Community-Based Participatory Research

Learning From the Ground Up

Pamela Rao, PhD
Farmworker Justice
August 3, 2009

FARMWORKER JUSTICE

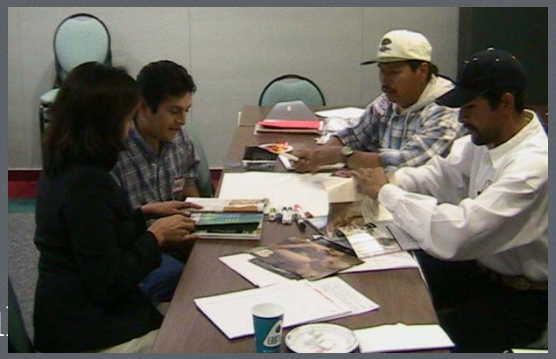
Definition

- Community-based participatory research (CBPR) is a collaborative research process involving researchers and community representatives that:
  - engages community members, employs local knowledge in the understanding of health problems and the design of interventions;
  - invests community members in the processes and products of research; and
  - invests the community in the dissemination and use of research findings and ultimately in the reduction of health disparities.

Source: http://www.ahrq.gov/about/cpcr/cbpr/cbpr1.htm

What CBPR is and is not

- CBPR *is*:
  - A collaboration of equal partners
  - A two (or more) –way process for learning and benefitting
  - Flexible and adaptable



- CBPR is *not*:
  - The same as research "in" the com
  - A "back door" means of accessing the community
  - Fully formed from the beginning

What is a community?

- Any group with a shared identity *and* shared issues and concerns
  - Geography is not the only criterion
  - Shared identity may be based on gender, race/ethnicity, occupation, or sexual orientation – but not necessarily

- In practice, the community is likely to be represented by an existing entity such as a community-based organization (CBO)

Collaboration

- Collaboration is not just “working together.” Rather, it is a(n):
  - Equal partnership
  - Long term commitment

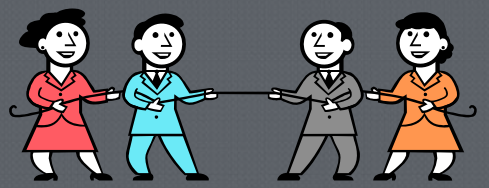
- Ideally, the partners share:
  - A vision for the community
  - Goals
  - Decision-making
  - Responsibility
  - Ownership of project products

Why CBPR?

- Conducting research with the community helps to:
  - Ensure that research is developed from the ground up
  - Increase acceptability of the project to the community ("buy in")
  - Improve the likelihood that research results are meaningful and useful to the target population

Considerations

- When working with community groups, researchers must be mindful of:
  - Tension between needs of community and need for scientific rigor
  - Capacity of community to participate fully
  - Equitable distribution of project funding
  - “Power struggle” over who is really in charge
  - Sustainability!



Example: The *La Familia* Project

- Aim: To develop, implement, and evaluate a pesticide safety education curriculum for farmworker families in North Carolina
- Community involvement:
  - Partnership between Wake Forest University School of Medicine and NC Farmworkers Project
    - Co-Principal Investigators on NIEHS grant
    - Co-authorship on publications
  - Advisory committee with CBO representatives
  - Community forums open to public

Thank you!

Pamela Rao, PhD
Farmworker Justice
1126 16th St NW, Suite 270
Washington, DC 20036
202-293-5420
www.farmworkerjustice.org
prao@farmworkerjustice.org

Healthy Homes Collaborative

Participatory Action Research
&
The Power of Hazard Assessment

Healthy Homes Collaborative

- Is a collaboration of organizations, reflective of the demographics of L. A.
- Member groups are:
  - Grassroots,
  - Community-based,
  - Non-profit organizations
- Dedicated to addressing environmental hazards in homes and their deleterious impact on the health of our communities.

