

Addressing Health Disparities In Community Settings

> An Analysis of Best Practices in Community-Based Approaches to Ending Disparities in Health Care

[Final Report to The Robert Wood Johnson Foundation]



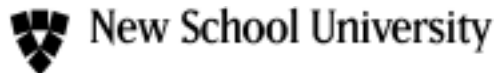
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Submitted by the
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Executive Summary

Much attention has been focused on health disparities for minority Americans in recent years. These disparities span the spectrum of health and health care services, and are reflected in increased incidence and mortality rates for minorities suffering from numerous diseases. Disparities are also seen in measures of health care access, with minorities often receiving fewer needed interventions, having less access to medical services, and more likely to lack health insurance.

Community-based initiatives to reduce these disparities have garnered much attention. Many programs targeting minorities and disparities have been started with federal, state and private funding. But little is known about what makes these programs successful.

To fill this gap, we studied community-based disparity initiatives at the request of The Robert Wood Johnson Foundation. Through internet and literature searches, expert interviews, surveys and site visits we have described and analyzed existing programs, delineated some of their “best practices,” and recommended future actions that might help strengthen these programs. We have also considered the potential of these projects to have a major impact on health disparities in America.

Our major findings include:

- > Good programs excel at the **mobilization and management of a continuum of resources**. They create a network of services, few of which are actually owned or operated by the program, and then assist their clients in gaining access to those services in a coordinated fashion.
- > A common element in these programs is some form of **one-to-one outreach** and ongoing contact between clients and some form of health worker. This facilitates both health education and health system navigation for clients.
- > Many disparity-reduction programs have embraced multiple strategies in **practicing cultural competence**, going far beyond just “speaking the language” of the client.
- > **Replication of various models will be difficult**, given the lack of good evaluations, the fact that many models develop in response to idiosyncratic local conditions, and the great differences in indigent care access between communities.
- > These are generally **small programs**. It is very unlikely that community disparity initiatives are currently having a large impact on the health of minority populations.

Finally, there are larger philosophical questions that must be considered. Community-based disparity programs may do much good in many communities, but these efforts cannot completely solve greater social issues of poverty, racism and lack of health insurance for millions of Americans.

Introduction

Disparities in minority health and health care will have growing implications for an increasingly diverse nation. Across a range of health conditions, African Americans, Latinos, Native Americans, Asian/Pacific Islanders, and other ethnic and racial minorities are at greater risk for a host of diseases. For instance, the prevalence of diabetes among African Americans is approximately 70% higher than that for whites. For Latinos, it is 50% higher. Prostate cancer for men under 65 years of age is almost twice as frequent for African American men than white men. Vietnamese women have cervical cancer at rates almost double those for whites.¹ Similar examples can be found for cardiovascular disease, breast cancer and other conditions.

Independent of the cause of the illness, minority Americans suffer worse outcomes from those same diseases than do whites. African Americans are not only diagnosed later with colorectal cancer; they also have much higher rates of inpatient mortality from that disease.² Asian American, African American and Latina women wait much longer from an initial abnormal screening mammogram to a follow-up diagnostic test than white women.³ Disparities are evident not only in disease incidence and prevalence, but also in the progression and eventual outcomes of disease.

It would be misleading to imply that ethnic and racial disparities are “new” or even newly recognized problems. *The Journal of the American Medical Association* devoted an entire issue to research and discussion of disparities 12 years ago.⁴ But the future impact of disparities has only recently become clear, as America’s demographic shift towards diversity has accelerated. With racial and ethnic minorities expected to comprise 40% of the U.S. population by 2030,⁵ persistent disparities among these groups will have an even greater impact on the overall health status of Americans.

Prior research done in this area has implicated a number of factors that lead to inequality in diagnosis and treatment. Latinos and African Americans often lack a usual source of medical care and are much more likely than whites to report being in poor health.⁶ In 1997-99, 34.3% of Latino adults lacked health insurance, while 21.6% of African Americans and 14.7% of whites went without coverage.⁷ Minorities often receive fewer therapeutic interventions than whites with the same conditions.⁸ Other work has shown that even when minorities are appropriately diagnosed they often receive inferior levels and qualities of care, often resulting in higher mortality.⁹ These disparities seem to persist regardless of the race of the treating provider.¹⁰ Added factors and underlying determinants, ranging from diet to the geographic location of health services to the cultural competence of health care workers also form part of the complex picture of health outcome disparities.

In response to this state of affairs, the 1999 President’s Initiative on Race outlined the issue of health disparities and its determinants. This led in part to the launch that year of the Centers for Disease Control and Prevention’s “Racial and Ethnic Approaches to Community Health (REACH 2010)” initiative. REACH 2010 is designed to fund 32 community coalitions (with three more funded by the California Endowment). The coalitions are to develop targeted interventions for geographically defined minority populations. Six health priority areas are included: infant mortality, breast and cervical cancer, cardiovascular disease, diabetes, immunization, and HIV/AIDS.¹¹ The planners of this \$9.4 million program hope that a community-based effort will aim preventive and treatment resources at populations most in need, in a culturally sensitive fashion. Interest in community-based solutions to disparities extends beyond the federal government. Similar initiatives have begun in other states, one example being the recently announced Florida “Closing the Gap” grant program, which provides six million dollars for an initiative closely patterned on REACH 2010.¹²

Many studies have attempted to quantify the relative contributions of economics, education, environment, health system deficiencies, cultural differences and racism to these disparities. Others have evaluated single clinical strategies. But we know little about how local communities can reduce health disparities. Even as government and non-profit agencies are moving to develop local disparity initiatives,¹³ not much is known about what is already being done and what works on a community level.

At the request of The Robert Wood Johnson Foundation, we identified and studied community-based initiatives addressing disparities in breast cancer, cervical cancer and diabetes. Our hope was to begin identifying best practices, success factors and the potential contributions of these programs. This knowledge may be useful to planners, activists and policy makers who are seeking to reduce health disparities.

Study Goals and Scope

Despite the burgeoning interest in community-based approaches to reducing disparities, there is little in the available literature on the practical aspects of these initiatives. We began to create such a body of knowledge as one resource to assist in the design and implementation of such programs. Our work was driven by three major goals:

- > To review and describe existing community programs designed to address health outcome disparities for specific conditions in minority Americans;
- > To identify “best practices” in the conceptualization, development and implementation of such programs;
- > To analyze the potential of these programs to have a significant impact on morbidity and mortality, given the current contexts of national, state and local health care.

We concentrated initially on those health priority areas identified in the recent federal disparity efforts and further narrowed our focus to initiatives designed to address disparities in diabetes and breast and cervical cancer. This emphasis is a result of several factors. The scope of this study did not allow for meaningful analysis of programs in all six federal priority areas. Infant mortality, immunization and HIV/AIDS disparities have been the subject of considerable prior work and it seemed any work done in these areas might well be redundant. Cardiovascular diseases include numerous different conditions and potential preventive and treatment strategies. Thus it was more difficult to define.

In contrast, diabetes is a well-defined condition with many adverse sequelae. Its prevalence and prominence have been rising. Breast and cervical cancer are also well-defined diseases with potentially well-defined interventions to address disparities. Our selection was conducted in close consultation with staff at The Robert Wood Johnson Foundation. Focusing on these conditions offered a “workable” number of conditions, allowing us to contrast, for instance, the challenges faced by breast cancer projects in different cities.

Our study was intended to be exploratory in nature, and certainly not exhaustive in scope. Within our time frame of nine months, we attempted to collect as much information as possible, but a more exhaustive effort would take much more time than we had available.

Methods

The selection of specific case study projects was governed by several criteria designed to select study sites most likely to offer important lessons on the organization and implementation of these initiatives. For the studies to be useful, they needed to focus on sites that had grappled with many of the issues we had observed in disparities programs, including those around securing care for underserved, often uninsured indigent populations. We sought to include programs that:

- > Were operational and fully implemented;
- > Had defined interventions to improve access to early detection and treatment;
- > Reported some method of outcomes evaluation;
- > Were targeted at different minority groups (African American, Latino, Native American, Asian/Pacific Islander, possibly others);
- > Were geographically diverse;
- > Represented a range of sponsors and governance models (i.e., government, private sector, and public-private partnerships);
- > Represented a range of program sizes and funding levels;

Initial work began with a scan of the disparities program environment. Given the nature of our study, our focus was on finding comprehensive operational programs that included education, screening and treatment. Our initial focus was on understanding the nature of disparities, as well as what is known about community-based initiatives in this area. This scan included three tasks described below.

Literature Review

This review concentrated on a survey of published materials on health disparities and the identification of operational disparity-reduction programs. We searched published professional literature, government and foundation reports, newspaper accounts and other sources. This work generated literally hundreds of program contacts, though many programs turned out to be just starting, defunct or purely educational in nature.

Internet Search

This was a more extensive undertaking than the literature search above. We located and reviewed web sites dealing with health disparities. These were generally sponsored by a variety of federal, state, municipal, non-profit and for-profit organizations. Our preliminary research suggested that information about disparities and disparity-reduction programs is abundant on the Internet. This search generated additional potential project sites.

Expert Interviews

The initial searches were followed by a series of 39 expert interviews of 42 individuals (Appendix 1).¹⁴ Individuals were identified as key researchers, policy makers and opinion-leaders in the area of disparities through the scan or personal referrals. They were interviewed in a structured format (see Appendix 2) for approximately one hour each, and asked their thoughts on identifying programs as well as on the general strategies for correcting minority health disparities.

These activities identified 89 separate community-based initiatives nationwide that appeared to meet the study criteria. These programs were then sent an electronic mail survey (Appendix 3) seeking basic information on the targeted population, program governance and design, budget, identified community partners, evaluated outcomes and other factors. Forty-six programs, listed in Appendix 4, completed the survey (response rate = 52%). From these survey responses, using the criteria above, we selected the six sites (with seven programs) listed in Table 1. These sites are also shown in Figure 1.

Table 1. Case Study Programs

PROGRAM	State	Ethnic Group	Breast CA	Cervical CA	Diabetes	Governance	Rural	Suburb	Urban
Unidas Podemos—Way of the Heart Institute	AZ	Latina	•	•		Non-Profit	•		•
Paso a Paso—Way of the Heart Institute	AZ	Latina			•	Non-Profit	•		•
Contra Costa Breast Cancer Partnership	CA	All	•			Public/Private Partnership	•	•	•
Sacramento Urban Indian Health Project	CA	Native Amer			•	Non-Profit		•	•
Women's Fest—Y-ME	IL	AfAm Latina	•			Non-Profit			•
Delta Community Partners in Care	MS	AfAm			•	Public/Private Partnership	•		
Chinatown Breast Health and Cervical Cancer Program	NY	Asian-Amer	•	•		Non-Profit			•

Figure 1. Map of Case Study Sites



The project team visited each site for approximately two days. A formal comprehensive document request, seeking planning, evaluation, budget, governance and other information preceded this visit. A site visit instrument, seen in Appendix 5, was developed in order to guide the semi-structured interviews with the program leadership and staff. These questions were generated by our own review of the literature, by issues raised in the expert interviews and by questions elicited by our review of the completed surveys. Where possible, in addition to program leadership and staff, we interviewed a variety of other parties. These included at various sites:

- > Program board members
- > Affiliated physicians
- > Local health department officials
- > Hospital partners
- > Municipal government leadership
- > State elected officials
- > Community health centers
- > Other local community organizations
(e.g., local council on aging)
- > Local clergy
- > Local health care advocacy organizations

The results of the site visit and document reviews were used in the creation of the following case studies. Following the descriptive case studies, we have outlined the common success factors we observed, identified best practices and offer some recommendations for strengthening the efforts of community-based health care disparity initiatives.

Chinatown Breast Health And Cervical Cancer Program

Charles B. Wang
Chinatown Health Center
New York, NY

At A Glance: New York County¹⁵

- > Population: 1,537,195
- > Racial/ethnic demographics: 27.2 % Latino, 17.4% African American, 9.4% Asian, and 45.8% White¹⁶
- > Median household income (1997 model-based estimates): \$38,224
- > Percent of persons below poverty level (1997 model-based estimates): 20.7%
- > Statewide rate of uninsured: 17%

Introduction

The Chinatown Breast Health and Cervical Cancer Program at the Charles B. Wang Chinatown Health Center provides Chinese-American women in New York City with preventive services to promote the early detection of breast and cervical cancer. Program staff offer one-to-one, same language, culturally based education and assistance, and help clients access services provided by a network of local providers, using a community health center model. The program serves the entire Chinese population of New York City, and makes special use of Chinese newspapers and radio, as well as other Chinese-American organizations to promote its preventive activities. It also serves other Asian -American communities. Over the six years the program has been in existence, the missed appointment rate for mammograms has fallen from 80% to 20%.

History and Background

The Chinatown Health Center (CHC) grew out of a 10-day health fair held in the Chinatown section of Manhattan, New York City in 1971. Local doctors volunteered and demonstrated a need for health care in the Asian-American community. Over the next four years, CHC used donated space in a church to provide services before being awarded a Public Health Service Section 330 grant in 1975. With the funding provided by this grant, they were able to move to their own building on Baxter Street in Chinatown. In 1995 they moved to their current facility on Walker Street and are about to expand to



a new facility on Canal Street. In 1999, the Clinic was named after Charles B. Wang, the CEO of Computer Associates.

CHC's Breast and Cervical Cancer Screening Program got its start six years ago when it was noted that there was an 80% no-show rate for mammography services. The program was established to extend CHC's existing, broad-based outreach activities to promote wider use of preventive breast and cervical cancer services by Asian-American women, especially those who are uninsured.

Organization and Mission

The Charles B. Wang Community Health Center is a Federally-Qualified Health Center (FQHC), organized as a not-for-profit corporation. It has an all-Asian Board of Trustees, which exercises program and policy control over the operations of the Center.

According to its draft mission statement, the CBWCHC seeks to:

...be a leader in providing quality and culturally relevant health care and education; to advocate on behalf of the health and social needs of the Asian American people; to pursue health careers and community involvement and to participate in clinical research that would be of benefit and interest to our community.

The key point in this statement is that the Board and staff of the CHC feel that to be merely culturally "competent" would be to admit failure. Since their client population comes almost exclusively from one group, they feel they should be more than just competent. Rather, they should be experts in providing culturally appropriate care to this community.

In pursuit of its goals, CHC is affiliated with virtually every Asian community group and Chinese family association in New York City. It has a long (30 year) history in the community and has identified itself closely with a vibrant commercial area. Although it belongs to all relevant trade and lobbying groups, it admits to not being well connected politically. Indeed, the CHC is seen as a place for health care and social services, not as a center for political action. However, the staff does note that, because of relatively low Chinese-American voter-turnout, it has been difficult to promote politicians' interest in their issues.

To support its mission to participate in research that might benefit the local community, the CHC actively participates in clinical research studies, including a 20-year New York City Department of Health longitudinal study of cancer incidence. They are also partnering with New York-Presbyterian Medical Center in a colorectal cancer-screening program. The CHC's support of such research is critical in light of the biases of many Asians against participating (many believe, for example, that blood is a life force and don't like to give it up voluntarily) and the need for translation of detailed questionnaires.

One final goal of the CHC is to identify individuals who may be eligible for health insurance and social welfare programs. The CHC staff then assists these individuals in signing up for these programs and securing the benefits to which they are entitled.

Funding

As a federally funded community health center, CHC receives payment to care for the medically indigent. CHC's Breast Health and Cervical Cancer program has a current budget of about \$200,000. The Avon Breast Cancer Fund provides \$100,000 for staffing and infrastructure development. Another \$60,000 comes from the Susan G. Komen Foundation for community education and patient navigation for breast health, and \$15,000 is provided by the New York City Department of Health for cervical cancer screening. The remainder is provided by the Manhattan Breast Health Partnership, itself a grantee under the Centers for Disease Control's National Breast and Cervical Cancer Early Detection Program, to cover breast and cervical cancer screening for uninsured women.

Target Population

The mission of the CHC is to provide health care and other services to the Asian American, and more specifically the Chinese, population of New York City. United States Census data reveal that between 1980 and 2000, the Asian population in New York City more than tripled to 787,047. In 2000, CHC had 16,855 users making 86,000 visits; 99% of the users were Asian.

While the CHC is located in Manhattan, 40% of its patients come from Brooklyn and 20% come from Queens. The ability of the CHC to reach so widely across New York City's Asian community owes to its central location in the heart of Chinatown and the ability of CHC staff to translate a range of Chinese dialects.

Census data from 1990 indicate that almost half of the population living in the lower Manhattan/Chinatown areas had incomes below 200% of the federal poverty level. In nearly 50% of Chinese households, adults spoke little or no English.

Breast Health and Cervical Cancer Program

Services

Women's health services at CHC consist of two components. The first is the care of women who are existing, often insured, patients of the primary care practice at the clinic. These patients generally get referred for mammography and cervical cancer screening by their internist or gynecologist. A second component of women's health services at CHC is care for "community women": women who have no other association with the clinic and are generally not insured. Providing screening services for these "community patients," who come to the center through outreach, and who number about 400-500 per year, is the main priority of the Breast and Cervical Program.

