3

Successful Examples in the Field

Chapter 3

Successful Examples in the Field

Robert Duffy, MPH (Chair), Sergio Aguilar-Gaxiola, MD, PhD, Donna Jo McCloskey, RN, PhD, Linda Ziegahn, PhD, Mina Silberberg, PhD

SUCCESSFUL EFFORTS IN COMMUNITY ENGAGEMENT

This chapter presents examples of successful community engagement efforts in health promotion, evaluation, and research that demonstrate the principles of engagement discussed in Chapters 1 and 2. The authors asked representatives from federal health agencies to recommend case examples of the effective use of community engagement that were published in peer-reviewed journals from 1997 to the present. Of the examples submitted, 12 are presented here. This chapter summarizes the articles associated with each case, emphasizing collaboration and the way the case illustrates the principles of interest. Information is up to date as of the time of the article's publication. At the end of each case, references and websites are provided for further information regarding findings, funding sources, and follow-up. The 12 examples are as follows:

1. Community Action for Child Health Equity (CACHÉ)
2. Health-e-AME

3. Project SuGAR
4. The Community Health Improvement Collaborative (CHIC)
5. Healing of the Canoe
6. Formando Nuestro Futuro/Shaping Our Future
7. Improving American Indian Cancer Surveillance and Data Reporting in Wisconsin
8. Children And Neighbors Defeat Obesity/La Comunidad Ayudando A Los Niños A Derrotar La Obesidad (CAN DO Houston)
9. The Dental Practice-Based Research Network
10. Diabetes Education & Prevention with a Lifestyle Intervention Offered at the YMCA (DEPLOY) Pilot Study
11. Project Dulce
12. Determinants of Brushing Young Children's Teeth

TABLE 3.1. MATRIX OF CASE EXAMPLES[1]

The following matrix summarizes the principles of community engagement illustrated by each of the case studies. The rationale for the selection of principles is included in each example.

Case Example	Principle 1 Be clear about the population/ communities to be engaged and the goals of the effort.	Principle 2 Know the community, including its norms, history, and experience with engagement efforts.	Principle 3 Build trust and relationships and get commitments from formal and informal leadership.	Principle 4 Collective self-determination is the responsibility and right of all community members.	Principle 5 Partnering with the community is necessary to create change and improve health.	Principle 6 Recognize and respect community cultures and other factors affecting diversity in designing and implementing approaches.	Principle 7 Sustainability results from mobilizing community assets and developing capacities and resources.	Principle 8 Be prepared to release control to the community and be flexible enough to meet its changing needs.	Principle 9 Community collaboration requires long-term commitment
1. CACHÉ	X	X	X	X	X	X		X	X
2.Health-e-AME	X	X	X	X	X				
3. Project SuGAR	X	X	X	X	X	X			X
4. CHIC		X	X		X		X	X	
5. Healing of the Canoe				X	X		X	X	X
6. Formando Nuestro Futuro/Shaping Our Future		X	X					X	X
7. Improving American Indian Cancer Surveillance and Data Reporting in Wisconsin		X	X		X	X			X
8. CAN DO Houston		X		X				X	
9. The Dental Practice-Based Research Network				X	X	X			
10. The DEPLOY Pilot Study			X	X	X		X		
11. Project Dulce					X	X	X		X
12. Determinants of Brushing Young Children's Teeth		X				X			

[1] The principles of community engagement have been abbreviated for this table.

1. COMMUNITY ACTION FOR CHILD HEALTH EQUITY (CACHÉ)

Background: In 2002, the National Institute of Child Health and Human Development (NICHD) began funding a five-site Community Child Health Network (CCHN) to examine how community, family, and individual factors interact with biological causes to result in health disparities in perinatal outcomes and in mortality and morbidity during infancy and early childhood. A large national cohort of families was recruited at the time of delivery with oversampling among African American and Latina women, women with preterm births, and low-income families. The investigators periodically assessed mothers and fathers, measuring individual, family, community, and institutional stressors as well as resilience factors. The three-phase study was designed to (1) develop academic-community partnerships and pilot studies; (2) conduct a longitudinal observational study to identify the pathways that lead to the disparities of interest, which would be informed by the initial developmental work; and (3) field a systematic study of sustainable interventions to eliminate these disparities, again informed by the observational study. At the time of publication, Phase 1 had been completed and Phase 2, also funded by NICHD, was under way.

CACHÉ is a partnership between the NorthShore Research Institute Section for Child and Family Health Studies and the Lake County Health Department/Community Health Center Women's Health Services. CACHÉ is a CCHN site in Lake County, located north of Chicago. During Phase 1, the county had 702,682 residents, comprising a diverse mix of individuals from varied races, ethnicities, and socioeconomic status. Even though Lake County had low unemployment between 2000 and 2005, 7.1% of the residents lived below the poverty line (Illinois Poverty Summit, 2005).

Methods: Community-based participatory research (CBPR) approaches were used for this study. Following a kickoff meeting, 27 community leaders volunteered to participate in a community advisory committee (CAC) that still shares in all program decision making. Interviews with these leaders were analyzed and findings shared with the CAC.

Results: This initial process allowed the community members to come to a consensus about the issues facing the Lake County families. The academic researchers and the community were able to create a vision for CACHÉ and

a mission statement written in the language of the CAC. As CACHÉ transitioned from Phase 1 to Phase 2, the sustainability of the CAC was addressed through an open-door policy for CAC members. Each member was asked to bring whoever they thought was "missing at the table" for the next meeting.

At the national level, community advisors informed academics that collecting saliva or whole blood spots from men in the community would be viewed suspiciously because of a legacy of distrust in this population and concerns regarding confidentiality. In contrast, CACHÉ CAC members insisted that all clinically relevant testing be offered to fathers and mothers (with adequate explanation of the reasons for testing) and that clinical outreach and referral be offered in cases of abnormal findings. CACHÉ found additional foundation funding to pay for biospecimen collection from fathers, as well as a clinical tracking system and a part-time clinical social worker to provide triage and referrals.

