

Community Based Participatory Research Applied to Evaluation

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Community Based Participatory Research/ Evaluation

WK Kellogg Foundation's definition of CBPR:

“A collaborative approach that equitably involves all partners in the research process and recognizes the unique strengths that each brings . . . with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities.”

As evaluators, we can incorporate and apply CBPR principles in our work to address problems in our communities.

History of CBPR

- Patterned after a Brazilian educator (Paolo Freire, *Pedagogy of the Oppressed*, English version, 1972) who believed in and practiced Community Based Action Research.
- Freire believed that there is wisdom and knowledge in communities and their voices and experiences are essential to the process of formulating solutions to systemic problems.
- Dr. Nina Wallerstein, UNM scholar, trained under and worked with Freire. She, with colleagues and students, has published extensively about her work with indigenous communities using a CBPR approach.

CBPR Is Relationship Oriented

- CBPR is a way to build community and trust between researchers (or evaluators!) and participants
- Intentionally focused on indigenous and critical methodologies
 - methodologies and approaches to research that privilege indigenous knowledges, voices, and experiences” (Smith 2005).
 - A collaborative partnership, where all the participants are equitably treated and heard.

Requirements of CBPR/E

- Researcher /Professional Self-Reflection re:
 - Our own core values/conceptual orientation
 - Our own intentions, capacities, and liabilities
 - Our institutions' strengths and liabilities
- Belief in the possibility that community members/participants can create and change things. Freire, 1971
- Intention to act on findings

CBPR is based on Participatory Traditions/ Principles

- Collective: All stakeholders/partners participate in deciding what questions they want to address
- Inclusive: Questions rise from the needs of the community or the organization
- Interactive: Relationship-based process allows for learning by all parties
- Outcome-oriented: The purpose is continuous learning and system improvement and sustainability
- Informational: Results are widely shared and disseminated among all partners and stakeholders

CBPR addresses Power and Privilege

- Identifies power held within stakeholder groups
- Identifies challenges posed by power imbalances
- Identifies ways groups can create equitable relationships
- Identifies ways groups can share power

History of distrust among marginalized communities

- When powerful interests ignore the communities they study, tragic consequences may follow.
- This is a reason why understanding and addressing power and privilege and power differentials is so important.

Next, we will show some historical examples of why the distrust exists.

Examples of research history gone wrong due to unilateral research and power and privilege misused

- Tuskegee Syphilis experiment



Legacy of Mistrust in Latino Communities

- Placebos to 70 Mexican-American women who thought they were receiving contraceptives; half received placebos, 1968: Study by San Antonio Planned Parenthood, South Central Texas and Southwest Foundation for Research and Education
- “Experimental” measles vaccine to Latino and African American babies and children, Los Angeles, 1990: CDC and Kaiser Pharmaceuticals of Southern California injected 1,500 six-month-old Black and Hispanic babies with “experimental” measles vaccine not licensed in U.S.

Cacari Stone, L. & Avila, M. (2012) Rethinking Research Ethics for Latinos: The Policy Paradox of Health Reform and the Role of Social Justice. *Ethics and Behavior*;22 (6), pgs 445-460.

Distrust in Native Indigenous communities

Havasupai Tribe files \$50M lawsuit against ASU

The Havasupai Tribe has filed a \$50 million lawsuit against Arizona State University, the Arizona Board of Regents and three researchers alleging that blood samples taken from tribal members under the pretext of diabetes research were destroyed, lost or used in studies of schizophrenia, inbreeding and population migration without the donors' consent.



Arizona lawsuit over misuse of Havasupai blood samples dismissed 5-4-07

A judge has dismissed a lawsuit against the University of Arizona, Arizona State University and researchers claiming they misused blood samples from Havasupai Indian tribal members.

Incorporating CBPR into Your Work

- Partnerships + Collective Processes → Better outcomes
- If stakeholder groups worked in harmony, what would the process look like?
- How would outcomes be affected by partnering and collective process?
- What would power equalizing look like?

Benefits of CBPE

- Collaboration at all levels of the community leads to meeting their needs
- Sharing decision-making increases community knowledge
- Balancing power at all levels contributes to better solutions to systemic problems
- Long-term involvement facilitates sustainability

Exercise: Let's Plan for Participatory Evaluation

Questions to Answer in Small Groups:

- Who are stakeholders you would include in a participatory evaluation?
- Think of 3 ways in which you can meaningfully engage stakeholders to collaborate
- What would it take to recognize power relationships in your work?
- What would it take to diffuse power relationships in your work?