As noted earlier, The Breast and Cervical Cancer Screening Program was launched in response to the 80% no-show rate for mammography services in the Asian/Chinese-American community. Today, the no-show rate is under 20%. This turnaround was accomplished through the utilization of certain basic principles, including:

- > One woman to one woman attention;
- > One-stop shopping;
- > System navigation services;
- > Sensitivity to cultural norms and practices;
- > Pre-scheduling and follow-up; and
- > Individual empowerment.

Through extensive outreach activities described below, women over 40 are encouraged to make appointments at convenient, monthly, weekend clinics. Up to 20 women are accommodated in each session. Reminder notices are mailed two months before the visit, with phone calls closer to the appointment. There they are given a clinical breast exam and asked to fill out forms to qualify their care for funding from the Breast Cancer Partnership, if they are uninsured.

The CHC does not have mammography equipment, but instead reserves blocks of time at neighborhood hospitals and private radiology centers for patients. After the clinical breast exam, a van takes the patients to the mammography site (such as Beth Israel Hospital). There, a volunteer patient navigator helps the women through the process, and helps with translation if necessary. After the mammogram, the patients are brought back to the clinic so they can either receive other services or do other errands in the neighborhood.

Women generally receive the results of their exam within two weeks (although it can take up to two months to get results back from the public hospital site), and case management services are provided for women who need follow-up care or referrals. Referrals and follow-up care are provided at the same community institutions that provide the mammography services.

In the future, CHC plans to add additional preventive services when women come for their annual screening. They believe they can perform simple osteoporosis screenings while women are waiting for their mammograms. They plan to test for colon cancer as well.

Outreach

The Chinese population, in general, believes in prevention. For this community, the major problem of access to care is the language barrier. Thus, CHC reaches the Chinese community through ethnic radio and newspapers. In addition to advertising in Chinese newspapers and on Chinese radio, the CHC has a radio call-in show in which the doctors and health educators answer questions and make announcements of program activities. CHC has also translated over 200 health education pamphlets into Chinese. Finally, CHC does outreach at worksites in the Chinatown neighborhood and holds an annual health fair in a neighborhood park that generally attracts 3,000 people. This last activity, like the Chinese language radio promotions, is especially critical for reaching that portion of the population that is illiterate.

Outcomes

The CHC is required, as a condition of its federal grant, to collect information on its activities. The CHC also surveys its patients for their satisfaction with the Center and the Program. The Breast Health Program performed 227 mammograms during calendar year 2000 and 189 during the first six months of 2001. Interestingly, only 21 cervical screenings were conducted in 2000 among the “community” population. Over 40% of the screened women report never having had a prior mammogram. As noted above, only 20% of appointments are now missed, compared to 80% at the program’s inception. Over 90% rated the quality of service as “excellent” or “good.”

Challenges

Funding is a major problem for the CHC. Like so many providers, CHC is seeing revenues drop as managed care exacts its toll. Increasingly, it must turn to use outside monies and grants to fund work within the community.

Changes in the diversity of the Chinese and Asian populations of New York pose their own challenges. In Chinatown, the fastest growing population is Vietnamese. Few Vietnamese use the CHC, although more may do so soon, since a Vietnamese-speaking staff member has been added, and health brochures will be printed in Vietnamese as well as Chinese.

Many of today’s Chinese immigrants already have a family network in place and can find employment and some housing. Meanwhile, wealthier Chinese have moved to the Flushing area of Queens. CHC has established a satellite clinic there, but since this is a wealthier area with more resources, it does not get any federal funding.

China is a large country and there are significant dietary and cultural differences between the regions of the country. There are a large number of dialects of spoken Chinese (although a single written language), and while many Chinese can switch between dialects as needed, those who cannot may have difficulty understanding difficult medical questions and concepts. The first Chinese immigrants came to New York primarily from Canton, and Mandarins followed. Today, most new immigrants are Fukinese.

Program Needs and Future Plans

The primary need of the program is increased and stable funding. As with most small health clinics, program budgets are not necessarily restricted to a single, given program: money is considered fungible (within limits) and used to support whatever programs need more resources. Chinatown Health Center has a policy of not laying off workers after a particular project has exhausted its funding, both out of concern for their well-trained workforce and to ensure that the skills that people have learned will not be wasted. This policy, coupled with the unstable funding environment, can make the ongoing operations of the center difficult.

Should they secure additional funding, the Women's Health staff would wish to fund:

- > More extensive outreach (more translated pamphlets);
- > More patient and staff education;
- > More and better case management;
- > Expansion of mobile mammography services to areas of the city where there are small, discrete Chinese communities (e.g., Canarsie and Sheepshead Bay in Brooklyn).

To continue to develop a culturally sensitive staff, CHC has established an internship program to encourage health professionals to work in Chinatown. The current medical director began his association with the clinic in this manner, as have several other staff members.

Contra Costa Breast Cancer Partnership

Contra Costa County Health Services
Contra Costa County, CA

At A Glance: Contra Costa County¹⁴

- > Population: 948,816
- > Racial/ethnic demographics: 17.7% Latino, 9.4% African American, 11% Asian, and 57.9 % White
- > Median household income (1997 model-based estimates): \$54,275
- > Percent of persons below poverty level (1997 model-based estimates): 8.7%
- > Statewide rate of uninsured: 21%

Introduction

The Contra Costa Breast Cancer Partnership serves a county in northern California that has high breast cancer incidence and death rates. The Partnership is a coalition of organizations and providers, who together coordinate and provide education and outreach activities and screening and diagnostic services, designed to increase early detection and treatment of breast cancer among low-income, uninsured, and underinsured women over age 40. A key feature of its program is the use of “patient navigators” to help Spanish-speaking women effectively access a fragmented provider system. The Partnership is based in the County Health Department and serves white, African American, Asian, and Latina women who live in Contra Costa County. The Partnership receives state and federal treatment and screening monies, as well as philanthropic donations and grants to support its efforts. Through the efforts of the Partnership (as well as some preceding entities), early detection of breast cancer

among African American women may have increased, offering them a better chance at positive outcomes.

History

Although the Contra Costa Breast Cancer Partnership wasn't organized until 1995, the County's efforts to provide outreach and to increase access to breast-related health care services for underserved women date back to 1991. Because petroleum and chemical refineries have historically been the major local employers, the County Health Department and local advocacy groups have long been attuned to environmental risk factors related to cancer. Indeed, the high incidence of breast cancer in the county



(among the highest in the state), and the stark disparities in early detection and mortality rates between African American and white women, were well-documented: In 1992, only 44 % of African American and 58% of Latina women with breast cancer were being diagnosed at an early stage, compared with 72% of white women.

In response to these trends, the County Health Department, began outreach activities to recruit uninsured and underinsured women, aged 40 and older, for free breast cancer screenings. Breast cancer activists, with the support of the Public Health Department, secured a commitment from the county to pay for the treatment of women diagnosed through these screening efforts. In 1995, the County procured state funding through California's Breast Cancer Early Detection Program (BCEDP) to support these efforts. One year later, the Contra Costa Breast Cancer Partnership was officially established.

Organization

The Breast Cancer Partnership is housed within the Community Wellness & Prevention Program in the Public Health Division of Contra Costa County Health Services. Contra Costa County Health Services is a complex organization with two distinct but coordinated health care delivery systems: The Public Health Division, comprised of Public Health Clinics and mobile vans, and the Hospital and Health Centers Division, which includes the County hospital (Contra Costa Regional Medical Center) and a network of thirteen ambulatory care centers providing outpatient, specialty, and geriatric care services.

The Community Wellness & Prevention Program, within which the Partnership is housed, has a \$4 million dollar budget¹⁷ and 50 full and part-time staff. This division utilizes a broad range of public health strategies to improve health in the community, including: educating individuals, communities and providers; fostering coalitions; changing organizational practices; and influencing policy and legislation.

Funding

As noted above, the Contra Costa Breast Cancer Partnership is primarily funded through California's Breast Cancer Early Detection Program (BCEDP). BCEDP funding comes from a statutory, two-cent per pack addition to tobacco taxes, which generate \$34 million per year and is administered by the California Department of Health Services (DHS). The Partnership is one of 14 regional partnerships to receive a portion of the monies that the DHS Cancer Detection Section distributes for the coordination and provision of screening services, diagnostic tests, education, and outreach activities. Statewide, over 2,000 enrolled providers are able to bill BCEDP for screening and diagnostic services at Medi-Cal rates.

The Partnership receives about \$360,000 a year in state funds to support coordination of outreach, education and early detection activities. An additional source of funding for the Partnership comes from the federally funded Breast and Cervical Cancer Control Program (BCCCP), and the County itself provides a small amount of additional funding.

The Partnership's Patient Navigator Project is not supported through BCEDP monies. The \$235,000 annual budget for this project is instead funded by the Susan G. Komen Foundation, the John Muir/Mt.Diablo Community Health Benefit Corporation, and the Keller Canyon Landfill Mitigation Funds.

It is worth noting that payment for treatment of women who are diagnosed with breast cancer is not covered by tobacco tax funds that support the Partnership. These costs are instead paid by the California Breast Cancer Treatment Fund, which is administered by the California Health Collaborative. The Treatment Fund was created in 1994 with an initial \$12.4 million grant from Blue Cross of California's Public Benefit Program (the predecessor to The California Endowment and the California Health Care Foundation). Case management and treatment costs are covered by this Fund for uninsured women, aged 18 or older with incomes at or below 200% of the federal poverty level.

Target Population

Through its outreach and education efforts, the Partnership primarily targets Latina and African American women. To qualify for free BCEDP breast screening services, a woman must:

- > Be at least 40 years old, uninsured or "underinsured" (e.g., lack this benefit under their insurance or have a co-payment they cannot afford);
- > Be ineligible for Medi-Cal; and
- > Have an income of no more than 200% of the federal poverty level.

Undocumented immigrant women are eligible for BCEDP services.

Program Operations

Clinical Services

The Partnership coordinates the continuum of breast health services from screening to treatment. Women identified through the Partnership's outreach efforts are referred to the county's network of BCEDP providers and to the sole BCCCP provider in the county.¹⁸ BCEDP providers are a mix of public health clinics, county ambulatory care centers, community clinics, Planned Parenthood clinics, public and private medical centers, and private medical practices.¹⁹ Thus, a woman may be referred to a different location for each service she may need: she might obtain a clinical breast exam at a public health clinic, then be referred for a screening mammogram to an ambulatory care center or a medical group, and be referred to yet another location for further diagnostic testing. Women diagnosed with breast cancer are referred to and treated at the public Regional Medical Center, or at Doctors Medical Center, if the woman was diagnosed there. The fact that Contra Costa County Health Services includes the full continuum of care, from public health to tertiary medical services, has been very helpful. As a result the county can guarantee that any county woman with a breast cancer diagnosis will receive treatment.

Patient Navigator Project

The Patient Navigator Project (PNP) hires and trains lay bilingual/bicultural community outreach and advocacy workers to additionally provide on-site interpretation and “navigation” services to Spanish-speaking patients who are utilizing breast-related health care services. Each navigator supports about 8-10 women through the system every month. Navigators also help patients fill out complex forms to determine eligibility for BCEDP, Medi-Cal or other programs.

Currently, four Spanish-speaking navigators staff the Patient Navigator Project. They receive training in medical interpretation, breast health, culturally competent outreach methods, communication, and medical terminology. The project also “borrows” Vietnamese and Laotian/Mien interpreters from the Public Health Department Interpreters Program on an “as needed” basis. To promote retention, program navigators are encouraged to become county employees, rather than remain contracted staff. They are paid \$13/hour with benefits, or \$16/hr without benefits.

PNP became part of a recently organized initiative that seeks to address gaps in services and other barriers to care that monolingual Latinas continue to face in Contra Costa County. Partners in this initiative include the American Cancer Society, the Contra Costa Crisis Center, the Wellness Community, La Clinica, The Women’s Cancer Resource Center, and Hospice and Palliative Care of Contra Costa. These organizations plan to expand: transportation services; outreach, education, and case management activities; and Spanish speaking grief counseling and psychosocial support. These activities will be supported by a \$500,000 grant from the John Muir/Mt. Diablo Community Health Benefit Corporation.

Outreach and Education

The Partnership’s outreach efforts reflect the Public Health Department’s principle of engaging local organizations and communities to affect individual behavioral change. The Partnership distributes mini-grants of \$5,000 to \$10,000 to community-based organizations to organize and conduct extensive outreach, education, and social marketing activities. Community-based organizations, faith-based organizations, breast cancer survivor spokespersons, lesbian softball teams, health fairs, poetry readings, community and public relations events, and educational videos all work to increase awareness of breast health and to promote early detection and screening services. The most highlighted effort is the African American Task Group production and distribution of 15,000 calendars featuring local women who have survived breast cancer. The calendar is being reprinted due to its popularity. Other outreach strategies include the distribution of \$25 food coupons to those who come in to get screened, and the promotion of the Partnership’s services on a Spanish-language call-in show (¡Vida Sana En Vivo!) about health issues on Contra Costa’s cable TV system.

Provider Education

The Partnership coordinates professional training for BCEDP providers. This training typically covers: clinical standards of breast cancer screening; communication with patients, including communicating diagnostic and treatment options; documentation and tracking issues; addressing women's emotional concerns and questions about mammography; working with interpreters and patient navigators; and cultural awareness issues.

Staff & Governance Structure

The Partnership staff consists of a full-time project manager, a project assistant, and a senior health educator. Part-time staff includes a clinical services coordinator, a provider relations consultant, and a planner/evaluator. Four Spanish-speaking navigators staff the Patient Navigator Program. The Partnership staff is responsible for implementing the program activities. They see their role as facilitators and enablers, convening and engaging communities and providing structure, technical assistance, training, and resources. Licensed medical staff oversee the patient navigators, as well as all of the Partnership's clinical staff.

The program is organized around four committees:

- > A Steering Committee composed of elected representatives from a variety of organizations,²⁰ that provides overall leadership and support to the Partnership by establishing priorities, and making recommendations regarding program administration, policy, and services.
- > A Committee on Outreach and Evaluation composed of community leaders and representatives from different organizations, which oversees the development and implementation of broad-based outreach and education activities and promotional campaigns.
- > A Continuous Quality Improvement Committee, that helps recruit, train, and support medical providers; identify training needs, design follow-up and tracking systems; provide oversight of quality assurance standards; and advocate for policy changes.

In addition to these committees, there are two community-based task forces—the African American Task Group and the Lesbian Task Force—that provide culturally appropriate strategies to educate and engage the communities they represent.

Outcomes

The latest State BCEDP Quality Indicator Report (QIR) shows that the Contra Costa Breast Cancer Partnership screened 917 women (51% Latina, 7% African American, 21% white, 5% Asian) from July 1999 through June 2000. However, the report may underreport the number of women actually screened and re-screened by BCEDP providers in the county, due to difficulties in tracking and reporting data. These difficulties arise from complex coding systems, coding inaccuracies, and a significant lag in time between services provided, claims submitted, and data reported.

A recent analysis of newly compiled county data for 1992-97 indicates that breast cancer early detection rates among African American women increased significantly from 44% in 1992 to 71% in 1997, achieving parity with rates for white women. The Partnership cites this data as evidence of the success of the county's breast cancer education and screening efforts that began in 1992. Although this is a promising trend, links to the county's activities are hard to assess.

Program Challenges

Stable Funding

Even with state funding, the Partnership must struggle to maintain adequate stable funding for services. A significant part of the project manager's job is securing additional funding through grants in order to enhance the services provided through efforts such as the Patient Navigators Project. The short-term nature of most grant funding makes it difficult to plan, develop, and provide services in ways that would have a longer-term impact on the community and on individual behavioral change.

Recruiting, training, and retaining bilingual/bicultural patient navigators from the community has been challenging for the Partnership. Patient navigators typically have high-school diplomas. High turnover is especially costly to the program in light of the four-month, intensive training those navigators must undergo before they can work with patients. While the Partnership works hard to encourage navigators to become county civil service employees, some leave shortly after getting trained to pursue better opportunities.

Finding Culturally Appropriate Services

Many of the key county agencies and community-based organizations providing cancer support services continue to lack linguistically and culturally appropriate educational materials. Moreover, bilingual/bicultural staff and providers are scarce. This is not a new problem, but nevertheless it is a persistent barrier for the clients of this and other programs.

Fragmentation of Services

As noted earlier, the Partnership faces a challenge in coordinating the continuum of breast services, because the County offers some services at public health clinics and others at ambulatory care centers. Such fragmentation of services is especially confusing to patients, who may need to go to a public health clinic for a clinical breast exam and to an ambulatory care center for mammography services. Usually these providers are in entirely separate locations. Only two BCEDP providers, Doctors Medical Center and Mt. Diablo Medical Center, a private non-profit center, offer one-stop comprehensive breast health services. However, even they only offer this opportunity to obtain all appropriate breast services at single location one day during every 4-6 week period.

