

Social Justice and Health in Arizona Border Communities

THE COMMUNITY HEALTH WORKER MODEL

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THE UNITED NATIONS WORLD HEALTH ORGANIZATION defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization 1986). Public health is the means through which society creates conditions that favor the achievement of optimal health within populations, and accordingly it focuses on prevention rather than treatment of disease. Public health is a collective response to groups and communities—the public as a whole—rather than to individuals. Thus, public health must be concerned with social and economic conditions that are at the core of health outcomes. Public health becomes an instrument of social justice, because it advocates for equitable distribution of the resources and circumstances that influence health, such as access to health care, adequate housing, availability of recreational areas and healthful food, and environmentally safe neighborhoods.

The magnitude of health disparities among subgroups of the U.S. population is a major public health concern and indicative of injustices that exist in our society. Latinos, African Americans, and Native Americans suffer higher rates of morbidity and mortality due to diabetes, asthma, cancer, heart disease, and a variety of other diseases than do whites.

Unfortunately, public health efforts to address health inequities tend to focus on symptoms: promoting personal behavior change through culturally appropriate educational interventions, increasing access to care through outreach and referral, improving health literacy, and improving patient provider communication. While perhaps effective in addressing

individual health outcomes among target populations, these strategies have had virtually no impact on closing the gap in health status between people of color and their white counterparts. Limited success is not surprising, given that traditional public health strategies are not necessarily grounded in a social justice perspective that seeks to transform the institutions that are at the root of health inequities. Hoffrichter (2003) makes the point that it is necessary to address the systematic treatment of people as members of a definable group and ensure an equal distribution of life opportunities.

People living in colonias along the U.S.–Mexico border suffer disproportionately from the root causes of health disparities and their health outcomes. If the U.S. border region were made into a state, it would rank last in access to health care, last in per capita income, first in number of children living in poverty, first in number of children who do not have health insurance, second in rates of hepatitis deaths, and third in death related to diabetes (U.S.–Mexico Border Health Commission 2003).

With a focus on Arizona, this chapter describes health issues in border communities from a broad perspective that includes the social determinants of health. The community health worker (CHW) model is explored as a means to address health disparities through case studies in two communities along the Arizona–Sonora border. Finally, recommendations to enhance the potential for the CHW model to address the root causes rather than symptoms of health inequities by advocating for community organization and empowerment are provided.

Social Disparities and Access to Health Care in the U.S.–Mexico Border Region

The U.S. border population has more than doubled since 1970, from 3.1 million people to 6.6 million people in 2000, and is projected to have 9.4 million people by 2020 (U.S.–Mexico Border Health Commission 2003). The border state of Arizona experienced the greatest increase in population, growing by more than four million people over the last 30 years. A growing percentage of the border population is of Latino origin. U.S. Census Bureau estimates for 2006 indicate that nearly 15 percent of the U.S. population identify themselves as Hispanic, while over

29 percent of Arizona's population is Hispanic. In border counties percentages fluctuate between 25 percent and 99 percent. These populations reflect a relatively young population and a high birthrate, as well as increased migratory flow northward from Mexico. Educational attainment among the U.S. border population, a fundamental indicator of social equity, is among the lowest in the nation and is even more striking based on proximity to the border. In Arizona, 50 percent of Nogales City residents in Santa Cruz County do not have a high school diploma or GED equivalent, compared to 25 percent of all residents in that county, a trend that is observed in all Arizona border cities (Arizona Department of Health Services 2003). Poverty rates are among the highest in the nation (U.S.-Mexico Border Health Commission 2003).

Access to Health Care

From a public health perspective, access to health care is the major indicator of social equity and a barometer of social justice. Access to care, including preventive care and general health information as well as the diagnosis and treatment of health problems, is critical to creating and maintaining healthy communities. For the purpose of this chapter, access to health care provides the lens through which to analyze problems and solutions.

