

Addressing Health Disparities In Community Settings

[**A Funding Guide**]



INTRODUCTION

Much attention has been focused on disparities in health and health care between minority and white populations in recent years, and with good reason: such disparities 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 than are whites for a host of diseases and for premature disability and death. Disparities between whites and minorities are also seen in measures of access to health care, with minorities often receiving fewer needed interventions, having less access to medical services, and being more likely to lack health insurance.

In growing recognition of this problem, many publicly and privately financed programs have been initiated to improve access for minorities to educational, screening, and clinical services. Community-based disparities reduction initiatives have garnered particular attention. Yet, even with growing governmental and philanthropic interest in this work, not much has been written about current initiatives and what works on the community level. Funders wishing to support disparities reduction efforts have thus lacked useful information about where best to invest their efforts. This paper is intended to provide some of this needed information.

In 2001, at the request of The Robert Wood Johnson Foundation, we started to seek answers to key questions about what is being done, what is working, and what challenges remain in the area of reducing health disparities. Through Internet and literature searches, expert interviews, surveys, and site visits we studied and analyzed existing disparities reduction programs and the environments within which they operate. Our principal goals were to identify the practices and factors that foster success and to begin to assess the contributions these programs are making towards reducing health disparities among the populations they serve.

The main purpose of our research project was to identify a base of knowledge that would be useful to planners, activists, and policymakers seeking to design, improve, or expand activities in the area of health disparities reduction. The findings of this research can be equally useful to funders wishing to support disparities reduction efforts. The findings summarized in the following pages are thus intended to help interested members of the philanthropic community decide what to fund and to understand what they might do to enhance the chances of success for programs they support. It will also attempt to assess what they can expect from investments they make.

More specifically, this paper will:

- Describe the research methodology that was employed;
- Describe what we learned about initiatives that appear to be successful in addressing health disparities in order to assist funders wishing to replicate or expand on these successes;
- Identify areas of need widely faced by such programs for funders wishing to spread their investment more broadly;
- Offer some specific recommendations to funders concerning actions they can take; and
- Assess potential impacts of funding in this area.

In sum, it is our hope that this paper will help parties interested in supporting efforts to reduce health disparities better understand how to proceed and what they may expect to achieve.

METHODOLOGY

Introduction

The funding recommendations contained in this report grow out of research undertaken at the request of The Robert Wood Johnson Foundation designed to improve understanding of what makes community-based disparities reduction initiatives succeed or fail. This research used Internet and literature searches, expert interviews, surveys, and site visits to study and analyze existing disparities reduction programs and identify their “best practices.” Our goal was to create a body of knowledge that could assist in the design and implementation of future disparities reduction initiatives.

Study Goals and Scope

Our work was driven by three major objectives:

- 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; and
- 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 the six health priority areas identified in recent federal disparity reduction efforts. Since the scope of this study did not allow for a meaningful analysis of programs in all six areas, at the request of The Robert Wood Johnson Foundation we narrowed our focus to initiatives designed to address disparities in diabetes, breast cancer, and cervical cancer. Given our limited time frame of nine months, our study was exploratory in nature, and certainly not exhaustive in scope.

Methods

Our first task was to gain a baseline understanding of the background and context of disparities reduction efforts. More specifically, we sought to understand:

- The nature of disparities in health outcomes between minority and white populations;
- What is known about community-based disparities reduction initiatives; and
- The environment in which the programs operate.

Our second task was to identify successful programs that provided educational, screening, and treatment services in order to study them more closely. To accomplish these two tasks, we conducted a literature review, an Internet search, and interviews with 42 key researchers, policymakers, and opinion leaders.



These activities provided a great deal of background knowledge. It also led to the identification of 89 community-based initiatives that potentially merited closer study. We evaluated these initiatives against a set of criteria developed to guide the final selection of sites for the case studies. Using these criteria 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 outcome 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); and
- Represented a range of program sizes and funding levels.

We sent an electronic mail survey to the 89 sites identified as potential case study candidates. Of the 46 respondents, seven programs at six sites appeared to satisfy the above criteria, and these were selected for more intensive study through site visits. Figure 1 lists the sites selected for our case studies and some of their key characteristics.