Chipping & Peeling Lead-Based Paint

Challenges Faced by Low-Income Tenants

- Bad Landlords
- Callous Bureaucracies
- Kids Used as Hazard Detectors
- Responsibility shifted to Parents (Blame)
- Lack of Political Will

Housing Hazards and Health

- These hazards have been studied extensively by
  - HUD
  - CDC
  - EPA
  - NHANES
  - NIEHS
- All have concluded that children's development is adversely impacted

Neighborhood Data Use Collaborative

Funded by the First 5 Commission

Our project was geared toward addressing the impact of environmental health hazards in the home on children's well-being and how that in turn affects their school readiness.

Participatory Action Research

Combines:

- the power of hard numbers
- with local organizing
- to trigger community-wide systems change
- as well as helping to protect individual families from health hazards in high-risk housing.

Two important advantages:

- It has allowed for the collection of more accurate and relevant information
- It has demystified the scientific information gathering process

Community proposed solutions

- By using PAR
- the information
- the process of gathering it
- has positively transformed the community
- enabling the community to take charge in proposing solutions to their problems

Community Access to Hazard Assessment Tools

- First generation tools were complex and expensive and reserved for experts and researchers
- PAR bridges the gap
- Low-cost, low-tech tools that can be mastered with limited training
- We trained over 300 community leaders from five distinct communities: Long Beach, Maywood, Huntington Park, Boyle Heights, and Pico-Union / Westlake

Home Hazard Assessments

- Surveys
  - Visual observations of peeling paint, mold and moisture, and housing code violations
  - Photographs of hazards
  - Health questionnaire (87 questions)
  - Visits took 2 – 3 hours per family
- Sampling Results Report
  - Lab results: Lead in dust, paint, and soil
  - Asthma triggers Cockroach infestation; moisture problems (mold)
  - Carbon monoxide

The Power of "Hard Numbers" Democraticizes Science

- Engages families
- Compelling documentation of problem
- Gives credibility & punch to complaints –triggers repairs, laws and regulations

Some Findings

- Income:
  - 70% reported a monthly income of less than $1,500 monthly or $18,000 annually
- Housing:
  - 97% are tenants
    - 35% have no written contract
    - 89% are on month to month arrangements
    - 71% live in housing built before 1979
    - Only 5% reported having ever received information about lead hazards in their buildings
- Health Care:
  - 80% reported having a regular health provider including the County hospitals and neighborhood clinics
  - 35% reported that at least one of their children has a health problem

Powerful Tool for Organizing

- Sampling homes builds relationships
- Vivid evidence of real problems
  - 80% had chipping and peeling paint
  - 65% had moisture problems and mold
  - 20% had water leaks on ceilings, walls or floors
  - 40% had vermin infestations
  - 77% had cockroach infestations
- Community wide problems unite neighbors
- Develop new skills and leaders

Engaging Community

- Vivid evidence of hazards
- Gripping photographs
- Hard numbers
- Bold maps
- Local data are the most compelling

Changing Policy
Prevention is the Goal

- Documenting hazards can help the individual families who participated; they will use the data to turn the table on their landlords
- But HHC's long term goal is to use data to trigger broader policy change that will affect all high-risk housing in the community

Systems Advocacy Broader Policy Change

- Improve enforcement of existing laws
- Highlight and correct agency failures
- Win increased resources: HUD Funding
- Pass new laws or ordinances
- Advance organizational objectives and meet the community's needs

Ethical Issues and PAR

Collecting samples is invasive:

- Going inside families' homes
- Crawling around on the floor
- Drawing sketches
- Taking photographs
- Documenting hazards
- Using data

Potential for Unintended Consequences

- Panic by tenants
- Eviction
- Sloppy and Unsafe repairs by landlord
- Property condemned by Agencies
- Undocumented residents risk deportation

HHC Resident Agreement

- Documents mutual understanding and expectations
- Must be signed before Home Hazard Assessment begins
- Obligation to explain results to residents
- Resident decides about sharing “property-specific” data with others

No Room for Error

- Protect residents' privacy
- Follow HHC's hazard assessment tools
- Submit accurate, complete, and timely data to HHC central
- Use data honestly

www.HealthyHomesCollaborative.org

Linda Kite
Director
LKite@HealthyHomesCollaborative.org