Health insurance is the single most significant contributor to accessing care (Centers for Disease Control and Prevention 2004; Cohen, Meister, and de Zapien 2004; Parchman and Byrd 2001). On average, one-third of border residents do not have health insurance, and in some communities the percentage of uninsured is as high as 60 percent (Bastide, Brown, and Pagán 2008). Among border residents in Arizona, those least likely to have health insurance include the unemployed (47 percent), those with less than a high school education (43 percent), and Hispanics (43 percent), further evidence of the association between access to care and other social inequities (Arizona Department of Health Services 2007). Uninsured residents in border communities are also more likely to deprive themselves of health care because of cost (U.S. National Center for Health Statistics 2006). The uninsured, and many times the insured, seek low-cost health care and the accessibility of Spanish-speaking providers across the border into Mexico (Hunter et al. 2003, 2004;

Landeck and Garza 2002; Macias and Morales 2001; Seid, Stevens, and Varni 2003).

However, insurance is only one aspect of health access. Even those who are eligible for federally funded insurance do not necessarily avail themselves of the resource. In Arizona in 2007, only 50 percent of children eligible for SCHIP (State Children's Health Insurance Program) or Medicaid insurance programs were currently enrolled in those programs, a percentage likely to be lower in border communities.

Other factors related to health-care access include having an adequate number of primary health-care providers, and in particular Spanish-speaking providers, culturally competent health-care organizations, health-care specialists, and specialty care requiring advanced technology, all located within reasonable proximity to the population in need. In border counties there are scarce health-care resources, insufficient hospital beds, few doctors, and fewer nurses and dentists. The majority of border communities are recognized and designated as health professions shortage areas (HPSAs).

Disempowerment of Border Communities

There is growing concern that the militarization of the border in response to immigration increases the stress of residents both documented and undocumented and negatively impacts their ability to access health and other services. Over the past few years, scholars, human rights groups, and journalists have found that U.S. Border Patrol enforcement practices and increasing political hostility (e.g., so-called "civil patrols" of anti-immigrant Americans along the border) toward Hispanics have created a climate of profound fear within the Hispanic community (Romero and Marwah 2005; U.S. Commission on Civil Rights 2002), resulting in underutilization of health and human services by the border population. Furthermore, recent legislation in Arizona denying undocumented immigrants access to public housing, public health care, a college education, publicly funded child care, and utility assistance has intensified the problem. Human services not even yet affected by such legislation have seen a drop-off in the level of participation by Hispanics due to fear that they will be harassed, lose their immigration documents, or be apprehended by U.S. Border Patrol agents.

The Community Health Worker Model

From a social justice perspective, solutions to the glaring health disparities in border communities lie in the potential for border residents to increase their participation in the civic process, to generate collective action, and to pressure private and public institutions to create a more egalitarian system that protects health (Wallack 2003). The current climate of fear and disempowerment, to even utilize available services, speaks of the challenges facing attempts at community organizing. For example, only 38 percent of registered voters in Santa Cruz County participated in the 2002 elections, compared to 56 percent for the state (Arizona Secretary of State 2002).

Community health workers (CHWs), also known as *promotores(as)*, community health advisors, lay health advisors, outreach workers, and community health advocates, have been working with Latino populations along the U.S.–Mexico border for several decades. CHWs are well-respected, indigenous community members who seek to eliminate prominent health problems by increasing health-care utilization, providing health education, and advocating for patient needs. CHWs have successfully increased health knowledge and/or health service utilization in many areas, including nutrition (Elder et al. 2005), diabetes (Corkery et al. 1997), chronic disease screening (Hunter et al. 2004), and cancer screening (Hansen et al. 2005; Navarro et al. 1998).

CHWs also have the capacity to address the root causes of health disparities. CHWs have an intimate knowledge of community needs and extensive awareness of community resources, and are considered leaders among their peers. These qualities place CHWs in a unique position to represent their communities and advocate on a community level by pressuring lawmakers to pursue structural changes that will address health inequities.

Use of the Promotor(a) Model in Arizona Colonias

Since the launch of *Comienzo Sano* in 1987, a prenatal outreach and education intervention in Yuma County along the U.S.–Mexico border, researchers in southern Arizona have collaborated with border communities in Yuma, Santa Cruz, and Cochise counties to develop, implement,

and evaluate programs utilizing the CHW model. Comienzo Sano was eventually sustained as a line item of the Arizona Department of Health Services budget and is now implemented in rural and underserved communities throughout Arizona (Meister and de Zapien 1989; Meister et al. 1992). Since that time, several CHW organizations have been initiated in border counties, with projects addressing chronic disease, environmental health, infectious disease, violence, and substance use. A common attribute of all programs is that CHWs advocate for members of their community to gain access to health-related resources.