F I G U R E 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			•

Members of our research team visited each of these sites for two days. A formal comprehensive document request, seeking planning, evaluation, budget, governance, and other information preceded this visit. Semi-structured interviews were conducted with program leadership and staff. Where possible, other key public and private players in the communities in which the sites operated were interviewed. The results of our in-depth examinations of these sites are presented in the case studies contained in our full report to The Robert Wood Johnson Foundation. The full paper can be found at: www.newschool.edu/milano/Health/cbohealth

WHAT'S WORKING AND WHY:

Elements of Success

Our research greatly improved our understanding of what makes certain programs succeed. More specifically, we identified four key organizational and environmental factors that fostered program success, as well as a number of “best practices” widely employed by the programs we studied.

Organizational and Environmental Factors That Foster Successful Projects

The following organizational and environmental factors appeared to be critically important in advancing program goals and objectives. These factors provided the necessary foundation on which effective programs could be built. In fact, one could argue that, absent these factors, few (if any) programs could ultimately survive in the long term — regardless of the level of innovation of their individual strategies or practices.

Sponsorship by an Existing Entity

All the programs we studied were in some way built on a preexisting organizational structure. This sponsorship had several benefits. Some projects were supported temporarily by these sponsor organizations when funding expired. Others were maintained by the parent organization even when external funding was clearly inadequate to cover program costs.

Leadership

Strong, committed leadership was central to the success of all the programs we visited. More specifically, the success of each of the programs we studied was strongly identified with the commitment of a single leader. These energetic, and often charismatic, individuals have a strong belief in what they are doing, and persist in developing and maintaining their programs in the face of financial and organizational adversity.

Strong Local Provider Interest

In all successful models we studied, local providers — doctors, hospitals, and clinics — offered support through program sponsorship or through formal and informal ties to the programs. These providers saw these programs as supporting their own missions and easing their clinical and financial burdens. Thus, they served as a source of referrals for these programs and, in turn, often served patients identified or managed by the programs themselves. In addition, hospitals and doctors were generally more likely than were community-based organizations to be an integral part of the local business elite. They were thus positioned to help create a political environment that would sustain the efforts of community-based programs.

Broad Indigent Care Finance Systems

The most successful programs we studied were able to access public health services for their clients that were available, for example, through federally funded community health centers or screening programs, or through state level charity care programs. In some cases, city-owned hospitals or clinics were available as well. When a supportive health care finance environment enabled local providers to do their parts, community initiatives flourished.

PROGRAM NAME:

The Contra Costa Breast Cancer Partnership

LOCATION: Contra Costa County, California

PURPOSE: To increase early detection and treatment of breast cancer among low-income, uninsured, and underinsured women over age 40

TARGET POPULATION: Black and Latina women

STRUCTURE: Public/private partnership comprised of breast cancer survivors, providers, advocates, and community agencies, and housed within the county health department

OUTREACH METHODS: Health fairs, marketing through community-based organizations and a variety of public relations events

SERVICES: The Partnership offers intensive education, outreach, and screening and diagnostic services (including clinical breast exams and mammograms), and makes referrals to a wide range of local providers for treatment.

ELEMENTS OF SUCCESS:

Use of One-to-One Outreach

The program uses “patient navigators” — recruited lay community members — to help Spanish-speaking women effectively access a fragmented provider system. Patient navigators also engage in advocacy, provide on-site translation, and assist patients in enrolling in MediCal and other indigent care programs. Navigators are trained in medical interpretation, breast health, communication, and medical terminology.

Mobilization and Management of Community Resources

The fact that the county itself provides a full range of health services, from public health to tertiary medical services, is a key element of the program's success. Women are referred to a mix of public clinics, Planned Parenthood centers, public and private hospitals, and physician practices. The program coordinates access to the continuum of services from screening to treatment, across the multiple providers.

NOTABLE OUTCOMES: Breast cancer early detection rates among Contra Costa's African American women increased significantly from 44 percent in 1992 to 71 percent in 1997, achieving parity with rates for white women. In 1999, 1161 women were screened.