Future Plans

The Partnership is ending a five-year contract with the state and currently seeking funds to continue. Working with the new breast cancer initiative, the Partnership staff plans to expand the Patient Navigator Project to offer services for Southeast Asian immigrants, and to provide case management services to monolingual Latinas who are undergoing diagnostic testing or who have been diagnosed with breast cancer. Future plans also include streamlining referral and tracking systems.

A long-term solution for providing treatment funds is presently being considered in the California Legislature. A new bill aims to institutionalize treatment funds by allocating \$20 million in state money to treat uninsured women for breast and cervical cancer.²¹ The Contra Costa Public Health Director has been an outspoken advocate and activist working to create and pass this legislation.

Delta Community Partners in Care, Inc

Clarksdale, MS

At A Glance: Delta Community Partners' Service Area¹⁴

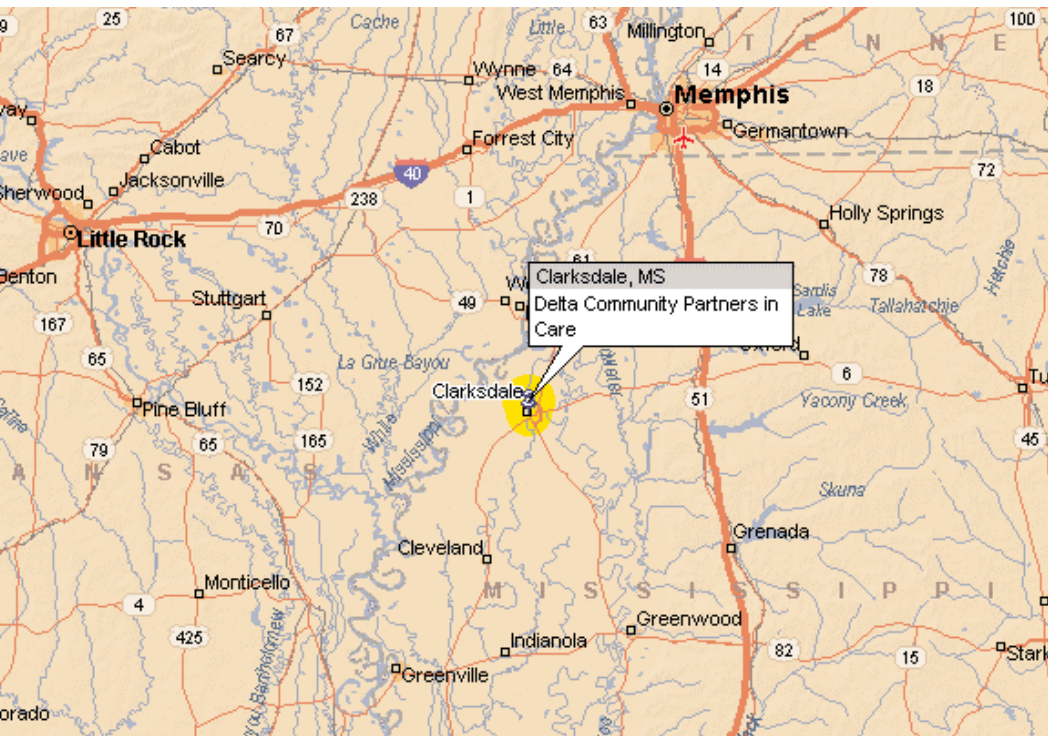
- > Ten county area population: 273,610
- > Racial/ethnic demographics: 68% African American, 31% White, 1% Other
- > Median household income (1997): \$19,600
- > Percent of households below poverty level (1997): 23%
- > Statewide rate of uninsured: 19%

Introduction

Delta Community Partners In Care (DCP) serves ten counties in the rural Mississippi Delta region. DCP seeks to improve outcomes for diabetic and hypertensive patients using a clinic-based, case management model. The project is a collaborative effort between community health clinics, the region's largest acute care hospital, and a small number of specialty clinics. It serves a highly dispersed, predominantly African American, low-income population that largely lacks health insurance. The project pays special attention to reducing educational and cultural barriers to effective care, as well as to reducing physical obstacles such as lack of transportation. A four-year evaluation of the project (1994-1999) revealed an increase in the proportion of project participants with controlled blood pressure and blood sugar levels, as well as an increase in other positive outcome indicators.

History

Delta Community Partners originally developed out of concern among health care providers at Northwest Mississippi Regional Medical Center (NMRMC) over two related issues: 1) the high number of preventable poor outcomes, such as loss of limbs and stroke, among patients with diabetes and 2) more generally, the quality of care being received by the area's large population of uninsured patients. A further concern was the cost burden on Northwest Mississippi Regional Medical Center, which was, at that time, a county facility. Early intervention, education and disease management appeared



to offer a means for improving diabetes patients' outcomes, as well as reducing ER utilization and hospital costs.

In 1993, Northwest Mississippi Regional Medical Center staff began meeting with providers from local clinics and the surrounding county hospitals to discuss ways to collaborate on these issues. In 1994, the Medical Center received a \$105,000 planning grant from the Kellogg Foundation to bring together local health care providers and other stakeholders from five local counties for a one-year planning process to shape a project designed to improve health care services for the un- and underinsured. This group became the planning committee for Delta Community Partners, and has now come to serve as an on-going coalition supporting the project. Planning committee members included providers, and representatives from educational institutions, community clinics, and county hospitals.

The planning process began with substantial information gathering. In addition to soliciting providers' recommendations, planning committee leaders asked community residents to identify the major barriers to health care in each of the targeted communities, and to describe what they perceived to be the broader causes for poor health outcomes in their communities. Project planners also gathered health status and demographic information on the population in the five-county area, identified the most prevalent chronic diseases among the target population, and gathered information on best clinical practices for disease management. Project leaders reported that it was very difficult to obtain useful, county-level, disease-specific data.²² Instead, planners relied on anecdotal information from providers, gathered what data they could from hospital utilization records, and undertook their own survey of patients in the community. This initial survey provided the baseline data for their later project evaluation, discussed below.

As a result of the planning process, NMRMC and its partners decided to develop an integrated system of case management for un- and underinsured diabetic and hypertensive patients. Taking into account provider concerns, and the barriers identified through the planning process, NMRMC and its partners designed Delta Community Partners In Care to serve patients in the five county region.

Organization and Funding

In 1995, NMMRC received funding from the Kellogg Foundation to implement Delta Community Partners as a four-year demonstration project. Project implementation was immediately complicated when, soon after receipt of the grant, Northwest Mississippi Regional Medical Center was leased to the private, for-profit corporation, Health Care Management Associates, Inc. (HMA). Rather than withdraw funding, the Kellogg Foundation agreed to allow HMA to continue to serve as fiscal agent for the grant. DCP established itself as an independent entity and became the official grantee.

During the project's first four years, caseworkers were placed at seven clinics and four hospitals, including Northwest Mississippi Regional, serving five counties: Bolivar, Coahoma, Tallahatchie, Quitman, and Tunica.

In 1999 the Kellogg demonstration project grant expired. The project then suffered a one-year slow down in services, due to lack of funding.

In FY 2000-2001, with the Aaron E. Henry Center, one of the project's clinic sites, serving as the lead agency, DCP received a \$976,000 Community Access Program (CAP) grant from the federal Health Resources Services Administration (HRSA). Under this new grant, DCP project director and support staff remain housed at Northwest Mississippi Regional, with HMA, Inc. donating office space, telephone, and covering the costs of utilities and overhead.

In addition to Northwest Mississippi Regional Medical Center and the Aaron E. Henry Center, project partners include three community health centers (FQHC's), which operate a total of 10 clinic sites, all three county hospitals, and two district health departments. The project's annual budget is \$976,000, which is completely covered by the HRSA CAP grant. Under the CAP grant, the project now serves five additional counties: Leflore, Sunflower, Humphreys, Washington, and Holmes.

DCP project staff includes a director, a project coordinator, an administrative assistant, and a data entry clerk. The project director formerly headed the social services department at Northwest Mississippi Regional. She has also run the local Head Start program. Born locally, she has long been actively involved in the local African American community. The project's case managers are employed by the participating clinics.

Target Population

DCP targets patients who are between the ages 21 and 64, and whose incomes are at or below the federal poverty level. Twenty-three percent of the population living in this ten-county region has incomes at or below the federal poverty level. The project's base in Clarksdale, Mississippi is located in the poorest Congressional district in the nation. Data from the 1990 census show 36% of the area's African American population living in poverty, compared to 4% of the white population.²³ The ratio of primary care providers to population in this rural, sparsely populated area is estimated at 1:3,000.²⁴

Data gathered on DCP participants in 1999 showed that 90% were African American and the remaining 10% were white. A full 49% were uninsured, and Medicaid covered 26%. Eighty-five percent of the participants surveyed reported having fewer than twelve years of formal education. It is worth noting that, in 1994 when project implementation began, 17% reported living in homes without telephones and 2% had no indoor plumbing.

Project Description

Case Management

DCP staff describe their approach as “outreach case management.” A caseworker is placed at each of the participating clinics and at the health department sites. At the health department sites (which do not provide primary care) the caseworkers serve to screen and recruit clients to the program, who are then referred to other sites for medical care.

At the clinics, caseworkers monitor patients, meeting with them on anywhere from a weekly to a monthly basis. They make referrals and provide ongoing education and counseling on managing diabetes through behavior modification and medication compliance. Meetings with clients occur primarily at the clinic site, but caseworkers report that they do make occasional house visits. Caseworkers are also now beginning to start support and walking groups with their clients.

Caseworkers interviewed suggest that they serve an important function not only in monitoring their clients’ conditions and providing education, but also in providing emotional support for clients. In addition, they assist clients in obtaining medical care even when clients lack the means to pay - a task that often goes well beyond simply “making a referral.” Staff report that caseworkers and other project staff wrangle health care for clients by persuading the doctors they know to take their patients, “begging,” and paying out of their own pocket for procedures.

Caseworkers and the project director describe part of the staff’s task as overcoming the “culture barrier” that exists between their clients and health care providers. They describe this barrier as arising from a host of factors including: low levels of education and health-related knowledge, clients’ fears, and providers’ attitude and assumptions about clients. Caseworkers attribute their own ability to communicate and work effectively with patients to the understanding of their clients’ diets, lifestyles, economic situations and general community. They view the fact that they live in the same local communities as their clients as an asset, providing them with a greater understanding of their clients’ situations.

Caseworkers are RNs, LPNs, LSWs, or lay workers and are recruited from the local community. Eleven of the positions are full-time; caseworkers at two of the smaller clinics work half-time. Many have worked in social service and health care settings previously. Nine of the 13 are African American and four are white. Although DCP sets the hiring criteria, caseworkers are hired and supervised on a daily basis by managers at each clinical site. The caseworker training curriculum, which is described as “informal,” provides information on diabetes and nutrition; directions regarding documentation for tracking the patients; counseling and interviewing skills; and training on blood pressure and glucose monitoring. (Caseworkers are certified in blood sugar and blood pressure monitoring by an independent RN.) The DCP director holds monthly meetings bringing all 13 caseworkers together to share strategies, address problems and discuss the project.

Outreach and Education

The majority of the project's participants are enrolled in the program through the ER or through clinic visits. Others are enrolled through DCP-sponsored screenings at health fairs. DCP also utilizes educational materials provided by Healthwise, a project of the Mississippi Cooperative Extension Service.²⁵

Transportation: A Key Element

In designing DCP, planners sought to address a number of specific barriers to care that confront un- and underinsured, chronically ill patients in their community. One major barrier repeatedly identified by community members and providers was the lack of non-emergency transportation to health services. The project solved this problem by leveraging existing resources: Aaron E. Henry, the project's lead agency, received a grant to provide general rural transportation. The clinic uses the vans funded by this grant to transport clients to their clinic appointments, free of charge.

Project Enrollment

Over the course of its first four years, the project served 1,361 diabetic and/or hypertensive patients, provided health education to 3,303 participants, and screened 10,841 community residents. Project enrollment as of July 2001 is 1,067.

Outcomes To Date

The initial, four-year Kellogg demonstration project grant included support for a project evaluation. Researchers at the University of Mississippi's Rural Health Research Program conducted the evaluation. The evaluation used a pre- and post-test design to measure changes in health status and disease management, health care utilization, knowledge of diabetes, and diabetes management. Health indicators included controlled blood sugar, controlled blood pressure levels, body mass index, sick days (self-reported), and other measures. Health care utilization indicators included emergency department utilization, number of nights hospitalized, use of multiple primary care providers, and number of prescriptions unfilled. Baseline data on these indicators was gathered as patients were initially enrolled in the project and then gathered again after four years.

Evaluators reported a statistically significant reduction in ER utilization, patient hospital nights, number of sick days and bed days, and use of multiple primary care providers.²⁶ They found a statistically significant increase in the proportion of participants with controlled blood pressure, in patient knowledge about hypertension, and in clients' overall quality of life assessment. Because there was no control group, it is not possible to compare these outcomes to the population at large.

Continued Challenges and Needs

The principal challenge faced by DCP is securing stable, continuing funding for its operations. As noted above, after a seemingly successful four-year demonstration project, DCP spent one year without funding. While HMA played an important role during this time by keeping central project staff on payroll, only the three largest clinics were able to keep their caseworkers on staff to meet with patients. The project's current funding is year-to-year, due in part to funders' expectations

Case Study:
Delta Community
Partners in Care, Inc

that the project would become self-sufficient over a period of a few years. Given the dearth of local resources, the state's health policy orientation, and the population served, this may not be a realistic expectation.

The project also continues to face a number of challenges associated with service delivery, including insufficient transportation and the high cost of prescription drugs. Project staff also cite a need for technical assistance and funding to refine and update their communications and educational materials.

Finally, DCP leaders describe state health care policy makers as only now "just beginning to recognize the value of prevention." DCP leaders, with coalition partners, are now advocating expanding Medicaid coverage to include diabetes case management services. Leaders see this as a vital next step in improving health care for their community, and as a strategy for project sustainability and replication. In addition, they are trying to create a "business case" for DCP that could demonstrate to state policy makers the economic advantages of early detection and management of diabetes in terms of Medicaid savings.

Sacramento Urban Indian Health Project

Diabetes Management Program
Sacramento, CA

At A Glance: Sacramento County¹⁴

- > Population: 1,223,499
- > Racial/ethnic demographics: 16% Latino, 10% African American, 11% Asian, 57.8% White, 1.1 % American Indian and Alaska Native
- > Median household income (1997 model-based estimates): \$39,461
- > Percent of persons below poverty level (1997 model-based estimates): 17.2%
- > Statewide rate of uninsured: 21%

Introduction

Sacramento Urban Indian Health Project, Inc. (SUIHPI) provides health care services to Native Americans in Sacramento County, in California's Central Valley. Located in the city of Sacramento, SUIHPI was created to serve Native Americans living in urban areas. SUIHPI is a non-profit clinic offering medical, dental, and community health services, as well as mental health and substance abuse counseling, and a youth alcohol prevention program. The organization's diabetes program began in 1996 to address the very high rates of diabetes among Native Americans. Through this program, Native American lay community health workers make home visits to clients, provide health education, monitor disease management, refer patients to services and link clients to nutrition classes. SUIHPI is currently in the process of expanding the program, adding a clinical case management component, and integrating diabetes outreach and education into all its program areas.

History

SUIHPI was established in 1972 by local Native Americans to provide health services to their community. The organization grew out of a medical needs assessment undertaken by the Sacramento Indian Center, a community-based organization. SUIHPI received its initial funding from the California State Department of Public Health and began operations by contracting with the local county health department to provide services targeting Native Americans through the county clinic. The organization soon incorporated as a non-profit, established its



own clinic site and, with support from the National Health Service Corps, hired a full time doctor and nurse.

SUIHPI's diabetes program, which is part of their Community Health Services department, began in 1996, with a grant from the Indian Health Services (IHS). Provider observation and national statistics show a very high rate of diabetes among Native Americans.²⁷ While no formal local needs assessment had been undertaken, the clinic's experience led clinic staff to identify diabetes as a growing problem among Sacramento's Native American population.

Organization and Funding

A five-member Board of Directors, all of whom are Native American, oversees SUIHPI. Members represent a wide range of organizations and interests, including the Bureau of Indian Affairs. The bulk of SUIHPI's annual \$1.9 million budget comes from the federal Indian Health Service (IHS), with a smaller portion coming from the state Indian Health Program. SUIHPI also receives small private donations (totaling approximately \$5,000 in 2000). Patients not covered by third party payers are charged for health care services on a sliding fee scale; those at or below the federal poverty level receive services free of charge. The organization writes off approximately \$100,000 annually in charity care. SUIHPI is a federally qualified health center (FQHC).²⁸

Target Population

SUIHPI accepts all Native Americans, whether members of a federally recognized tribe or not. The most recent census identified 13,359 Native Americans representing over 30 tribes in the greater Sacramento Area. Much of SUIHPI's client population is relatively transient, moving on and off nearby reservations or *rancherias*.²⁹ SUIHPI also treats a small number of non-Native Americans in their medical and dental departments.