There is limited academic research on the role of CHWs as community organizers. But one Arizona border project, the Border Health Strategic Initiative (Border Health ¡SI!), built on an academic–community partnership and funded by the Centers for Disease Control and Prevention from 2000 to 2003, was a comprehensive diabetes prevention and control program that centered around the use of CHWs to work across multiple domains of the community (Cohen and Ingram 2005). CHWs were crucial in engaging the community to address environmental changes conducive to health, and in successfully mobilizing program participants to lobby local politicians for increased funding for recreational areas (Meister and de Zapien 2005).

The remainder of this chapter uses case studies of diabetes and childhood obesity to explore the potential of CHWs as instruments of social change. We also discuss the CHW model's potential for addressing the core determinants of health disparities through community advocacy.

The Campesino Diabetes Management Program. Yuma County, Arizona, located along the border adjacent to Sonora, Mexico, is known as the lettuce capital of the nation. Yuma County has the largest number of farmworkers in the state: an estimated 35,000 to 60,000 farmworkers during the peak growing season. Strenuous labor, poverty, and social isolation place farmworkers at high risk for health problems and severely limited access to health care (California Institute for Rural Studies 2000). A 2002 survey found that only 10 percent of Yuma farmworkers completed the equivalent of a high school education (Yuma Private Industry Council 2002). The Arizona Department of Economic Services estimates that the average annual family income for farmworkers equals \$13,440. Lettuce workers may earn up to \$7 per hour, but the average is \$5.50 to

\$6 per hour. During growing season, their day spans 12 to 14 hours in the fields and often includes commuting long distances to and from work. The long day combined with odd work schedules, language barriers, lack of insurance, and constant migration hinders the ability of farmworkers to access services. This causes a considerable gap in health-care access; the California Agricultural Workers Survey documents that 68 percent of male participants have never seen a doctor. More than two-thirds of the men and women have never had an eye exam, and there is extremely low access to dental care, as reflected by the high proportion of dental problems in the study sample. A household survey of farmworkers conducted in Yuma in 2007 finds that nearly half (46 percent) have no medical insurance, and 28 percent do not access needed medical care because of cost.

The Campesino Diabetes Management Program (CDMP) was created by Campesinos Sin Fronteras (Farmworkers without Borders), a promotor(a) program in South Yuma County serving farmworkers. The CDMP was one of eight demonstration projects funded by the Robert Wood Johnson Foundation Diabetes Initiative. The CDMP sought to build community support for diabetes self-management, because it is a growing health threat among farmworkers. The prevalence of diabetes in the Mexican American population is at least two to three times greater than among non-Hispanic whites (Bastidea, Cuéllar and Villas 2001; Health Resources and Services Administration 2000), and they are two to three times more likely to suffer from serious secondary complications (Garcia et al. 2001; Haffner et al. 1988; Haffner et al. 1990; Hanis et al. 1983). These challenges do not escape the farmworker population in Yuma County; in a Yuma household survey of farmworkers, 16 percent reported having been diagnosed with diabetes. The CDMP embraced the rationale that promotores(as) can build effective social support among diabetics in farmworker communities and, in so doing, improve self-management behaviors and clinical outcomes (Ingram et al. 2007).

Promotores(as) developed project activities and provided services that respond to the working hours and seasonal nature of farmworker communities. Participants determined both the duration and intensity of their involvement, rather than being forced into a controlled intervention. Promotores(as) supported participants through telephone calls and home visits, by encouraging more participation from those who did not

attend meetings regularly, and by continuing to (re)invite nonparticipants. In crisis situations, promotores(as) increased their contact and at times made hospital visits. Weekly or biweekly support groups, facilitated by the promotores(as), became the principal CDMP activity. The gatherings were designed to provide information, build shared empathy, and create a support network. Emotional health was a common theme in group meetings, and, based on participant input, stress and depression became major topics. Patient advocacy was also a core component of the program.

