Building Blocks: Community Health Worker Evaluation Case Studies

The Community Health Worker Evaluation Tool Kit

A Project of the University of Arizona
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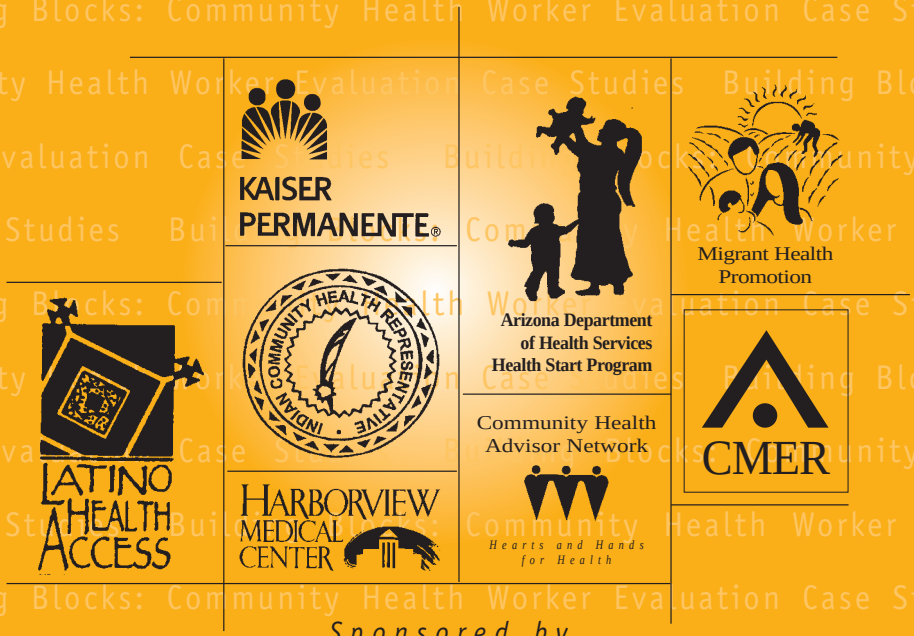

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Building Blocks: CHW Evaluation Case Studies

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Tribes Nationwide and the Indian Health Service

Regional:

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Hattiesburg, Mississippi and Selected U.S. States

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Case Study Methods and Format

To better understand how program evaluation in Community Health Worker (CHW) programs is actually conducted and how evaluation influences the sustainability of CHW services, eight diverse CHW programs were selected as case studies by a panel of experts. Selection criteria included diversity of location, race or culture served, and the health issues addressed. Programs selected had to have strong evaluations or be well sustained by their funding steam or both.

In each of the eight cases selected, a key individual was identified and interviewed to provide a program overview based on the CHW Program Wheel framework (Koch, 1997). This same individual, along with the program evaluator, then provided an overview of the program's evaluation methodologies. Each program submitted evaluation instruments and reports. At each site, these individuals and a small group of other staff, including CHWs, were interviewed about factors that have an impact on their program's sustainability, including evaluation data. The majority of the interviews were conducted by telephone.

Each case study presented includes a brief program description, a review of the program's evaluation methods and challenges and a discussion of factors that affect the overall sustainability of the program. Each also briefly reviews the program's evaluation design in terms of the Tool Kit's four level evaluation framework (client, CHW, program, community/system). For most of the cases, the evaluation tools discussed can be found in the Tool Kit.

Tool Kit Framework

Program evaluations varied in which aspects of the CHW Evaluation Tool Kit's four-level framework they included and emphasized. All program evaluations to some extent look at the individual and family (client) level as well as the program performance level. Only a few programs emphasized evaluation of change in CHWs as individuals. Even fewer looked at the program's influence on the community, organizational and political systems in which they operate. Only one program reviewed conducted its evaluation at all four levels of the Tool Kit's framework. Not surprisingly, this is the Community Health Advisor Network whose first evaluator (Eng, 1992) contributed to the development of the evaluation framework presented in the National Community Health Advisor Study (University of Arizona, 1998). These limitations are representative of the CHW field in general.

The tendency to document program results at the individual level is not surprising, given the medical model that dominates health care in the United States. It is unfortunate that the more ambitious goals of community and systems change embraced by some CHW programs (Meister, 1997) are not captured in their evaluations. Analysis of the documentation process in several of our cases suggests that reinforcing goals in the documentation process can foster activity to meet those goals. The lack of documentation in a specific area, such as changes in community or systems, may erode the implementation of activities designed to meet goals at that level.

Evaluation in CHW Programs

Although the programs reviewed address different health issues and diverse populations, several common threads ran through the interviews with the program staff and evaluators:

- *It is Difficult to Isolate CHWs' Contribution to Health*

Many of the staff and evaluators interviewed remarked about the challenge of teasing out the influence of CHWs on those they serve versus other factors influencing people's health and behaviors. In the case of the national Community Health Representative (CHR) program, this issue took on an interesting twist. CHRs are imbedded in the system of care for American Indian communities and some fear there may be disadvantages for CHRs if they single out their unique contribution, undermining the collective approach to care they have worked hard to develop. Also, particularly in American Indian communities, there is resistance to taking credit for work individually done when ultimately it is the work of a team (or tribe) that makes things happen.

> **If we are a health care team, we all contribute as a body, not individually.**
> Dena Transgrud
> CHR Program Regional Director,
> Indian Health Service

- *CHW Programs are Dynamic and Defy Traditional Evaluation Models*

> **Prevailing evaluation methods have not provided the knowledge needed to make good judgements about the very social programs that hold the most promise. . . . The evaluations on which most policy makers rely overwhelmingly favor activities where one circumscribed problem is addressed by one circumscribed remedy.**
> Lisbeth Schorr
> Common Purpose, 1997

CHW programs are community-based programs. Even when based in a hospital or health maintenance organization, they emphasize community connections. To be effective, CHWs have found they must be responsive and flexible and so, too, must the programs of which they are a part. This fluidity poses evaluation challenges that must be met head-on through evaluation approaches that not only capture the impacts of planned activities but allow for the timely integration and assessment of the actual services delivered.

Continual refinement of evaluation approaches and instruments is needed to assure that the data gathered compliment and reinforce services delivered. This is both because the programs are dynamic, changing in the face of changing community needs, and because at different phases in the development of a program, different types of data are needed.

- *Evaluation is at its Best as a Support to Program Improvement*

Programs have found that an important key to successful evaluation is defining evaluation as a support to, rather than a judgement about, programs. When evaluation is seen as a problem-solving endeavor rather than an opportunity to identify inadequacies, fears and resistance to evaluation by program staff, including CHWs, are diminished, allowing staff to become full partners in the evaluation process.

- *Community Health Workers are Evaluation Partners*

In the programs reviewed, CHWs play an active role in developing and refining the evaluation tools and instruments used by their programs. In some cases, this CHW involvement helps to refine evaluation methods overall.

Evaluation Building Blocks

The Tool Kit embraces a logic model approach to program planning and evaluation. Some of the cases reviewed here formally utilize such a mode, but in most cases the programs have evolved without the benefit of the model, implicitly embracing its principles. The logic model developed by the W. K. Kellogg Foundation uses the terms outputs, outcomes, and impacts to categorize program activities and results over time.

Outputs

Without exception, the programs reviewed document program activities or outputs. Although CHW programs (University of Arizona, 1998) report that documenting program activities is often burdensome, these cases show that the detail about program activities contained in their output data is a core building block that can strengthen programs on a daily basis.