PROGRAM NAME:**Women's Fest (Festival de la Mujer), Y-ME National Breast Cancer Organization****LOCATION:** Chicago, Illinois**PURPOSE:** To address the geographic, financial, and cultural barriers to early detection of breast cancer**TARGET POPULATION:** Low-income Latina and African-American populations across Chicago**STRUCTURE:** Operated by the Y-ME National Breast Cancer Organization, one of the nation's largest non-profit breast cancer organizations**OUTREACH METHODS:** Monthly health fairs hosted by local community-based organizations in various parts of the city**SERVICES:** The program offers education and screening services at monthly fairs. Some participants receive mammograms in a county-owned mobile unit, others are referred by outreach workers to municipal clinics, non-profit hospitals, or the Cook County hospital for low-cost or free mammograms.**ELEMENTS OF SUCCESS:*****Fostering Volunteerism***

Y-ME relies extensively on volunteer peer counselors to operate its 24-hour, English and Spanish hotline through which they provide information, referrals, and emotional support to callers. Trained Latina volunteers also provide breast health education, outreach, and support to breast cancer patients and their families.

A Commitment to Cultural Competence

Volunteer training programs are conducted in English and Spanish, and systematic education in cultural belief systems around breast cancer is an important part of this training. The organization also provides diversity training at all levels, and recruits minorities into senior positions.

Sponsorship by an Existing Entity

Y-ME's ability to conduct this particular initiative has been greatly aided by other activities undertaken by the national organization. As America's largest breast cancer support organization, Y-ME has 26 affiliates, developed a national bilingual hotline, translated and tested Spanish-language literature, and created the only bilingual breast cancer newsletter in America. The hotline also maintains a national database of breast cancer diagnosis and treatment resources, with special emphasis on options for low-income women.

NOTABLE OUTCOMES: In 2000, three events drew 215 participants; 116 clinical breast exams were performed; 32 women received mammograms; and seven others received referrals for mammograms at local clinics.**Best Practices**

Through our research, we identified certain practices employed by most, if not all, disparities reduction programs. These key practices are described below.

The Mobilization and Management of Community Resources

One practice central to all our study sites was the mobilization and management of a continuum of disease-specific resources available within a community. None of the organizations we encountered possessed all the services that were offered to patients under their programs. Instead, they coordinated and promoted services provided by other organizations. In some cases, this meant coordinating patient care among physician's offices, hospitals, clinics, and social services. In others, it entailed assembling widely dispersed educational, diagnostic, and treatment resources into one rational whole. Thus, successful programs were involved in both broad-based network development, as well as with ensuring that patients received services on a day-by-day basis.

One-to-One Outreach

All six study sites engaged in some form of one-to-one outreach, whether through volunteers, lay navigators, or caseworkers. These workers identified clients, enrolled people in programs, assisted people in navigating a complex and unwelcoming health care system, and served as health educators. They formed strong bonds with clients and families, which enhanced the credibility and acceptance of their educational message. Moreover, they often served as advocates for their patients and sought to obtain additional services for them.

Building Bridges to the Provider Community

The involvement of local doctors, hospitals, or clinics was a key factor in the success of the programs we examined. The programs we examined all recognized the importance of building formal and informal bridges to the provider community. They all invested significant time and resources in cultivating, maintaining, and reinforcing links with local providers.

Practicing Cultural Competence

At all of the study sites, practicing cultural competence extended beyond the ability of program staff to speak their clients' language. It also involved their having knowledge of the culture, lifestyle, diet, beliefs, and values of the client population, as well as of the barriers to care that these clients face. This was often accomplished by hiring workers or training volunteers who came from the cultures they were to serve. At some sites, cultural competence also involved the inclusion of minority representatives on governing boards and among upper level management.

Fostering Volunteerism

Several of our sites made extensive use of lay and clinical volunteers. Volunteers provided a low-cost, culturally competent method for strengthening links with the community and directly serving patients.

Taking an Active Role in Policy and Advocacy

All of the programs we examined viewed their roles as extending beyond service provision to actively advocating for change, though their methods of doing so varied widely. A few engaged in very focused, sustained efforts to change laws and policies at the state and national levels, while others engaged in more sporadic or less formal activities designed to focus public attention on their concerns.

