

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I went in and was having real bad pains inside, in my stomach and in my cervix, and I couldn’t walk . . . and my cousin had to carry me in, put me in a wheelchair. And when they seen tracks on my arms, doctors . . . male doctors, they were saying it’s her imagination. She’s on drugs. And then the female doctor came in and said no this is an emergency. My temperature was 105, and they found out I had disseminated gonorrhea . . . they kept me in the hospital for a couple weeks. But they were just gonna leave.

Focus Group Participant, 1989

Women at highest risk for contracting and transmitting HIV are poor, nonwhite, and struggling with multiple social and economic problems. Because these women have difficulty accessing and utilizing health care, they are at increased risk of unintended pregnancy and sexually transmitted diseases.

Creation of the Perinatal HIV Reduction Education Demonstration Activities (PHREDA) Project in San Francisco, California—a collaborative project between the San Francisco Department of Public Health, the University of California at San Francisco, and five non-profit community agencies—was inspired by the recognition that a broad array of strategies are needed to reach this vulnerable popula-
tion of women with information, education, counseling, and reproductive health services.

PHREDA’s primary goal was to lower the incidence of new HIV infection in women at the greatest risk for HIV transmission and unintended pregnancy: injection drug users, partners of high-risk men, and sex industry workers. A second goal was to prevent unintended pregnancy and perinatal HIV transmission in women already infected with the virus.

In this chapter, we start with a brief background on PHREDA, then describe the three phases of the project. We include a summary of the collaborative organization and highlights of our main research findings from each phase. We also explore how differences in the collaborative organization, decision-making and research protocols contributed to the project’s successes and failures. Finally, we discuss the unique challenges and benefits of a collaborative approach to reaching women at high risk for HIV. Through the sharing of our experiences, we hope to offer insights, suggestions, and encouragement to others attempting a collaborative approach to their community-based research.

**BACKGROUND**

I was working as director of Family Health at the San Francisco Department of Public Health. Every day I heard about new cases of and deaths from HIV in gay men, some of who were friends. I read about the rapid spread of HIV among heterosexual women in New York City and Newark and the increasing number of HIV-positive babies who needed to be placed in foster care there. Knowing that our county family planning programs were not reaching the highest-risk women, I became alarmed about the potential for the same scenario in the West. I began meeting with community-based organizations and UCSF faculty to discuss how we could confront this issue. We established PHREDA with a consensus that we had to do whatever was necessary stop the epidemic in women before it got out of control.

Geraldine Oliva, Principal Investigator

The project began with the observation by Dr. Oliva and her staff from the Perinatal and Family Planning programs at San Francisco’s
Department of Public Health (SFDPH) that despite the wide availability of low-cost or free family planning services in the city, few high-risk women seemed to take advantage of them. A network of family planning clinics funded by a combination of federal Title X and state Title XX dollars had ongoing funding and the mandate to provide services to this group of women. However, a survey of women attending these “traditional” family planning clinics in 1987-1988 revealed that only a very small proportion had recognizable risk factors for HIV (Darney et al., 1989). A baseline seroprevalence study of women in San Francisco showed that HIV infection rates were very low in family planning clinics (0.3 percent) compared to women attending STD clinics (2 percent) abortion clinics (4 percent), women in drug treatment programs (15 percent), and sex workers (4 percent) (San Francisco Department of Public Health, 1990).

Community meetings were held and included nonprofit community agencies providing some type of women-focused services to low-income minority populations, SFDPH staff, faculty from the University of California at San Francisco, and staff from the family planning program at San Francisco General Hospital. It was at these meetings that the PHREDA collaborative was born.

There were huge challenges in bringing together multiple institutions with different perspectives on collaborative research. The outreach staff, often women in recovery from alcohol and drugs, sometimes resisted the demands of a structured research protocol, giving priority to the needs of clients. The building the program was in burned down, necessitating a move. Coordination of many agencies required tremendous time and diplomacy. Tensions arose between staff and clients from different communities, races, and classes.

Despite challenges, the collaboration created a deeper understanding of these high-risk women, improving the quality of services and research to combat the spread of HIV. Most significantly, lives may have been saved by offering high-risk women, recruited from the streets, access to badly needed medical care and HIV prevention services.

**THE THREE PHASES OF PHREDA**

The PHREDA project had three distinct phases of funding and research, with collaborative partners and structure varying in each phase.
Phase One

We’re pretty much all educated on AIDS and condoms, and we’re not stupid. We’re pretty smart for being drug users, and that’s because of the outreach workers who have reached our community. But if you had that person out there constantly, constantly getting familiar with the people and getting the confidence of the girls and all that, they’d begin to trust that person. They’d eventually begin to listen to that person.

Focus Group Participant, 1989

The first phase started in 1988, when the initial PHREDA partnership was awarded the first of two rounds of funding from the U.S. Centers for Disease Control (CDC). The collaborating agencies agreed that the first step was to hold focus group discussions with the target population to better understand why they had not used the existing family planning services, and to solicit and integrate their feedback regarding the assumptions and strategies being developed by the project. Attention was then turned to investigating ways to overcome some of the barriers that prevented high-risk women from utilizing available services. To that end, PHREDA conducted a study to determine whether targeted street outreach by peer or near-peer community health outreach workers (CHOWs) was needed—and if so, whether it would be effective in identifying high-risk women and bringing them into family planning clinics for HIV prevention and reproductive health services. The study also investigated whether women contacted by these outreach workers would be more likely to follow through on referrals and participate in follow-up care at “traditional” family planning clinics (i.e., Planned Parenthood) versus new, “non-traditional” or alternative clinic sites established by PHREDA.