The collection of these data also has implications for the analysis of program impacts in the long run. For example, staff at the Kaiser Permanente program for frail elderly recognized that the CHW activities they document on their evaluation forms affect the way CHWs perceive their roles. Specifically, they observed that when asked to document social support provided, CHWs recognized that program administrators valued their social support role, and thus they were reinforced to provide it. Over time, the documentation of that support will allow this relatively young program to examine this variable and see how significant a component of the CHW role it is and then determine whether greater social support leads to better Kaiser member outcomes.

Outcomes

Outcomes, or short-term results, logically follow from the outputs but they often elude program staff actively involved in program management and service delivery. In the cases reviewed for the Tool Kit, all programs sought to document program outcomes, using their output data, when possible, to help them move to an analysis of outcomes. Better established programs had the edge on newer programs in terms of refining documentation approaches to capture program outcomes. In many cases this had to do with emerging pressures for such data. For example, in the case of the Arizona Health Start program, state policy makers became the audience for two competing program evaluations trying to demonstrate the outcomes of the program, one conducted by the state's Auditor General and one by outside evaluators hired by the program.

Enrollment in and utilization of health care services is a common outcome variable examined in CHW programs. In the Arizona case, both evaluations tried to compare women and children inside and outside the program to understand if the program influenced the outcome variable of the number of prenatal visits made by pregnant women. In Massachusetts, a statewide mini-grants program looks at the outcome variable of enrollment of its target population in the state's publicly funded insurance programs. The Harborview Medical Center's Community House Calls program, supported by the hospital in which it is based, has been able to show hospital administrators that it has brought in many new patients. It has further calculated the monetary value of those new members to its HMO (see the Tool Kit's Cost-Benefit Primer). Some would call this monetary analysis a component of documenting impacts, or long term results. Some programs have been able to identify short-term medical markers as outcome variables. Latino Health Access tracked indicators of diabetes management success in individuals before and after contact with CHWs. When, as Latino Health Access did, this type of variable is documented a year following an intervention (CHW diabetes classes) many would say it becomes an impact variable.

Impacts

Like most CHW programs, the CHW programs reviewed in these cases for the most part were not in a position to speak of the broader impacts on the communities served. Program staff reports that the short-range funding cycles under which most CHW programs operate are a factor contributing to the lack of long-range data. Their funders demand documentation of outputs and often outcomes, but they have not sustained program efforts through a long enough period to gather impact data. Some programs reviewed, such as Migrant Health Promotion and the Community Health Representatives program, have sources of longer-range core financial support that should make longer-range evaluation possible. Ironically, however, it is in these very programs that a lack of ongoing pressure to document success may in some ways impede the collection of impact data.

Learning from the Case Studies

The case descriptions that follow are intended to help users of the Tool Kit, especially CHW program staff, who want to learn about different CHW programs and their approaches to evaluation. The detail provided about the eight programs' evaluation methods and challenges faced is intended to help readers learn about evaluation overall and provide an opportunity to understand how specific evaluation tools are utilized in documenting a program's story. The cases are also intended to help readers think about how programs can use evaluation findings to promote their sustainability.

One important lesson is this - programs without strong evaluations are increasingly at risk of losing funding and of being unable to defend themselves, but a strong positive evaluation is no guarantee of sustainability. Marketing your program, making it visible and attractive as well as credible, is another key to sustainability.

No evaluation presented is without the potential for improvement. Use these cases as teaching tools to explore how a given program's evaluation might be improved and to examine how these evaluation approaches apply to CHW programs closer to home.

The Community Health Representative Program

Tribes Nationwide and the Indian Health Service

Program Overview

The Community Health Representative (CHR) Program, begun in 1968, is the nation's oldest and largest Community Health Worker (CHW) program, with more than 1,600 CHRs. At the turn of the millennium, the CHR Program receives more than 45 million dollars annually to support CHRs nationwide among more than 250 American Indian tribes.

The CHR program is managed at the local level by each participating tribe, with funds from the Indian Health Service (IHS). This program management approach pioneered an increasingly important contractual model for U.S. governmental and tribal relations. As a part of the management of the CHR program, the tribes select the CHRs and the issues they will address. The most common issues addressed are maternal and child health, diabetes and elder care. Within a given tribal program, each CHR may specialize in a different health issue. CHRs work in collaboration with IHS staff but are tribal employees. CHRs see fellow tribal members in their homes as well as in IHS clinics and hospitals. Most CHRs receive their training in a three-week IHS coordinated course.

Evaluation

Evaluation of the CHR program has focused primarily on the individual and program performance levels of the Tool Kit's framework. There have been several evaluation efforts over the life of the program, some internal to IHS and one external to IHS conducted by the federal Inspector General's Office.

In the very early years of the program, evaluation efforts were overwhelmed by the challenges posed by mounting and managing CHR program partnerships between IHS and more than 500 eligible tribes. At first, evaluation was left up to programs in the interest of tribal autonomy, and only a brief monthly narrative report was required. In the early '80's, as the federal budget came under scrutiny during the Reagan administration, the CHR program budget was also reviewed. Although the program had steadily grown until that time, it had little data to show for its more than ten-year history. Following the review, its budget was cut by more than 20 percent, and the program continued to be downsized through 1990. In 1983, Congress mandated that IHS "establish guidelines, goals and clear evaluation standards for the CHR program" (Inspector General's Report, p.2). In response, IHS hired the first national director of the CHR program, and evaluation efforts were initiated at the national level across all programs.

Scope of Work

A fundamental element of these early CHR program evaluation and program monitoring efforts was a Scope of Work (SOW) contract form that was filled out by a tribe as it developed its program goals for the year. For example, a tribe

would set the goal that 25% of their effort would be targeted to home care for diabetics. For one week each month, CHRs document their activities, including type of service delivered and location. From this, each tribe assesses whether it has met its SOW goal. It reports on this to I.H.S., although there are no requirements at the federal level to meet SOW goals. This system allows for a comparison baseline. These early evaluation efforts allowed I.H.S. to count "touches", or contacts, data that translated into compelling testimony for the Congress when needed.

Patient Care Component

CHR program data collection efforts are currently focused on adding a more patient-centered component. The Patient Care Component (PCC) is built on a patient interaction system emphasizing clinical data. The PCC data collected by CHRs are linked to the computerized patient management system of I.H.S., which is shared by all providers, including physicians, pharmacists, lab technicians and others. The PCC system brings greater depth to the data collected by CHRs and allows for the timely integration of those data into patient management decisions.

As the data collection systems for CHR services become more comprehensive, growing decentralization of the federal bureaucracy serving American Indians means mounting challenges for collecting data across CHR programs. The IHS now monitors only two areas nationally—-transportation, with a limit of 15% of the total program budget, and program administration, with a limit of 12%. These two areas were targeted in response to the 1993 Inspector General's report.

Inspector General's Evaluation

In the early 1990's, the Inspector General's Office undertook a study to review elements of the CHR program, including identification of "factors that make the CHR program strong, factors that IHS - and tribes - could use in the future as a basis to manage and evaluate the program"(Office of Inspector General, 1993). The evaluation included a review of related literature, particularly enabling legislation and governing regulations. There were three phases in the data collection phase. The first phase identified themes influencing program effectiveness. The second phase worked to illuminate these themes and to prioritize them. The final phase included field visits that allowed for observations to validate the themes generated in the two previous phases. The reviewers spoke with and/or surveyed over 400 individuals about the program, including many at the federal level with program oversight responsibilities as well as representatives from each of the 12 jurisdiction areas of the IHS. The study found that the goals of the CHR program as outlined in national guidelines were not well known by many tribal members and IHS employees at the local and national levels. It also found disagreement about appropriate roles for CHRs, particularly related to transportation issues. The review also revealed mixed feelings about the usefulness of documentation and evaluation methods.