AREAS OF NEED

The preceding section highlighted practices employed by community-based programs that made them especially effective, as well as organizational and environmental factors that underpinned their success. We now turn to needs and challenges that must still be addressed if such programs can be expected to continue to develop and thrive. During our research, a number of needs were repeatedly articulated or became obvious — even at the most successful sites. These needs fall into two broad categories: structural needs and research needs.

Structural Needs

The Need for Stable, Predictable Long-term Funding

The most common and far-reaching challenge facing community-based disparities reduction programs is the absence of adequate and stable funding. In fact, it seems safe to say that short, unpredictable funding cycles are the major impediment to the growth and success of such programs. Nearly all such 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. This chronic instability breeds anxiety, makes recruitment and retention of talent difficult, weakens the initiatives' credibility, and makes it very hard for them to have a demonstrable impact on the problems they are trying to solve. 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 lack the history and tradition of philanthropy, volunteerism and business leadership seen in the white community. In addition, securing funding from Medicaid or other indigent health care finance systems is a slow, uncertain, and usually unsuccessful effort.

The Need for Leadership Development

As already noted, highly committed, experienced, and often charismatic individuals headed all the projects whose successes we highlighted. Yet even with all that they bring to their programs, these individuals frequently need support and assistance. Some of these leaders seem to be at risk of isolation, often working in small communities or communities isolated by poverty and ethnicity. They have few peers with whom to share knowledge and experiences, and often a great gulf of education and experience separates them from their immediate subordinates. Indeed, many programs could suffer irreversible harm should one or two senior staff members depart.

The Need for Organizational Development

Lacking adequate resources, many programs operate with minimal management and human resource infrastructures. Budgets are often quite rudimentary, and few programs can afford to hire individuals with solid financial backgrounds. Personnel policies and procedures are frequently inadequate. Training is often obtained in a piecemeal fashion from many outside agencies, often without a curriculum in place. All told, these programs have many basic needs that are shared by community-based organizations of all stripes.

Information and Communications Needs

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 that lists community-based disparities reduction programs or describes the approaches they have adopted. Information about such programs must be obtained in a relatively haphazard, word-of-mouth fashion. 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 issues and disparity reduction efforts, and frankly surprised by how little each knew of others' efforts.

Research and Evaluation Needs

Evaluation of Strategies and Programs

Program leaders have little guidance in assessing which interventions might be worth implementing. Indeed, few have a clear sense of how their own programs are doing in meeting their goals. Fewer still have knowledge of what is being tried elsewhere and with what degree of success. In our own research we tried to identify those factors and practices that may be most promising, but much more work is needed in this area. While the Evidence-Based Medicine movement is helping clinicians make better-informed clinical decisions by assessing the medical literature, little similar exists for community-based disease prevention and health promotion efforts.

Rigorous evaluation of strategies and approaches being pursued by different community-based programs is needed to answer a number of key questions. One set of questions concerns the relative merits of different approaches adopted by the programs we studied. For example, while some initiatives depended heavily on lay workers and volunteers, others primarily used health professionals for outreach and case management. Interviewed experts and program leaders expressed strong but divergent opinions about the “right” ways to do this, yet none could cite strong evidence to support their assertions. Rigorous evaluation of these different strategies would be very helpful to existing and future undertakings.

A second set of questions concerns the effectiveness of strategies common to most of the programs we examined. For example, can the effectiveness of one-to-one outreach efforts be shown to justify the presumably high cost of this widely-used, labor-intensive strategy? More rigorous cost-analysis of this practice could help shape the design of future programs.

At the most basic level, most program leaders need to know more about how their programs are doing. Many programs lacked complete evaluations of their initiatives, while others lacked evaluations of any sort. This was not because program leaders did not recognize their value, but because they lacked the resources to undertake them; the necessary time, money, and management capacity just did not exist.

Economic Benefit Analysis

As yet, no sophisticated economic argument has been developed to demonstrate why disparities reduction initiatives deserve public or private financial support. An analysis is needed that documents the economic benefits that might accrue to businesses, hospitals, doctors, and insurers (including Medicaid) from disparities reduction programs. Local decision makers and providers will



support such efforts only if they believe that it is in their own best economic interest to do so. Thus, state Medicaid directors must be shown that their states will save money were they to fund case management and patient navigation services. And the private sector may be interested in the economic benefits of reducing lost days at work or preventable hospitalizations associated with untreated diabetics in minority communities.