Medi-Cal or Medicare covers close to 80% of SUIHPI's patients. The remaining 20% are uninsured. Roughly 75% of SUIHPI's medical and dental patients live below the federal poverty line. Staff describe the reading comprehension level of many of their clients as below a 6th grade level. Lack of transportation is a major barrier to health care access. Clients also lack access to safe spaces for outdoor activities, as well as convenient local sources of fresh produce and healthy food options. As in other poor, Native American communities, there are high levels of alcohol and substance abuse.

Overview of SUIPHI

Services and Staffing

As noted in the introduction, SUIHPI's diabetes program is just one of a wide range of services that SUIHPI provides to the Sacramento Native American community. SUIHPI's broadly defined mission is to provide comprehensive primary medical, dental, community education, mental health, social services, and substance abuse

treatment health care to Native Americans in the Sacramento area. The medical department estimates that it provides approximately 4,400 patient visits annually.

To this end, SUIHPI now employs 32 staff (29 FTE) who offer both health care and counseling services. Organization-wide, 24 staff members identify themselves as Native American. Clinical staff includes one full-time MD, one family nurse practitioner and one RN. The Community Health Services department, which operates the diabetes program, as well as the infant health and child safety programs, currently employs two community health workers and one health educator. SUIHPI benefits from having a medical director who has worked for SUIHPI for 15 years, and who is described as being very active in local politics and community issues; staff describe her as being “well connected” locally, and capable of helping to generate positive attention for SUIHPI’s efforts.

Collaboration with Other Organizations

SUIHPI partners with a number of Native American organizations and other health care and community service providers locally and statewide. Local community partners include a Native American employment and training organization, a domestic violence organization, and an Alcoholics Anonymous group. SUIHPI also has agreements with local public social services agencies. They work with two area public school districts to provide health education as part of an American Indian education program. SUIHPI is linked to other IHS-funded Native American health service providers through its collaboration with the California Rural Indian Health Board (CRIHB) and with other Indian health clinics regionally and statewide.

The Diabetes Program

Outreach

Patients are recruited to the diabetes program by SUIPHI’s primary care staff, through their dental department, and through outreach at pow-wows and other Native American cultural and community events. SUIHPI has begun sponsoring its own annual pow-wow, and reports that this event has been highly successful, with their first pow-wow attracting approximately 800 Native Americans. Staff also note the importance of the “Native American grapevine” in recruiting patients, explaining that word of mouth is a vital means of publicizing their programs in this community.

Information, Education and Support

Individuals identified as diabetic are contacted and offered information about the program and the monthly nutrition classes, which are sponsored by the county health department and held at SUIHPI. They are also given free glucometers and taught how to measure their blood sugar. Native American lay community health workers conduct home visits to clients, providing ongoing education about diet and exercise and monitoring disease management. Community health workers describe their role as offering general support and also hands-on concrete strategies, particularly for improving clients’ diets. They also provide transportation to the nutrition classes. Home visits occur weekly for new clients. Once a client’s condition is controlled, visit frequency may be reduced to monthly.

Community Health Workers: “Insider” Status is Vital

SUIHPI’s current community health workers have high-school level educations and have received three weeks of training, sponsored by IHS. The training curriculum includes general information on diabetes, instruction on reading patients’ blood pressure, nutrition and diet information, and an overview of anatomy. Staff at a variety of levels, including the community health workers themselves, described this training as sorely inadequate. SUIHPI’s community health workers work full-time, and are paid \$10/hour, plus benefits.

Both the health workers and other staff note the importance of the health workers being Native American, citing the high level of mistrust of whites among the Native American population. In addition, health workers said that having lived on reservations, and had life experiences similar to those of their clients, provides them with important insights into their clients’ lifestyles, beliefs and needs, as well as the challenges clients face beyond diabetes management.

It is worth noting that the current Director of Community Health Services, who is trained as an RN and holds an MPH, is not Native American. She describes herself as a relative newcomer to the Native American community. Community health workers believe that the effectiveness of the diabetes program has been greatly enhanced as a result of the Director’s willingness to learn about Native American culture and beliefs, and the value she places on their observations from the field.

Cultural Competence & Culturally Appropriate Strategies

SUIHPI recognizes the importance of family and community networks in Native American culture and of framing diabetes management strategies in terms of “Native American values.” Good health and healthy behaviors are explicitly defined as “consistent with Indian values.”³⁰ Thus, SUIHPI community health workers tout the benefits of a “more traditional diet,” which relies less on sugared drinks and fast food. In stressing the importance of exercise, published materials suggest that it is both healthy and culturally appropriate to return to a more physically active life, reminding clients that the traditional Native American lifestyle was very active.

SUIHPI staff and their partners also noted a number of key cultural issues—beyond the obvious barriers created by poverty—that must be understood to competently serve the Native American population. For example, the current high-fat diet of many older Native Americans is the direct result of having been raised on reservations where they received cheese and lard among the “surplus” foods supplied by the government.

“Outsiders” may also fail to understand the role of the elder (roughly defined as 55 years and older) in Native American culture. Viewed as teachers and mentors, elders may be loathe to admit to health problems, particularly where behavior may be a contributing factor, since such illnesses might be viewed as a sign that they have failed to serve as good role models. It is also highly inappropriate for a younger person to “correct” or criticize an elder. Community health workers must walk a

careful line between gently encouraging change and being overly direct when offering behavioral modification advice to elders. This is particularly relevant to SUIHPI's diabetes program, where the median client age is 56. Finally, in a community where "the grapevine" is a highly effective means of communication, issues around shame and a concern for privacy act as further barriers to treatment.

Upcoming Plans & Future Directions For The Diabetes Program

SUIHPI has recently received an additional IHS grant for \$123,000 per year over the next three years. All of this is earmarked for the diabetes program. They have also received \$65,000 per year over two years through the California Medical Risk Management Insurance Board (MRMIB).³¹ These new funds will support the hiring of a health educator (trained as an RN) and an additional lay community health worker.

Most significantly, the organization is now looking to incorporate their lay health worker approach into a cross-disciplinary case management framework and integrate diabetes work clinic-wide. Program leaders believe that creating a more formal case management system, in which representatives from each department meet to discuss client cases, would provide community health workers with more support and direction and ensure more comprehensive care for diabetes patients. Integration of some clinic-wide diabetes work is already underway. For example, counseling intake questionnaires include indicators of diabetes risk.

Challenges

Stable & Sufficient Funding

SUIHPI's primary ongoing challenge is lack of adequate funding. Staff note that, until recently, they "never knew if the clinic would be able to keep its doors open or not." The Executive Director earns \$50,000 annually. Not surprisingly, there has historically been high turnover in the organization's leadership.

Part of SUIHPI's funding problem springs from the way IHS funding is allocated between services on reservations and services for urban Indians. "Urban Indians" are defined as those Native Americans living in areas *other than* "Indian areas," that is, other than on reservations and federal land trusts. IHS' total annual appropriation was approximately \$2.2 billion in 2001.³² Of that total, \$29 million was directed toward urban Indian health programs. This is despite the fact that the 1990 census showed 63% of the Native American population live in non-Indian areas.³³ SUIHPI staff say that an additional barrier is funders' and the general public's misconception that urban Indian clinics like SUIHPHI are well funded by the tribes and by money generated from casinos on Native American lands.

In addition to the need for increased, ongoing funding for services, SUIHPI's most pressing current financial need is for money to expand their physical space. The organization cannot further expand services without additional space. As is the case with most non-profits, finding private funding for capital improvements is proving difficult.

Lack of Willing Providers

In addition to lack of funding, the lack of willing providers, especially specialty providers, in the area continues to be a major barrier to treatment. Hospitals are increasingly reluctant to treat Medi-Cal and uninsured patients. For example, staff reports the local university hospital will not accept the uninsured patients they refer. In addition, SUIHPI's medical director describes the area as suffering from an overall physician shortage. SUIHPI staff describe it as very difficult, and frequently even impossible, to refer patients for needed ophthalmology, neurology, surgery and other specialty services. As noted above, the organization has earmarked some of their new IHS grant money to pay for specialty services for their clients.

Unidas Podemos and Paso a Paso

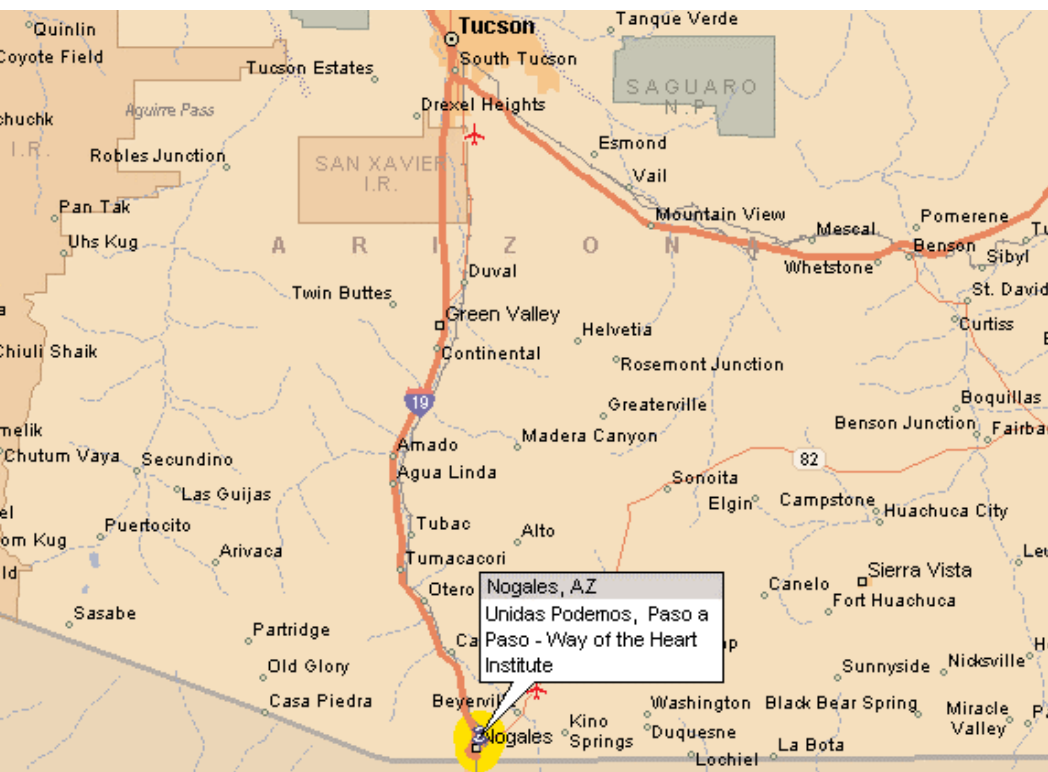
The Way of the Heart:
The Promotora
Institute, Inc.
Nogales, AZ and
Nogales, Sonora, Mexico

At A Glance: Santa Cruz County, Arizona¹⁴

- > Population: 38,381
- > Racial/ethnic demographics: 80.8% Latino, 0.4% African American, 0.5% Asian, and 17.8% White
- > Median household income (1997 model-based estimates): \$26,515
- > Percent of persons below poverty level (1997 model-based estimates): 25.8%
- > Statewide uninsured: 23%

Introduction

The Way of the Heart: The Promotora Institute provides a variety of health screening and educational services to the predominately Latino populations in and around Nogales, Arizona and its much larger adjacent city of Nogales, Sonora, Mexico. It is a freestanding, non-profit organization that focuses on diabetes, breast cancer, cardiovascular health, perinatal care, tobacco prevention, HIV/STD, environmental health and other services for a largely poor, undocumented, Spanish-speaking population. Through the organization's diabetes and breast cancer programs, bilingual, bicultural, lay community health workers, known as *promotoras de salud*, engage in a variety of health outreach activities, make home visits, manage the care of patients and link them to a variety of community resources, including the Institute's own education and support services.



The promotora model, while not new, has received increased emphasis as governments and community organizations grapple with the severe health problems of the US-Mexico border region.³⁴ The area is experiencing rapid economic and population growth,^{35,36} and the once small city of Nogales, Sonora has increased perhaps eight-fold in population to 350,000 since the mid 1980's. The area is home to one of the largest *maquiladora*³⁷ concentrations on the border, with 80 factories producing electronic components and plastics.³⁸ Environmental issues including air and water pollution are major concerns in Nogales, as they are in many border communities.

Having demonstrated promising outcomes in this difficult environment, the Institute is now seeking to stabilize its funding while it plans to expand into the direct provision of medical services. We reviewed two promotora-staffed programs at the Institute: the *Paso a Paso* diabetes program and the *Unidas Podemos* breast and cervical cancer initiative.

Overview of Organization and Funding

The Way of the Heart Institute traces its origins to an earlier health navigator program developed at the local, federally funded, community health center. That program was initially funded under a 1991 Rural Health Policy Grant from the US Health Resources Services Administration. After internal disagreements over what center staff viewed as an inappropriately categorical approach which ignored broader family, environmental and psychosocial issues, most of the individuals involved there departed and formed the freestanding, non-profit, Way of the Heart Institute in 1999. Through this change, the staff hoped to implement a more holistic approach, driven by community need rather than by the nature of the latest grant. An 11-member board of directors, drawn from the surrounding community, governs the entity. Its membership includes former clients, the county sheriff, religious leaders and others.

The Institute currently employs seven full-time workers and an executive director. The Way of the Heart's budget of approximately \$110,000 per year is supported by several small federal, local and private grants. Core support comes in the form of a \$60,000 annual grant from the Esperanca international medical relief organization. The U.S. Office of Minority Health has lent some support through its Region IX office. Sporadically, the City of Nogales makes grants of about \$1000 to help defray clients' transportation costs, and the remainder of funding comes from individual donations and assistance from some churches. Funding has been tight, with the executive director unable to draw compensation and the staff sometimes paid irregularly.

Target Population

The Institute's programs target poor, uninsured, primarily Latino residents of the twin border cities of Nogales, Arizona and Nogales, Sonora. The two cities together are often referred to as *Los Ambos Nogales*. In the year 2000 census, almost 81% of the residents of Santa Cruz County (which includes Nogales, AZ as the county seat) were Latino. Data from 1995 collected by the program show an unemployment rate in Santa Cruz County of 18.4%, more than triple that of Arizona as a whole. The 1990 census showed that 26.4% of all individuals had incomes below the poverty level. That same year, 76% of the county population spoke Spanish and 36% reported being born outside the US. Santa Cruz County is a designated Health Professions Shortage Area.

The Promotora Program: A Culturally Competent Approach

Based on the use of lay health workers from the clients' communities, the promotora model emphasizes one-to-one health education and navigation for individuals who are often undocumented immigrants lacking access to regular health care. As one physician associated with the program noted, Mexican women may be more receptive to advice from a female peer (a *comadre*) than from a more distant health professional. The promotoras translate language and medical concepts for the patient.

Health fairs, screening events and simply walking the streets of the *colonias*³⁹ form major parts of the promotoras' outreach. Events have been held in supermarkets, churches, maquiladoras, Head Start centers, jails, and other venues. Diabetes screening and education, breast cancer education and referral for mammography are included in the events. The six promotoras wear a standard blue uniform with gold nametags to give them additional visibility in their travels; referrals often begin with people simply asking them who they are and what their uniforms signify.

A recent survey of 100 Latina women by the Institute highlighted the need for education. While 97% had heard of a mammogram, 32% did not know what it was. None knew what a baseline mammogram was. Public health messages may be getting through, but with little understanding of the content.

Family-centered Education and Referral

Rather than focusing simply on one disease, promotoras begin any contact with an environmental and family assessment. The presence of an open sewer, for example, will be referred to the local health department. From this assessment comes an individualized referral plan delineating what the family or client will need, and describing where those services can be obtained. The plan might address mental health and substance abuse issues, in addition to breast cancer screening or diabetes management. The Institute believes that this family-centered approach creates an environment that allows the management of complex conditions (especially diabetes) that require long-term monitoring, drug regimen compliance, and behavioral change.

Once a plan has been developed, the promotoras help their clients access various services both initially, and on an ongoing basis. This is a difficult undertaking given that, in 1990, almost 13% of households in Santa Cruz County had no telephone.⁴⁰ Ensuring that clients take their medications and keep their appointments is also difficult, as is getting people enrolled in any available indigent care program. This last effort is especially important given the paucity of affordable care, though it does less to help those who are undocumented.⁴¹ (The state KIDS CARE program is the only program that does not require documented status for enrollment). All clients are screened for eligibility in the Arizona Medicaid managed care program known as AHCCCS.⁴² When operating on the Mexican side of the border, promotoras are allowed to deliver some basic medical services like immunizations.

Collaboration with Other Organizations

An informal network of providers allows access to a limited number of free or low-cost drugs, mammography, treatment and other services. This network includes volunteer physicians on both sides of the border, the local federally funded community health center, the local Catholic hospital on the US side, the Shriner's Hospital in Phoenix, hospitals in Tucson, the Mexican public social security hospital in Sonora, and the Santa Cruz County health department.

The promotoras support the Santa Cruz County health department, doing home visits and translation on its behalf. When the county identifies diabetics, follow-up management is often handled by the promotoras. The promotoras have also been involved in a number of community issues. When the controversial replacement of a local well was proposed, promotoras and Institute-organized volunteers headed the county steering committee and organized door-to-door activities to advertise public meetings on the issue.