One challenge to a long-term relationship between academic researchers and community organizations is the perception that the academic team has an unfair advantage in writing grants to obtain scarce funds from local foundations. CACHÉ attempts to overcome this challenge by offering technical assistance for preparing submissions for foundation grants to any agency that belongs to its collective.

Comments: Community wisdom brought to bear on the research process addressed local needs and moved CACHÉ to be highly innovative in both the collection of biospecimens from fathers and the communication of clinically relevant research findings to research participants in real time.

Applications of Principles of Community Engagement: The decisions and the decision-making roles that community members and academic members assumed during the initial development phase of CACHÉ exemplify many of the principles of community engagement. The decision to form a partnership with the community by creating a CAC was in line with Principles 1–5. The CAC shared in the process of creating a mission statement, and the collaboration continued throughout this long-term program (Principle 9). One unique aspect of CACHÉ is its insistence that goals be consistent with the overall CCHN objectives but be modified for local conditions. By

including the collection of biospecimens against the advice of the CCHN but in response to the needs of Lake County, the CACHÉ program exemplifies Principle 6, which stresses that all aspects of community engagement must recognize and respect community diversity, and Principle 8, which cautions that an engaging organization must be prepared to release control of actions or interventions to the community and be flexible enough to meet the changing needs of that community. Finally, by responding constructively to perceptions that the academic team had an unfair advantage in writing grants, CACHÉ is using Principle 2, which acknowledges that the initiator of community engagement, in this case researchers, must become knowledgeable about the community's experience with engagement efforts and the community's perceptions of those initiating the engagement activities.

References

Illinois Poverty Summit. *2005 report on Illinois poverty.* 2005. Retrieved Mar 25, 2010, from http://www.heartlandalliance.org/maip.

Shalowitz M, Isacco A, Barquin N, Clark-Kauffman E, Delger P, Nelson D, et al. Community-based participatory research: a review of the literature with strategies for community engagement. *Journal of Developmental and Behavioral Pediatrics* 2009;30(4):350-361.

Websites

www.northshore.org/research/priorities

www.nichd.nih.gov/research/supported/cchn.cfm

2. HEALTH-E-AME

Background: The Medical University of South Carolina (MUSC) and the African Methodist Episcopal (AME) church had worked together on several health-related projects prior to this initiative. A needs assessment completed in 2002 with a sample of AME members revealed that physical activity (PA) was low. The AME Planning Committee, a group comprising AME members, pastors, and presiding elders as well as members of academic institutions, identified PA as an important target for reducing health disparities. MUSC, the University of South Carolina, and the AME Planning Committee then collaborated on a proposal to CDC. All three organizations participated actively in the proposal and the subsequent project, although the church opted to have the two universities handle the grant funds.

Methods: A CBPR approach using a randomized design with a delayed intervention control group.

The Health-e-AME Faith-Based PA Initiative was a three-year project funded through a CDC CBPR grant. Because a traditional randomized controlled design was not acceptable to AME church leaders, a randomized design with a delayed-intervention control group was chosen instead.

Results: More than 800 volunteers from 303 churches participated in the program. Among survey respondents as a whole, PA did not increase significantly over time. However, 67% of respondents were aware of the program, and program awareness was significantly related to PA outcomes and to consumption of fruits and vegetables. Pastoral support was significantly associated with increased PA.

Comments: The successful partnership between the researchers and the AME church continues to this day through the newly formed FAN (Faith, Activity, and Nutrition) initiative. Those wishing to participate in partnerships between academic and faith-based organizations can glean useful information from Health-e-AME, including the process partnerships can use to develop, implement, and evaluate PA interventions. PA interventions that actively engage faith-based organizations in decision making and program implementation are rare, making this approach and the lessons learned unique.

The successful partnership between the researchers and the AME church continues to this day through the newly formed FAN (Faith, Activity, and Nutrition) initiative.

Applications of Principles of Community Engagement: The researchers' partnership with the AME church reflects Principle 3, which asks organizers of community engagement to establish relationships and work with existing leadership structures. The initiative was designed to increase participation in PA among adult members of the AME church community. All decisions are based on active input and approval from the AME church. In this way, the project is built on Principle 4, which stresses that those engaging a community cannot assume that they know what is best for the community. Instead, decision making must occur on a partnership basis that results in shared power and mutual understanding. This group collaboration also reflects Principles 1–5 by establishing relationships and trust, allowing community control, and developing partnerships for change. MUSC, the University of South Carolina, and the AME Planning Committee have collaborated throughout, beginning with the CDC application for a CBPR grant. Because the partners have worked together from the beginning of the grant proposal and all decisions have been made through active input, this program exemplifies many of the principles of community engagement.

References

Wilcox S, Laken M, Anderson T, Bopp M, Bryant D, Carter R, et al. The health-e-AME faith-based physical activity initiative: description and baseline findings. *Health Promotion Practice* 2007;8(1):69-78.

Wilcox S, Laken M, Bopp M, Gethers O, Huang P, McClorin L, et al. Increasing physical activity among church members: community-based participatory research. *American Journal of Preventive Medicine* 2007;32(2):131-138.

3. PROJECT SUGAR

Background: Gullah-speaking African Americans have high rates of type 2 diabetes characterized by early onset and relatively high rates of complications (Sale et al., 2009). Researchers hoped to discover diabetes-specific alleles in this community because the Gullahs have a lower admixture of non-African genes in their genetic makeup than any other African American population in the United States due to their geographic isolation on the South Carolina coastline and islands. In addition to the scientific objective of identifying the genetics behind diabetes, Project SuGAR (Sea Island Genetic African American Family Registry) had an important second objective: to provide community outreach to promote health education and health screenings relative to metabolic and cardiovascular diseases.

Methods: The project used a CBPR approach. Investigators organized a local citizen advisory committee (CAC) to ensure that the research design was sensitive to the cultural and ethnic background of the community. This committee was involved in all phases of the research study.

Results: Services provided to the community included health education fairs, cultural fairs, a mobile "SuGAR Bus" to conduct health screenings, and jobs for community members who were staff on the project. Investigators exceeded their enrollment goal with 615 African American families, totaling 1,230 people, contributing to the genome study. The success of their recruitment strategy helped researchers create a world-class DNA registry that has been used to identify markers for diabetes, including novel type 2 diabetes loci for an African American population on chromosomes 14q and 7.