Quality and Patient's Rights

A number of programs required assistance in developing simple quality assurance and quality improvement methods. While all tried, at a minimum, to track some process outcomes, some still needed to develop formal, ongoing feedback mechanisms to continuously monitor, and act upon, quality measures. In addition, some programs may need guidance with regard to issues of patient confidentiality and informed consent. If community-based disparity reduction initiatives are to be held to the same standards as apply to the rest of the health care system, they will need help in these areas. While some may argue that these programs should not, or cannot, be held to these standards, to do otherwise would mean endorsing a lower standard of quality for the most vulnerable members of our communities.

PROGRAM NAME:

The Paso a Paso Diabetes Program and the Unidas Podemos Breast Cancer and Cervical Cancer Initiative of The Way of the Heart: The Promotora Institute

LOCATION: Nogales, Arizona

PURPOSE: To provide health screening and educational services to poor, uninsured Latina residents of the region, including many undocumented immigrants

TARGET POPULATION: Latina populations in and around Nogales, Arizona, and Sonora, Mexico.

STRUCTURE: Freestanding, non-profit organization

OUTREACH METHODS: Health fairs, screening events, and walking the streets of the colonias (un-zoned, semi-rural communities without access to public drinking water or wastewater systems, with an estimated population of 350,000 on the U.S. side of the border)

SERVICES: The program offers diabetes screening and education, breast and cervical cancer education, and referrals for mammography.

ELEMENTS OF SUCCESS:

One-to-One Outreach and a Commitment to Cultural Competence

Promotoras de salud, bilingual, bicultural, lay community health workers, engage in 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.

Building Bridges to the Provider Community

The Institute has developed collaborative relationships with local clinical providers and social service agencies. As a result, an informal network of providers offers access to a limited number of free or low-cost drugs, as well as to limited mammography, treatment and other services. This network includes volunteer physicians, the local federally funded community health center, the local Catholic hospital on the U.S. side, the Mexican public hospital, and the Santa Cruz County health department.

NOTABLE OUTCOMES: Between August 1999 and January 2001, 39 new diabetics were identified. During that period, 203 managed diabetics had a net decrease of serum glucose of 51mg/dl since the project began. Weight loss averaged 3.5 pounds for 94 exercise class attendees, while about 85 percent of medical referrals were completed.

PROGRAM NAME:**Delta Community Partners
in Care Project****LOCATION:** Clarksdale, Mississippi**PURPOSE:** To improve outcomes for diabetic and hypertensive patients using a clinic-based, case management model**TARGET POPULATION:** Highly dispersed, predominantly African American, low income, largely uninsured population in the surrounding 10-county Delta Region**STRUCTURE:** A public/private partnership comprised of community health clinics, universities, hospitals, and state agencies**OUTREACH METHODS:** Professional caseworkers based in doctors' offices and clinics**SERVICES:** Professional caseworkers (principally licensed practical nurses and social workers) provide home visits, follow each patient through the continuum of care, and work to foster behavior change as well as compliance with treatment plans. The project also transports clients to and from clinic appointments free of charge.**ELEMENTS OF SUCCESS:*****A Commitment to Cultural Competence***

Caseworkers are recruited from the local community and receive health education and clinical training tailored to their own backgrounds. Training emphasizes the development of active listening and interviewing skills. The caseworkers' understanding of their clients' beliefs, diets, and lifestyles is recognized as critical in overcoming the "culture barrier" that often exists between clients and health care providers.

Strong Local Provider Interest

This project demonstrates the key role that local providers can play in identifying and working to address local needs. Health care provided at the Northwest Mississippi Regional Medical Center became increasingly concerned about the high number of preventable, poor outcomes (e.g., loss of limbs and stroke) among patients with diabetes, and with the cost burden this was placing on the Medical Center — at that time a county facility. This prompted Medical Center staff to work with local clinics and hospitals to develop a program to better manage care for poor, diabetic patients.

NOTABLE OUTCOMES: As of 2001, 1067 patients were enrolled in the program, of whom 346 were uninsured, and about 90 percent were African American. An evaluation of four years of data from the project revealed a statistically significant reduction in ER utilization, patient days, number of sick days and bed days, and use of multiple primary care providers. There was also 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.