Given their cross-border environment, the Institute has also fostered close working relationships with Mexican consular officials and municipal officials in Nogales, Sonora. The Institute has assisted *Plan Retorno* with donated supplies and health education. Plan Retorno helps deported individuals who have been dropped off in Nogales, Sonora far from their towns and villages of origin.

The Way of the Heart model is different from what is more commonly seen in other promotora initiatives: It is a freestanding entity that has built a set of collaborative relationships with clinical providers and social agencies. Most other promotora projects appear to be sponsored by existing clinics and hospitals that use them to augment their outreach and patient management efforts.

Staff Recruitment, Training and Retention

Promotoras are recruited mainly through word of mouth, postings in community agencies and sometimes through newspaper ads. In the future, promotoras may be recruited from the teen promotora program that has developed out of the Institute's peer counseling work. The program explicitly seeks promotoras who reflect the culture, economics and demographics of the Nogales community. Persistence and resilience in navigating systems are the most sought after attributes. Pay is set at \$8.50 per hour; other benefits are not offered. Pay has sometimes been delayed. Most promotoras are themselves enrolled in the AHCCCS program.

Each promotora receives an initial three months of training in basic health education and communications skills. Much stress is placed on verbal communication, as the Institute strongly believes that the border Latino culture is one of oral, not written, communication. Active listening, body language and other skills are emphasized. Each promotora-in-training then shadows a working promotora for 16 hours of home visits. This apprenticeship is followed by random evaluations, and formal assessments at six months and one year after training, with evaluations annually thereafter. The promotoras keep encounter logs, which are also randomly sampled and reviewed by the Institute's executive director.

The county health department and the volunteer medical director review all training materials and protocols, and provide some of the education gratis. Much of the curriculum is based on the published materials of federal and state authorities and national disease organizations. The training also concentrates on familiarizing the staff with local services and providers. The promotoras tend to specialize in certain areas: one handles breast cancer, another diabetes, while others focus on prenatal care, cardiovascular disease and exercise. Each handles navigation for 75 to 200 clients at any one time.

Other Outreach and Educational Activities

The Institute uses a variety of marketing and outreach strategies beyond those undertaken by the promotoras themselves, several of which target young people. Ten “teen promotoras” have been recruited and trained to function as health educators for their fellow adolescents. Some were recruited through a self-esteem, healthy eating/healthy living class that the Institute hosts. This class is presented as modeling training, and has attracted 80 girls who would probably not otherwise attend health classes. The “Gear-Up” program includes field trips and other educational activities and is designed to foster educational achievement among seventh-grade students. The extension service of the University of Arizona holds classes on nutrition; a total of 43 different health education classes sponsored by many organizations are offered at the center. Scheduled disease support group meetings and aerobics classes are other sponsored community activities. The Institute was also the lead organizer in *El Dia del Nino* (The Day of the Child) celebrations held at the US-Mexico border that highlighted children’s issues in both nations.

The Institute’s weekly radio show is another form of outreach. It regularly focuses on critical health education messages, and is apparently one of the more popular programs in Nogales, Arizona. But it serves another purpose as well. Every local candidate for elected office is interviewed; the Institute believes it has a responsibility to lay the groundwork for system reform as well as individual change.

Finally, the Institute’s location, and its continuous hum of activity, makes it a visible, and attractive community magnet. The Institute is located next to the local senior center and a Head Start facility, in a building provided by the city at low cost.

Preliminary Outcome Data

The Institute has tried to measure its success in identifying and managing diabetics using some simple information. Thirty-nine new diabetics have been identified. Data shows 203 managed diabetics had a net decrease of serum glucose of 51mg/dl. Weight loss has averaged 3.5 pounds for 94 exercise class attendees, and approximately 85% of medical referrals are completed.

Challenges and Plans for the Future

Financial Stability and Growth

The Institute hopes to raise more funds to stabilize and enlarge its promotora effort. Funding has been very much on an ad-hoc basis, and much of the executive director’s

time is spent seeking dollars to maintain an already inadequate budget. The loss of any grant is damaging; the loss of its core funding from Esperanca could well be catastrophic. Nogales is a poor community, and raising money is very difficult. State officials made it clear in our own discussions with them that the state was in no position to fund the Institute.

Securing Medical Services

Given the large numbers of undocumented immigrants, the frequency of cross-border travel, and the limited scope of indigent care finance in both Arizona and Sonora, the binational provider network is absolutely essential. But at the same time it is limited in how much it can do. Hospitals and doctors will only do so much for free or steeply discounted rates. Many clients are ineligible for public assistance by virtue of their undocumented status. Much of the promotoras time is spent securing one free mammogram for one woman, or free drugs for her diabetic husband. Even if payment could be secured, there simply may not be enough physicians and other providers to handle the unmet needs of border communities like Nogales.

The Institute hopes to begin volunteer clinics on both sides of the border, in an effort to alleviate its chronic shortage of willing providers. Already the Institute has incorporated in Sonora, Mexico. These clinics would be built on the foundation of free services already provided by local physicians. Funding would come from philanthropic support, as well as from modest patient fees based on an income-dependent scale. Linked to the Sonoran clinic would be newly trained Mexican promotoras who would increase the Institute's activities in Nogales, Sonora.

Creating an Enabling Environment

While the Way of the Heart has been able to stitch together a network of critically needed services, it still finds itself in a somewhat unwelcoming environment. Health has not been a priority for the local political leadership on either side of the border. No major provider or other community organization is advocating on behalf of the Institute, which has jealously guarded its independence. Unlike most other promotora initiatives, it is not a part of an existing clinic or hospital. The leadership believes that by being independent of any major health care provider, the promotoras can avoid the potential conflict of interest that might arise when the navigator works for an entity seeking a copay or other payment from the client. The promotoras also believe that much of their success results from the fact that they are viewed as a true grass-roots organization in a community with some mistrust of traditional institutions and elites. It will be interesting to see if the promotoras' perceived relationship to the community changes with the Institute's opening of its own clinics.

The Institute's future cannot be secure without substantially increased, long-term financial commitments. Finding those commitments while creating a more enabling local environment will be the promotoras' greatest challenges for the future.

Women's Fest (Festival de la Mujer)

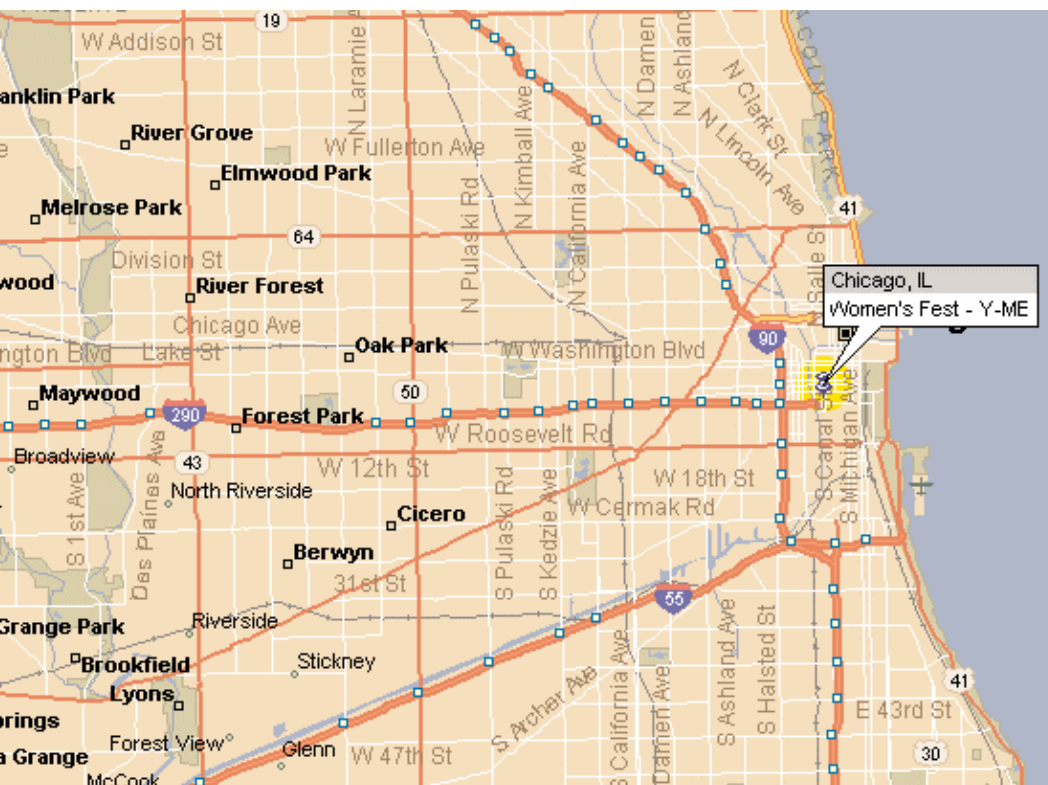
Y-Me National Breast
Cancer Organization
Chicago, IL

At A Glance: Cook County, Illinois¹⁴

- > Population: 5,376,741
- > Racial/ethnic demographics: 19.9% Latino, 26.1% African American, 4.8% Asian, and 47.6% White
- > Median household income (1997 model-based estimates): \$40,181
- > Percent of persons below poverty level (1997 model-based estimates): 14%
- > Statewide uninsured: 14%

Introduction

Women's Fest is a Chicago-based program sponsored and operated by the Y-ME National Breast Cancer Organization. Y-ME is one of the nation's largest breast cancer organizations. Its national office and 26 affiliates focus on breast cancer education and peer support. Y-ME's Women's Fest explicitly targets low-income Latina and African American populations across Chicago, and is designed to address the geographic, financial, and cultural barriers to early detection of breast cancer. Women's Fest coordinates a series of health education fairs throughout the year at different sites in Chicago, in collaboration with City of Chicago Department of Public Health, Cook County Bureau of Health Services, and community-based organizations. During these events, low-income women can get free breast education and screenings services.



Overview of Y-ME Organization

Mission and Program Operations

Founded in 1978 by two mastectomy patients as a “kitchen table” support group of 12 women, Y-ME National Breast Cancer Organization now provides breast cancer information, counseling, and support nationally. The organization has annual revenue totaling \$3,712,000, 26 affiliates throughout the U.S., and approximately 15,000 volunteers nationwide.⁴³ The stated mission of Y-ME is to:

...decrease the impact of breast cancer; create and increase breast cancer awareness; and ensure, through information, empowerment, and peer support that no one faces breast cancer alone.

Case Study:
Women's Fest
(Festival de la Mujer)

Y-ME operates a 24-hour, English and Spanish hotline staffed primarily by trained volunteer peer counselors who are breast cancer survivors. These counselors provide information, referrals, and emotional support to callers; upon request a caller can be matched to a breast cancer survivor with a similar diagnosis. Hotline volunteers undergo fairly rigorous training. The English hotline receives over 30,000 calls a year. The hotline counselors rely on an extensive database containing information on mammogram facilities, research protocols, hospitals, support groups, and cancer support services for low-income women.

Y-ME also operates a number of other programs and services to address the wide-ranging needs of those who are, or could be, affected by breast cancer. These include:

- > A Men's Match Program, to support men whose partners have breast cancer by matching them with a male volunteer counselor who had a similar experience;
- > Public education seminars and workshops on early detection and breast self-examination for adult women and high-school seniors;
- > Publications, including patient education brochures and newsletters;
- > A website with information and resources; and
- > A wig & prosthesis bank for low-income women.

Y-ME holds workshops for health care providers addressing the emotional needs of breast cancer patients, and has established an advocacy network to focus attention on the need to increase funding for breast cancer research and for access to quality treatment.

In 1995, Y-ME made a commitment to provide services to the Latino community affected by breast cancer and established a Spanish hotline, currently staffed by four bilingual/bicultural breast cancer survivors and a host of volunteers who manage over 6,000 calls per year. Y-ME also recruited and trained Latina volunteers to provide breast health education, outreach, and support to breast cancer patients and their families. Training for these volunteers included education about culturally-based beliefs concerning breast cancer. Y-ME further translated and tested much Spanish-language literature, included information in Spanish on its website, and created the only bilingual breast cancer newsletter in the U.S. Finally, as part of its initiative to broaden its services to the Latina community, the Women's Fest Program, described more fully below, was launched by Y-ME in 1995.

Governance and Staffing

At the national level, a Board of Directors oversees Y-ME. Under its bylaws, the Board must reflect the ethnic and geographic diversity of Y-ME's catchment area (the entire US) and must reserve at least two seats for affiliates. Currently the National Board includes two African Americans. Three affiliates have seats on the Board and 60% of the Board members are breast cancer survivors.

Case Study:
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(Festival de la Mujer)

Y-ME affiliates vary somewhat in their governance structure, but all have a formal or informal Board structure. Each Board includes breast cancer survivors. Some affiliates are formally connected to churches or hospitals.

Recently, Y-ME has undergone several structural and image changes. The national office separated from the Chicago-based affiliate and restructured its departments and leadership. The goal of the national office is to primarily focus on fundraising, training volunteers, developing educational materials, and providing technical assistance and support to the affiliates, while continuing to operate the bilingual hotlines. Other direct service programs, such as breast health education workshops, Women's Fest events, and support groups, are mostly left to affiliates.

As part of the restructuring, Y-ME has formally affirmed its commitment to diversity and cultural competence. The national Board has included diversity and cultural competence training annually for the Board, all staff, and all volunteers in its institutional development plan. This commitment is demonstrated in the recruitment and retention of minorities at all levels of the organization. The Y-ME senior management team includes a Director of Cultural Relations and Diversity. She is a Latina woman trained as a physician in Mexico. African Americans hold two senior staff positions.

The Director of Cultural Relations and Diversity oversees Women's Fest and the Spanish hotline, and is responsible for the recruitment and training of Spanish-speaking bilingual/bicultural hotline staff and program volunteers. She develops and translates into Spanish educational materials and training manuals and actively participates in several national and local committees addressing issues concerning breast cancer services for minorities.

Funding

Y-ME is supported by contributions from corporations, individuals, and foundations. Most of its revenue comes from special events such as the Annual Race Against Breast Cancer, which takes place in Chicago on Mother's Day and draws about 30,000 participants. One and a half million dollars was raised this year at this event.⁴⁴ Y-ME's affiliates undertake their own fundraising activities, which range from seeking foundation funding to sponsoring special benefit events. In addition to the training and services the national office provides affiliates, it also offers financial support in the form of scholarships for trainings.

The budget for the Women's Fest Program is \$38,200 per year. In 2000, the organization received a one-year grant of \$14,900 from the Illinois Department of Public Health, Office of Women's Health, which went toward covering program costs. In prior years, Y-ME has funded the program solely from their general budget. The Women's Fest staff's salaries continue to be largely absorbed by Y-ME's operating budget.

Women's Fest Program

Mission and Target Population

Women's Fest was launched by Y-ME in 1995 as a series of health education fairs targeted to the Latino community. More recently it was expanded to the African American community. Funding was secured from private foundations and the state health department. The goal of the program is to provide underserved populations with access to information about breast cancer and as well as to early detection services.

Program Operations

The core program consists of monthly fairs, hosted by local community-based organizations in various parts of the city.⁴⁵ These are preceded by intense outreach and neighborhood publicity, urging local residents to attend the fair, and to sign up beforehand for mammograms. Trained community volunteers and staff conduct education on breast cancer and breast self-examination at these fairs, while bilingual nurses from the State Department of Health conduct clinical breast exams. In addition, some educational activities are aimed specifically at Latino and African American men as part of a family-centered strategy to foster support for breast cancer screening and treatment. The first participants to sign up -approximately 16 per event- receive mammograms in a county-owned mobile unit. All others are given appointments by the city health department's breast health outreach worker for low-cost or free mammograms provided by municipal clinics, non-profit hospitals, and Cook County hospital. About 60 clinical breast exams are administered as a result of each monthly event.

Y-ME sends program participants age 40 and over yearly mammogram reminder notices. Hotline operators (all of whom are breast cancer survivors) manage much of the follow-up work with individuals who attend Women's Fest and need follow-up care of some form. Although they do not provide case management, Spanish-speaking hotline operators do help some monolingual women to make follow-up and re-screening appointments at a variety of hospitals and clinics. The uninsured are directed to Cook County Hospital. The hotline also maintains a national database of breast cancer diagnosis and treatment resources, with special emphasis on options for low-income women.

Y-ME staff relies mainly on volunteers and collaborative relations with other organizations to coordinate Women's Fest events. The Y-ME Director of Cultural Relations and Diversity and her assistant participate in and implement the events. Y-ME's ability to implement Women's Fest events has been greatly aided by the organization's other activities, described above, and by its established infrastructure, including its Spanish hotline, its published materials targeting the Latino community, and its formal volunteer training programs, conducted in Spanish.

