

June 24, 2008: Engaging in CBPR: Tips & Strategies for Community Leaders ~Summary~

Note: The key points of the call are listed below for your convenience. We strongly encourage you to listen (available on the CCPH website) to this very engaging call.

Key Questions

- How do community leaders concerned about the health of their communities get connected with researchers who share their interests?
- Why would they even want to?
- What resources are out there to help support community leaders to develop and sustain effective CBPR partnerships with researchers?
- What infrastructure needs to be in place in community-based organizations to engage in research partnerships and conduct research?

Speakers

Lola Sablan-Santos, Guam Communications Network, Long Beach, CA

Randy Jackson, Canadian Aboriginal AIDS Network, Ottawa, Ontario, Canada

Ann-Gel Palermo, Harlem Community and Academic Partnership, New York, NY

Moderator

Susan Gust, CCPH Board Member and Community Partner/Activist, Minneapolis, MN

Guam Communications Network (Lola Sablan-Santos)

- In 1997 Dr. Sora Park Tanjasiri approached the Guam Communication Network to partner on a study looking at Chamorro women's knowledge about breast cancer. The project was funded by the California Breast Cancer Research program.
- Dr. Tanjasiri encouraged community based participatory research, mentoring the organization on qualitative and quantitative analysis, and the scientific approach.
- The baseline data collected with Dr. Tanjasiri enabled the Guam Communication Network to apply for a 3-year research grant looking at social networking—how information about breast cancer is diffused in order to improve breast cancer education in Southern California. Through organizational contacts our project was able to form a control group of Chamorro women in Northern California.
- There was a commitment to equal partnerships: listed as principle investigators, separate budgets, community council, publications, and presentations. The Guam Communication Network was taught about the research process and how to be investigators.
- Guam Communication Network was able to expand research partnerships with other organizations. Currently, they are working on a project on cancer survivorship. Also secured a grant from the Office of Minority Health to build the programmatic capacity of faith-based and community organizations on HIV/AIDS issues.
- Guam Communication Network is also mentoring other Chamorro organizations (on the mainland and in Guam), to help expand their programs and funding. Also, Guam Communication Network is identifying and training key community members about the research environment and encouraging their education.

- The research culture can sometimes be very alien in contrast to the Chamorro social culture. Guam Communication Network tries to engage the community by showing the community the outcomes of the program—emphasizing that the community is a part of the results.

Canadian Aboriginal AIDS Network (Randy Jackson)

- CAAN is a non-profit national organization established in 1990. Over 300 organizations and individuals are members. The Network allows members to express needs and concerns, promote issues (advocacy), and provide up-to-date HIV/AIDS information.
- CAAN is involved in a wide range of research involvement: barriers to treatment/care, mental health, HIV testing experience, culture competence in service provision, and clinical trials. CAAN is also initiating international work—looking at cultural resiliency in response to blood borne pathogens.
- Since March 2008, they've received two new research grants: effectiveness of arts-based methodologies in HIV prevention programs and alcohol use (or perceived use) as a barrier to receiving care.
- Two research synthesis projects are: issues surrounding stigma, and prevention in aboriginal and non-aboriginal women. They also have a development grant to study the creation of a national housing strategy for aboriginal women.
- Details on all these grants can be found on their website: www.caan.ca
- Work utilizes the principles of OCAP (Ownership, Control, Access and Possession) or self-determination applied to research. These principles were established to prevent further marginalization of the First Nation peoples, and ensure mindfulness and respect of the First Nation culture.

Harlem Community and Academic Partnership (Ann-Gel Palermo)

Tips/Suggestions for Community Leaders

- Understand the researcher's approach to CBPR. Is it really CBPR?
 - A good visual of the differences between traditional research and CBPR is available at : <http://www.cbprcurriculum.info/> (Unit 1, Figure 1.1.1)
- Know what CBPR is—it is a process that embodies justice and advocacy. It is an authentic partnership. It is a diverse, organic experience.
 - Community leaders should see which faculty are really doing CBPR work via publications and funding databases.
 - Dedicate time to determining who would be a good match.
- Be sensitive to the researcher's career and performance measures.
 - Additional information available at:
http://depts.washington.edu/ccph/pdf_files/ECAPppt.pdf
- Look for other community organizations that have participated in similar partnerships/research.
 - Seek mentorship of other community organizations.
 - Build capacity within your organization and in other community organizations.
 - Building an alliance of community organizations can be powerful.
- The social justice component of CBPR is critical, but not always a motivator for researchers. Researchers may not know how to translate their study findings into advocacy or policy points (action items).

- The action board might need to have a subcommittee to specifically address the policy implications of the research findings.
- Community groups should be up front to their potential research partners on their desire for action and what they want.
 - Might chose to transition from a community advisory board, to a community action board.
- In the end, the community has the power since they chose to participate (they do not have professional or monetary incentives to be involved).
 - CBPR is based upon relationship-building and can be messy.
- Partnerships are not limited to academic institutions—think tanks, department of health, etc.
- Be saavy in selecting your partner. Specifically look for characteristics that will help ensure a good partnership. Be committed to the process.