Comment: The success of the community engagement employed by Project SuGAR is further evidenced by the fact that the local CAC that started in 1996 is still operating today with the dual goals of establishing a family registry with DNA and developing long-term collaborations to promote preventative health. Under the new name Sea Islands Families Project, the local CAC oversees the use of the Project SuGAR registry and has branched out into similar community engagement projects such as Systemic Lupus Erythematosus in Gullah Health and South Carolina Center of

The success of the community engagement employed by Project SuGAR is further evidenced by the fact that the local CAC that started in 1996 is still operating today with the dual goals of establishing a family registry with DNA and developing long-term collaborations to promote preventative health.

Biomedical Research Excellence for Oral Health. The local CAC adheres to the principles of CBPR and advocates community input at the initial development of the research plan. To this end, investigators who are new to the Gullah community and interested in community-based genetic research are asked to present their research plan to the council members before initiation of research projects. Investigators are also asked to present their findings as well as any publications to the group.

Applications of Principles of Community Engagement: Project SuGAR exemplifies Principles 1–6, which ask researchers to be clear about the purposes or goals of the engagement effort, learn about the community, and establish long-term goals based on community self-determination. Consistent with these principles, this partnership used a local CAC to ensure that the goals of the researchers were consistent with the goals of the community. The ongoing nature of the MUSC-Gullah collaboration illustrates Principle 9.

References

Fernandes JK, Wiegand RE, Salinas CF, Grossi SG, Sanders JJ, Lopes-Virella MF, et al. Periodontal disease status in Gullah African Americans with type 2 diabetes living in South Carolina. *Journal of Periodontology* 2009;80(7):1062-1068.

Johnson-Spruill I, Hammond P, Davis B, McGee Z, Louden D. Health of Gullah families in South Carolina with type 2 diabetes: diabetes self-management analysis from Project SuGar. *The Diabetes Educator* 2009;35(1):117-123.

Spruill I. Project Sugar: a recruitment model for successful African-American participation in health research. *Journal of National Black Nurses Association* 2004;15(2):48-53.

Sale MM, Lu L, Spruill IJ, Fernandes JK, Lok KH, Divers J, et al. Genome-wide linkage scan in Gullah-speaking African American families with type 2 diabetes: the Sea Islands Genetic African American Registry (Project SuGAR). *Diabetes* 2009;58(1):260-267.

Websites

http://academicdepartments.musc.edu/sugar/progress.htm

http://clinicaltrials.gov/ct2/show/NCT00756769

http://academicdepartments.musc.edu/cobre/overview.html

4. THE COMMUNITY HEALTH IMPROVEMENT COLLABORATIVE (CHIC): BUILDING AN ACADEMIC COMMUNITY PARTNERED NETWORK FOR CLINICAL SERVICES RESEARCH

Background: In 1992, CDC funded Healthy African American Families (HAAF) to study the reasons for high rates of low birth weight and infant mortality among African Americans in Los Angeles. The success of this collaboration led to the expansion of HAAF to investigate other health issues, including preterm delivery, mental health, diabetes, asthma, and kidney disease, as well as to look at various women's health projects. The academic component of HAAF evolved into the development of a research infrastructure, the Los Angeles Community Health Improvement Collaborative (CHIC). The purpose of CHIC was to encourage shared strategies, partnerships, and resources to support rigorous, community-engaged health services research within Los Angeles that was designed to reduce health disparities. Partners in the collaborative were the RAND Health Program; the University of California, Los Angeles (UCLA), branch of the Robert Wood Johnson Clinical Scholars Program at the David Geffen School of Medicine; the UCLA Family Medicine Research Center; three NIH centers (at UCLA, RAND, and Charles R. Drew University of Medicine and Science); the Los Angeles County Department of Health Services; the Los Angeles Unified School District; the Department of Veterans Affairs Greater Los Angeles Health Care System; Community Clinical Association of Los Angeles County; HAAF; and QueensCare Health and Faith Partnership.

The success of this collaboration led to the expansion of HAAF to investigate other health issues, including preterm delivery, mental health, diabetes, asthma, and kidney disease, as well as to look at various women's health projects.

Methods: A CBPR approach using the principles of community engagement was employed to develop a community-academic council to coordinate the efforts of several research and training programs housed at three academic institutions.

Results: The conceptual framework developed for CHIC emphasizes the use of community engagement to integrate community and academic perspectives and develop programs that address the health priorities of communities while building the capacity of the partnership. Priorities for developing the research infrastructure included enhanced public participation in research, assessment

of the community context, development of health information technology, and initiation of practical trial designs. Key challenges to addressing those priorities included (1) obtaining funding for community partners; (2) modifying evidence-based programs for underserved communities; (3) addressing diverse community priorities; (4) achieving the scale and obtaining the data needed for evaluation; (5) accommodating competing needs of community and academic partners; and (6) communicating effectively, given different expectations among partners.

Comments: With strong leadership and collaboration based on the principles of community engagement, it is feasible to develop an infrastructure that supports community engagement in clinical services research through collaboration across NIH centers and the sharing of responsibilities for infrastructure development, conceptual frameworks, and pilot studies.

Applications of Principles of Community Engagement: Interventions developed by CHIC are designed to meet research standards for effectiveness and community standards for validity and cultural sensitivity. The engagement process of first forming the partnership between the convening academic researchers and the community organizations and then deciding on health priorities together demonstrates Principle 5, and knowledge of community needs demonstrates Principle 2. Community participation demonstrates Principle 3, and the convener's flexibility in meeting the needs of the community demonstrates Principle 8. After four tracer conditions were established (depression, violence, diabetes, and obesity), the CHIC presented four areas for development of research capacity in line with several of the community engagement principles: public participation in all phases of research (Principle 5), understanding community and organizational context for clinical services interventions (Principles 2 and 3), practical methods for clinical services trials (Principle 8), and advancing health information technology for clinical services research (Principle 7).

References

Jones L, Wells K. Strategies for academic and clinician engagement in community-participatory partnered research. *JAMA* 2007;297(4):407-410.