Outcomes

Women's Fest tracks the number of participants and assesses participant satisfaction through an evaluation form distributed to event participants. The most recent quarterly program report (fourth quarter of 2000-2001) shows that three events drew 215 participants; 116 clinical breast exams were performed; 32 women received

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mammograms; and seven others received referrals for mammograms at local clinics. To date, 94% of participants completing the evaluation reported learning something new through their participation; 100% rated the event and the presenters as “great.” Participants particularly noted the convenience of having these services in their neighborhood and their appreciation at being treated with consideration and respect by the Women’s Fest staff and volunteers. Participants also expressed a desire for Women’s Fest events to be held more frequently.

Future Plans

With the expiration of its state grant, Y-ME is now seeking funding not only to maintain Women’s Fest in Chicago through the City’s affiliate office, but also to begin its replication nationally. Plans call for three national affiliates to begin similar programs each year. To this end, the staff at Y-ME have begun a fairly detailed planning process to identify which affiliates have the requisite capacity, and are located in the best communities, to replicate Women’s Fest. Y-ME projects a cost of \$15,000/year to provide training and support to the affiliates, in addition to the cost to the affiliate of implementing the Women’s Fest activities.

In addition to securing funding, Y-ME faces several challenges in replicating Women’s Fest through its affiliates. These include building the affiliates’ capacity by increasing their staff and volunteers as well as finding local champions to spearhead the efforts. The Director of Cultural Relations and Diversity expressed concern that Women’s Fest might not be able to meet the overwhelming service needs in some of these communities.

Findings

In this section we discuss three sets of findings. First are the success factors and critical challenges that exist within these organizations and their respective environments; factors that may help or hinder progress. Second are “best practices” which, when implemented, may make these programs more effective. Finally, we have other findings, which include observations around data, planning and evaluation.

Success Factors and Critical Challenges

There is considerable activity nationally designed to address disparities on a community level. Many initiatives are underway, with little coordination between them. But some common themes emerge when one examines what organizational and environmental factors seem to foster successful projects.

Leadership

We observed strong, committed leadership at all the sites we visited. The existence of these programs owes much to the presence of energetic, sometimes even charismatic, individuals who have a strong belief in what they are doing, and who are willing to persist in developing and maintaining their programs in the face of financial and organizational adversity. In at least one instance (Way of the Heart in Nogales, AZ) that leader serves as executive director but has not drawn a salary. At another (Delta Community Partners in Clarksdale, MS), the project director has kept the operation going even through times when it lost external funding, and maintained the continuity that allowed it to gain new funding from a different source. At all our sites, the programs are strongly identified with the commitment of a single individual leader. The loss of that leader could have catastrophic consequences.

Sponsorship by an Existing Entity

All the programs we studied were in some way built on a preexisting organizational structure. This sponsorship seems to have several benefits. Some projects were supported temporarily by these sponsor organizations when funding expired. Such was the case temporarily at the Delta Community Partners project in Mississippi, and it is currently occurring at the Women’s Fest initiative at Y-ME in Chicago. Others

were maintained by the parent organization even when external funding was clearly inadequate to cover program costs. Such is the case at the Sacramento Urban Indian Health Project.

The experts we interviewed in some cases advocated building disparity programs on preexisting community organizations. They often held that this gave these new initiatives some administrative and management capacity to begin their work, as opposed to beginning a significant undertaking without this infrastructure. Our own observations ratify this, and indicate that these programs may need some form of existing structure and sponsorship to succeed. Other experts took a different tack, and endorsed creating new initiatives as stand alones. This stemmed from a belief that “de novo” models could be more innovative and less constrained by existing bureaucracies and organizational beliefs. While there may be value in such an approach, we found few such programs surviving for long.

Strong Local Provider Interest

In all these programs, providers demonstrated their interest and support through program sponsorship, or through formal and informal linkages to the programs. Those providers somehow saw these programs as fulfilling their own important missions and easing their own clinical and financial burdens. In Mississippi, the Delta Community project grew out of the recognition that unmanaged diabetics were placing a strain on the region’s emergency departments and physician practices. In Sacramento, the diabetes program for Native Americans grew from seeing how diabetes seemed to be one of the most important drivers of clinical needs among the population served. The network created to serve the women at the Chinatown project in New York came together as associated hospitals and clinics together recognized the need of Chinese-American women for more aggressive breast cancer screening and treatment. Without this support, needed personal health services could not be obtained at any program.

Broad Indigent Care Finance Systems

The vagaries of state and municipal health finance systems play a significant role determining the ultimate success of new community-based initiatives. Not surprisingly, programs that were established in less generous environments reported the greatest difficulties in obtaining free or low-cost services. On one extreme are the Chinatown and Contra Costa breast cancer initiatives. They have had perhaps the least trouble in securing screening and treatment services for their clients. Chinatown benefits from a federally-funded community health center sponsor, federal breast cancer screening dollars, a state hospital charity care pool, Medicaid Disproportionate Share Hospital funding, and city-owned hospitals and clinics. In Contra Costa, the Breast Cancer Partnership benefited from federal, state and foundation-financed breast cancer screening and treatment monies. In contrast, The Way of the Heart in Nogales must often seek mammograms and treatment services for their clients on a time-consuming, case-by-case basis, in an area with a less generous Medicaid program, no public hospital or municipal clinics, and less safety net funding in general. Its plans to start volunteer clinics are at least partly designed to improve access to clinical services. The Sacramento and Delta Community projects reported similar frustrations in accessing specialty and hospital services in counties lacking explicit safety-net providers and generous funding of indigent care.

The long-term success of initiatives such as those studied may be as much a function of the local health care environment as it is a function of the qualities of these programs. The implications for replication are very important. Some areas may be fertile for the development of vibrant initiatives to address disparities in health and health care, because the necessary partners have the financial ability to do their part, as a result of a supportive health care finance environment. Other places may simply lack the health care finance system necessary to support the essential clinical services these programs and clients need.

Best Practices

The case studies revealed certain practices that seem to hold promise for addressing disparities. The use of these practices was supported through the literature review, surveys and expert interviews.

The Mobilization and Management of Community Resources

The most predominant practice among these programs is the mobilization and management of a continuum of disease-specific resources across a community. In the case of diabetes, this means ensuring that patient care is coordinated between physician's offices, hospitals, clinics and social services. It also means bringing resources like nutrition classes to bear on behavioral change. For the early detection and treatment of breast and cervical cancer, this entails assembling community resources like breast health education, clinical breast exams, mammography and further diagnostic and treatment resources into one rational whole. In no instance did any of these organizations possess or offer all these services. Indeed, for the most part they coordinated and promoted the services of other organizations. For example, the Way of the Heart Promotora Institute delivered a variety of navigator, screening and educational services. It depended on a host of other community resources for mammograms and breast cancer treatment.

This function of community mobilization and management is critical, especially for populations facing a whole series of financial and non-financial barriers to care. It includes network development, but also entails making the necessary arrangements, in advance, to ensure that individuals will actually be able to get, and do get, the network's services. In each of our case studies, that assurance was provided through some form of one-to-one outreach.

One-to-one Outreach

All six of the studied sites engaged in some form of one-to-one outreach, whether through the volunteers at Women's Fest in Chicago, the lay navigators in Contra Costa, or the caseworkers at the Delta Community Partners project in Mississippi. These workers, in all their manifestations, identified clients,

enrolled people in some way into the program, served as health educators, and assisted people in navigating a complex and unwelcoming health care system. Whether they were health professionals (as in Mississippi) or lay workers (as in Nogales and Sacramento), they formed strong bonds to clients and families that increased the credibility and acceptance of their educational message. They served as the unifying factor in the community network. Perhaps just as importantly, they advocated to obtain services for their patients (e.g., hospital services in Nogales, AZ). A lot falls to these staff in these initiatives, and their presence becomes the linchpin of program operations.

Our interviewed experts frequently supported the use of community health workers, although some viewed this as a relatively expensive, labor-intensive strategy. We found little unanimity among our sites and experts about the appropriate training and qualifications of these workers, as we discuss later.

Improving Physical Access to Care

Transportation was a challenge identified by all the programs we studied, as well as by many of our interviewed experts. The people served by programs such as these tend to be poor, and often lack access to a private vehicle. Public transportation is difficult in most places. In southern Arizona and the Delta of Mississippi it is essentially non-existent.

Several programs thus strove to make parts of the health care continuum more physically accessible to individuals. At four of our sites, transportation is actually one of the services that are provided to clients. The Delta Community Partners in Clarksdale, Mississippi took a particularly creative approach to this issue, and leveraged existing transportation resources (vans) to transport patients to services, and to drive members of the community to work. The principle underlying this broad service is that that improving community health in their area means, among other things, helping people to hold regular jobs.

At a few programs, improving physical access took the form of putting multiple resources under one roof. The Way of the Heart facility in Nogales developed, over time, into a more general community center that housed offices and provided health screenings, counseling services, self-esteem building programs, aerobic exercise classes, and nutrition sessions. The programs at Chinatown in New York and in Sacramento benefited from being associated with community health centers, so that clients could access a broad range of clinical and educational resources when they were on-site.

Focus on Multiple Determinants of Health

All of the studied initiatives saw the health of their clients as extending beyond the one or two diseases they were trying to prevent, detect or manage. They were very sophisticated in understanding the multiple factors that can determine health, and the many ways that an individual and his environment must change to restore health. In Sacramento, it takes the form of inquiring about family activity levels and television-viewing habits to gauge diabetes risk during a mental health assessment. In Nogales, promotoras begin the initial home visit by assessing water supply, sewage systems and general housing conditions. In Contra Costa, it takes the form of sensitivity to environmental toxins in an area with a history of industrial pollution. Making multiple services available to clients was a common feature of the programs we studied, and represents an important, broad-based approach to health.

Enlarging the Concept of Community

A few of the programs we studied broadened their definitions of community. The Chinatown Community Health Center once viewed its mission as serving the Chinese-American population of the Lower East Side of Manhattan. But that changed with the rapid growth and dispersal of the Chinese population to many parts of New York City, and the arrival of new Asian immigrants into what was once the almost exclusively Chinese area around the clinic. Hence, the clinic now sees its community as being citywide, and including Vietnamese and other Asian immigrants. In Nogales, the realities of the frontier and

immigration mean that the promotoras must view their community as crossing the border to encompass a good deal of Sonora as well as Arizona. Clearly the realities of immigration in a rapidly diversifying America are going to force new definitions of communities' boundaries.

Practicing Cultural Competence

Perhaps our richest finding came in the area of cultural competence. Our experts repeatedly cited the need for staff and organizations to be culturally competent: a need that was well understood at each of the sites we studied. At these sites, cultural competence took the forms of linguistic competence, understanding of the client population's barriers to care, and knowledge of the client population's predominant diet, lifestyle, culture and beliefs. At some sites, it also meant including minority representation on governing boards and among upper-level management.

The four sites with significant non-English speaking populations (Contra Costa, Nogales, Chinatown, Chicago) all had workers, volunteers and providers whose first language was the same as that of their clients. People fluent in the language of their client populations predominantly staffed the programs in Nogales and Chinatown. In all cases the ability to speak the patients' languages was considered absolutely essential by program leadership to maintaining an effective initiative.

At a few sites the emphasis on linguistic competence manifested itself in other ways. Among the Native American population of Sacramento, it meant a strong emphasis on non-verbal communication. Our experts, as well as program leaders, repeatedly noted that Native Americans are very sensitive to many non-verbal cues; often posture, facial expression and other signals are as important as the spoken word. Women's Fest, Chinatown and Way of the Heart expended great efforts to translate English health education literature into other languages. SUIPHI and the Delta Partnership worked to ensure that their literature was aimed at an appropriate reading level and that it placed health issues in a culturally

appropriate context. All of the sites reported the paucity of culturally appropriate literature.

Cultural competence extends beyond simply speaking someone's language. Some sites placed a strong emphasis on understanding the belief systems and every day lives of their clients. Staff in Clarksdale and Sacramento had an understanding of their clients' diets, and nutrition education focused on including traditional foods as much as reasonably practical in a diabetic diet. In Chicago and Nogales, we observed an emphasis on communicating with entire families as a strategy to address health issues for Latinas. In Chinatown, activities were suspended around the time of the Chinese New Year, a time considered inauspicious for activities that could lead to bad news.

This sensitivity to culture was greatly aided at each program by efforts to hire and train workers and volunteers who came from the cultures they were to serve. This reflects a recognition that cultural competence relates to the entire complex and sensitive relationship between staff and patients, including to the degree to which staff share patients' cultural attributes. The Chinatown project in New York recently began the recruiting of Vietnamese staff to reflect the increasing diversity of their community. In Nogales, new promotoras are being identified through the "teen promotora" program. The community health workers in Sacramento are all Native American, while in Chicago the recruitment of Spanish-speaking hotline operators and volunteers has been strengthened by a formal training curriculum in Spanish.

The programs we studied used a variety of approaches to address cultural competence at the organizational level. In some cases, members of the Boards of Directors that run the projects were drawn mainly or exclusively from the served community. In contrast, Women's Fest in Chicago is overseen by the Y-ME organization, whose origins are in the white community, but whose Board has formally endorsed and mandated cultural diversity training at all levels of the organization. Women's Fest and other programs

have consciously recruited and retained minority executive leadership, while Chinatown operates a health professions internship that assists in recruiting Asian-American providers. Clearly, practicing cultural competence in some organizations means more than just “speaking the language.”⁴⁶ It also means a deliberate program of organizational development.

Building Bridges to the Provider Community

Building formal and informal bridges to the provider community is also important. We noted above that having interested providers at the outset is necessary for these initiatives. It is also difficult, given the economic disincentives of caring for poor, often uninsured people. These linkages must therefore be constantly cultivated and reinforced. Be they doctors, hospitals or clinics, these providers help the community-based initiatives in a number of ways.

They can serve as a key source of referrals, as is the case of Clarksdale, where all diabetic patients identified by the local community health center are referred to the Delta Community project. These providers are also necessary to serve those patients who are managed or screened by these projects.⁴⁷ Given the often slim resources for indigent specialty and tertiary care in these communities, these linkages need to be as strong as possible, and their rupture can be catastrophic. The strategy of placing case-workers with a variety of providers across Northwest Mississippi in the Delta Community project is one innovative way of addressing this issue: Hospitals and clinics in that region have a direct stake in a project that helps them, as well as their community. They help promote community health, and avoid more expensive care of uncontrolled diabetics with multiple complications. These providers are thus much more likely to maintain support of the program.

Finally, these providers are often necessary to creating an enabling political environment. In many of these communities, the hospitals are the dominant, or even the largest employers, and local physicians have a very active say in community life. Hospitals and doctors, as opposed to community-based organizations, are frequently an integral part of local business elites.

Fostering Volunteerism

Several of our sites made extensive use of lay and clinical volunteers. Access to physician services was especially dependent on a cadre of committed doctors on both sides of the US-Mexico border in and around Nogales. These physicians volunteered their clinical services, while one served as the project medical director. Y-ME’s Women’s Fest program used lay community volunteers, recruited both by itself and by partner community organizations, to provide outreach and health education services. In Chinatown, lay volunteers served as patient navigators. In all cases, volunteers represented a low-cost, culturally competent strategy to strengthen community links and to directly serve patients.

Several of our experts commented on the promise, and limitations, of volunteerism in addressing health disparities in minority communities. Most experts strongly supported volunteerism as a way to engage a community, while securing the needed human resources to get the job done. But a few cautioned us against expecting too much from these strategies. They warned that poorer, minority communities often lack the tradition of volunteerism and depth of volunteer resources that one sees in the white community. One expert noted that while it is relatively easy to find highly skilled, retired businessmen to volunteer their efforts and community contacts on behalf of a worthy cause in the white community, these people are much rarer in poorer, less-educated communities of color. This may have important implications for the development of these initiatives in these communities.

Formally Seeking Community Input

At least three of our study sites formally sought community advice, a practice that was overwhelmingly endorsed by our experts. This took a number of different forms. At the Delta Community Partners in Mississippi it was best seen in an exhaustive community needs assessment and planning process, conducted before the program’s launch in 1994. A series of town meetings helped the planners focus their strategies, while heightening focus on the issues of diabetes and hypertension for that area.

At the Partnership in Contra Costa, California, a formally chartered system of committees solicits the advice of a variety of community segments including African Americans and Lesbians. Y-ME's Women's Fest program has adopted a somewhat different approach, using focus groups across the nation to vet its messages and materials.

An Active Role in Policy and Advocacy

Soliciting community input can often go hand-in-hand with a conscious attempt to change the environment through advocacy. Some programs viewed political advocacy and other efforts to influence policy as a core function. This took many forms. As noted above, Way of the Heart in Nogales sponsored a reportedly widely heard weekly radio program on the city's major Spanish language radio station. While content usually included health promotion issues, every candidate for local office was interviewed concerning his or her positions on health issues of local concern.

Other programs have sought specific policy and legislative changes. In Mississippi the project partners have adopted a very focused approach, lobbying state officials for a statewide Medicaid plan amendment that would allow payment for case management services similar to the one the program now operates. The state has apparently indicated that it intends to implement such an amendment, which should ease replication of the project's model across the state. Y-ME engages in extensive state and federal advocacy on a range of health issues relevant to breast cancer. Through its role as a major member of the National Association of Breast Cancer Organizations, Y-ME helped lobby the White House and Congress for passage of the Breast and Cervical Cancer Prevention and Treatment Act of 2000. The Partnership in Contra Costa is pushing state legislators for more permanent state funding for breast and gynecologic treatment.