Collaborative Organization

In Phase I, the project had coprincipal investigators from SFDPH and UCSF, with coinvestigators from five nonprofit agencies: Planned Parenthood, Glide Memorial Church, Bayview Hunter’s Point Foundation, Haight-Ashbury Detox Clinic, and Dolores Street Community Center. The PHREDA project staff included clinic site teams, a research team, and administrative personnel. Staff were employed
through a variety of different organizations, often with staff from one organization supervising staff from another organization. To provide and evaluate services at community-based organizations that had not traditionally provided these services, complex administrative and fiscal relationships had to be developed. The administrative team worked hard to coordinate activities between the contractors and subcontractors and regular meetings were necessary to ensure that things ran smoothly.

The collaborative participants also held regular meetings to make decisions about all aspects of the project, ranging from the framing of the research questions to the running of the clinics. Staff members also attended regular training sessions to enhance their skills in working with high-risk women, improve their understanding of the research project, and strengthen working relationships within the collaborative.

The collaborative nature of the PHREDA project allowed staff from a variety of institutions and agencies to participate in both creating PHREDA and its day-to-day management. The organizational structure was designed to maximize the strengths and capacities of the participating agencies. We also wanted to establish a structure that would allow the clinics started in conjunction with the project to continue operating independently after the research funding ended.

Focus Groups

In a series of four focus group discussions with high-risk women, participants identified many barriers to using available reproductive health care services. These included lack of insurance or money for health care; lack of transportation and geographic accessibility; lack of cultural sensitivity by providers; homelessness; perceived poor quality of care and experiences of discrimination and stigmatization; fear of punitive actions by the legal or social services systems; health as a low personal priority; lack of self-esteem and self-efficacy; social isolation; and lack of trust in providers (Oliva, Rienks, and McDermid, 1999).

Despite these barriers, women in the focus groups were enthusiastic about the prospect of having new services in their neighborhoods.
Targeted Street Outreach and Traditional versus Nontraditional Clinic Sites

**Study Sites.** PHREDA project staff selected four San Francisco neighborhoods as study sites because they had a high proportion of low-income residents, high rates of drug abuse, and high rates of STD and HIV infections: the Tenderloin, Bayview Hunter’s Point, the Mission District, and the Western Addition.

To investigate whether nontraditional clinics might be more effective than traditional clinics in providing services to high-risk women, traditional clinics had to be identified and alternative clinics created. The traditional clinics already established in the participating targeted neighborhoods included: Planned Parenthood near the Tenderloin, Southwest Health Center in Bayview, San Francisco General Hospital Family Planning Clinic in the Mission District, and SFDPH District Health Center #2 in the Western Addition.

Community-based agencies already providing substance abuse, mental health or social services to high-risk women in these same neighborhoods were recruited to host new, “alternative” family planning clinics established by the project. Glide Memorial Church in the Tenderloin—which already housed a drug treatment program and many social services in its church buildings—agreed to house a new women’s clinic. A clinic was also created at Dolores Street Mission, known for providing a host of social services to undocumented immigrants in the Mission District. Bayview Hunter’s Point Foundation, a drug treatment and mental health center in the Bayview area and Women’s Needs Center in the Western Addition, later replaced by the Haight-Asbury Drug Detox Center, also agreed to house new clinics.

**Study Methods**

Community health outreach workers (CHOWs) recruited high-risk women and randomly assigned them for referral to either the traditional clinics or alternative clinics to receive reproductive health care and HIV/STD prevention services. CHOWs were women hired from the target neighborhoods and trained in peer-based community health education. The CHOWs made themselves known to the neighborhood residents. They went to “hang outs” where high-risk women and men congregated and made contact with women in drug treatment facilities. Because many of the women at the highest risk are ex-
tremely isolated and not accessible on the street, outreach workers encouraged the more accessible community members to refer their friends, girlfriends, and wives to the project. Over time, some high-risk women were willing to introduce the CHOWs to or show them where to find other hard-to-reach high-risk women.

CHOWs distributed condoms and information to the people they met and introduced the activities of the PHREDA project. After identifying a high-risk woman, a forty-five-item survey instrument was administered by the CHOWs to assess knowledge, attitudes, and behaviors with regard to HIV, STDs, birth control, and use of clinical services. Women were then given an envelope containing either a list of the traditional clinics or the alternative clinics and an incentive coupon that could be redeemed for food when they came in for women’s health care and enrolled in the study.

Subjects. Of the 1,438 women who were identified by CHOWs and completed the survey (the outreach sample), 794 women (55.2 percent) followed through with the referral, 384 (48.3 percent) received services at an alternative clinic, and 410 women (51.7 percent) were seen at traditional family planning clinics. At the clinics these women completed an additional 166-item questionnaire addressing perceptions regarding recent health care experiences.

The four traditional family planning clinics also allowed the project to collect data from 235 of their female clients (the family planning sample) who completed a self-administered version of the same questionnaire being administered by the CHOWs to high-risk women on the streets. Women in the family planning sample came into the clinics on their own seeking reproductive health services—the outreach workers did not recruit them. Data from the family planning sample were used to determine whether or not high-risk women were coming in for services on their own, how many were doing so, and if and how they differed from the women recruited through outreach.

Challenges. The CHOWs were recruited from the communities where they would work and were selected jointly by the project director from the SFDPH and the representatives from the CBO connected with a particular nontraditional site. The CHOWs were often women who had been clients of the CBO and drug users in recovery. Although we had a policy to hire only those who had been sober for at least six months, we had a number of CHOWs who relapsed. Some CHOWs would disappear for periods of time when they were sup-
posed to be working. They would recruit friends for the project who
would give the CHOWs some of the money they received in incen-
tives. At first, the other CHOWs would not let their supervisors know
about these incidents. Project directors only found out what was go-
ing on when things got blatant.