Wells KB, Staunton A, Norris KC, Bluthenthal R, Chung B, Gelberg L, et al. Building an academic-community partnered network for clinical services research: the Community Health Improvement Collaborative (CHIC). *Ethnicity and Disease* 2006:16(1 Suppl 1):S3-17.

Website

http://haafii.org/HAAF_s_History.html

5. HEALING OF THE CANOE

Background: The Suquamish Tribe is a federally recognized tribe that resides on the Port Madison Indian Reservation in the rural Puget Sound area of Washington state. Of the tribe's more than 800 members, approximately 350 live on the reservation. The University of Washington's Alcohol and Drug Abuse Institute and the Suquamish Tribe have a partnership that began when the director of the tribe's Wellness Program inquired about the possibility of collaborating on the development of culturally relevant interventions on substance abuse in the community. At the same time, NIH's National Center on Minority Health and Health Disparities had called for three-year planning grants for CBPR with communities to address issues of health disparities. Following approval by the Tribal Council, an application was submitted and subsequently granted. The Healing of the Canoe (HOC) set out to reduce health disparities by (1) conducting assessments of community needs and resources; (2) identifying and prioritizing the health disparities of greatest concern to the community; (3) identifying strengths and resources already in the community that could be used to address concerns; (4) developing appropriate, community-based, and culturally relevant interventions; and (5) pilot testing the interventions.

Methods: The project used CBPR and tribal-based research approaches, the Community Readiness model (Pleasted et al., 2005), interviews with key stakeholders, and focus groups from four populations identified by the Suquamish Cultural Cooperative (SCC) and the researchers: Elders, youth, service providers, and other interested community members recruited through flyers, word of mouth, and personal recommendations.

Results: Key stakeholders and focus group participants identified several behavioral health issues of concern. Of particular concern were prevention of substance abuse among youth and the need for youth to have a sense of tribal identity and a sense of belonging to the community. Participants identified three strengths/resources in their community that they thought would be critical to addressing the areas of concern: the tribal Elders, tribal youth, and Suquamish culture and traditions.

Comments: The findings from this community assessment were used to develop a culturally grounded curriculum for Suquamish youth called "Holding Up Our Youth" that incorporated traditional values, practices, teachings, and stories

to promote a sense of tribal identity and of belonging in the community. The result was an intervention that uses the canoe journey as a metaphor, providing youth with the skills needed to navigate through life without being pulled off course by alcohol or drugs, with culture and tradition serving as both anchor and compass (Pleasted et al., 2005; Thomas et al., 2010).

Applications of Principles of Community Engagement: The HOC project, by asking the community to identify its key health issues, demonstrates Principle 4, which states that communities need to "own" the issues, name the problems, identify action areas, plan and implement action strategies, and evaluate outcomes. Principle 7, which emphasizes the need to build on the capacity and assets of the community, is also evident in the project as it sought to identify the strengths and resources within the community. True partnership, as stressed in Principle 5, is evident at both the macro and micro levels in the HOC. A tribe member with a master's degree in social work is part of the research team and a coinvestigator. Following the completion of stakeholder interviews and focus groups, the HOC submitted a report to the SCC for review, feedback, suggestions, and approval, all in accordance with Principle 8, which states that principal investigators must be prepared to release control to the community. Finally, the foundation that was set by including the Suquamish Tribe in all aspects of the HOC project allowed for continued collaboration over time, in synchrony with Principle 9, long-term commitment by the engaging organization

References

Pleasted BA, Edwards RW, Jumper-Thurman P. *Community readiness: a handbook for successful change*. Fort Collins (CO): Tri-Ethnic Center for Prevention Research; 2005.

Thomas LR, Donovan DM, Sigo RLW. Identifying community needs and resources in a native community: a research partnership in the Pacific northwest. *International Journal of Mental Health and Addiction* 2010;8(2):362-373.

Websites

http://adai.washington.edu/canoe/history.htm

www.wcsap.org/Events/PDF/CR%20Handbook%20SS.pdf

6. FORMANDO NUESTRO FUTURO/SHAPING OUR FUTURE

Background: Formando Nuestro Futuro/Shaping Our Future (Formando) is a CBPR project focused on type 2 diabetes within the Hispanic farmworker communities in southeastern Idaho. In Idaho and elsewhere in the U.S., Hispanic farmworkers are at risk for many health conditions. This effort, which involved Idaho State University, evolved out of the Hispanic Health Project (HHP), a needs assessment survey conducted in 1998–1999, a review of diabetes charts at a community health center performed in 2000, and a binational ethnographic project conducted in 2001. Interestingly, there was a discrepancy between the community health clinic's estimate of the magnitude of the diabetes problem and the farmworkers' estimate.

Methods: The project used CBPR approaches that employed needs assessment and qualitative and quantitative methods. In 2001, to uncover the true effect of diabetes in the farmworker community, the HHP engaged in a binational ethnographic study of families that were split between Guanajuato, Mexico, and southeastern Idaho. A team of university researchers, promotores (community health workers), and students interviewed families in Guanajuato and southeastern Idaho.

Results: Some individuals described causes of diabetes that are congruent with the medical literature: herencia (heredity), mala nutrición (poor nutrition), and gordura (obesity). However, other individuals attributed their diabetes to such causes as susto (fright), coraje (anger), or preocupaciónes (worries). Thematic analysis of the interviews demonstrated that ideas about diabetes were linked to ideas of personal susceptibility; having diabetes was a stigmatized condition that connoted weakness. Individuals with diabetes were seen as weaker and vulnerable to being shocked and physically harmed by situations that others could withstand.

Comments: In 2004, Formando used the results from the ethnographic project to create a dialogue between the health care workers and the community of farmworkers. Currently, promotores visit each family once or twice a year to conduct interviews and collect data on biomarkers of diabetes. A series of educational modules is being presented at each home visit throughout the five-year study. These modules are based on the questions that the participants had during the previous round of visits from the

Currently, promotores visit each family once or twice a year to conduct interviews and collect data on biomarkers of diabetes.

promotores. In this way, the educational component of the intervention builds continuously on the questions and previous lessons that the families have had. The long-term commitment to using the CBPR approach in these agricultural communities is an effective way to engage in health research and to establish real and meaningful dialogue with community members.