The Office of Management and Budget

Federal government oversight in 1999 again brought attention to the CHR program. The Office of Management and Budget (OMB) recommended a cut to the CHR program budget. The lack of evaluation data documenting the contributions of the CHR program was cited as a factor leading to this recommendation. Hue and cry

from tribes across the nation and the National Association of CHRs was able to prevent the cutback, and instead the program received a small budgetary increase.

Evaluation Challenges

The CHR program, although managed by each tribe, is well integrated into the health care delivery system of the IHS. This means that the CHRs themselves are a part of the team that promotes the health of tribal members. As such, it is difficult and to some extent inappropriate to isolate the input of CHRs as just one component of the team, with the intent to show how they alone have impacted health outcomes. This problem, although relevant to other CHW programs, is perhaps most pronounced in the CHR program. It might even be said that seeking to disentangle the CHRs' contribution to health could be disempowering for the CHRs, who are now imbedded in the delivery system. Further, it could also be seen as culturally inappropriate for one set of tribal members to claim that they are responsible for certain outcomes, i.e., good health, in their communities (1998). Nonetheless, as can be seen from the history of the program's evaluation and funding challenges, the lack of CHR-specific outcome data has threatened the stability of the program.

Sustainability

Although the CHR program has often been challenged by limited evaluation data, the program has remianed strong. The CHR program now has the stability that comes from a long-standing tradition at the tribal level, where CHRs have established an identity for themselves through their daily presence in the community. The National Association of CHRs has also helped to make the CHR contribution more visible to tribes and to IHS, thus helping to build support for the program. The tribal management and ownership of each individual CHR program has further helped to strengthen the program's political influence. With greater decentralization in the management of health and related services for American Indians, it is clear that continued tribal commitment to CHR programs at the local level will be key to their sustainability.

The Community Health Advisor Network

Hattiesburg, Mississippi and Selected U.S. States

Community Health Advisor Network

Hearts and Hands for Health

Program Overview

The Community Health Advisor (CHA) program began in Humphrey's County, one of the poorest counties in the Mississippi Delta, in 1987. The original project was a component of Partners for Improved Nutrition and Health (PINAH), formed by the California-based international community development organization, Freedom from Hunger, the Mississippi Cooperative Extension Services, and the Mississippi State Department of Health.

The Community Health Advisor program promotes individual self-reliance by empowering volunteer natural helpers to solve hunger and health problems. The program recruits existing natural helpers to participate in a training program, links them with service providers and community leaders to discuss local health problems and supports them in implementing short and long-term self help action in response to local needs. The Community Health Advisors provide advice, assistance, referrals and linkages to needed services in their natural helping contacts with family, friends and neighbors.

In 1993, in response to broad-based interest from a variety of health organizations, Freedom from Hunger established the Community Health Advisor Network (CHAN) to assist organizations in establishing Community Health Advisor programs. CHAN moved to the University of Southern Mississippi in 1996 and is now a program of the national Center for Sustainable Health Outreach (CSHO).

Evaluation

Freedom from Hunger, recognizing the importance of documenting this demonstration project, committed significant resources to support a thorough evaluation. The initial evaluation of the CHA program looked at health and social indicators that cut across all four levels outlined in the Tool Kit's framework, including individuals and families, community health workers (CHWs), program performance and communities and systems. The similarity to the Tool Kit framework is not surprising because the work of the project's original lead evaluator (Eng, 1992) influenced the development of the Tool Kit's framework.

Early Evaluation: Looking at the Framework's Four Levels

The program's early evaluators and staff believed that the evaluation must not only document the progress of the program for the outside world but that it must also serve the CHAs themselves to aid them in improving the program.

Individual and Family Changes

In order to look at the program's impact at the individual level, the evaluators workerd with the state's Bureau of Public Health Statistics to identify three comparable counties in which they could track parallel data. The data focused on a number of variables, including service utilization over the life of the program, the percent eligible for Medicaid and Medicare, as well as changes in the percent of individuals enrolled in these programs. As the program unfolded, it became clear that many of the individuals helped by the CHAs, such as teens, would not routinely utilize health department services and thus their behavior change would not be reflected in this database.

In addition to the county data on individuals, the evaluation sought to look specifically at the program's clients. The evaluation team interviewed individuals in clinic waiting rooms to ask if they knew individual CHAs. If they did know a CHA, they then explored what problems, if any, the CHAs had helped them with. At first, when funding allowed, the original evaluation protocol included follow-up interviews in the home. Later, these were conducted by telephone. This component of the evaluation was difficult to implement but was maintained to provide evidence of how CHAs' services were perceived. The evaluators and staff recognized early on that many, including community members, were skeptical about CHAs, and so they felt this component of the evaluation was important in order to have data about how those served by CHAs experienced that assistance.

To further document CHA services delivered, the CHAs themselves were asked to fill out a questionnaire. In the questionnaire they described those whom they were helping and where and how they were helping them. At a peak of participation, only about 60% of the CHAs returned forms. The CHAs who were the busiest helping others were the least likely to turn in their forms. Recognizing that these data undercounted the helping behaviors of the CHAs, the evaluators decided to initiate an intensive data-gathering period during which they interviewed health and human service providers and others to supplement the data.

Changes in CHAs

Changes in CHAs themselves were tracked, utilizing interviews of a sample of CHAs at the end of the evaluation. A spectrum of CHAs classified as "active to inactive" were interviewed. Interestingly, one of the CHAs defined as inactive reported that the program had been instrumental in her decision to get her GED and to move on professionally.

Program level changes

Interagency coordination was explored at the program level. In particular, changes in the number of referrals and the patterns of those referrals were tracked through health and welfare department records. Comparisons to the referral patterns in the comparison counties were then made. Community newspapers and newsletters also helped to track the initiation of community events and other new programs. Trends in these data were tracked over time. Comparison counties were not tracked for these changes.

Community level changes

The CHAN program aims to promote community empowerment and thereby improve health, so measuring community development was central to this evaluation. Community competence indicators were identified building on mental

health outcomes (Cottrell, 1976), such as community participation and conflict accommodation. To refine these, local service providers and community action leaders participated in workshops to identify competence characteristics for their own communities. As a result of this participation, the area of "social support" was newly identified and included among the indicators for evaluation.

The Second Wave of Evaluation: Narrowing the Lens

As the project progressed beyond the early demonstration phase, the project staff began work with new program evaluators and more limited evaluation funds. The evaluation narrowed from a wide qualitative and quantitative spectrum to emphasize quantitative data. The revised evaluation design tracks CHAs' increase in self-confidence and participation in helping activities following training. Community competence data are gathered utilizing input from local steering committee members.

Evaluation Challenges

Gathering data from the volunteer CHAs is an on-going challenge for the program. CHAs are reticent to take their personal time and put their work in the community on hold in order to make records of actions taken. Another challenge to gathering data from the CHAs is the ability of volunteer CHAs to identify the activities in their daily living that are specific to the CHA role. At times those judgments about what to document may result in CHAs not recording "helping behaviors". The combination of resistance to record keeping and the difficulty in drawing the line between personal life and CHA "helping behaviors" may have led to significant undercounting of program benefits.