Consequently, we began to have regular peer support meetings
with a facilitator to help the CHOWs cope with the stresses of work
and to support them in their recovery. We created a periodic check-in
procedure in which the outreach supervisor would page the CHOWs
and arrange to meet and accompany them on their rounds. We also es-
ablished a schedule of training sessions to continue to build the skills
of all the staff members. Finally, the data collected by CHOWs when
they had fallen out of recovery were purged to maintain the integrity
of research.

The alternative clinics were established in CBOs that had been
providing some type of service to very high-risk women for many
years. One site was selected because of a track record in reaching
"street people" in the Haight-Ashbury section of the city. This clinic
had a special commitment to serving lesbian women and a tradition
of making decisions by consensus involving all staff. Many staff had
objections to questions on the CDC questionnaire, and felt it was bi-
ased toward heterosexual women. We shared those concerns with the
CDC program officers who felt that since this was a perinatal HIV
prevention project and focused on prevention of heterosexually trans-
mitted HIV, the target population should be heterosexual women. The
CDC would not alter the questionnaire, so the clinic withdrew from
the study six months into the project. This caused a significant delay,
as we had to identify another clinic, develop administrative and bud-
getary agreements, and equip the facility.

Research Findings

Overall, data analyses indicate that the CHOWs were very effec-
tive in reaching high-risk women and recruiting them into the clinics
for services. The women who came into the clinics after outreach en-
counters were, for the most part, not significantly different from the
women who did not. Furthermore, women contacted through out-
reach were at much higher risk for HIV infection and differed in im-
portant ways from the family planning sample, suggesting that out-
reach is needed if family planning clinics hope to serve women at high risk for HIV.

Comparison of Study Joiners and Nonjoiners. Of the 1,438 women recruited by the CHOWs, 794 (55 percent) came into a family planning clinic and formally agreed to participate in the PHREDA project and receive reproductive health services. Data analyses were done to compare these two groups.

Only a few differences were found between those who enrolled in the project and those who did not. Women who enrolled in the study were significantly more likely to live in stable housing (50 percent) than women who did not enroll (40 percent), more likely to desire a pregnancy, and considered themselves at higher risk of becoming pregnant in the future. The women who responded to outreach efforts were not a select group of lower-risk women but in most cases shared the same risk factors and demographic profile as those who did not attend the clinic. Not only did outreach provide education and condoms to all women reached, but significantly more women followed up by coming to a clinic for care than those who did not participate.

Comparison of Alternative and Traditional Clinics. There were no statistically significant differences in the percentages of women who were seen at the alternative versus traditional clinics (48 percent versus 52 percent), or in six- and twelve-month follow-up rates at either kind of clinic (about 38 percent for both types of clinics). This was presumed to be the result of the fact that the outreach workers met the women at whichever clinic they attended so that the women could feel comfortable and welcomed at either site.

Once the first phase of the project ended, however, and both the outreach workers and the specially trained staff at the traditional clinics were gone, there was a dramatic drop in the number of high-risk women seen at these clinics. Women who had attended the traditional family planning clinics reported that staff no longer treated them with respect, and staff reported having difficulty dealing with a drug-using population that they felt disrupted their clinic flow and disturbed other patients. In contrast, many high-risk women continued to attend the alternative clinics.

Comparison of Outreach and Family Planning Samples: Demographics. Women recruited through street outreach were more likely to be African American (OR = 3.5, CI 2.3-5.1), unemployed (OR = .24, CI .20-.29), receiving some kind of government support (OR =
3.5, CI 2.7-4.6), lacking health insurance, and living in unstable housing situations (OR = 4.1, CI = 2.6-6.5) than women in the family planning sample (see Figure 7.1).

Prevalence of HIV Risk Factors. The outreach women were far more likely to have one or more risk factors for HIV, indicating that efforts to recruit such women were successful (see Figure 7.2). They were six times more likely to have injected drugs (OR = 6.0, CI 4.1-8.8), eight times more likely to have exchanged sex for money (OR = 8.4, CI 5.8-12.2), and six times more likely to have traded sex for drugs (OR = 6.4, CI 4.0-10.3). The outreach sample was also twice as likely to have a known or suspected injection drug-using sex partner (OR = 2.2, CI 1.6-2.8), six times more likely to have a partner who served time in prison since 1978 (OR = 6.3, CI 4.7-8.5), and three times more likely to have a known or suspected HIV-positive partner than family-planning-clinic women (OR = 3.1, CI 2.1-4.8). Outreach women were also more likely to report having sex with more than one man in the last month. Despite these increased risks, outreach women

![Graph showing the percentage of women with various characteristics.]

- **African American**: 66%
- **Employed**: 14%
- **Income support from government**: 70%
- **Unstable housing**: 30%

- Women surveyed by outreach workers (n = 1,438)
- Women in traditional family planning clinic (n = 235)

*All differences reported were significant at p < .05.

**Includes AFDC**

FIGURE 7.1. Comparing Demographic Data for Women in Family Planning Clinics and Women Surveyed by Outreach Workers*
*All differences reported were significant at p < .05.

**Serious STD defined as gonorrhea, hepatitis B, herpes, syphilis, genital warts, PID, and trichomoniasis.

FIGURE 7.2. Comparison of HIV Risk Factors of Women in Family Planning Clinics and Women Surveyed by Outreach Workers*

did not differ significantly from family-planning-clinic women when it came to condom use, with only about 32 percent of both groups reporting doing so at last intercourse.

History of Sexually Transmitted Diseases. When compared to women found at traditional family planning clinics, outreach women were more than twice as likely to report a history of multiple sexually transmitted infections (STDs), and more likely to have had a serious STD or an STD that poses a risk to newborns (see Figure 7.2).