Applications of Principles of Community Engagement: Uncovering the hidden health problems of the Hispanic farmworker families requires researchers to use Principle 2, which emphasizes the need to become knowledgeable about the community's culture, economic conditions, and other factors. The HHP's success in working continuously with the community of southeastern Idaho farmers is evidence of its long-term commitment to community engagement (Principle 9) and to its ability to establish relationships and work with existing leadership (Principle 3). Finally, the process by which the Formando project evolved and the development of educational modules based on a specific family's questions about diabetes is illustrative of Principle 8, which stipulates that an engaging organization must be prepared to release control of interventions and be flexible enough to meet a community's changing needs.

Reference

Cartwright E, Schow D, Herrera S, Lora Y, Mendez M, Mitchell D, et al. Using participatory research to build an effective type 2 diabetes intervention: the process of advocacy among female Hispanic farmworkers and their families in Southeast Idaho. *Women and Health* 2006;43(4):89-109.

Website

www.isu.edu/~carteliz/publications.htm

7. IMPROVING AMERICAN INDIAN CANCER SURVEILLANCE AND DATA REPORTING IN WISCONSIN

Background: In 2002, Spirit of EAGLES, a Special Populations Network program funded by the National Cancer Institute to address comprehensive cancer control through partnerships with American Indian communities, and its partners submitted a letter of intent in response to an invitation by the Great Lakes Inter-Tribal Council. After the Wisconsin Tribal Health Directors' Association had reviewed the letter, Spirit of EAGLES and its partners were invited to prepare a full proposal for submission as part of the larger Great Lakes Native American Research Center for Health grant proposal to NIH and the Indian Health Service. Following scientific review, this cancer surveillance research study was funded and conducted through a subcontract to Spirit of EAGLES.

Initially, the project staff spent significant time traveling and meeting with the director and staff of each American Indian tribal and urban health clinic in the state. Eight of the 11 Wisconsin tribes and one urban health center agreed to partner in the project. These nine partners decided that Spirit of EAGLES and the academic staff of the University of Wisconsin Paul B. Carbone Comprehensive Cancer Center in Madison should be responsible for the coordination of this large, multisite project. The clinics agreed to participate in each step of the research study and to audit the cancer cases in their records. Funds were provided to each participating clinic to help offset the demands on their staff time. All partners agreed to a core set of questions to be answered by abstracting data from clinic records, but the clinics could include additional questions specific to their community.

Methods: The project had two phases: (1) a community-specific phase to provide each participating American Indian health clinic with a retrospective profile of its cancer burden, and (2) a statewide phase in which all the cases identified by the individual health clinics were matched with the state cancer registry and an aggregate report was prepared.

Project staff taught staff members at the American Indian clinics how to abstract data; after abstraction, the data were analyzed at the Great Lakes Tribal Epidemiology Center. Spirit of EAGLES and staff at the center drafted an individual report for each community that described its cancer burden. American Indian health directors, clinic staff, and project staff met to discuss and interpret findings. Final, clinic-specific reports were presented to each

clinic. Presentations were made to health boards or tribal government committees as requested.

During the second phase, staff from the Wisconsin Cancer Reporting System matched cancer cases to the state registry and provided a de-identified database to tribal epidemiology center staff, who analyzed the aggregate data. At the time of publication, a draft report of the aggregate data and matches had been developed and presented for review and input at a meeting of the Wisconsin Tribal Health Directors' Association. The final aggregate report was to be disseminated to each participating community; each community would receive a report of the match between the cancer cases identified by its clinic and those identified by the Wisconsin Cancer Reporting System.

Results: Assessing the local cancer burden of American Indian communities in Wisconsin and improving the accuracy of the state American Indian cancer data necessitated multisite partnerships. Project leads embraced and used the diversity of backgrounds, skills, and experience of the partnering institutions.

This project demonstrates the successful application of CBPR in a complex, multisite project with multiple partners.

Comments: This project demonstrates the successful application of CBPR in a complex, multisite project with multiple partners. The approach developed reflected the time, availability, and skills of all partners; it was acceptable to all those involved and not unduly burdensome to any one individual or group. The project's success is measured not only in terms of improving the accuracy of cancer data for American Indians in Wisconsin but also by the ongoing, deeper relationships that were formed. At the time of publication, an independent evaluation of the project was being conducted, and new collaborations were under way.

Applications of Principles of Community Engagement: This project, a CBPR effort among diverse partners, adheres to Principle 3, which asks organizers of community engagement to establish relationships and work with existing structures. Working with multiple sites through several organizations within a community allows organizers to form a true partnership, as stressed by Principle 5. By using CBPR, the project acknowledges Principle 2, which stresses the importance of understanding the community's perceptions of those initiating the engagement activities. This is of utmost importance because of the history of racism suffered by American Indian communities

and the mistreatment of some American Indians by researchers, which has fostered mistrust of researchers. The researchers also circumvented mistrust by putting extra emphasis on ways to deepen trust between partners. One example was the researchers' return of raw data to the health directors and clinic staff for interpretation; this allowed the clinic personnel to give unique perspectives on the data, and some community-specific cancer interventions were developed using their insights. In addition, by sharing the data with all the different clinics, the project reflected the clinics' diversity, as stressed in Principle 6. Finally, through its four years of partnership and the potential for more projects in the future, this program demonstrates Principle 9, which states that long-term commitment is required for community engagement to truly succeed.

Reference

Matloub J, Creswell PD, Strickland R, Pierce K, Stephenson L, Waukau J, et al. Lessons learned from a community-based participatory research project to improve American Indian cancer surveillance. *Progress in Community Health Partnerships: Research, Education, and Action* 2009;3(1):47-52.