Sustainability

The original vision for the CHAN program was that over time it would be integrated into the local public health care system for Mississippi. In terms of integration within the state, the CHA model is found in 10 of Mississippi's 82 counties. Outside the state, the program has to some extent surpassed expectations for disseminating the model program nationwide. CHAN was recognized with an Honorable Mention by the Health and Human Services Models That Work competition in 1996. More recently, CHAN was the key CHW organization leading to the creation of the national Center for Sustainable Health Outreach.

The CHAN project is well sustained. Many factors have contributed. A visionary group of initiators including funders, staff, and a cadre of volunteer CHAs, is at the core. The media have also contributed, with several articles about CHAN in peer review journals and the popular press.

How has evaluation helped contribute to sustainability? When soliciting potential funders, CHAN staff can pick and choose from the various levels of evaluation data collected. Some funders want to know how the program impacted individuals while other funders want to know if CHAN helped the Health Department expand its clinic hours. Still others want to know if CHAN increased the presence of cross-racial communications, and they are impressed by the fact that CHAN inspired the creationof a community-run food pantry. Having a wide range of outcomes to reference, the CHAN project has been well prepared to attract funders' attention.

Migrant Health Promotion

Saline, Michigan and Progreso, Texas

Program Overview

Migrant Health Promotion, formerly known as the Midwest Migrant Health Information Office, was established in 1983 as a community health worker program targeting migrant farm workers in the Midwest. Over the years, the agency expanded its target communities and health issue foci to provide continuity in the lives of migrant farm workers as they travel throughout the United States. The core of the Migrant Health Promotion program is a training program for adult and teen migrant farm workers so that they can become Camp Health Aides (CHAs) and Teen Health Aides. The aides receive a stipend while in training and learn about an array of health topics and popular education health promotion techniques. The aides then carry out health promotion activities in migrant camps and related communities. They undertake health promotion activities among farm workers, facilitate access to care and help educate providers about their community's needs.

Start-up and continuing support for Migrant Health Promotion comes from the Catholic Consortium for Migrant Health. Migrant Health Promotion also receives core support from the Migrant Health Program of the federal Health Resources and Services Administration (HRSA). In its ninth year, Migrant Health Promotion received a grant from the W. K. Kellogg Foundation. This support enabled Migrant Health Promotion to expand its program to new migrant groups in several states. In 1996 Migrant Health Promotion won the Bureau of Primary Health Care's "Models That Work" competition. The agency has received numerous other grants and honors and continues to be recognized as a premier CHW program.

Evaluation

Migrant Health Promotion evaluation efforts have touched on many levels of the Tool Kit's framework, but the level most emphasized and publicized by Migrant Health Promotion is the impact of the program on the CHAs themselves. When Migrant Health Promotion first began its work, the pressure to evaluate was limited. It seemed to be accepted by funders and other supporters of the agency that the migrant farm worker community was in need and that efforts to improve health information and health care access in that community would be beneficial. Comparisons of baseline and outcome data as such were not needed to make the case. Migrant Health Promotion staff observes, however, that, over the life of the project, pressure from funders for outcome data has been increasing. Still, Migrant Health Promotion has remained in the driver's seat in terms of the data they collect. Their focus in the early years of the project was on process or output data, not uncommon for a project at its initiation. They documented the services they delivered, such as the number of CHAs trained and the number of referrals made.

The W.K. Kellogg Foundation grant included strong support for evaluation. The agency chose to assess the individual empowerment experienced by the CHAs participating in the program as well as a number of output measures. The empowerment evaluation consisted of an interview with open-ended and close-ended questions on a number of factors, such as self-efficacy and the CHAs' roles in their communities. The interview, administered three times, tracked changes over more than one year from before the training began to the end of the second harvest season. The evaluation found that participation as a CHA did contribute to increased individual empowerment (Booker, 1997). Although Migrant Health Promotion is pleased with the evaluation results, they acknowledge that such findings have been of little interest to potential funders. The staff now believes that it might have been more valuable to document the program's influence on health status and health care utilization.

More recently, as their expertise has grown and with the growing interest from funders, MHP has begun to set outcome goals and collect data to document outcomes. Examples of outcome targets they have set for the farm workers they serve include: 50% of women breast feeding, 80% of immunization records up-to-date, parents of 90% of children approached about Children's Health Insurance Program (CHIP) enrollment, and 90% of women enrolled in prenatal care in the first trimester.

In order to collect data needed to evaluate the program, the agency staff has worked to refine data collection forms. They recognize that collecting good data requires facilitating the easy documentation of services delivered and the outcomes experienced. While in the early years of their programs their forms allowed for narrative descriptions of CHW work, over the years they have found that the need for that level of detail has decreased. Now, documentation tools are more often in the form of checklists. CHAs themselves have helped to develop these lists, assuring that they accurately reflect the work done in the field.

Reach 2010

The recent funding of this project by the Centers for Disease Control and Prevention (CDC) is another example of the capacity of this agency to attract national attention. This new project focuses on building coalitions in south Texas to reduce disparities in diabetes between Hispanics and Anglos. The evaluation focuses in part on coalition development processes and the results achieved through collaboration as well as specific health outcomes.

Evaluation Challenges

Migrant Health Promotion's early decision to focus evaluation efforts on changes in CHAs themselves was in part a pragmatic one made in the face of significant challenges posed by conducting long-term follow-up in a migratory population. Their choice has meant that these evaluation data have to be directed to those who value empowerment and who have a long-term vision that empowerment of a few will ultimately improve the health and well-being of the population as a whole.

People's sense that Migrant Health Promotion programs work and their willingness to communicate it has perhaps made it too easy not to invest more in evaluation. For example, the nurse in the clinic down the road from Migrant Health Promotion's Michigan office lets the staff know that she can tell what classes have been taught to the CHAs in any given week. She observes, for example, that the following week there is a great increase in requests for diabetes screening and treatment. The project delivers, and the story is told locally and nationally by those who see the changes. Clearly this has helped the program in the short-run, but, as the staff has noted, the pressure for harder outcome data is mounting.

Sustainability

With a budget of more than one million dollars, Migrant Health Promotion is a well-supported organization. Evaluation findings to-date have not played a significant role in their ability to attract funders or their ability to be noticed as an effective program. The farm workers served by Migrant Health Promotion have been central to their ability to bring in funds while at the same time they have been at the root of the greatest challenges to gaining support. Migrant Health Promotion's focus on migrant farm worker health has made them stand out to those funders who are committed to needs of this population. Still, this is a relatively small number of grantmakers, limiting Migrant Health Promotion's ability to diversify funding sources as well as to move beyond grant-based monies. Migrant Health Promotion staff recognizes that there are tremendous prejudices that keep many from committing resources to better the lives of migrant farm workers. The migrant nature of this population has meant limited access to place-based public and private funding, including managed care organizations.

The key to Migrant Health Promotion's long-term sustainability is a few strong and vocal advocates and funders. In particular, early support lasting through the present and providing the agency with unrestricted funds to both pursue service delivery and fund-raising efforts, has given Migrant Health Promotion needed flexibility. Agency visibility from awards won and through funder networks has also been invaluable. Migrant Health Promotion has a momentum that has made them a bright star among CHW projects and among those serving farm workers.