Drug Use History. The outreach sample reported consistently higher rates of drug usage, and was fourteen times more likely than family planning women to have used crack in the past six months. A
substantial proportion of women contacted through outreach (42 percent) reported having used injection drugs since 1978, one of the primary modes of HIV transmission for women. Only 11 percent of the family planning sample reported past injection drug use.

Overall, these findings indicate that poverty, unstable housing, drug use, and sex work act as barriers that keep the highest risk women from coming into family planning clinics on their own for care. Although family planning clinics serve some self-referred high-risk women, clinic women are more likely to be employed, have stable housing, and less likely to use drugs than the highest-risk women contacted through outreach. Without targeted street outreach, family planning clinics are missing the most socioeconomically disadvantaged and behaviorally highest-risk women. In addition, more recent seroprevalence data collected by the state of California continues to demonstrate that without targeted outreach to bring high-risk women in for services, family planning clinics mainly serve women who are not at high-risk for HIV.*

Phase Two

Da Money, da Money, da Money!! I was in a Glide drug recovery program. I had shot dope for twenty-three years. A PHREDA outreach worker came to our meeting. She was a model for us since she had been through the program. But, frankly da reason I went was da money, cause I was scared of the exam... lots of cancer in my family. I got to the clinic and there was this smiling, kind, pretty woman there. She didn’t mind my scarred arms and dirty clothes. She didn’t shrink when she touched me... opening up to physical contact built a trust that helped me stay in recovery. At my last visit they said they had a job for an outreach worker. I was afraid. But I was clean for a year. The pretty counselor said, “Try it. You can do it. Just be yourself.” So I took the job. It was hard. I had to be on time and there was all this paperwork... temptation to use drugs... to deal in stolen objects. When I took the CHOW training in drawing blood they passed around a bag of needles. My stomach got

sick. But I had to stay focused on one thing. I needed a job to get my kids back . . . a real job with benefits. The PHREDA staff supported me and the daily check-in meetings were critical. I made it.

PHREDA client/CHOW

The second wave of CDC funding began in 1992, and funded both a clinic-based study and a community-based study. The initial design for the clinic-based study was to explore the efficacy of adding a comprehensive case management component at two clinics in comparison with routine family planning care at two other clinics. The second study sought to evaluate the effectiveness of a multipronged community mobilization effort to change community norms regarding risky behaviors and condom use in two housing projects. Our experience with the first phase had shown us that women were not following up with reproductive health care because of the overwhelming nature of their social and economic problems. During contract negotiations with CDC, the program officers informed us that this cooperative agreement would require that we change our design to be identical to other sites. This entailed dropping the case management design and instead adopting a theory-based counseling model that they felt had great potential. Theory-based activities were to be conducted in both clinic settings and in community settings.

Collaborative Organization

The collaborative organization in phase 2 was essentially the same as in phase 1. Our experiences during the first phase taught us that the CHOWs needed to be included in the regular meetings of the research team, as their perspectives and knowledge of the community could be used to improve the research. Meetings with the entire project staff were held at least monthly to review progress and to deal with problems as they arose. However, the collaborative partners did not have the same level of involvement in decision making about the research as in phase 1. Instead of framing the research question, study design, and execution ourselves in this second phase, the collaborative had to follow instructions from the CDC regarding these issues.
Using Theory-Based Clinic Counseling in the Clinic and in the Community

In the Clinics. During this second wave of CDC funding, only the alternative clinic sites were included. Because of input from the staff and community-based agencies, we moved from a traditional case-control model to an intervention-comparison model in which all clients received basic reproductive health services and routine counseling. The intervention sites would add more intensive theory-based counseling. Glide Church and Dolores Street Community Center were designated as intervention sites and Bayview Hunter’s Point Foundations and the Haight Detox Clinic were comparison sites. Outreach workers recruited subjects into the clinics for family planning services including counseling and education according to the Title XX guidelines. At the intervention sites, clients were also asked to attend a series of counseling sessions based on the stages of change (SOC) model.

The SOC model developed by James Prochaska and his colleagues postulates that individuals pass through five distinct stages representing a continuum of motivational readiness for behavior change: precontemplation, contemplation, preparation, action, and maintenance (Prochaska and DiClemente, 1984). The model suggests that interventions will be more efficacious and cost-effective when matched to an individual’s stage of change. Prochaska worked with the CDC to develop a manual of stage-based counseling exercises for use in the clinic.

In the Community. The community intervention (also known as the community mobilization) was based on the theory that women who are inaccessible to “outsiders” can be reached through a network of outreach workers, peer volunteers, neighbors, tenants’ associations, local businesses, and family members. Outreach workers provided stage-based one-to-one outreach and prevention education, and trained housing project residents to serve as peer volunteers and deliver stage-based health educational materials. Education included stage-based role model stories and condoms, and the mobilization of local merchants to also distribute these materials. Special events for the community were also organized.

The project was designed to build a movement among residents that promoted the reproductive health of women and the well-being
of their offspring. A primary goal was to have HIV-prevention messages, risk reduction behaviors, and social norms supportive of prevention behaviors diffused throughout the community to ultimately become prevalent characteristics of that community. Through the use of community peer volunteers to further the goals of the project, the community becomes both the “target” and the “agent” of change. As members of the target community, peer volunteers help shape the knowledge and norms of the community. This strategy maximizes the potential impact of the prevention education intervention.

**Research Challenges**

During phase 2 we again encountered clinic site problems. One of the nontraditional clinics housed in a very old building burned down after we had been recruiting clients for more than six months. It took another four months to find a suitable site in the same neighborhood. Many clients were lost to follow-up during the transition. In addition, the protocol called for specifically timed follow-up visits, so even those clients we managed to stay in touch with missed some of their visits.