The collaboration and commitment of the Sunset Community Health Center (SCHC) was essential to the CDMP. A promotor(a) at the clinic handled cross-referrals, provided basic diabetes education, set appointments for CDMP participants, and interacted with providers on patient issues. Over a two-year period, 260 people were recruited into the program. The CDMP participants were older, with an average of 59 years of age. Females comprised three-quarters of the participant population. Thirty-four percent of the 260 participants reported having no insurance, and 34 percent reported not having a regular doctor.

The CDMP had the luxury of resources for project evaluation that are found rarely in promotor(a) programs. In addition to collecting clinical data and conducting periodic questionnaires, promotores(as) carefully tracked their interactions with program participants and recorded comments for each contact. Over the course of approximately three years, the promotores(as) documented roughly 14,000 contacts with 260 CDMP participants. Among the 260 participants, promotores(as) provided a total of 120 advocacy services to 68, or one-fourth, of CDMP participants. The majority of these received more than one advocacy service.

The CDMP focused on self-management of a specific disease to minimize health complications. Advocacy activities, therefore, tended to focus on individual rather than community advocacy. A qualitative analysis of advocacy comments reveals that the majority of contacts were related to medical care (76 percent). Specific types of advocacy included helping participants find a medical home, completing and submitting insurance applications, providing medical advocacy in appointments, assisting participants in making timely or urgent medical appointments, and accessing free diabetes education. Medication is a cornerstone of diabetes care, and promotores(as) spent a substantial part of their contacts ensuring that participants were able to access medical supplies from

insurance providers, including glucometers, strips, lancets, shoes, and medical transportation.

Promotores(as) often found that their advocacy required social support for retired farmworkers who are chronically ill and live in isolation. Promotores(as) also accessed free glaucoma exams for participants without insurance and provided health screenings and referrals to connect participants to the health care system. In a couple of cases, promotores(as) helped participants work through the process of obtaining medication.

In addition to medical care, advocates helped participants access community services. This can empower community members who are often unaware of their right to access a variety of resources and services. One example involved signing up participants for library cards. The promotor(a) indicated, "We took the group to the library to teach them how to look up information about diabetes and we helped them sign up for a library card." In several cases, the promotores(as) helped participants with paperwork related to Social Security or disability compensation. Promotores(as) also found themselves helping with basic needs such as food boxes and house repairs.

These activities demonstrate how promotores(as) advocate successfully by helping individuals overcome barriers to diabetes self-management, access resources, and participate in the public arena. This type of support empowers the community as knowledge and learning spillover over from family members to friends. This case study demonstrates the intimate relationship that promotores(as) have with the community, and their feeling of responsibility for confronting problems. Community advocacy seems a natural step in the progression of CHW efforts.

Steps to a Healthy Family (Pasos a una Familia Saludable). This program responds to the problems of overweight and obesity among Arizona border youth. These are serious problems across the nation, and in the border region in particular. Seventeen percent of children and adolescents in the United States are overweight, three times the percentage 30 years ago (Ogden et al. 2006). Childhood overweight and obesity raise the risks for the leading causes of death, including diabetes, cardiovascular disease, and cancer. Childhood overweight imposes even greater threats to ethnic and economically marginalized groups that already reveal major disparities in health and wellness. According to Ogden et al. (2006),

Mexican American children and adolescents are significantly more likely to be overweight than their non-Hispanic white counterparts. In Arizona border counties in 2006, the percentage of high school students reporting a body mass index (BMI) at or above the 95th percentile was higher (14 percent) than Arizona's youth (12 percent). In Santa Cruz County, where Steps to a Healthy Family is targeted, upward of 18 percent of girls and 17 percent of boys were at risk of becoming overweight. Seven percent of girls and 17 percent of boys were currently overweight (Youth Risk Behavior Surveillance System 2007).