Community Health Worker Outreach and Children's Health in Massachusetts

The Commonwereth of Massachusetts

CMER

Program Overview

Massachusetts is at the forefront of the field of community health work, with many model approaches to training and service that have enjoyed considerable national attention. Massachusetts is also known as an innovator in insurance coverage for children through their MassHealth (Medicaid) and Children's Medical Security Plan (CMSP). Expanded insurance coverage for children has been achieved through participation in the federal Children's Health Insurance Plan (CHIP). To ensure that this expansion results in enrollment, the state has initiated a model community health worker (CHW) outreach program.

The National Governor's Association recognized Massachusetts for Best Practice in its approach to the CHIP program. The cornerstone of their innovation is a mini-grants program funding outreach through community-based agencies to promote insurance enrollment. In its first year the program funded 52 agencies. Now in its third year, it supports outreach in 84 agencies. The mini-grant program awards grants of $5,000-$20,000 and is administered and funded by the state's Medicaid agency, the Division of Medical Assistance (DMA), with additional support from the Department of Public Health (DPH). The cost of the mini-grants program is partially reimbursed by federal funds from CHIP.

The Area Health Education Center (AHEC)/Community Partners, part of the Massachusetts Statewide AHEC system, plays a lead role in supporting the mini-grant program. To do this the AHEC formed six regionally based Health Access Networks (HAN) that meet monthly to bring together community-based organizations working on outreach, state agency representatives, and health care consumer advocates. The HAN goals for participants are to 1) promote information exchange, 2) provide opportunities to share promising outreach practice, and 3) serve as a link between communities and state agencies. The HAN participants discuss issues regarding enrollment of fellow community members, such as barriers to access, best practice for outreach, and policy/ program developments pertinent to state health insurance programs. Based in part on discussion in the HAN meetings, several follow-up projects are being developed.

Evaluation

Evaluation questions about the mini-grants for community health worker outreach cover several arenas: 1) the outreach and enrollment efforts themselves, 2) the HAN and state agencies supporting the mini-grantee outreach and enrollment efforts, and 3) efforts focused on moving beyond enrollment. For purposes of the Tool Kit, this case study will limit itself to the first area, exploring evaluation strategies documenting the the mini-grants outreach and enrollment efforts.

The Center for MassHealth and Evaluation Research (CMER), based at the University of Massachusetts Medical School, is conducting an evaluation of the mini-grants program for the Massachusetts Division of Medical Assistance. Their evaluation touches on several levels of the Tool Kit's framework, including the individual and family level, the program performance level, and the community and systems level. In this early stage of the program, the strongest element of the evaluation is aimed at documenting and analyzing program activities. State agency and field staff, including CHWs, helped to design and refine the 1999/2000 evaluation instruments utilized to collect three types of evaluation data.

Quarterly Reports

Mini-grantees are asked to report every three months on a program update form that gathers narrative about how they are doing in reaching their project's goals and objectives.

Outreach/Marketing Activity Logs

Projects are also asked to keep logs of outreach and marketing activities that they submit on a monthly basis. The information collected in the log focuses on the setting and type of outreach undertaken, the target audience, the number reached and success and barriers to outreach.

Enrollment Tracking

Mini-grantees are asked to provide documentation about the potential enrollees with whom outreach workers have contact. The form documents the number of households with and without children to whom CHWs have spoken about Mass Health (for adults and children) and the Children's Medical Security Plan (for children and youth under 19 years old). The form also allows for documentation of the number of individuals and families for whom CHWs filed eligibility paperwork, as well as how many of the applications filed were accepted and how many were denied. The information on denials allows the evaluators to better understand and quantify the gaps in the current public health insurance programs.

Evaluation Challenges

Measuring the success of an outreach and enrollment program may seem straightforward at first glance. We can ask, "How many people were enrolled in a given time period?" The data should be available and easy to track. But just as insurance enrollment efforts beg the question, "Are mere enrollment efforts enough to promote the health of children?", so, too, must we ask whether counting who is enrolled is enough of a measure of success, particularly when outreach and enrollment efforts are taking place on a number of fronts. Massachusetts outreach workers involved in the mini-grants program work with families to help them address other social needs in the process of exploring their health insurance needs. The services provided in the contacts have value and could be included in the measure of accomplishments achieved by these enrollment efforts.

Sustainability

Several factors affect the sustainability of CHW outreach efforts aimed at families and children in Massachusetts. One key factor appears to be the presence of a critical mass of CHWs in the state, linked to a growing commitment to CHW outreach from the public health community and, more recently, from those concerned with insurance enrollment. In the early '80's, in the face of the AIDS epidemic, Massachusetts initiated numerous CHW programs. In that same period, funding for maternal and child health CHWs, particularly through the federal Healthy Start program, increased CHW numbers and visibility. In the early '90's, the issue of uninsured Massachusetts residents served as a catalyst for further expansion of outreach programs — in 1993, with the start of the CMSP (the model for the national CHIP program), and then again in 1998, with the start of the mini-grant program in response to the nationally funded CHIP program.

Visibility of CHWs does appear to be a key to sustainability, helping especially to increase interest and commitment among policy makers. Coverage by the press, including newspaper and local television, has helped to increase CHW visibility. Local advocates have helped to build interest through public events, such as Boston's Outreach Worker Day. More recently, the Health Access Networks have helped to build CHW visibility among state agency staff. Through these networks and related efforts, the need for continued CHW outreach to promote enrollment and services beyond enrollment is kept before the public.

Evaluation of CHW programs is also part of outreach sustainability in the state. State government has already begun to see that its policies are more effective when implemented at the local level in conjunction with community-based outreach. Current mini-grant program evaluation efforts can further help to inform public policy as the data collected document outreach and enrollment successes, innovations and barriers overcome.

Arizona Health Start

The State of Arizona

Arizona Department of Health Services Health Start Program

Program Overview

Two small demonstration projects that began in rural Arizona in 1987 led the way for a statewide perinatal Community Health Worker (CHW) health promotion program. *Comienzo Sano* (A Healthy Beginning), serving pregnant women in the Yuma area and based at the University of Arizona's Rural Health Office, received its initial funding — a one-year demonstration grant — from the New York-based A. L. Mailman Foundation. The second project was based at the Arizona Department of Health Services (ADHS) and served women in Eloy, Arizona. In 1992, building on these outreach projects, the state legislature funded Arizona Health Start. The program is coordinated by the ADHS Office of Women's and Children's Health through a competitive Request for Proposal process that funds an average of a dozen sites. Health Start has a budget of 1.2 million dollars for the year 2000.

At the state level the Health Start program has had a checkered funding history. In 1998, after several years of implementation, the state budget for this program was cut completely. Several factors played a role, including concern about duplication of services and questions about its benefits as well as reticence by some to aid the population targeted by the program and concern that the program invaded family privacy. For one year the state health department managed to sustain the project sites through donated funds. In 1999, after advocates for the program worked hard to bring more visibility to the program and a better understanding of its services, Health Start was funded again by the state legislature. New sites are required to give a graduated in-kind contribution to complement state dollars. Notably, sites were already making contributions, although these were not previously recognized.