Implementation of the research protocol in the clinic was also problematic from the start. Outreach workers, family planning specialists, and the clinic social workers were used to responding to the needs of each client in a personal way that gave priority to those issues the client felt were most important. These staff members were resistant to a protocol that limited the type of assistance they could provide.

**Numbers, Numbers, Numbers**

What I remember about the project (PHREDA 2) was the pressure to produce numbers . . . no numbers, no job. The questionnaire was too long and the clients would get bored and leave so I had the temptation to shorten the questions to the main point so I could enroll more. We got conflicting messages. Take time to carefully fill out the questionnaire . . . get more clients. But clients really liked the clinic . . . said they felt good about love, support, respect . . . so it was worth it.

CHOW
The stage-based exercises in the clinics were to be done by CHOWs, who in this project were women with no more than a high school education. Implementing the protocol required that they master Prochaska's stages, the process of change, and the stage-based exercises. This required extensive training. However, even with this training there was repeated confusion. The protocol also demanded that clients come in at very specific intervals, and this was very difficult. Our clients had been recruited from the street or from drug programs. Their lives were unstable. Many were lost to follow-up due to being in jail, the hospital, or having moved away from the neighborhood. They would often show up at the "wrong time" and we had to decide whether to serve them if it wasn't on "schedule."

CHOWs wanted to spend time with clients in the clinics and get them connected to social service agencies, medical referral agencies, or drug treatment programs instead of following a rigid protocol. CHOWs reported that clients were not interested in the exercises and instead wanted help with "real-life" problems. Other clients who had substance abuse problems would come in high and could not sit down and concentrate on a structured activity.

We had reasonably good follow-up rates at the clinics, but virtually no participants in the counseling activities. The CBO partners were angry with the CDC for imposing a protocol they did not agree with. After three years, the CDC suspended the project because they realized that the intervention was not appropriate for a population of women not in drug treatment.

In contrast to protocol implementation in the clinics, the implementation of the community intervention proceeded smoothly. However, problems were encountered in collecting the cross-sectional survey data needed to evaluate the effectiveness of these efforts. As in the first phase of the project, we had hired outreach workers from the target communities, most whom were drug users in recovery with little work experience and no research experience. A number of them had relapses during the project, and it took a while for this to be discovered.

After conducting site visits, accompanying outreach workers into the field, and reviewing completed surveys, the CDC determined that some of the outreach workers were not adequately administering the survey. In addition, a review of the surveys showed that in some instances, the CHOWs had fabricated survey responses. This situation
resulted in the CDC ending funding for this study. In analyzing the problems, it was found that the supervisory staff was overextended due to limited funds and had not been able to adequately supervise the workers.

Research Findings

For the clinic-based project, we were able to recruit 301 women into the intervention and 243 women into the comparison sites. Follow-up rates for the family planning visits at six months were 64 percent for the intervention sites and 51 percent for the comparison sites. However, virtually no clients completed the minimum required visits for the theory-based counseling so we were not able to evaluate its impact and concluded that this type of intervention was not appropriate for drug-using women or for women without stable housing situations.

In the community mobilization project, the intervention was well received and appreciated by the participants in the housing projects. Outreach workers made over 3,000 contacts to provide educational materials and condoms. Many women were trained as peer volunteers and reported distributing condoms at all hours of the day and night. Local merchants distributed numerous role model stories and also provided free condoms. Special events and house parties were also held and well attended.

Problems were discovered with some of the quantitative data collected, so it was decided that a qualitative study with a sample of thirty peer volunteers should be conducted (Downing et al., 1999). These volunteers indicated that they had joined the project for a variety of reasons, including an opportunity to contribute to the community, boredom, lack of knowledge about HIV/STDs, and personal experience with STD infection or with family or friends who had HIV/AIDS. Through participation in the project, these women gained extensive knowledge about HIV/STDs and safer-sex practices. Peer education activities boosted volunteers’ own self-esteem. As one participant stated:

PHREDA helped a lot because not only do they tell you to go and pass condoms out, you know, they teach you how to present yourself, how not to be afraid, how to approach the individual. . . . And PHREDA told me how to go out and present myself to help another individual to keep from dying and they gave me that and I
used what they taught me. They didn’t tell me to be mean, they
didn’t tell me to be so aggressive, or even aggressive, but protect
myself and help them protect themselves and that what PHREDA
gave me.

Interviewees also reported that the condoms they distributed were
a major benefit of the intervention to the community. Several peer
volunteers emphasized that most community members would not use
their own money to purchase condoms. Many volunteers reported
community members coming to their homes at all hours of the day
and night in search of the free condoms, advice, or information.

Phase Three

The third wave of funding (1995-1997) came from the University-
wide AIDS Research Program (UARP). In this study, UCSF partnered
with Planned Parenthood Golden Gate, Glide Memorial Church, and
Bayview Hunter’s Point Foundation. The research questioned (1)
Prochaska’s stages of behavior change (SOC) for condom use and
whether getting yearly checkups were related to rates of HIV and other
STDs; and (2) if SOC-based follow-up schedules could improve client
continuation rates.

Collaborative Organization

The organizational structure was far more compact during phase 3.
The coprincipal investigators were from UCSF and Planned Paren-
thood Golden Gate. The research staff was employed by UCSF and
the outreach and clinic staff were employed by Planned Parenthood.
However, the UCSF staff was very involved in training and functional
supervision of the staff who conducted the outreach and follow-up
activities; they also administered surveys and collected lab informa-
tion. Unlike the research grant in phase 2, which involved the imple-
mentation of a rigid CDC protocol, Planned Parenthood and UCSF
worked together on the survey design, development, and implemen-
tation of the protocol.
Use of a Stages of Change-Based Assessment Tool to Guide Intensity of Clinic Follow-Up

Although the SOC counseling sessions proved unworkable with high-risk women during phase 2, PHREDA staff wanted to know if an assessment tool based on the SOC could be utilized to help health care providers more effectively target limited outreach and intervention resources toward women who need them most. An assessment tool was developed that measured SOC for use of birth control, condoms, and reproductive health services. Questions about high-risk sexual behavior and drug use were also included in the assessment questionnaire.