Like so many youth in the United States, few adolescents in the Arizona border region heed recommended levels of nutritional and physical activity. Survey data (Youth Risk Behavior Surveillance System 2007) indicate that as of 2007, only 17 percent of Arizona border youth reported eating the daily recommended five or more fruits and vegetables required for maintaining good health. Twenty-nine percent were physically active for the recommended 60 minutes for five days of the week. Survey results also indicate that half of all border youth tried to lose weight or to keep from gaining weight (68 percent) through exercise and consuming less food, fewer calories, or less fat. These are positive prevention efforts, even proactive. But they are often coupled with negative weight loss behavior such as fasting for 24-hour periods (13 percent) and using diet aids in the form of pills, powders, or liquids without a doctor's advice (8 percent). Such self-harming behaviors are detrimental to youth's ability to maintain long-term health, academic achievement, and positive self-image and self-esteem. Finally, in 2007, one-third of border youth reported signs of depression, 15 percent considered suicide, and 10 percent had attempted suicide during the last year.

It is important to reflect on the basis of obesity among America's youth, especially those living in the border region. In simple terms, obesity is socially produced and evolves from interactions between the individual child and her or his environment. By this we mean that children respond to a multitude of socio-environmental factors that impact their decisions to "be healthy." In this regard, the built environment is particularly important, because it offers opportunities for healthful behavior. Publicly provided infrastructure such as parks, playgrounds, and sidewalks encourage children to engage in activities that promote health. At other times, however, the environment can thwart efforts to engage

in healthful activities. These include real or perceived threats and dangers such as the absence of lighting and sidewalks, neighborhood decline, crime, "stranger danger," and roaming dogs, to name a few (Krahnstoevers-Davison and Lawson 2006). These obstacles to building children's health are especially important in border colonias, because they often lack the infrastructure needed for safe and healthful environments.

These deficiencies, coupled with limited household budgets, prevent many parents from providing safe environments and encouraging healthful diets. Parents with limited financial resources and time cannot prepare meals at home or offer quality "family time" at the dinner table. Both these behaviors are associated with healthy weight in children (Krahnstoevers-Davison and Lawson 2006).

Steps to a Healthy Family was developed within the context of the Mariposa Community Health Center (MCHC) *Platicamos Salud* Health Promotion Division. Project funding was provided by the Steps to a Healthier Arizona Initiative, funded by the Centers for Disease Control and Prevention and the Arizona Department of Health Services. Healthy Families is based on the CHW model and seeks to transform families experiencing childhood overweight by fostering communication and active relationships within families. The program also seeks to equip children and parents as advocates that promote change in the broader community.

Steps to a Healthy Family targets third- through fifth-grade children with body mass indices at or above the 95th percentile and includes the participation of at least one parent or guardian. The program spans a six-month period and consists of two 12-week phases. The program features weekly two-hour sessions that are facilitated by a nutritionist, a behavioral specialist, a physical educator, and a promotor(a). The first 12-week phase focuses on family awareness of healthful habits and communication. Participants discuss current approaches to healthful nutrition for families. They also explore physical activity through interactive family-oriented games. Family education stresses learning about positive reinforcement, emotions and eating, identifying overeating triggers, strategies for communication, self-talk, self-image, and self-esteem exploration.

The second 12-week phase emphasizes family readiness to change and individual goal setting. Families are encouraged to put in motion information acquired about healthful nutrition, family-based physical activity, and game time learned in the first session. At the end of each weekly

session, children and parents set a weekly goal for discussion at the next session. During weekly sessions families learn strategies to increase fruit and vegetable intake and replace soda and sweet drinks with milk and water products. Family meal time and meal planning are introduced, as well as media literacy and television viewing and screen time. Physical activity is reinforced with a structured martial arts programs that claim 30 minutes of each two-hour session. Families are encouraged to supplement physical activity with participation in weekly structured school or community-based sports activities. Program organizers provide community resources to families concerning free and reduced-cost activities that promote physical activity and group play.