Notably, few of our experts highlighted advocacy as an integral part of these initiatives. They often told us about the need to have community linkages and grass roots appeal, but said little about these programs engaging in very focused, sustained efforts to change laws and policies. Yet the changes in state and federal

Medicaid policy advocated by the projects above could have profound and long-lasting benefits to the people these programs serve.

Other Findings

Data and Evaluation

The use of federal, state and local data differed widely across our programs. In some, the presence of a large body of analysis by a local university made local area data much easier to obtain. Population based data from the University of Arizona and the University of Mississippi helped the efforts of the Way of the Heart and the Delta Community Partners, respectively. In other areas this was much harder, especially when the population served was dispersed across a wide area (as was the case with the Chinatown project), or when the population was a relatively small minority in a much larger community (e.g., Native Americans in Sacramento).

Nevertheless, it is not clear how much of a problem this posed, as it was not obvious that any of the projects that lacked comprehensive data would have necessarily changed their models or strategies if such data had been available. Most of our program leaders were not greatly focused on this issue, and seemed to have had much more pressing concerns, e.g., secure funding. This was in contrast to many of the experts we interviewed, who repeatedly pointed to the need for more ethnic and race specific health data for small areas. There seems to be a disconnect between needs as perceived by our experts versus those identified by program leadership. Government and foundations have stressed the need for better data, but front-line managers seem to have other concerns.

Several of our sites had collected and analyzed meaningful clinical and health service evaluation data. Others had collected data and not analyzed it. Some were conducting relatively rudimentary evaluations, reviewing simple patient satisfaction measures or knowledge self-assessments. This was consistent with what many of the experts noted: that these programs were often not conducting outcome evaluations.

All our program leaders thought good evaluations were important. But some simply lacked the resources to conduct them. Again, faced with the few dollars and the daily challenge of serving their clients and community, the time and dollars were not available for program evaluation. We suspect that this is a very common occurrence in community-based initiatives. While 31 of the 46 sites completing our initial survey reported having done an evaluation, we suspect some of these may not have been as rigorous as one might expect.

Program funding cycles play a critical role here. Clinical outcomes of a breast cancer initiative may not be apparent for many years, which may be far longer than the life of some of these initiatives.

In addition, population-based evaluations of these programs may be impossible. A small program operating in a large community may have no statistically discernible effect, even though it may be preventing and effectively treating disease. Given the small size of many of the programs we observed (see below), this may be a common situation. The transience and frequently undocumented status of these populations pose further impediments.

The results are that it is difficult to know which programs are working. It is also hard for these programs themselves to make an effective argument that their work deserves financial support from government, business, or philanthropies.

The Preeminence of Local History and Dynamics in Planning

Indeed, many of the program designs seemed to be more driven by history, and by local idiosyncrasies of the health care system, than by “objective” quantitative analysis. Local observations, organizational sponsorship and mission, and the identities of willing community partners seemed most important in determining what these programs did, even when the environment was rich in quantitative data. In most of our cases, program leaders seemed to be attacking what they viewed as problems in their community, as opposed to working to correct this or that quantified disparity, per se. They were in many cases responding to what they and others

experienced first hand as problems in their community, not to problems someone else may have found in their community.

This responsiveness, combined with the local “lay of the land,” often drove the model and the intervention. A partnership approach that included multiple community organizations made sense in the Delta of Mississippi, where multiple providers felt overwhelmed by the fallout of untreated and undiagnosed diabetes. In Sacramento, the project had to adopt a much more stand alone approach as it served a smaller minority in that community, with perhaps fewer potential providers viewing Native American health issues as a major priority. Hence, we saw a very wide range of models, each more responsive to a local environment than to any particular theory of community health promotion.

Information is Difficult to Obtain In a Fragmented Field

In our own investigations we were struck by the difficulty of obtaining helpful, user-friendly information on disparity reduction strategies and programs. There is no central resource listing community programs that seek to address health disparities among minority Americans. Information must be obtained in a relatively haphazard, word-of-mouth fashion. Neither is there any known resource that lays out what strategies may be most useful to community-based organizations. This fragmentation of information seems to mirror the fragmentation of effort we observed. We were struck by how many federal and state agencies are officially involved in minority health and disparity reduction efforts, and frankly surprised by how little each knew of others’ efforts.

The closest thing to a central resource we found was the “*Pocket Guide: Minority Health Resources*” published by the federal Office of Minority Health. This is a very helpful contact listing of hundreds of government and non-profit agencies that are somehow involved with minority health issues, analysis and information. But frequently we encountered difficulties when calling listed agencies. Often calls were not returned, or we were told that the responsible individuals had left and had not yet been replaced.

These are Small Programs...

These are all relatively small, young programs. The largest was serving over 1000 clients, providing them with some sort of comprehensive screening and treatment services. In our larger survey sample, the 46 responding sites reported having served a total of 123,000 individuals throughout their history. The median lifetime of these projects was less than three years, and the median number served in that time was 978. There are few longstanding models, and those few are quite small.

Given the youth of these programs, perhaps in five or ten years we will observe larger programs demonstrating an impact. That would be an optimistic scenario. Constraints in current funding, difficulty in securing permanent sustaining support, and resulting instability make it unlikely.

...With Many Needs

In our interviews and surveys, a number of needs were repeatedly articulated or became obvious.

Stable, Predictable Long-Term Funding: All of our sites were at least partially dependent on time-limited grant funding. At least two had experienced loss of funding. In our initial work, we came across numerous programs that were now defunct because “the money ran out.” This chronic instability breeds anxiety, makes recruitment and retention of talent difficult, weakens these initiatives’ credibility, and makes it very hard for them to have a demonstrable impact. Many interviewed experts considered short, unrealistic funding cycles to be the major impediment to the growth and development of community-based disparities reduction programs. This may require government and foundations to rethink their funding policies, as we discuss later in this report.

Leadership Development: In all our sites we saw committed individuals leading programs in very adverse circumstances. All brought great experience to their positions. Yet the nature of their work, and the environments within which they operated made certain needs apparent. These leaders seemed in some instances to be at risk of isolation, working in small communities

or communities isolated by virtue of poverty and ethnicity. They had few peers with whom to share experiences, and often a great gulf of education and experience separated them from their immediate subordinates. These leaders need more support, more connection to peers nationally, and some mechanism to ensure that a new generation of leadership is ready to fill their shoes when that time comes. This was not an issue highlighted by our experts, but one that nevertheless merits great attention.

Organizational Development: The sites we surveyed and visited also demonstrated broader organizational needs. Community-based disparities reduction programs, lacking a lot of resources, often operate with minimal management and human resources infrastructure. In some cases, budgets are fairly rudimentary, and programs may not have the luxury of hiring individuals with solid financial backgrounds. Personnel policies and procedures may be inadequate. Training is often obtained in a relatively patchwork fashion from many outside agencies, often without a curriculum in place. As our experts indicated, these organizations have many basic needs that are shared by community-based organizations of all stripes.

Quality and Patient’s Rights: We observed a number of programs that required assistance in developing simple quality assurance and quality improvement methods. While all tried to at least track some process outcomes, some still needed to develop more formal, ongoing feedback mechanisms to continuously monitor, and act upon, quality measures. In a few instances we observed significant lapses in maintenance of patient confidentiality and possibly in the use of informed consent. Community-based disparity reduction initiatives need help in these areas if they are to be held to the same standards that have been created for other parts of the health care system. While some may argue that these initiatives should not, or cannot, be held to those standards, to do otherwise would mean endorsing a lower standard of quality for the most vulnerable members of our communities.

Assessing Potential Interventions and Identifying Promising Strategies: While we have tried to identify those factors and practices that may be most promising, much more work is needed to help inform these programs. We have not found a single authoritative source that uses evidence-based techniques to review the published literature or other data, and which might then allow programs to make well-founded decisions on what they should be doing. While the Evidence-Based Medicine movement is helping clinicians make better-informed clinical decisions by culling and assessing the voluminous medical literature, nothing similar exists for community-based work to prevent disease and promote health. The experts we interviewed confirmed this need, and saw it as inextricably linked to the paucity of good evaluations.

Advocacy and Making a Business Case Around Disparities Reduction: As we noted above, several of the programs we studied considered advocacy a core function. But all needed some more help in this area. Some did not seem especially prepared to assertively and confidently move community sentiment to force changes in government health care funding policies. They were not familiar with the regulatory and legislative processes, and were not necessarily known by local, state or federal officials.

One specific need was the ability to create a sophisticated economic argument as to why government and the private sector should care about reducing disparities. We did not see, for instance, any well-developed arguments laying out the possible economic benefits of cutting lost days at work or preventable hospitalizations for untreated diabetics in our minority communities. It will be hard to convince state Medicaid directors to fund case management and patient navigation services unless they believe there will be some positive benefit to the state budget. In some cases, it may be hard to make just these arguments; the numbers and supposed risks and benefits may be highly debatable. But at a community level, it seemed no one had the expertise and access to information to attempt to do so.

The programs we reviewed have many similarities. They are often dependent on the sponsorship of a larger, older parent organization. They all use some form of one-to-one patient navigation or case management, and mobilize a continuum of community health care resources, which are outside their direct control. All made formal efforts to address cultural competence, using a very broad array of strategies. Given their largely indigent populations, it is no surprise that community and health care provider support is critical to their ability to secure treatment for the diseases they seek to detect.

But in other ways there is clear diversity of approach. While some initiatives depended heavily on lay workers and volunteers, others used primarily health professionals for outreach and case management. At least one project opted for unpaid volunteers as community workers. Our interviewed experts and program leaders expressed strong but divergent opinions about what each thought were the “right” ways to do this. Some held that a lay approach is the culturally sound strategy, because it ensures that clients are served by people who are in touch with their needs, and who have the greatest community credibility. Others felt that professionals needed to be employed at all levels of these initiatives, otherwise, they argued, these programs would lack needed credibility in the world of health care, and the professional health sector could then more easily ignore the issues of disparities. Neither side cited strong evidence to support their assertions. Evaluation of these different strategies would be very helpful to existing and future undertakings.

Highly committed, indeed often charismatic, individuals headed all our projects. This is a clear strength, but it was also clear that these individuals and their respective programs frequently need more support and assistance. They operate in adverse conditions in poor, often isolated communities. Information on best practices, training materials and administrative support is hard to obtain. Many of our interviewed experts also viewed these “capacity” issues as major challenges. Without external assistance, demoralized leadership and tenuous administrative structures will

Discussion

hobble these programs. A program may be fatally injured should one or two senior staff members depart for less isolated, more remunerative positions. Developing and recognizing leadership in these programs will be key to ensuring that they achieve stability and permanence.

An associated theme came from our expert interviews and case studies. These programs are dependent on short-term, public and private grants, usually lasting three years or less. It usually takes a year just to get the various sectors of a community talking to one another. At least two of our programs have had to temporarily suspend operations when grant funding expired and our initial review found many that had closed in similar circumstances. Potential funders need to think long and hard about this issue. The expectation that one can fund these initiatives for a few years, demonstrate success, and then they can somehow sustain themselves is simply not realistic. As one expert noted: “These problems took 300 years to develop, they won’t be solved in three years.” Even in the best of circumstances continued funding from new sources is hard to find, and it is doubly hard in poor minority communities that, as one expert noted, lack the history and tradition of philanthropy, volunteerism and business leadership seen in the white community. A solution may be securing funding from Medicaid or other indigent health care finance systems, but that is a slow, uncertain, and usually unsuccessful effort.

The need for more and better evaluations will also be frustrated by the lack of stability and resources. Many of our programs lacked complete evaluations, or evaluations of any sort. This makes it that much harder to know what works, and to support their expansion and replication. Evaluation was not devalued by our programs, and certainly not by our experts. The time, money and management capacity are just not there to allow it to happen. Many of the individuals working at these programs are more concerned with helping people than with more abstract considerations of measurement. One might say that for them it is the numerator that counts. And as we

noted above, the small size of these initiatives may preclude the measurement of any population impact.

The replication of these projects will stumble over these same obstacles. Policy makers and funders need to know what works, and to foster organizations with enough management horsepower to make a long-term dent in health disparities. Our own findings indicate that these initiatives have the most staying power when built on or within existing organizations. These can weather “dry spells,” have access to more management and finance expertise, possess existing community relationships, and do not need to create personnel and clinical systems from scratch. But funding only those initiatives that are parented by larger organizations will reduce both risk and innovation. The most innovative work may come from projects not affiliated with older bureaucracies, yet the risk of their failure may be high. A balanced, “portfolio” approach could be used, in which very deliberate decisions are made to support a range of different types of programs, knowing that some will have greater chance at long-term modest success, while others will be more likely to either fail or produce breakthrough strategies.

The issue of replication must be handled with care. Local politics and health care finance environments will strongly influence what interventions may be effective. What works in a community with a long history of community activism, volunteerism and a public hospital may fall flat in an area without them. Successful models in states with richer public and private funding sources (like New York and California) may not be replicable on the US-Mexico border. Case management for diabetics seems to be a very effective strategy. But it will not achieve permanence if, in the long run, it is not eventually paid for by state Medicaid agencies. The art of replication will include the art of assessing local political realities.

A simple lack of health care providers may hinder replication. We saw this first hand in Nogales, Arizona, a federally designated Health Professionals Shortage Area. A lack of enough providers was probably as much an issue as a lack of willing

providers. When a community simply doesn't have enough primary care physicians and radiologists, there may not be much more that can be done to manage diabetics or screen for breast cancer. The best-planned initiative will be frustrated in such a place.

Replication must also take account of other local conditions. A model that depends on a broad coalition of community providers and social service agencies may not work in serving an isolated, small minority community that is not well-recognized or served by local networks. Few may think that serving members of that group will appreciably advance their interests, be they altruistic or fiscal in nature. In this case, one might be more successful emphasizing a more "stand alone" approach— such as that of the Sacramento Urban Indian Health Project— in which one clinic or hospital handles more of the tasks needed by that community.

Even when a model is transferable, it may not take root in a given community if local decision makers and providers don't see it in their best economic interest. None of the programs we studied had developed a "business case" around their activities, namely an analysis detailing what economic benefits might accrue to businesses, hospitals, doctors and insurers (including Medicaid) if disparities could be reduced. Perhaps no such case can be made, or maybe no one has tried to create it. And the movement of many of our poor into managed care may create economic incentives that actually increase disparities. But without this business case, getting a community or state government to invest in disparity reduction will be a tough sell.

The small size and short track records of these programs have implications. Our 46 surveyed programs reported they served 123,000 people. The year 2000 census counted almost 87 million Americans who could be classified as minorities based on race or ethnicity. While our sample was in no way universal, we strongly suspect that community-based disparities reduction initiatives are, at best, having an effect on select, very local populations. It will take huge

increases in the numbers and sizes of these programs to see discernible national reductions in health disparities. Those increases would have to be matched by finance and delivery system changes to make sure that the found diabetics have doctors or nurses to see, or that women needing breast cancer treatment can actually get it.

Finally there are broader philosophical arguments that influence how one approaches community-based programs to reduce disparities. The programs we studied saw their goal as helping people in their community, not necessarily as reducing disparities. As noted, few had statistics that would allow them to analyze disparities in their service areas, but even if they did, this was not how they chose to operate. For these communities, poverty, unemployment, and stress are more immediate issues than health disparities.

These initiatives can do much good in local settings. Early detection of a case of breast cancer or keeping a diabetic healthy is an invaluable service. Yet this focus on the individual can distract us from the broader social obligations incumbent on a nation with 40 million uninsured and a long history of racial discrimination. Finding the ways to overcome the non-financial barriers is certainly a good thing. Few would maintain that financial barriers alone create disparities. But neither can one maintain that these programs will be able to eliminate disparities without a radical change in the American social and health care finance systems.

Recommendations for Action

The recommendations that follow could be implemented individually or as part of a conscious coordinated strategy. Many of them would require overlapping resources, and might best be implemented and supervised by a single organization.

Research

Our literature review suggested there is little good information on effective screening and treatment strategies in minority communities; this finding has been confirmed by larger literature reviews as well. Most studies that have been done focus on purely educational efforts in urban African American communities, and few describe coalition-based efforts.⁴⁸ Government and philanthropies should consider several research initiatives:

Controlled Evaluation of Different Organizational Models

We articulated a set of strategies and approaches we believe to be “best practices.” However, other organizational questions remain: Are coalition approaches more effective than single-organization undertakings? Are new, start-up community organizations able to demonstrate greater innovation than existing organizations? What governance models are most effective (public vs. non-profit vs. mixed coalitions)? The limited scope of our study has not allowed definitive answers to these questions. Systematic evaluation of the effectiveness of different organizational models would be very helpful.