One hypothesis was that women who were not regular users of birth control and condoms or who had not regularly received reproductive health services were in need of the greatest amount of outreach and follow-up. A second hypothesis was that women in earlier stages of change (i.e., less use of birth control, condoms, and reproductive health services) would also have higher rates of infection with STDs than women with higher SOC scores.

To test these hypotheses, women at high risk for HIV were recruited into two nontraditional clinics. The clinic at Glide Memorial Church served as the intervention site and the clinic at the Bayview Hunter’s Point Foundation was the comparison site. Women at both sites were to have full clinical exams and surveys at enrollment, and at six and twelve months. Women enrolled at the intervention site would receive additional contacts based on their SOC.

Challenges

Initially, we had proposed that clients at each site be randomized into experimental and control groups. The clinic staff and outreach workers for these sites felt that it was not “fair to randomize women” and that they would have a problem giving different levels of care to women based on some randomization procedure. Therefore, we selected two of the nontraditional clinics in communities that were similar in racial composition and degree of poverty.

One of the primary collaborators on this project, Planned Parenthood, underwent significant changes during the course of the study and merged its San Francisco affiliate with over twenty other clinics.
A change of administration and a number of staff reassignments took place in the clinics. This resulted in two severe consequences to the research project. One of the key relationships at the intervention site in the Tenderloin was with Glide Memorial Church, which housed the nontraditional clinic. The Planned Parenthood administration inadvertently made decisions about the clinic without consulting Glide. This alienated the administration of Glide, which then decided to close the clinic after the first year of the two-year research protocol.

This meant that we needed to identify another site in the neighborhood to continue the research project. Unfortunately, when the clinic at Glide closed, a new clinic location had not yet been identified and we were unable to immediately refer clients to a new site. Three months passed before a new clinic located at Milestone, a drug treatment facility, opened. During that time, outreach workers tried to check in with the clients and let them know that the clinic was moving, but no follow-up surveys or exams could be conducted. This had a major detrimental impact on follow-up rates. Many of the subjects enrolled at the original site were never located again. Consequently, we had to change the evaluation design from monitoring compliance with a fairly rigid schedule of follow-up visits to examining the impact of differing numbers of follow-up contacts.

The closing of the Glide clinic was hard on the morale of the clinic staff, particularly the outreach workers. The outreach workers felt that by closing the clinic without a replacement, Planned Parenthood had abandoned its commitment to serve these clients. The outreach workers contacted their union representatives, who immediately started circulating a flyer accusing Planned Parenthood of abandoning the Glide clients.

Due to uncertainty about how the merger would affect their jobs and the frequent changes in supervision for the CHOWs and the clinic staff, workers became insecure about their jobs and morale sank. CHOWs that had been functioning well began to misplace forms. Clinic assistants who felt pressured would neglect to do all of the required lab work or draw blood on all participants. University staff had to assume a supervisory role and also provide advocacy and support for the staff. After repeatedly meeting with the staff to discuss the problems, a project assistant for the university was assigned to be in the clinic to assure that the protocol was being followed and to do some of the paperwork during busy clinic hours.
Finally, in the last twelve months of the project, Planned Parenthood was able to assign a more senior staff person to the clinic who worked closely with the research staff to salvage the project.

Communication and coordination with a competent manager/supervisor at the CBO is essential. In my experience, I came to the project as the manager about one year into the study. Unfortunately, there had been a lack of communication during the merger of four Planned Parenthoods, each with multiple clinics. Staff had gotten very confused about service delivery, surveys, and protocols. From Planned Parenthood’s perspective, the services to the clients were being provided via several funding sources with slightly differing protocols for each source (UARP, California State Office of Family Planning, federal Title X, etc.). Staff had become unclear about which funding source covered the client and thus which services were to be provided. Due to this confusion, many clients were not receiving the appropriate services for the UARP project and had to be called back in or located again; a difficult feat in working with such a transient population. Clients had to return for missed HIV blood draws, syphilis screenings, three-month follow-up questionnaires or annual surveys and had to be given additional incentives, thus increasing the costs of the project. Many clients could not be located to return and therefore had missing data. It had become chaotic without the communication, organization, and direction of an effective supervisor who could foster teamwork among the staff.

(Lisa Netherland, Planned Parenthood Golden Gate)

Research Findings

Study participants (n = 327) in the this third phase were primarily African-American women (71.5 percent), ages sixteen to fifty-six. Most (73.5 percent) reported welfare, AFDC (Aid to Families with Dependent Children), or general assistance as their main source of financial support and many (63.1 percent) had no health insurance. The majority (82.5 percent) were in the precontemplation (PC) or contemplation (C) stage of change (53.3 percent were not regularly using
birth control, 81.7 percent were not consistently using condoms, and 51.6 percent were not having yearly women’s health care checkups).

Data analyses indicated that SOC for condom and reproductive health service use was not significantly correlated with the presence of sexually transmitted infections and should not be used to determine the need for STD screening. One explanation for the presence of STDs in women who said they had consistently used condoms for the past six months is that women with STDs are often asymptomatic and may have been infected prior to initiating consistent condom use.