Websites

www.cancer.wisc.edu/uwccc/outreach.asp

http://mayoresearch.mayo.edu/cancercenter/spirit_of_eagles.cfm

8. CHILDREN AND NEIGHBORS DEFEAT OBESITY/LA COMUNIDAD AYUDANDO A LOS NIÑOS A DERROTAR LA OBESIDAD (CAN DO HOUSTON)

Background: After *Men's Fitness* magazine named Houston the "Fattest City in America" in 2005, the Office of the Mayor initiated the Mayor's Wellness Council (MWC) to encourage and motivate Houstonians to eat healthfully and engage in regular physical activity. The following year, the MWC created the Houston Wellness Association (HWA), a nonprofit association that endeavored to engage businesses and the wellness industry in efforts to increase the wellness of all Houston residents. Through informal networks of HWA and MWC members, momentum and interest began to grow, and a large consortium of stakeholders, including city services, experts in health disparities and childhood obesity, pediatricians, universities, and community programs, coordinated efforts to tackle childhood obesity. From this collaboration, CAN DO Houston (Children And Neighbors Defeat Obesity; la Comunidad Ayudando a los Niños a Derrotar la Obesidad) was created as a comprehensive, community-based childhood obesity prevention program.

Methods: CAN DO Houston stakeholders chose the city's Sunnyside and Magnolia Park neighborhoods to be the pilot sites for the program. They then selected an elementary school and park within each neighborhood to serve as anchors for the program. With the locations finalized, the stakeholders researched the available programs in the Houston area that addressed childhood obesity. They posted a database of more than 60 programs online so the participants in the program could become aware of and use them. Subsequently, interviews were conducted with key informants, including the school principals, park managers, physical education teachers, staff of the Metropolitan Transit Authority of Harris County, and police officers, to prioritize the needs for each community. Additionally, CAN DO Houston held multiple focus groups with parents from Sunnyside and Magnolia Park. Interviewees and the focus group members were asked to describe both strengths and barriers in their communities relative to being physically active, accessing good nutrition, and developing healthy minds. They also were asked to identify and prioritize possible initiatives.

Results: The findings showed the unique strengths within each community as well as the specific challenges that the program initiatives could address. For example, in Magnolia Park, participants indicated that children had good

access to resources for healthy eating, and in Sunnyside the participants indicated that children were engaging in more than the recommended 60 minutes of moderate-to-vigorous activity each day. The primary barrier identified in Magnolia Park was the lack of physical activity; in Sunnyside, it was the lack of education on nutrition for the children and parents. With this information, the CAN DO Houston program was able to tailor specific interventions for each community.

The interviews and focus groups in Magnolia Park revealed a safety and logistical problem that was contributing to the underuse of the free after-school program in the city park. The park was only 0.4 miles from the elementary school, but a busy four-lane street and a bayou prevented most parents from allowing their children to walk to it. To address the problem of safe access, CAN DO Houston partnered with the park recreation staff and arranged for them to conduct an after-school program at the school twice per week. The park staff led the activities, and CAN DO Houston provided volunteers to assist the park staff and supervise the students. More than 80 students signed up for the program. Because of the pilot's success, the school district agreed to provide bus transportation between the school and the park during the 2009–2010 school year.

Because of the pilot's success, the school district agreed to provide bus transportation between the school and the park during the 2009–2010 school year.

In Sunnyside, CAN DO Houston coordinated a monthly wellness seminar to educate parents on good nutrition and various wellness topics. In addition, it offered tours of grocery stores that focused on how to buy healthy foods on a budget. A nutrition carnival was hosted during the park's after-school program, and the project provided the park with supplies to incorporate education on nutrition into this program.

Comment: The pilot initiative of CAN DO Houston successfully formed a consortium of people and organizations interested in addressing childhood obesity that continues to link Houston neighborhoods with resources that can be used to address the unique challenges that these communities face. CAN DO demonstrates that, through the use of existing resources, implementing a successful initiative on the prevention of childhood obesity in an urban setting is feasible even with minimal funding.

Applications of Principles of Community Engagement: More than 70 organizations participated in the development of the CAN DO Houston pilot program, establishing a broad collaboration of community members, institutions, organizations, and local government. Uniting so many groups reflects Principle 2, which asks organizers of community engagement to establish relationships and work with existing leadership structures. The implementers of CAN DO Houston coordinated various activities to promote healthy living, including after-school programs, grocery store tours, wellness seminars, cooking classes, and staff wellness clubs, all on the basis of the input and priorities of community members. By implementing the initiatives chosen by the community through the existing community organizations and resources, CAN DO Houston provides opportunities for partner ownership, consistent with Principle 4, which stresses that no external entity should assume that it can bestow on a community the power to act in its own self-interest. Finally, engaging and listening to the communities and allowing them to prioritize the initiatives of the program fulfills Principle 8, which counsels the engaging organization to be prepared to relinquish control of actions to the community.

Reference

Correa NP, Murray NG, Mei CA, Baun WB, Gor BJ, Hare NB, et al. CAN DO Houston: a community-based approach to preventing childhood obesity. *Preventing Chronic Disease* 2010;7(4):A88.

Website

http://ccts.uth.tmc.edu/ccts-services/can-do-houston

9. THE DENTAL PRACTICE-BASED RESEARCH NETWORK

Background: Practice-based research networks (PBRNs) are consortia of practices committed to improving clinical practice. Operating internationally since 2005, the Dental Practice-Based Research Network (DPBRN) is a collaborative effort of Kaiser Permanente Northwest/Permanente Dental Associates in Portland, Oregon; Health Partners of Minneapolis, Minnesota; University of Alabama at Birmingham; University of Copenhagen; Alabama Dental Practice Research Network; and clinicians and patients in Oregon, Washington, Minnesota, Florida, Alabama, Georgia, Mississippi, Norway, Sweden, and Denmark.

Methods: DPBRN began by obtaining patient input during feasibility/pilot testing of certain studies, then progressed to a study that formally included patient perceptions, and later made plans for a community advisory board. Additionally, patient representatives serve on an advisory committee managed by the main funder of DPBRN activities, the National Institute of Dental and Craniofacial Research.

Results: As different parties became familiar with each other's priorities, they were able to establish common ground and carry out successful collaborations. DPBRN has provided a context in which researchers and community clinicians collaborate as equals, and in keeping with the basic principles of CBPR, it engages patients as well. DPBRN practitioner-investigators and their patients have contributed to research at each stage of its development, leading to improvements in study designs and customization of protocols to fit daily clinical practice. At the time of publication, 19 studies had been completed or were ongoing. The studies include a broad range of topic areas, enrollments, and study designs.