Health Start's Lay Health Advisors/*Promotores/as* (or LHAs) are trained at their project site, utilizing a curriculum shared by all the Health Start projects. Within three months of joining the project a LHA must pass a core competency test given by the state. There are annual continuing education requirements. Women served by the program are selected when they are found to be at risk for poor pregnancy outcomes based on a scoring system administered by the LHAs themselves. A range of variables is considered, including a previous pregnancy history with complications or no prenatal care, medical history overall and social risk factors. Recruitment of the families into the program is through formal and informal channels, such as radio spots and health fairs. LHAs assist pregnant women in enrolling in perinatal services. Working in coordination with other health care providers, LHAs visit pregnant women in their homes and offer a series of prenatal classes in local community centers and clinics. Following the birth, the program serves women and their newborns for the first two years of life, focusing on parenting and child development issues.

Evaluation

Evaluation efforts for the early phases of this program and the formal Health Start program address three levels of the Tool Kit's framework, including individuals and families, LHAs, and program performance. The early project site in Yuma, *Comienzo Sano*, evaluated the adequacy of prenatal care and the empowerment of the *promotores/as*. Output data were also collected, such as the number of classes given and referrals made. Findings from this evaluation led to the publication of several articles as well as conference presentations highlighting the transformative effect of the project on the LHAs themselves (Warrick, 1992).

Although the national visibility of *Comienzo Sano* played a role in moving the CHW field ahead as a whole, the key to the expansion in the state in the early '90's appears to have been the presentation of cost-savings data generated by the *Comienzo Sano* directors in 1992. These data were collected after the original evaluation effort because advocates realized that these additional data were needed to make a compelling case to policy makers. The new data compared costs of neo-natal intensive care episodes and the enrollment rates of women in the state's subsidized insurance program in areas with similar demographic characteristics of those women served and not served by the program. Findings indicated that the program saved the state funds and this moved the legislature to support the program.

Competing Evaluation Efforts: External and Internal Reviews

The Auditor General

Legislative support for Health Start was hard won and has been even harder to keep. A mandated evaluation of the program by the state's auditor general was initiated in 1994. The evaluation looked at "the effectiveness of the program, its organizational structure and efficiency, the type and level of criteria used to establish eligibility, and the number and demographic characteristics of persons who receive services from the program" (Auditor General, 1996). The tone of the auditor general's evaluation reflected their auditing role. For example, Health Start participants were formally tested about their knowledge of a variety of topics, such as nutrition, breast feeding, immunizations and drug use. The women were found to have a good understanding of these topics and of how to put their knowledge into action. Evaluators also looked at the cost per client, observing that fewer visits per client generated savings. Overall, the program was found to be more efficient in urban settings. Numerous recommendations were made for improving the program, all of which were implemented. Ultimately, the auditor general gave the program mixed reviews, thus fueling debate about its future.

Internal Evaluation

When the statewide program started in 1992, staff members at the state level conducted their own evaluation and monitoring. These efforts were expanded when the auditor general's evaluation began. At that time, the program staff hired outside evaluators to aid them in collecting qualitative and quantitative data. These evaluators monitored many of the same variables as the auditor general, such as the number of prenatal and postpartum visits, smoking,

drug and alcohol use. A comprehensive cost-benefit analysis was also undertaken, utilizing a comparison group. The analysis looked at the reduction in the incidence of low a nd very low birth weight infants per dollar spent (Irvine, 1997). The program as a whole was found to generate cost-savings. A minimum scale of operations was found to be important for realizing savings at the individual site level. Overall, this evaluation showed more favorable outcomes than did the auditor general's evaluation, and it aided the program in defending itself for a time from threats to cut program funds.

Evaluation Challenges

Ongoing evaluation efforts require continued commitment from staff at all levels of a program. When evaluation data are utilized to penalize a program, that commitment wears thin. State Health Start staff now see the ongoing evaluation and monitoring effort as an opportunity to identify problem areas to be resolved through training and technical assistance. Defining evaluation as a problem-solving endeavor rather than as an opportunity to identify program inadequacies has helped to overcome resistance from LHAs and program site directors. With limited resources, efforts have been made by state staff to streamline evaluation processes while not losing data needed for program improvement or to make a case for the program. Also, opportunities to share data across related programs, such as Women, Infants, and Children (WIC), are being maximized. In order to gather data, sites now receive a monthly payment to enter and submit data collected in encounter forms shared by all the sites. Having sites individually manage data builds capacity and fosters a collaborative approach.

Sustainability

Numerous factors have contributed to the overall sustainability of the Health Start program. Many individuals, including LHAs and people from the communities they serve, as well as program directors, researchers, advocates and the media, have helped to make the program visible to the policy makers who ultimately decide its fate. The political climate in Arizona's legislature has presented some keen challenges for the program. Program staff and supporters have worked so that the program would be seen as a community capacity-building program rather than as a handout program. Health Start demonstrated that it is about "neighbors helping neighbors" and about communities contributing their resources to help one another. It has needed to help policy makers understand LHA services and how Health Start differs from other programs with similar target populations and even similar names, such as Arizona's Healthy Families program.

At times, the evaluation arena has been a battlefield, reflecting the competing political interests for and against the program. Ultimately, however, evaluation has played an important role in defining the value of the program and helping to tip the scales in the debate about the program's ability to save money for the state while improving the wellbeing of the families it serves.

The Harborview Medical Center House Calls Program

Seattle, WA

Program Overview

The Harborview Medical Center's (HMC) Community House Calls (CHC) program, based in Seattle at the University of Washington Medical Center, is a community advocacy and outreach program employing community health workers as Case Worker Cultural Mediators (CCMs) for identified populations at risk, particularly immigrants.

Activities of these CCMs include home visits, provider education and community education. Funding for the first two years of the program came from Opening Doors, a joint initiative of the Robert Wood Johnson and Henry J. Kaiser Family Foundations. The project is linked in its management with the hospital's interpreter services, and the medical center assumes responsibility for both programs from its own funds, in large part covered through outside reimbursement streams.

The medical center, as a state facility, is required to provide medically certified interpreters to all patients and medical providers who request them. This standard exceeds the state standard for private facilities, which requires only that any certified interpreter address the need for medical interpretation. As the lead trauma center in the region, HMC surgeons and related staff value this standard, recognizing the need for accurate interpreting to meet the needs of those they serve. State funding for medically related interpretation and case management helps to cover approximately 65% of the cost of delivering the CCM services.

Evaluation

The House Call Program tracks its activities through regular documentation. In addition to this general tracking of the program, several distinct evaluations that parallel the Tool Kit's framework levels have been undertaken. The two physicians who first established the program coordinated these efforts.

Tracking Activities

The project utilizes a daily log sheet to track activities. Monthly summary reports bring this information together for regular review. CCMs helped to refine these tracking forms. Program managers believe that these forms promote accountability and thus aid in motivating staff as well as providing documentation.

Patient Satisfaction with CCMs

A patient satisfaction assessment (Graham, 1999) was undertaken early in the program, focusing on the individual/ family level of the Tool Kit's framework. The assessment, made with just under 100 Cambodians, compared satisfaction among those who were served by CCMs and a comparable group that had not received these services. Trained interviewers not directly linked to the

CHC programs gathered data from patients in their homes. No differences were found between the two groups in terms of satisfaction. The only significant difference noted was that those with exposures to the CCM felt that they had a contact person in the institution.

Based on the assessment, the staff determined that soliciting direct patient satisfaction data from an immigrant population with differential expectations about health care systems is problematic. They suggest that a better measure of satisfaction would have been to look at use patterns over time for those exposed to CCMs. They also suggested that rather than direct satisfaction questions, other sorts of questions might have better assessed how CCMs are perceived, such as, "Does your CCM listen to you carefully and get your point across to the medical provider?"