IMPLICATIONS FOR THE PHILANTHROPIC COMMUNITY

Funding Options

The research findings presented here point to a variety of opportunities for funding disparities reduction initiatives. Funders wishing to expand the capacity of existing community-based programs can build on successful initiatives. More specifically, they can use the best practices described above to identify initiatives worth expanding or replicating. Alternatively, funders can opt to invest in activities that will address unmet needs identified above — needs faced almost universally by disparities reduction programs. Finally, investments can be made in research that will address unanswered questions and create a broader understanding of what works and how best to achieve it.

Below are recommendations for action in each of these areas. These recommendations could be implemented individually or as part of a coordinated strategy.

Building on Success: Service and Replication

Funding the growth and replication of existing programs is an obvious strategy for expanding disparities reduction efforts. Such a strategy could both increase the capacity of existing community-based agencies and serve as the basis for needed, rigorous evaluations. The best practices identified earlier in this report should help in the identification of programs that, with additional funding, might produce the greatest benefits. Funders may wish to focus on increasing the use of a particular model or, recognizing that local conditions demand tailored responses, a funding strategy could be pursued that would support a variety of models.

To enhance their chances of success, funders wishing to invest in the expansion or replication of successful programs must pay particular attention to the following issues:

The importance of stable funding

As already noted, short funding cycles breed instability and vulnerability. At present, few programs have access to stable, non-governmental funding. A development and replication program should be undertaken only if funders are willing to consider long-term financial commitments, on the order of at least five, and possibly as long as 10, years. This may allow some efforts to attain the critical mass, credibility, and visibility that could ultimately result in permanent, stable funding.

The importance of developing advocacy skills

The development of advocacy skills as an integral part of program activities is crucial to the growth and replication of good models. Unless diabetes management programs can, for instance, make the case that state Medicaid programs should pay for outreach and case management services, there is little chance that they will be replicated on a broad scale. Making that case involves not only being able to present a well-founded argument, but also having a set of advocacy and public relations skills that are often seen in large hospitals and trade organizations, and rarely in small community agencies. Funders should be sure that some of their investment supports these critical skills.

Support of new vs. existing programs

Funders will need to decide whether to target extant community organizations with track records or to “seed” the development of new organizations. Our own findings indicate that initiatives with the most staying power are those 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 parented by larger organizations may risk reducing opportunities for innovation. The most innovative work may come from projects not affiliated with older bureaucracies. A balanced, “portfolio” approach could be used, in which very deliberate decisions are made to support different types of programs, knowing that some will have a greater chance at long-term, modest success, while others may involve greater risk but could produce breakthrough strategies.

Meeting Needs: Capacity Building

We earlier identified a number of key needs and challenges that disparities reduction programs commonly face. The following recommendations could expand the capacity of existing programs by addressing widespread needs for management skills, administrative infrastructure, training resources, and technical expertise.

Creation of a Disparities Leadership Institute

At present there are hundreds of individuals in leadership positions at disparities reduction programs around the country. These individuals have very different personal and educational backgrounds, yet need a core set of competencies to be effective. Funding a leadership institute would provide basic training to selected program leaders, allow them to learn from each other, provide recognition for their dedication, and enable them to form their own morale-building network of peers.

Such an institute might cover the following topics:

- Epidemiology of health disparities conditions
- Evidence-based review of community disparity reduction strategies
- Quality improvement in community-based organizations
- Patients’ rights and confidentiality
- Practicing cultural competence
- Coalition formation techniques
- Building finance and human resource systems
- Development strategies
- Public relations and advocacy
- Program evaluation: theory and tools

Development of general capacity-building programs

Many of today’s disparities reduction programs would greatly benefit from investments in their administrative and clinical infrastructures. The philanthropic community might thus wish to consider funding one or more organizations that would provide training to the leadership or staffs of existing community-based programs. This training could focus on enhancing understanding of clinical issues (such as the epidemiology of health disparity conditions) or on strengthening administrative skills (including management, development, and advocacy skills). This training could be offered to any number of programs, and



focus on as many — or as few — issues as one would want to target. The issues could be drawn from the suggested list of topics for the leadership institute mentioned above. This training could be further supported with direct grants to provide community-based programs with the ability to develop these capacities. Many programs would, for example, welcome the funding that would allow them to hire an accountant or a grant writer.