Comments: DPBRN practitioners and patients from diverse settings are partnering with academic clinical scientists to improve daily clinical practice and meet the needs of clinicians and their patients. PBRNs can improve clinical practice by engaging in studies that are of direct interest to clinicians and their patients and by incorporating findings from these studies into practice. Patients' acceptance of these studies has been very high.

Applications of Principles of Community Engagement: The DPBRN exemplifies several principles of community engagement. For example, community practitioners are coming together with academicians to develop and answer relevant research questions that can directly affect daily clinical practice. By engaging dentists in private practice, the network is able to reach the site of dental care for concentrated groups of patients and to conduct research that spans the geographic, cultural, social, and rural/urban diversity of different patient populations. This ability to connect with different groups is congruent with the diversity required by Principle 6. Researchers are partnering with the DPBRN in a way that allows for practitioners in the community, who traditionally are outside of academic institutions, to participate in all stages of research (Principle 5). This can not only close the gap between academic and community practices but also empower the dentists to name the research questions and participate in the quest for solutions. This acknowledges Principle 4, which reminds researchers that no external entity can bestow on a community the power to act in its own self-interest.

References

Gilbert GH, Williams OD, Rindal DB, Pihlstrom DJ, Benjamin PL, Wallace MC. The creation and development of the dental practice-based research network. *Journal of the American Dental Association* 2008;139(1):74-81.

Makhija S, Gilbert GH, Rindal DB, Benjamin PL, Richman JS, Pihlstrom DJ. Dentists in practice-based research networks have much in common with dentists at large: evidence from the Dental Practice-Based Research Network. *General Dentistry* 2009;57(3):270-275.

10. DIABETES EDUCATION & PREVENTION WITH A LIFESTYLE INTERVENTION OFFERED AT THE YMCA (DEPLOY) PILOT STUDY

Background: With its exceptional reach into diverse U.S. communities and long history of implementing successful health promotion programs, the YMCA is a capable community partner. Over a period of four years, the YMCA of Greater Indianapolis participated with researchers at Indiana University School of Medicine (IUSM) to design, implement, and evaluate a group-based adaptation of the highly successful Diabetes Prevention Program (DPP) lifestyle intervention. This project, DEPLOY, was conducted to test the hypotheses that wellness instructors at the YMCA could be trained to implement a group-based lifestyle intervention with fidelity to the DPP model and that adults at high risk for developing diabetes who received this intervention could achieve changes in body weight comparable to those achieved in the DPP.

Methods: DEPLOY, a matched-pair, group-randomized pilot comparative effectiveness trial involving two YMCA facilities in greater Indianapolis, compared the delivery of a group-based DPP lifestyle intervention by the YMCA with brief counseling alone (control). The YMCA, which was engaged before the development of the research grant proposal, collaborated with researchers at IUSM throughout the study. Research participants were adults who attended a diabetes risk-screening event at one of two semi-urban YMCA facilities and had a BMI (kg/m^2) greater than 24, two or more risk factors for diabetes, and a random capillary blood glucose concentration of 110–199 mg/dL. Multivariate regression was used to compare between-group differences in changes in body weight, blood pressures, hemoglobin A1c (glycosylated hemoglobin), total cholesterol, and HDL (high-density lipoprotein) cholesterol after six and 12 months.

Results: Among 92 participants after six months, body weight decreased by 6.0% in intervention participants and 2.0% in controls. Intervention participants also had greater changes in total cholesterol. These significant differences were sustained after 12 months, and adjustment for differences in race and sex did not alter the findings.

Among 92 participants after six months, body weight decreased by 6.0% in intervention participants and 2.0% in controls.

Comments: With more than 2,500 facilities nationwide, the YMCA is a promising channel for wide-scale dissemination of a low-cost model for preventing diabetes by changing lifestyles.

Applications of Principles of Community Engagement: Bringing health promotion activities to members of the community often requires mobilizing the community's existing assets, both people and institutional resources, as described in Principle 7. In line with Principles 3, 4, 5, and 7, the YMCA was engaged before the development of the research grant proposal, and it collaborated on the study design, approach to recruiting, delivery of the intervention, development of measures, interpretation of results, and dissemination of findings. DEPLOY demonstrates how intensive programs designed to change lifestyles can be more sustainable when health care centers engage established social institutions like the YMCA.

Reference

Ackermann RT, Finch EA, Brizendine E, Zhou H, Marrero DG. Translating the Diabetes Prevention Program into the community. The DEPLOY pilot study. *American Journal of Preventive Medicine* 2008;35(4):357-363.

11. PROJECT DULCE

Background: Diabetes management programs have been found to improve health outcomes, and thus there is a need to translate and adapt them to meet the needs of minority, underserved, and underinsured populations. In 1997, a broad coalition of San Diego County health care and community-based organizations developed Project Dulce (Spanish for "sweet") to test the effectiveness of a community-based, culturally sensitive approach involving case management by nurses and peer education to improve diabetes care and elevate health status among a primarily Latino underserved community in Southern California. Partners included the San Diego Medically Indigent Adult program and San Diego County Medical Services.

Methods: The goals of the project are to meet the American Diabetes Association's standards of care and to achieve improvements in HbA1c (glycosylated hemoglobin), blood pressure, and lipid parameters. A bilingual team, consisting of a registered nurse/certified diabetes educator, a medical assistant, and a dietitian, travels to community clinics to see patients up to eight times per year, then enters patient-specific data into a computer registry that generates quarterly reports to guide future care. In addition to having one-on-one clinic visits with the Dulce team, patients are encouraged to participate in weekly peer education sessions.

At each clinic, "natural leaders" are identified out of the patient population with diabetes and trained to be peer educators or *promotores.* The training consists of a four-month competency-based and mentoring program that culminates with the promotor providing instruction in concert with an experienced educator.