Physicians Learning from CCMs

This component of the evaluation addresses the program level of the framework, looking at how pediatric and internal medicine residents' knowledge base changes with exposure to CCMs. The pre-post survey, in particular, assesses knowledge about the cultures of the populations they serve as well as capacity to effectively use interpreter services.

Community Leaders' Perceptions of CCMs

A survey of eleven community leaders from the five distinct cultural groups served by the program corresponds to the community level of the framework. This qualitative study identified three distinctive CCM roles — community participation, comprehensive health care and leadership.

Health Care Utilization

This evaluation component looks at individual behavior change within the institutional context, addressing individual and family change within the context of the medical systems. A primary goal of the CHC program is to increase the appropriate utilization of health care services. To examine this, the evaluation component solicits comparable data from medical providers who have contact with CCMs and from the CCMs themselves about their interactions. Communication channels included in the evaluation are e-mails, telephone calls, and hallway conversations. The researchers recognize that many management decisions are made through brief formal and informal encounters, so they have made these the unit of analysis.

This evaluation, now in progress, will include four two-week time samples over a year, during which time all communication between CCMs and providers is tracked, utilizing a form that takes 1-3 minutes to answer. Providers and CCMs individually fill in the form, answering questions about patient management decisions made. The form assesses such elements as whether a medical, social, and/or legal management issue was reviewed and if the results of that review included, for example, scheduling of an appointment or a medication management decision.

Preliminary analysis of the data gathered to date indicates that multiple issues are discussed during contacts and that 10 % of the time an urgent care or emergency room visit is prevented as a result of the communication. Researchers are hoping to expand the analysis of the data to look at other variables, including cost savings, and they are hoping to share their findings through publications.

Evaluation Challenges

Researchers at HMC note that evaluating the impacts of the CCMs is confounded by the tendency of several elements to improve over time among individuals utilizing new health services systems. They note specifically that both with and without the presence of a CCM, a trusting relationship often develops over time with a medical provider, and there is improvement in capacity to utilize the system, including health maintenance organizations such as HMC. Further, they note that patients most in need of assistance are the ones referred to the Community House Calls program, thereby complicating efforts to compare this population to those who are not triaged into the program. One area researchers say they have yet to measure, and one that they feel would be a true measure of program success, is how many people have left the CCMs' case management services because they feel they have graduated to independence.

Sustainability

Support from community leaders as well as from physicians has helped to gain the support of the hospital administrators who have made the choice to sustain this project. Another key to gaining support has been the high visibility of the Community House Calls program at the national level.

Other keys to Community House Calls' sustainability may be that CCMs are well integrated into the hospital staff, increasing their visibility on the home front and their opportunity to contribute to the health care of those they serve. They play a role in teaching at the hospital, participate in hospital staff team meetings and in cross-cultural committees. Community House Calls program staff also cite the importance of good supervision and mentoring for CCMs to promote program success.

One important barrier to the sustainability of CCMs services may be the lack of a standard at the national level that requires medically trained interpreters. Community House Calls staff observes that requirements may ultimately be developed in light of recent malpractice suits based on poor interpretation in trauma and surgery cases.

Documenting and evaluating the role of CCM services at the hospital also plays a role in the sustainability of the Community House Calls program. Hospital records indicate that the program has helped to increase the number of clients from the target groups served by the program. Specifically, the program appears to have drawn in approximately 400 new patients. For each individual, the hospital receives over 100 dollars per person per month, almost $500,000 per year. Although this money does not go directly to the hospital, these funds help support the university/ hospital infrastructure overall. Sharing these findings with decision-makers at the hospital has increased support for the program and helped to build on-going commitment.

Latino Health Access

Santa Ana, CA.

Program Overview

Latino Health Access (LHA) was established as a non-profit community-based agency in 1993 in Orange County, California. It serves uninsured, underserved people, providing quality preventive services and educational programs. Its stated mission is to promote "responsibility and full participation in decisions affecting health." More than thirty youth and adult Community Health Workers (CHWs), known in Spanish as *promotores* or *promotoras*, coordinate and offer services such as home visiting, school and community health promotion classes, and health fairs. The *promotores* work in the areas of chronic disease management, including diabetes and cardio-vascular health, and in a general wellness promotion project targeting their zip code area of 65,000 people. Both projects are implemented in partnership with others in the county.

The agency receives funding from multiple sources. Early funding support for strategic planning from the California-based James Irvine Foundation was critical in facilitating their growth and ongoing success. Support continues from this Foundation for core administrative expenses and for outside consultants who help with activities such as publication production and marketing plan development. There are many other funders, both local and national, that have contributed to LHA, including the Robert Wood Johnson Foundation Local Initiatives Program, the California Wellness Foundation, the California Endowment, St. Joseph Foundation, the Alliance for Health Care Foundation and the federal Empowerment Zones initiative. Latino Health Access also has contracts with the county health department, hospitals and managed care plans to teach their 12 week diabetes curriculum. Additional contracts provide for follow-up home visiting services. The contracts for classes are on a fee for service rather than a capitation basis.

Evaluation

Evaluation of LHA takes place on all levels represented in the Tool Kit's framework except for evaluation of the impact of participation on the *promotores/as* themselves. LHA's two main projects, chronic disease prevention classes with a focus on diabetes, and the Healthy City project, "Santa Ana 92701", have resulted in two separate evaluation efforts.

Diabetes Classes

The evaluation of the diabetes program tracks the influence of the program on the individuals who have participated in the series of health classes given by the *promotores/as*. At the program's outset, participants' knowledge, attitudes, and behaviors (KAB) related to diabetes were assessed and then measured again following the classes. To explore perceptions of health, the program evaluator used the widely known evaluation tool, the MOS 36 Item Short-Form Health Survey (SF 36), which looks at such variables as perceived vitality, emotional

health, and mental health (Ware). The evaluator utilized SF 36 national norms as a comparison point for measurement of changes in this uninsured population. Other than this, there was no control or comparison group. There were numerous early efforts to establish such a group, but it was too difficult to isolate a comparison group from this community-based project. Several clinical indicators of diabetes were also utilized in the evaluation. These include the HbAlc Test, a key indicator of diabetes control. Measures were taken at baseline, 3 months, 6 months, and one-year following participation in classes taught by the *promotores*. The evaluator for this project was an independent consultant hired directly by the funder rather than LHA. The clinical data belong to the clinics. These early evaluations showed that the *promotores* had a positive impact on those they served. Given this strong early evaluation, subsequent evaluation efforts on this component of the program have been narrowed in scope, focusing on program outputs that need to be documented for program management purposes.

Santa Ana 92701

The Healthy City project evaluation looks at individual and family, program performance, and community/systems levels of the Tool Kit's framework. One important element of this evaluation is a baseline and a three-year follow-up household survey conducted in partnership with the project's major collaborator, the Orange County Health Department. The health department took the lead in designing this component of the evaluation, helping LHA to identify health indicators that were appropriate for individuals and families and the population as a whole. Key indicators tracked by the survey include enrollment in prenatal care during first trimester and immunization levels. To allow for comparisons, select data, such as immunization levels, were gathered on first grade classes both within and outside the target area.