A significant difference in the overall follow-up rates between the control group and the experimental group was found (22 percent of subjects in the control group compared to 36 percent in the experimental group, p < .01, OR = 1.9, CI 1.4-3.2), indicating that the additional contacts provided to the experimental group improved follow-up. A further examination of follow-up rates by experimental group and stage of change (see Figure 7.3) reveals that women in the pre-contemplation/contemplation stage in the experimental group had a significantly higher follow-up rate than women in that stage in the control group (p < .04, OR = 1.79, CI 1.02-3.14). For women in the

![Bar chart showing follow-up rates by stage of change and condition.](image-url)

**FIGURE 7.3. Follow-Up Rates by Stage of Change and Condition**
ready for action/action stage of change, the differences between experimental and controls were in the expected direction and almost significant ($p < .07$, OR = 7.5, CI .86-64.96). No significant differences were found between experimental and control groups for women in the maintenance stage, with 31 percent in the control group returning for follow-up compared to 38 percent in the experimental group.

Logistic regression using follow-up as a dependent variable revealed that older women who lived in stable housing, had been treated for an STD in the past year, and who received multiple contacts from outreach workers were the most likely to return for follow-up ($-2 \log \text{Likelihood} = 80.75$, $p < .0001$; $R^2 = .25$; $C = .814$; Hosmer-Lemeshow). In contrast, younger women living in unstable housing situations, who were not diagnosed with an STD in the past year, and who had few or no contacts with outreach workers were the least likely to return for follow-up visits. Doing an assessment of stages of change is useful in tailoring follow-up schedules, however, due to low overall follow-up rates, additional pilot testing is recommended to confirm these results.

Another interesting finding that emerged with regard to sexually transmitted infections was the positive correlation between treatment for an STD in the past year and stage of change for condom use with a main partner ($r = .24$, $p < .001$). Women who reported a higher level of condom usage in the past six months were also more likely to have had an STD in the past year.

**BENEFITS AND CHALLENGES OF COLLABORATION**

**Benefits to the Community**

From the first planning meeting, the community-based organizations (CBOs) argued for the use of nonprofessional indigenous members of the target community as outreach workers. Over time, this process created a group of trained lay health educators who would remain in the community as a resource after the research project ended.

The CBOs also argued for clinics at alternative sites, including drug treatment centers. This gave the high-risk women, such as those in drug treatment, much easier access to medical care and HIV pre-
vention services. It also introduced drug-using women recruited through street outreach to drug treatment programs.

Benefits to the Community-Based Organizations

Planned Parenthood gained experience in serving a high-risk population and made contact with other community-based organizations (CBOs). Working with such high-risk women helped Planned Parenthood recognize the need for providing these women with a more comprehensive set of services. Planned Parenthood and the other CBOs also obtained training and experience in conducting a research study.

An important, often-overlooked benefit of the collaboration was the complementary effect produced by multiple agencies sharing resources to enhance the performance of all involved. This was done by joint trainings, sharing of space and materials, sharing of part-time staff, and coordination of services and activities to avoid duplication of effort. Agencies maximized their effectiveness in advocating for their communities at the governmental level by combining forces. Joint fund-raising and grant proposals increased the resources available to generate high quality proposals as well as increased the marketability of programs by demonstrating widespread community support for the proposed programs.

Benefits to the Department of Public Health

The DPH gained the ability to target services toward those at highest risk, thereby more effectively combating the spread of HIV. They also got exposure to the experience and wisdom of the CBOs in working with diverse communities previously not adequately served by public health or other traditional family planning agencies. Due to this experience, the DPH now collocates family planning services in its homeless and STD programs.

Benefits to the University

The university was able to have access to a population for conducting research that it had not effectively worked with in the past. The input from the CBOs and the DPH in terms of appropriate staffing and outreach techniques made it feasible to recruit and maintain high-risk
women in a setting where the study could be conducted. Researchers also learned the wisdom of consulting the target community and CBOs in developing designs that could succeed.

Research staff learned that to be successful, intervention must be tailored to a targeted community rather than imposed and “forced” on the population. Researchers also recognized that there is not a magical solution to a complex problem that can be solved by one theory implemented in a rigid manner. The community had stated from the beginning that no intervention would be effective if it did not include dealing with the nitty-gritty day-to-day concerns of this population. However, the rigidity of the CDC protocol would not allow this approach. Only through the collaborative process fostered by the UARP project was PHREDA able to begin to respond appropriately to the needs of its particular target population.

**CHALLENGES TO RESEARCH**

In collaborative research projects like PHREDA, you’ve got to teach clinic and outreach staff about research, how and why it’s done, and the importance of following protocols. By helping them to realize how research findings can be applied to shape policy and improve the lives of women all over the country at high risk for HIV, staff members understand the importance of accurate record keeping and following procedures. They understand what’s going on behind the mountains of paperwork.

Jennifer Rienks, UCSF Project Coordinator 1996-1998

Utilizing indigenous staff, often women in recovery from alcohol and drugs, made implementation of a structured research protocol very difficult in all phases of the PHREDA project. Initially, staff did not place high value on the paperwork they were asked to generate, and sometimes misplaced or lost records. They also did not understand the critical nature of administering questionnaires in a consistent manner. They had a hard time with the skip patterns on the questionnaires and it took training, retraining, and more retraining to finally achieve consistency.

The community did not agree with the idea of experimental versus control sites. This controversy was resolved by providing some re-
sources to the “comparison” sites. This meant that there was less money for the research component, resulting in delays in the data entry and analysis functions, which led to less productive research.

Compromise, Compromise, Compromise

From the beginning there was tension. The CBOs wanted more and better services, the university wanted publishable research, and the county had to referee, distribute resources, and make sure that we met the CDC contract requirements. As PI, I was often caught in the middle of intense arguments. Did we need more data entry hours or more clinic counseling hours? Did we need to increase the numbers of clients seen to get the statistical power for the research sample or spend more time with clients to improve their compliance? Should we hire trained interviewers or recruit indigenous outreach workers and train them in research protocol?