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 community-based organizations have done this to date or have the internal capacity to produce such a document.



Creation of a central management services corporation

An alternative to training the staffs of community-based programs in the various functions described above would be to provide these functions directly to these programs at little or no cost. A new management services organization (MSO) could be created and staffed with a variety of individuals with specialized skills who would essentially serve as consultants to these programs in the areas identified above. Thus, rather than hiring its own grant writer, a program could pay a nominal fee for the services of a grant writer employed by the MSO.

Assuming the MSO were created as a non-profit entity, it could deliver services at prices far below those charged by for-profit consulting firms. Philanthropic support for such an entity would provide community-based programs with capacities and skills taken for granted in other parts of the health care world. The control of all these resources by the MSO — a single entity — would provide funders with accountability and attention to outcomes.

Creation of a core curriculum and competencies for promotoras

The use of promotoras — bilingual, bicultural lay community health workers — is one of many outreach models we encountered in our research. This particular model holds great promise, and promotoras should have access to the highest quality training. This is a model with implications for all the border states, for Latino communities across America, and for Mexico. The State of Texas has begun some work in defining a core curriculum, and credentialing trainers. The creation of a model national curriculum and training standards to be adapted on a state-by-state basis could provide valuable support for promotoras and the programs they support. This work would need to be coordinated as much as practical with Mexican health authorities, given the cross-border work done by many promotoras.

It is important to note that 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 communities. However, the work done by promotoras is both important and sensitive. Promotoras 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, and issues such as patient's rights, informed consent, confidentiality, and other matters. This training would also likely bolster promotoras' confidence and esteem, aiding recruitment and retention.

Creation of a national web portal on disparities in health and health care

There is much information about disparities programs residing in many different organizations, publications, and websites. Various agencies within the US Department of Health and Human Services, for example, contain substantial information on disparities on their websites. However, there is no one place to go for information on disparities. The creation of a national web portal on disparities would fill this void. It could include:

- Contact information for agencies and organizations involved in the reduction of disparities;
- Listings and contact information for community-based initiatives;
- Summaries of recent research findings;
- Best practices tips;
- Critical, evidence-based assessments of intervention strategies;
- News concerning policy changes at the federal and state levels;
- Information about available funding;
- Notices of upcoming public events;
- Highlights of selected community programs; and
- Links to other relevant websites.

A properly maintained site would also help agencies and foundations interested in marketing educational and grant opportunities. Such a site would give agencies and foundations a single place to post these opportunities, requests for proposals, and other important announcements. Similarly, a state health department holding a conference on disparities could announce it on the site.

Improving Understanding: Research, Evaluation, and Analysis

As noted earlier, future disparities reduction efforts would benefit from better information concerning different approaches currently being pursued, from rigorous evaluation of competing strategies and outcomes, and from a sophisticated analysis of the benefits of such programs. This set of needs thus offers additional opportunities for investment by the philanthropic community. More specifically, funders may wish to consider supporting the following research initiatives:

Controlled evaluation of different organizational models

Through our research, we identified a set of strategies and approaches we believe to be “best practices.” However, many organizational questions remain: for example, 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 did not allow us to pursue these questions. Systematic evaluation of the effectiveness of different organizational models would be very valuable.

Controlled evaluation of different outreach worker models

We encountered a variety of 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 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, if so, in what populations? What is the relative cost-effectiveness of various types of workers? Are so-called “indigenous” workers more effective than other workers? What are the merits, and drawbacks, of using volunteers? Should workers have lay or

PROGRAM NAME:**The Sacramento Urban Indian Health Project, Inc.**

LOCATION: Sacramento, California and its environs

PURPOSE: Diabetes management

TARGET POPULATION: Native Americans

STRUCTURE: Non-profit clinic governed by an all Native American Board of Directors

OUTREACH METHODS: Screening and education events held at regular pow wows (sponsored or attended by the clinic) and referrals from other area providers such as county health clinics

SERVICES: Native American lay community health workers make home visits to clients, provide health education, assist with disease management, refer patients to clinical and social services and link clients to nutrition classes.