Since 2005, twenty families have participated in the Steps to a Healthy Family program, with children ranging from six to twelve years of age. Approximately two-thirds were girls. The 23 parent and guardian participants were predominantly female (86 percent). Families are Latino (95 percent) and predominantly of Mexican heritage. One-third of parents (34 percent) have less than a high school education, and 17 percent completed elementary school only. Almost half (48 percent) of families rely on publicly funded health-care mechanisms like Medicaid, Medicare, and the MCHC plan, which covers those who do not qualify for other federal programs. Seventeen percent of families reported no source of health care, while 21 percent had private U.S. insurance, and 13 percent accessed health care through the Mexican private sector. A little less than half (43 percent) of parent participants had someone they thought of as their primary care physician, and 17 percent of families went without medical attention in the prior year due to cost.

As the CHW model prescribes, Steps to a Healthy Family ensures that participant families have access to health care, and supports families in developing long-term relationships with primary care providers. Steps to a Healthy Family took the lead in connecting the dots between patients and providers by emphasizing dialogue and strong patient-provider relationships as the centerpiece of empowerment. CHWs and other program staff worked with clinic insurance liaisons to help families apply for publicly funded health access mechanisms.

The program also worked with families to advocate for policies that address school and community environments. Steps to a Healthy Family brought parents and school health personnel together to learn how to

advocate for more nutritious school lunches and better physical education through a Family Health Advocacy Forum. The Advocacy Forum stressed the role of the built environment in enabling family activities outside the home. More than half of the Steps to a Healthy Family parents (56 percent) described living in neighborhoods beyond walking distances to a park, playground, or open space. Sixty-four percent believed the park or playground nearest their home was not safe during the day. Parents participating in the program believed that there are mechanisms to voice concerns about inadequate school services or resources (85 percent). They also expressed comfort in voicing their concerns (63 percent), and more than half (63 percent) actually do so more than half the time.

To better engage these already active families, community partners of the larger Steps to a Healthier Santa Cruz County Initiative developed a collaborative of 11 local youth-focused health and social service agencies, which included community health workers, to plan and organize a family health advocacy forum. The objective of the forum was threefold: (1) develop a collaborative of Santa Cruz County health and social service agencies and university partners to increase leadership and advocacy skills among all agencies and the families they serve; (2) inform parents and teens about the health status of their community through the most recently available Youth Risk Behavior Survey (YRBS) and Behavioral Risk Factor Survey (BRFS) data; and (3) develop an advocacy plan for neighborhood and community change.

Program organizers selected components of the University of Arizona Cooperative Extension's Arizona Community Training (ACT) curriculum and developed a bilingual workshop for parents and teens. A parent-versus-teen "jeopardy" game was developed to present the Santa Cruz County YRBS and BRFS data. This game engaged parents and teens in learning about the differences and similarities in youth and adult health behaviors, such as tobacco use, physical activity, and nutrition. Some families had reported prior experience in advocating for change with school boards and school administration. After the forum, parents and teens reported increased knowledge and confidence in their ability to advocate for or make changes in their home and family (70%), school (73%), neighborhood (81%), and county or state (85%).

The collaborating partners of the forum were activated by the process of planning and implementing the forum. Members continue to meet

and focus on a county-wide initiative to increase enrollment of eligible children into the Arizona Health Care Cost Containment System (AHCCCS) KidsCare program, with the long-term goal of establishing school-based health centers.

Summary

Closing the gap in health disparities among communities on the U.S.–Mexico border will require drastic changes in the political sphere. Foremost is acceptance of health as a human right and the need to engage the most vulnerable populations and create a collective voice that resonates with agency and power. There is evidence that CHWs in Arizona are communicating with elected officials and political bodies, as well as with health and social service agencies, about making changes in their communities (Ingram et al. 2008); however, it is rarely the program focus. Community health worker training and job roles/responsibilities fail to stress the role of community advocacy and leadership, partly because CHW employment opportunities tend to stem from grant-funded programs that focus on short-term individual health outcomes. A collective shift in the field is needed to increase CHW community advocacy and address the root causes of health disparities. Collaboration between CHWs across agencies should be supported, and CHWs should be “expected to function as an advocacy group, meeting together to initiate interaction among their respective networks on a regular basis to carry out community wide activities” (Eng and Young 1992). Funding organizations and community members must understand that CHWs not only work to improve the health of individuals; they also elevate community health. Ultimately, this is the domain of public health.

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