Geraldine Oliva, Principal Investigator 1989-1997

Research and evaluation are important in documenting what works and what does not work, but protocols developed by researchers often interfere with the delivery of services. The priority of staff in the clinics was to meet the needs of the clients, and the extra time and effort needed to carry out these research projects was often perceived as getting in the way.

Finally, the very nature of community-based research almost guarantees that some problems will arise. Community-based research usually takes place in the field—on streets corners, at public housing projects, or in a clinic cubicle or exam room. Unlike most true experimental research conducted in labs where the researchers have a high degree of control over all aspects of the research, field research takes place in the context of people’s lives and the community. Buildings burning down and staff in recovery who relapse are just two examples of the kinds of challenges that can arise when doing research in the field.

Rather than trying to control all these threats to the research itself, the researchers and project staff must become adept at recognizing problems and be flexible in their approaches to finding solutions. This may mean redesigning a protocol that is not working, tossing out
data from an outreach worker who has started using drugs on the job, or taking on tasks that another collaborative partner could not complete. Although researchers may not be able to prevent all of these problems, with a bit of experience they can become skilled in identifying and resolving problems to minimize the impact on the integrity of the research.

My Years in the Collaboration from Hell

Try juggling: (1) the clinical and personnel policies of a progressive and controversial family planning program; (2) the unique cultural environment of a powerful, inner-city, faith-based service organization; (3) the fiscal and civil service constraints of a public health department; (4) the scientific strictures and academic atmosphere of university-based research; and (5) the peculiarities and rigid requirements of a nationwide, multisite, federally funded, research intervention, and what do you get? The collaboration from hell! The PHREDA project attempted to marry the best aspects of these organizations in order to eliminate the weakest parts.

My years as the director of such a multiarm monster have left me with a set of skills that enables me to tackle almost any type of administrative, political, fiscal, personnel, program, or research challenge. But what enabled this collaboration to succeed against all odds? There is no doubt in my mind that we were successful because of the singular commitment on the part of most of the players to provide services to medically underserved and economically disenfranchised, drug-using women. Because we believed everyone was dedicated to this marginalized population, we were empowered to push through mountains of red tape and political jungles. With pitchforks, we stood in the middle of this monster that we created to hurl barriers aside that prevented us from delivering quality health care and HIV prevention to inner-city women. If I ever lost the belief that everyone wanted this to happen, I wouldn't have been able to get out of bed.

Moher Downing, MA, PHREDA Project Director,
San Francisco Department of Health 1988-1995
Administration

Collaborations among agencies with vastly different cultures present major challenges. It takes a lot of processing time for individuals to learn to respect one another’s values and work styles and build the trust necessary to develop and manage a new service model. Trying to coordinate up to seven agencies requires tremendous time and diplomatic skills. Dividing resources equitably in a way that satisfies all participants again requires consummate communication skills, time, and effort. This requires a lot of meetings that take personnel from the streets and the clinics.

Dividing the financial resources makes for very complex budgeting, contracting, and accounting. This takes a tremendous amount of staff time. Again, this takes a project director away from monitoring service provision and compliance with research protocol and puts her or him in the administrative offices of large agencies. It also requires the hiring of additional staff to assist the director.

The use of peers as outreach workers and educators has been well received by the target group. However, many of these workers are themselves in recovery from drugs and alcohol and relapses among them have to be recognized and appropriately managed. Many of these women have limited job skills and education and some have not held a regular job before and may have trouble with punctuality, accountability, and the careful completion of paperwork. These staff members require sustained in-service training and close and skillful supervision.

Community

The community-based organizations (CBOs) joined the collaborative to increase and improve services for their particular target populations. They also wanted to make sure that the research conducted in their communities was ethical, fair, and of benefit to the community. The CBOs were frustrated by long and tedious research protocols that took time and resources and were not “user friendly.” They were forced to learn the language of research and to demand an equal say in decisions. This meant having to develop the assertiveness and confidence to take on university and health department staff who were used to being in charge and calling the shots. In some cases, the CBOs
were forced to accept research designs developed thousands of miles away by professionals who did not understand their communities.

The CBOs often carried the burden of recognizing and calling attention to tensions that arose from race and class differences among staff from different institutions and between staff and clients. Although these situations were stressful for everyone, the CBOs felt the most pressure for seeing that these issues were fairly addressed and resolved.

CONCLUSION

The PHREDA collaborative provided an important opportunity for researchers to gain a deeper understanding of women at high risk for HIV while providing much needed medical and social services to these women. The linkage between community-based organizations and traditional, Title X-funded family planning clinics has been successful in San Francisco. Many of the medically underserved, high-risk women enrolled in PHREDA continue to be served at these clinics because each of the “mother” sites have made a commitment to provide those services in their alternative clinics.

Current Status

With the conclusion of the CDC-funded research project, the alternative clinics started by PHREDA sought ongoing funding. Haight-Ashbury Detox Clinic received ongoing funding from a nonprofit foundation. Glide Memorial Church developed a partnership with Catholic Healthcare West, a nonprofit health care group, to establish a comprehensive clinical program on site. Planned Parenthood continued services at the Bayview Hunter’s Point Foundation and at Milestones Clinic, a drug rehabilitation program in the Tenderloin. Both Planned Parenthood clinics are supported through grants from the California Department of Health Services Family Planning Program. The only alternative clinic that has not continued service was in the Mission District. The UCSF-administered family planning clinic at SFGH established a satellite clinic that they feel will serve the same population.
Many of the agencies that participated in the PHREDA project and had participated in the CDC-funded efforts for women in other counties are attempting to establish an ongoing collaborative network called the Bay Area Women's Health Coalition (BayWHAC). The goal of this group is to continue the collaborative interagency training, advocacy, fund-raising, and research activities that had been coordinated by the PHREDA project.

REFERENCES