ELEMENTS OF SUCCESS:***One-to-One Outreach***

The centerpiece of this program is its home visiting activity. Through home visits, community health workers provide dietary and lifestyle assessments, serum glucose checks, remind patients to make and keep appointments, provide patients with free glucometers, and encourage patients to attend county-supported nutrition classes. Through such visits, project staff additionally seek to meet other health needs of their patients’ families.

A Commitment to Cultural Competence

The “insider status” of Native American community health workers is vital to the success of this program, given the high level of mistrust of whites among the Native American population. Equally important is the program’s focus on developing culturally appropriate strategies for addressing patients’ needs, and on framing of diabetes management strategies in terms of “Native American values.”

NOTABLE OUTCOMES: As of 2001, the home visiting activity served nearly 100 diabetics.

PROGRAM NAME:**The Breast Health and Cervical Cancer Program of the Charles B. Wang Chinatown Health Center****LOCATION:** New York, New York**PURPOSE:** To promote the early detection of breast and cervical cancer**TARGET POPULATION:** Uninsured Chinese-American women**STRUCTURE:** Not-for-profit corporation governed by an all-Asian Board of Trustees**OUTREACH METHODS:** Ads placed in Chinese newspapers and on radio, a regular health information radio call-in show, and large health fairs.**SERVICES:** Clients are assisted in accessing services provided by a network of local providers, and in enrolling in available indigent care programs. Interested women aged 40 and over are offered clinical breast exams and pap smears at center clinics. These clinics also offer general health education in Chinese on a number of relevant topics.**ELEMENTS OF SUCCESS:*****Fostering Volunteerism, A Commitment to Cultural Competence and One-to-One Outreach***

This program offers one-to-one, same language, culturally-based education and assistance. Volunteer patient navigators help patients access available screening services and assist in translation. 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 activities. It also serves other Asian American communities.

Broad Indigent Care Finance Systems

The Wang CHC benefits from being a federally-funded community health center, and has access to many more financial resources than are generally available to most stand alone programs. In addition, Wang is also able to refer its clients to a broad array of services provided by city-owned hospitals and clinics that are supported by financing vehicles such as the New York State indigent care pool.

NOTABLE OUTCOMES: During the six years the program has been in existence, the missed appointment rate for mammograms has fallen from 80 percent to 20 percent. The Breast Health Program performed 227 mammograms during the year 2000 and 189 during the first six months of 2001. Over 40 percent of the screened women report never having had a prior mammogram. Over 90 percent rated the quality of service as “excellent” or “good.”

professional backgrounds? A thorough, objective, and systematic evaluation of the different outreach worker models currently in use would help answer these key questions.

Demonstration of economic benefits

As already emphasized, the long-term viability of disparities reduction programs requires stable funding above all else. In order to acquire such funding, programs must be shown to produce economic benefits to the public and private sectors. As yet, no case laying out these benefits has been made of which we are aware. The philanthropic community can help by funding efforts to determine whether such a case can be made. If economic benefits can be demonstrated, community-based organizations must be given the data and tools with which they can make their case in their own communities and states. This would be a powerful adjunct to their advocacy work.

Potential Impacts

A variety of options for funding disparities reduction efforts have now been identified. What can the philanthropic community expect to achieve from support of such efforts? It is perhaps too early to really know. Community-based disparities reduction initiatives are inarguably providing valuable services to the populations they serve. We strongly suspect that these initiatives do have an effect on select, local populations. Yet, across the board, these programs are small and have short track records. The largest served 1,000 clients. Combined, our 46 surveyed programs reported that they provided assistance to a total of 123,000 people throughout their history. It will take significant increases in the number and size of these programs to yield discernible national reductions in health disparities. Even hopes for more narrowly defined success must be tempered by recognition of obstacles that could hobble even the best-planned, best-financed ventures. Many of these have been mentioned above: unstable funding; a lack of willing providers; local politics; and the like. Yet these programs also hold great promise. Close to the people they serve, and often led by people from these same communities, they may be most able to mount meaningful local efforts. With some technical and financial support, they may be able to do much more.

CONCLUSION

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.



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Additionally, the investigators would like to thank the interviewed experts, surveyed programs, and the leadership and staff of the six case study sites for their important contributions.