Evaluation consultants hired by a principal funde of the Healthy City project are conducting another important component of the evaluation. This evaluation component is based on a logic model developed under the guidance of the evaluators by LHA staff and local stakeholders. The logic model process explores project goals and objectives and anticipated challenges. Building on this, it identifies changes hoped for as a result of the project and identifies indicators of that change. An example of an indicator identified through this process is the number of times that parents go out with the whole family. Youth *promotores* suggested this indicator because they saw it as a sign of community wellness. When recording the variables identified in their logic model, the CHWs collect data in a family chart. Family charts are then organized by residential buildings. In addition to this individual and family health documentation, project staff actively tracks project outputs such as phone calls made and meetings held. At the community/systems level, the project is looking at changes in local community networks. The project, which also targets alcohol abuse, is tracking variables such as changes in the number of alcohol licenses sold.

Evaluation Challenges

Latino Health Access's programs are dynamic and changing, responding to community needs. At times this creates evaluation challenges. Within LHA's diabetes education project, efforts by the evaluator to establish a control group referenced earlier were unsuccessful due to high interest in the program in

potential control sites and expansion efforts to meet community needs and interests. In the Santa Ana 92701 project, the planned sequence of events and related evaluation efforts laid out through the logic model process must be regularly modified due to an expanding agenda developed through community participation.

The Santa Ana 92701 project, which was initiated following the diabetes education project, has pushed LHA's staff to expand their awareness about the types of evaluation data needed to document change. This expanded thinking to some extent parallels the Tool Kit's evaluation framework levels --moving LHA from a focus on the individual and family level to look at community and public health population data. While that expanded vision has been a welcome one, it has required an active educational approach to ensure that all staff at LHA, including the *promotores,* fully understand the need for the data they ultimately must generate.

Sustainability

Numerous factors have led to the sustainability of this organization. Among them appears to be a dynamic and visionary leader who has helped to generate interest and commitment to the program and the people it serves. Visibility also appears to be a key contributor to LHA's on-going sustainability. All *promotores* in the agency know they represent the agency, both on the job and off. The agency also emphasizes the importance of relationships at the local and national level, including building strong relationships with funders, who in turn have strong relationships with one another. LHA has national visibility that was hard won and now seems to carry the program forward, building the confidence of funders. These funders' capacity to publicize the projects in which they invest further builds LHA's capacity to sustain its programs.

The agency has identified several areas in which they invest their efforts to sustain their programs. Demonstrating results is one of these areas. Results are tangible and help others understand what they do. They seek opportunities to share their successes, using their data as a marketing tool to interest those who can help fund their work. LHA has worked to keep evaluation results under the control of others, seeking to ward off skepticism about findings. Indeed, LHA is one of the CHW programs that has been able to move beyond an ongoing struggle to garner funds. The agency is well sustained for the present and optimistic about its future

The Community Health Worker Project Serving the Frail Elderly with Dementia

Kaiser Permanente, San Diego County, CA

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Program Overview

Kaiser Permanente in San Diego County, California, a health maintenance organization (HMO), is managing an innovative community health worker project serving members who have dementia and their caregivers. The project's start-up funds came from a grant by the Kaiser Permanente Interregional Coalition on Aging. The funds were granted to numerous projects throughout the Kaiser system to pilot innovative programs in community-based care. In 2001, with the original funding stream gone, the project will be funded by foundation grants.

The project employs four half-time CHWs who work with the social work staff on care coordination within the organization's continuing care department. While CHWs support social workers in their roles, they do not supplant the services provided by these professionals. The CHWs' roles in the project grew out of a series of focus groups with caregivers, who identified the kinds of challenges they face, internal and external to the Kaiser system, in caring for their loved ones. The CHWs' role is to follow-up with caregivers and frail elders with dementia, aiding them to implement the care plans developed by the social work staff. When no caregiver has been identified, CHWs work directly with the Kaiser member. The CHWs meet regularly with the social work staff to update them on member status and to modify the care plans as needed.

Evaluation

The program has been studying its own evaluability, focusing on how it might implement a more comprehensive evaluation if they had greater resources. At this stage, the project has been tracking a number of variables, primarily at the individual and family level of the Tool Kit's framework, as well as the system level in terms of the Kaiser Permanente system as a whole.

A simple step-by-step process was used to develop the program and the evaluation - ask what is needed, design a program to address it, and then document whether it has been accomplished. To carry out this documentation, the project developed a daily productivity tracking log with a checklist of the activities of the CHWs. The activities to be documented on that form were drawn directly from the caregiver responses in the focus groups.

The CHWs also kept progress notes about their visits. The evaluator received ongoing input from CHWs on their roles and performed a content analysis of these notes. The CHW feedback and the content analysis of the progress notes revealed that the CHWs provide more social support than the concrete health education anticipated by the project staff. When this was recognized, the

tracking form was updated to include "social support" with examples. Staff feels that this change not only helps CHWs better document services delivered, but also helps communicate to the CHW that the social services they deliver are valued. In addition to assessing CHW roles, information was gathered from project staff mid-way into the project and at project completion on what had been learned about other program activities. Information was gathered on such areas as training needs and policies and procedures for home visits.

In addition to the data collected by the CHWs themselves, the project administers a Memory and Behaviors Problem Check List and Burdens Interview (Zarit, 1990) to caregivers. Researchers at the Pennsylvania State University developed both instruments. Unfortunately, only a limited number of dementia patients have identified caregivers, and the program has collected limited evaluation data in this area.

Finally, the project would like to look more closely at changes in emergency room and hospital utilization and appointment keeping behavior as part of documenting program outcomes. A pilot analysis of these data was performed at project completion; however, a more precise research approach is needed in order to draw conclusive results. The project staff acknowledges that the CHWs may actually generate increased use of outpatient services, including the pharmacy (reminding members to take their medicines), but they also suspect that more appropriate use of services will ultimately lead to lowered costs overall per member.

Evaluation Challenges

One of the greatest challenges to evaluating the project is assuring that, during this formative stage, a sufficient level of detail is recorded to help build the case for long-term support in a HMO. For example, the project took on that challenge when it responded to concerns from the CHWs about accurately filling out the activity log. As described earlier, this concern led to the addition of progress notes to their documentation process. Analysis of these notes then led to a revision of the tracking log.

Another important challenge in evaluating this program is faced by all projects serving the elderly and those with debilitating diseases. Overall health status is worsening over time, and success must be documented in other ways. A comparison group could help to tease out this influence, but, due to limited resources, no such group is included in the current evaluation design.

Sustainability

Committed and visionary staff at all levels of Kaiser Permanente at San Diego has been the key to this project's initiation and implementation. Staff has contributed many hours to design and carry out this project. The project is seen at the local level as helping to put Kaiser Permanente on the cutting edge in the competitive market of San Diego. Nevertheless, the project's sustainability in its first year might be better called "instability". Budget crunches throughout Kaiser Permanente have meant that the funding for the long-term care initiative of which this project is a part, was reduced from the original budget. With limited funding in its first year and no funding allocated for the second year, the

project staff has dedicated significant time to look outside the system for funds. The project originators are committed to seeing the project continue.

Project administrators have come to recognize that the CHWs benefit from oversight and supervision that requires more time than had originally been anticipated. Still, the social workers who provide much of that supervision have called for the project to continue and even to expand. They believe that they can improve patient and caregiver quality of life in partnership with the CHWs, who make it possible to implement care plans more effectively.

Evaluation findings have been limited by the project's short history, but findings to date show the project in a positive light. The project administrators know that, over time, the data gathered in an evaluation will be critical to building support in the Kaiser system. They have committed to a more substantial evaluation with their future funding, including resources to conduct a cost-benefit analysis.

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