Controlled Evaluation of Different Outreach Worker Models

We encountered a variety of different types of outreach workers, from the hotline operators at Y-ME’s Women’s Fest in Chicago, to the promotoras at the Way of the Heart in Nogales. We believe this one-to-one outreach is a best practice, but we do not know the relative clinical and cost effectiveness of various models. Is the comprehensive promotora approach most effective, and in what populations? What is the relative cost-effectiveness of various types of worker? Are so-called “indigenous” workers more effective? What are the merits, and drawbacks, of using volunteers? Should workers have lay or professional backgrounds? Many of our interviewees and program leaders had strong opinions on these issues, based mainly on anecdote.

Develop a Business Case Model of Disparities

Today a compelling economic argument around disparities reduction cannot be made to government and the private sector. No such case has been made of which we are aware. It is not clear that a state Medicaid official or a local employer should care about increasing benefits or reducing eligibility limits to address disparities. Government and foundations need to first test whether such a case exists, and if so, begin to give community-based organizations the data and tools so they can make that case in their own communities and states. This would be a powerful adjunct to their advocacy work.

Evaluate the Breast and Cervical Cancer Prevention and Treatment Act of 2000

The federal Breast and Cervical Cancer Prevention and Treatment Act of 2000 creates a particularly interesting environment to help us understand better the causes of disparities. The Act gives states the option to provide medical assistance through Medicaid to eligible women screened through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), who are found to have breast or cervical cancer, including pre-cancerous conditions. Under this new option, women must be under age 65, uninsured, and not otherwise eligible for Medicaid. They receive access to the full range of Medicaid benefits in each state. To date, 19 states have approved State Plan Amendments to adopt this option. The Act should correct some of the shortcomings of the NBCCEDP, under which low-income women without insurance could be screened, but not receive free care for diagnosed cancer.⁴⁹

This new program may allow health services researchers to gauge the impact of extending health insurance to low-income, minority individuals suffering well-known health conditions for which disparities in incidence or treatment are documented. Given the evidence that insurance status is one of the factors driving cancer treatment delays and cancer mortality, one could now theoretically measure the effect of removing the barrier of being uninsured. Researchers should also review the state’s efforts to implement this landmark program.

Service and Replication

Funding the growth and replication of existing programs is an obvious strategy. This could be the vehicle for increasing the capacity of existing community-based agencies, and for conducting needed, rigorous evaluations. Or it could be done on a larger scale, after some preliminary evaluation of current models is conducted. It might focus narrowly on some current models, e.g., a program to develop promotora-centered programs in our border regions and in emerging Latino communities nationally. Or, recognizing that local conditions demand tailored responses, include a variety of models. All the issues included in this report would need to be considered in such a program. But there are several to be highlighted.

Our experts and program leaders repeatedly decried the short funding cycles usually seen in government and private grants. We witnessed the program instability and vulnerability this creates. We also noted how many programs are in communities in which non-governmental, sustaining funding is extremely difficult to access. A national development and replication program should be undertaken only if funders are willing to consider much longer-term financial commitments, on the order of at least five, and possibly as much as ten, years. This may allow some efforts to reach the critical mass, credibility, and visibility that allow for permanent, stable funding.

Assuming that large-scale growth and replication of good models is the goal, then the advocacy skills and expertise of these programs should be developed as part and parcel of their program activities. Unless diabetes management programs can, for instance, make the case that the state Medicaid program should pay for outreach case management services, there is little chance that they will be replicated on a broad scale. Making that case includes not only being able to make a good argument, but also having a set of advocacy and public relations skills that are more often seen in large hospitals and trade organizations, not in small community agencies.

A national disparities reduction program that develops and creates initiatives will need to decide whether it

targets extant community organizations with track records, or whether it attempts to “seed” the development of new organizations. As we have noted, our experts were divided on this issue. Our own review indicates that using extant organizations increases stability by building on existing management capacity and potentially allowing “bridge” funding when grant dollars run out. This is a safer approach that will allow government or funders to show success more quickly. But we are sensitive to the belief that this may not be the approach that develops innovation and new models. We also realize that an approach that focuses on existing organizations could lead to overrepresentation of projects in some minority communities. We recommend that any funder either focus on extant organizations, or adopt a balanced portfolio approach in which new or nascent programs receive copious training, technical assistance, and general capacity building. We discuss these needs in more detail below.

Capacity Building

Community-based initiatives’ need for additional management skills, administrative infrastructure, training resources, technical expertise and other “capacities” was a frequent theme of our expert interviews. In our own investigation we saw these needs, and also noted the potential isolation and lack of support of program leaders. We make several specific and general recommendations.

Disparities Leadership Institute

Our brief review indicates that there are probably hundreds of individuals in leadership positions at programs aimed at reducing minority health disparities in the United States. These individuals will have very different personal and educational backgrounds, yet need a core set of competencies to be effective. These skills include an understanding of the following topics:

- > Epidemiology of Health Disparity Conditions
- > Evidence-based Review of Community Disparity Reduction Strategies
- > Quality Improvement in Community-based Organizations

- > Practicing Cultural Competence
- > Coalition Formation Techniques
- > Building Finance and Human Resource Systems
- > Development Strategies
- > Public Relations and Advocacy
- > Program Evaluation: Theory and Tools

A three-month leadership institute, paid for by external sources, would provide training in these competencies to selected program leaders. The initial session would be followed by periodic web-based updates and learning modules, as well as by yearly two-day reunions. The purpose of the institute would be not only to learn from these leaders and recognize their dedication while they gain additional skills, but also to help them form their own morale-building network of peers.

General Capacity-building Programs

Current disparity reduction programs would benefit from funding that would support or build various facets of their administrative and clinical infrastructure. Many of our experts supported this concept. This funding could be delivered to any number of programs, and focus on as many or as few issues as one would want to target. The skills to be developed and supported would be similar to the competencies suggested in the preceding section.

Under this recommendation, one or more organizations might be funded nationally to provide training in these areas to community-based initiatives. This could be further supported with more direct grants to these initiatives to provide them the ability to develop these capacities. Many initiatives would, for example, welcome the funding to allow them to hire an accountant or a grant writer.

This approach may allow more programs to participate than the institute above; many initiatives will not be able to spare their directors for several months. But it will not allow program leaders to develop a supportive peer network.

The area of cultural competence deserves special mention here. In December 2000, the federal Office of Minority Health published its final recommended standards for culturally and linguistically appropriate services (CLAS) in health care. These 14 standards are extensive, and many community-based health organizations will need help in meeting them. For instance, the standards recommend that all health care organizations have a written strategic plan to provide CLAS. It is doubtful that many have done this to date.

Creation of Core Curriculum and Competencies for Promotoras

We studied one promotora program, and learned of the existence of others in the course of this study. The promotora model holds great promise, and promotoras should have access to the high quality training. The State of Texas has begun some work in defining a core curriculum, credentialing for trainers and other standards.⁵⁰ But this is more than a one-state issue. It has implications for all of the border states, for Latino communities across America, and for Mexico. A broader approach, supported by federal health authorities and philanthropies, could create a model national curriculum and training standards to be adapted on a state-by-state basis. This work would need to be coordinated as much as practicable with Mexican health authorities, given the cross-border work done by many promotoras.

Some program leaders may see this as a first step towards formal regulation of promotoras as health professionals, which could undermine their credibility as lay members of their community. We do not know enough to recommend whether that regulation is a good or bad idea. However, the work done by promotoras is important and sensitive enough that they should be expected to have some minimal level of training. Individuals who are screening for disease should understand the basic epidemiology of certain diseases, the clinical implications of their work, understand patient's rights, informed consent, confidentiality, and other matters. This training would indeed bolster promotoras' confidence and esteem, aiding recruitment and retention.

Creation of a Central Management Services Corporation

An alternative to training staff at community-based programs initiatives in the various functions described above would be to actually provide these functions to them at little or no cost. A new management services organization (MSO) could be created which would be staffed with a variety of specialized individuals who would essentially serve as the initiatives' consultants in the areas identified above. So rather than hiring a grant writer (an impossibility given the finances and locations of many programs), a program would have formal access to the management services organizations' grant writers at minimal cost. Assuming the MSO were created as a non-profit entity, it could deliver these services at a price far below that of for-profit consulting firms. With funded support, community-based initiatives could, for the first time, have access to the capacities and skills taken for granted in other parts of the health care world. With single management, the resources of the MSO could be used with great accountability and attention to outcomes.

Build A National Web Portal on Disparities

There is much information about disparities residing in many different organizations, publications, websites and the like. Various agencies within the US Department of Health and Human Services have substantial information on disparities on their websites. However, there is no one place to go for information on disparities. Several of our experts suggested a national web portal on disparities. We think that, done carefully, this could have some value. It would include:

- > Contact information on agencies and organizations involved in disparities reductions;
- > Contact information for specific resources available to initiatives;
- > Listings and contact information for community-based initiatives
- > Summaries of recent research findings;
- > "Best practices" tips;
- > Critical, evidence-based assessments of intervention strategies;
- > News on latest policy changes on federal and state levels;
- > Available funding;
- > Upcoming public events;
- > Highlights of selected community programs;
- > Links to other relevant websites.

A properly maintained site could be of great value to front-line individuals, and would help agencies like the Bureau of Primary Health Care market educational and grant opportunities.

Conclusions

Our study indicates that there is considerable, though uneven community activity around reducing health disparities in America. Large numbers of initiatives have been launched, and many have the ability to inform future efforts in this area. Program success seems to center around existing organizations mobilizing and managing a broad range of community resources, using one-to-one contact with individuals to provide them with education, screening, and treatment. But much more needs to be known about the relative effectiveness of different strategies. If these initiatives are to have any hope of stabilizing and growing, there must be investment in helping community organizations build management capacity. Funding cycles will need to be lengthened and models carefully evaluated in different communities.

These initiatives are now reaching small numbers of people often in localized areas. They are helping to abate many of the cultural and geographic obstacles to better health in our communities. They are changing behaviors that contribute to ill health. These programs are bringing limited amounts of needed medical care to a limited number of people. In these respects, they are successful. But they will continue to be hampered without more financial support, stability, and permanent solutions to the problems of poverty and lack of insurance coverage. Any strategies based on community disparity-reduction initiatives will have to be tempered with patience, realism, and an understanding that these programs alone cannot solve these complex problems.

End Notes

- 1 *Healthy People 2010*, Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services 2000.
- 2 Ball J, Elixhauser A, “Treatment Differences Between Black and White Patients with Colorectal Cancer,” *Medical Care* 1996;34: 970-984.
- 3 Addressing Racial and Ethnic Disparities in Health Care. Fact Sheet, February 2000. AHRQ Publication No. 00-P041. Agency for Health Care Research and Quality.
- 4 *Journal of the American Medical Association* 1989: 262.
- 5 United States Census Bureau, Statistical Abstract of the U.S., 1997 mid-projection series.
- 6 Addressing Racial and Ethnic Disparities in Health Care. Fact Sheet, February 2000. AHRQ Publication No. 00-P041. Agency for Health Care Research and Quality.
- 7 United States Census Bureau, Current Population Surveys, March 1998, March 1999, March 2000.
- 8 Harris D, Andrews R, Elixhauser A, “Racial and Gender Differences in the Use of Procedures for Black and White Hospitalized Adults.” *Ethnicity and Disease* 1997; 91-105.
- 9 Ayanian JZ, Weissman JS, Chasan-Taber S, Epstein AM, “Quality of Care by Race and Gender for Congestive Heart Failure and Pneumonia,” *Medical Care* 1999;37:1260-1269.
- 10 J Chen et al, “Racial Differences in the Use of Cardiac Catheterization after Acute Myocardial Infarction,” *New England Journal of Medicine* 2001; 344:1443-9
- 11 HHS News, U.S. Department of Health and Senior Services, Centers for Disease Control Media Relations Press Release. 30 September 1999.
- 12 Florida Department of Health, Office of Equal Opportunity and Minority Health, “Closing the Gap” Notice of Grant Opportunity. July 2000.
- 13 HHS News, U.S. Department of Health and Senior Services, Centers for Disease Control Media Relations Press Release. 30 September 1999.
- 14 In several interviews more than one individual was present.
- 15 Infant mortality rate (1,000 live births): New York State Department of Health Vital Statistics 1998 (<http://www.health.state.ny.us/nysdoh/search/index.htm>). For all case studies the following sources were used— Population, racial demographics, median household income, and percent of persons below poverty level: US Census Bureau, 2000 Census (<http://quickfacts.census.gov/qfd/index.html>). Rate of uninsured: Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on pooled March 2000, 1999, and 1998 Current Population Surveys (<http://www.statehealthfacts.kff.org>).
- 16 In all cases, “White” refers to Caucasians of non-Latino descent.
- 17 About 2/3 of the CW&PP budget is grant-funded.
- 18 Doctors Medical Center is the only NBCCEDP provider in the county. They are also a BCEDP provider. Doctors Medical Center was recently converted into a for-profit organization. The San Pablo Campus in West Contra Costa County offers both inpatient and outpatient services and houses the J.C. Robinson, MD Regional Cancer Center.
- 19 Women who do not meet BCEDP eligibility criteria may be able to access payment for screening through other privately supported charitable funds.
- 20 Steering Committee Members represent the Northern California Cancer Center, Doctors Medical Center, Raging Light Projects, Pittsburgh Preschool Coordinating Council, Mt. Diablo Medical Center, American Cancer Society, Valley Diablo Hadassah.
- 21 Undocumented immigrants, who constitute a significant percentage of women accessing treatment funds, might face barriers to treatment once this bill is implemented. Breast cancer advocates are currently attempting to address this issue.
- 22 Project leaders report that the State Department of Health’s information systems recently have improved somewhat.
- 23 *A Sociodemographic And Health Profile of Ten Mississippi Delta Counties*. The Rural Health Research Program, The Environmental and Community Health Research Unit, The Research Institute of Pharmaceutical Sciences at the University of Mississippi. Publication undated.
- 24 *The Delta Community Partners in Care Project Report*. The Rural Health Research Program, The Environmental and Community Health Research Unit, The Research Institute of Pharmaceutical Sciences at the University of Mississippi. Undated.
- 25 Purchase of these materials was made possible through a one-time grant from the Hearst, Inc. Foundation.
- 26 Self-reported; defined as client didn’t feel well enough to get out of bed.
- 27 Staff notes that IHS statistics are often inaccurate and difficult to access due to the agency’s obsolescent software and data tracking system.
- 28 Under OBRA-93, Urban Indian Health providers funded through the Indian Health Care Improvement Act are automatically determined to be federally qualified health centers.
- 29 *Rancherias* refers to the smaller reservations located in California.
- 30 SUIHPI organization brochure.
- 31 The MRMIB is a state entity that administers a number of health insurance access programs.
- 32 <http://www.ihs.gov/AboutIHS/ThisFacts.asp>.
- 33 Activity/Mechanism Budget Summary, Department of Health and Human Services, Indian Health Services, Urban Indian Health Programs, Document 75-0390-0-1-551. P.93.
- 34 Williams DM, “La Promotora,” *Health Affairs* 20(3): 212-218
- 35 “Special Report: The U.S.-Mexican Border, Between Here and There,” *The Economist* (July 7, 2001): 28-30

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- 36 Ruiz A, Editorial, *Journal of Border Health*, (January-June 2000), 1-2
 - 37 Maquiladoras are factories that make products from duty-free imported parts for re-export, mostly to the United States.
 - 38 Mier SA, "Final report: Evaluation of HRSA Sanitarian Assignment in Nogales, Arizona," Health Resources Services Administration, March 25, 1996
 - 39 Colonias are un-zoned, semi-rural communities without access to public drinking water or wastewater systems. The U.S. Health Resources and Services Administration estimates that 350,000 people inhabit colonias on the U.S. side of the border.
 - 40 United States Census Bureau, 1990.
 - 41 Ku L and Matani S, "Left Out: Immigrants Access to Health Care and Insurance," *Health Affairs*, 2001 20(1): 247-256
 - 42 For "Arizona Health Care Cost Containment System."
 - 43 Y-ME is a founding member of the Cancer Leadership Council and the National Breast Cancer Coalition (NBCC), and works with these organizations to advocate for increased public awareness regarding breast cancer. Y-ME currently maintains a seat on the Board of Directors of the NBCC.
 - 44 The 2001 expense breakdown is as follows: 45% staff related, 25% volunteer and other expenses, 8% occupancy, 12% equipment and office expenses, and 10% events.
 - 45 Community-based organizations that collaborate with Women's Fest include Centro Comunitario Juan Diego, located in an Latino neighborhood, and Howard Area Community Center in the multi-ethnic Rogers Park area
 - 46 Brach C and Fraser I, "Can Cultural Competency Reduce Racial and Ethnic Health Disparities? A Review and Conceptual Model," *Medical Care Research and Review* 2000;57 suppl 1, 181-217
 - 47 Yardley J, "A City Struggles to Provide Care Ensured by U.S.," *The New York Times*, August 7, 2001: 1
 - 48 Carlisle DM et al, "Community-based Approaches to Reducing Racial and Ethnic Disparities in Health: Synthesizing Lessons Learned," RAND, March 20, 2000
 - 49 Pear R, "Quiet Signing for Cancer Bill that was Backed by Lazio," *The New York Times*, October 24, 2000
 - 50 Williams DM, "La Promotora," *Health Affairs* 2001 20(3): 212-218

Appendices