The instructors use a detailed curriculum in teaching the weekly sessions in the patients' native language. The classes are collaborative, including interactive sessions in which the patients discuss their personal experiences and beliefs. Emphasis is placed on overcoming cultural factors, such as fear of using insulin, that are not congruent with self-management.

Results: Project Dulce's first group showed significant improvement in HbA1c, total cholesterol, and LDL (low-density lipoprotein) cholesterol compared with chart reviews of patients having similar demographics from the same

The success of the initial program has led to the creation of modified offshoots to address the diabetes-related needs of African American, Filipino, and Vietnamese communities.

clinics over the same time period. Participants' belief that personal control over their health was possible and that contact with medical service providers was important in maintaining health increased. The success of the initial program has led to the creation of modified offshoots to address the diabetes-related needs of African American, Filipino, and Vietnamese communities. In 2008, Project Dulce added the care management program of IMPACT (Improving Mood-Promoting Access to Collaborative Treatment) to address the problem of depression among patients at three community clinics serving a low-income, predominantly Spanish-speaking Latino population. Up to 33% of patients tested positive for symptoms of major depression upon entering the program, and intervention resulted in a significant decline in the depression identification scores.

Comments: The ability to adapt Project Dulce to new communities and new components attests to its potential as a vehicle to administer care to underserved populations.

Applications of Principles of Community Engagement: Project Dulce has been shown to help patients overcome many cultural barriers to care that can result in poor adherence to medical advice. A key to the program is the identification and training of individuals within the community to lead the intervention's interactive educational component. By facilitating the transformation of patients into peer educators, Project Dulce mobilizes the community's existing assets and incorporates Principle 7, which stresses capacity building for achieving community health goals. Creating a peer education group coupled with a bilingual/bicultural nursing team illustrates the true partnership prescribed by Principle 5, and it is a model for community engagement that can be modified appropriately to reflect cultural diversity, as stressed in Principle 6. After initial success within the Latino community, Project Dulce has been able to adapt its curriculum and group education approach to address the needs of other communities. At the time of publication, it had programs in eight languages. These adaptations respond to the diversity of San Diego County and are congruent with Principle 9, which emphasizes that a long-term commitment is required to improve community health outcomes.

References

Gilmer TP, Philis-Tsimikas A, Walker C. Outcomes of Project Dulce: a culturally specific diabetes management program. *Annals of Pharmacotherapy* 2005;39(5):817-822.

Gilmer TP, Roze S, Valentine WJ, Emy-Albrecht K, Ray JA, Cobden D, et al. Cost-effectiveness of diabetes case management for low-income populations. *Health Services Research* 2007;42(5):1943-1959.

Philis-Tsimikas A, Walker C, Rivard L, Talavera G, Reimann JO, Salmon M, et al. Improvement in diabetes care of underinsured patients enrolled in Project Dulce: a community-based, culturally appropriate, nurse case management and peer education diabetes care model. *Diabetes Care* 2004;27(1):110-115.

Website

http://www.scripps.org/services/diabetes/project-dulce

12. DETERMINANTS OF BRUSHING YOUNG CHILDREN'S TEETH: IMPLICATIONS FOR ANTICIPATORY BRUSHING GUIDANCE

Background: The roles played by health beliefs and norms, standards, and perceived self-efficacy have been largely untapped in studies of tooth-brushing behavior. Rural parents with limited incomes are more likely to be young and geographically isolated than their urban counterparts, and thus these rural parents might be less knowledgeable about where to turn for advice about oral health or to obtain oral health services. Moreover, even if parents are aware of and have access to resources for their children, rural parents might avoid using them, preferring to "get by" on their own or with the help of family members. Utilization data show that, overall, rural children are less likely than children living in other areas to use dental services overall and that rural parents are more likely to report the purpose of the last dental visit as something "bothering or hurting" their children.

Methods: Researchers from the University of Washington included parents and community-based health professionals in each step of the study design and data collection. Parents were interviewed as expert informants to elucidate a diverse set of viewpoints regarding the value and ease of brushing young children's teeth. Study protocols and the interview guide were reviewed, revised, and approved by a steering committee consisting of seven community residents, including five professionals in early childhood health or education and two low-income mothers with young children. Interviews were conducted by three paid community residents trained by the study investigators.

Results: Just under two-thirds (26 of 41) of the parents who reported the age at which they began brushing their child's teeth said it was before the child's first birthday. No single explanation emerged as a majority reason for initiating brushing. The most common reason was an external cue, such as the eruption of the child's first tooth. Other common reasons reflected health beliefs, followed by normative expectations, including advice from early childhood educators, health professionals, or peers.

Nearly all parents (91%) thought the recommendation to brush a child's teeth twice a day was realistic. However, only slightly more than half (55%) reported achieving this goal. Parents who achieved twice-daily brushing were more likely than those who did not achieve this standard to accurately discuss

milestones in child development, children's oral health needs, and specific skills to engage the child's cooperation. The most common barriers to brushing, cited by 89% of all parents, were lack of time and an uncooperative child.

In summary, the study found that determinants of parents brushing their children's teeth vary. For this reason, rural children would benefit from simple interventions to encourage an early and regular habit of tooth brushing by their parents. Guidance given to parents about the oral health of their children should include discussion of ways to overcome the challenges identified in the study.

Comments: Because parents participated in the advisory board as expert informants on tooth brushing and served as study designers, data collectors, and study participants, new knowledge was generated.

Applications of Principles of Community Engagement: Principle 6 emphasizes that all aspects of community engagement must recognize and respect community diversity; this research project demonstrates this principle by acknowledging that the determinants of brushing the teeth of one's children vary. By going into the community and learning about the community's norms and values, the researchers were also demonstrating Principle 2.

Reference

Huebner CE, Riedy CA. Behavioral determinants of brushing young children's teeth: implications for anticipatory guidance. *Pediatric Dentistry* 2010;32(1):48-55.

CONCLUSION

This chapter provided examples of successful community engagement projects that took place in a variety of communities, including academic health centers, community-based organizations, churches, and the public health sector. Only 12 projects were presented here, but the literature now offers many such examples. However, little has been written about the organizational capacities required to make these efforts successful. The next chapter addresses the organizational supports necessary for effective community engagement.