Community Based Participatory Research (CBPR): Principles and Strategies for Health Equity

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Objectives of Presentation

Rationale for Community Based Participatory Research (CBPR)

Definitions and Principles of CBPR

How CBPR was used to develop a prevention program and partnership for participatory evaluation
“One of the canons of good research is that it should never hurt the people studied.” (Peacock, quoted in Crazy Bull, 1997)

To be a good educator (researcher) “means above all to have faith in people; to believe in the possibility that they can create and change things.” Freire, 1971
Challenges for Bridging Science to Practice: Need for CBPR

• Challenge of bringing evidence to practice
  • Internal validity insufficient for translational research
  • External validity: Implementation/Role of context
• Challenge of what is evidence
  • Evidence-Based Practice vs.
  • Practice/Indigenous/Community-Based Evidence
• Challenge of one-way translation/ colonizing methodologies
• Challenge of translation to action and policy
Shifting the Privilege and Power Paradigm

• “Expert” or “Scientific” knowledge can obscure or prevent community knowledge
  • Empirically Supported Interventions (ESIs) privileged over Culturally/Community Supported Interventions (CSIs) (Gordon Hall)
• Who has power of knowledge?
  • Knowledge defined by whom? About whom? For what purpose? Who makes the decision of what to study?
• Who has power to act and decide?
“Research” and Federal Indian Policy

• Assimilation and Allotment 1870-s - early 1900s
  – 1880’s Growth of BIA boarding schools
  – 1883 Some Traditional Medicine Outlawed
  – 1887 Allotment Act abolishes group title to Native land

“The United States government did something that was wrong, deeply, profoundly, morally wrong. It’s an outrage to our commitment to integrity and equality for all our citizens... clearly racist.” President Clinton's apology for the Tuskegee Syphilis Experiment to the eight remaining survivors, May 16, 1997
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.
Current Micro-aggressions: Discrimination Distress
Collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities.

W.K. Kellogg Community Scholar’s Program (2001)
CBPR: What it is and isn’t

- CBPR is an orientation to research/data
  - Changes the role of researcher and researched

- CBPR is **not** a method or set of methods
  - Typically thought of as qualitative

- CBPR is an applied approach with a goal to influence change in community health, norms, systems, programs, policies.
CBPR Principles

• Recognizes community as unit of identify
• Cooperative and co-learning process
• Systems development & local capacity building
• Long term commitment
• Balances research and action

(CBPR Principles according to Israel et al, 1998 and 2008)

CBPR Relevance

• Counters historical research abuse
• Complex health and social problems ill-suited to “outside expert” research
• Increasing community and funder demands for community-driven research/collaboration
- It is Participatory involving a Partnership
- Capacity Building and Mutual Learning of All Partners
- Supports Community Ownership
- A Balance Between Research and Action

Shared Decision Making

University Control  CBPR  Community Control
Community Based Participatory Research

- Building Partnerships
- Identify Research Questions & Design
- Co-creating interventions
- Participatory Evaluation & Dissemination
## Stages of Research/Evaluation: How participatory? Power sharing?

<table>
<thead>
<tr>
<th>Stages</th>
<th>Details</th>
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<tbody>
<tr>
<td>Stages</td>
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<tr>
<td>Identifying a problem</td>
<td>Creation of intervention/ Making a plan</td>
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<tr>
<td>Literature review/ Theory Development</td>
<td>Data collection</td>
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<tr>
<td>Pulling the team together: support letters</td>
<td>Analyzing data</td>
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<tr>
<td>Research proposal/Getting the funds</td>
<td>Interpreting data</td>
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<tr>
<td>IRB/Ethics review</td>
<td>Dissemination of data</td>
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<td></td>
<td>Use of Research Findings/ Advocacy: Policy and Practices</td>
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</table>
CBPR: Building Partnerships

• Researcher /Professional Self–Reflection
  – Our own core values/conceptual orientation
  – Our own intentions, capacities, and liabilities
  – Our institution’s strengths and liabilities

• Identify Potential Partners

• Create and Build Participatory Structures:
  – between Academia, PH Agencies and Community (principles/budgets/data)

• How to ensure continual participation throughout? Who is participating?

What to you is authentic partnerships?
Identify Research Questions & Design

• Negotiate Health Issues and Research Questions: Where do questions come from: community or university or negotiated?

• Co-Development of:
  – Instruments/Sample
  – Interventions (What evidence are you bringing in?)
  – Evaluation of Research and of Partnerships
Contexts provide grounding for collaboration on priority Health issues. i.e.: Socio-structural and political conditions; Community and academic capacities; History and levels of mutual trust

Contexts, such as policies, resources, and histories, influence Partnership Processes and the ways partners work together to develop their Interventions and Research.

Community capacity (Pueblo) & community profile (Navajo) (CDC: 1999 – 2003)


NARCH V GRANT FAMILY LISTENING PROGRAM APACHE (2009-2014)
CBPR Conceptual Model

Adapted from Wallerstein et al, 2008 & Wallerstein and Duran, 2010

Partnership Processes are based on:
- Individual skills, positions, motivations
- Relationship capacities and shared power
- Multiple structures and stakeholders

Research Activities

University Control

Community Control

CBPR

- Tribal systems shall be and respected and honored
- Tribal government review approval
- Tribally specific data shall not be published without prior consultation; data belongs to tribe
- Core Values: trust, respect, self-determination, mutuality of interests, perspective taking, reciprocity
Intervention and Research reflect how contexts and partnership processes interact to influence:

- Integration of community knowledge into culture-centered interventions
- Partnership synergy to get tasks done
- Community involvement in research steps
- Community appropriate methods and designs

Decolonizing approach

- Native language
- No time constrains
- Used appropriate ways of communicating
- Importance of the home (hogan) and the teachings on the traditional ways of life (e.g. clanships)
- Personal histories and stories
- Importance of education, respect and discipline
CBPR Conceptual Model
Adapted from Wallerstein et al, 2008 & Wallerstein and Duran, 2010

Intervention & Research

<table>
<thead>
<tr>
<th>Processes</th>
<th>Outputs</th>
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<tbody>
<tr>
<td>Integrate Community Knowledge</td>
<td>Culture-Centered Interventions</td>
</tr>
<tr>
<td>Empowering Processes</td>
<td>Partnership Synergy</td>
</tr>
<tr>
<td>Community Involved in Research</td>
<td>Appropriate Research Design</td>
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</table>

Tribal Specific Family Curriculum

Decolonizing Approach
- Locally produced artwork, stories, video & activities
- Included importance of sharing a meal
- Developed culturally appropriate activities

1. Welcoming
2. Tribal History
3. My Family
4. Tribal Way of Life
5. Tribal Vision
6. Community Challenges
7. Communication, Help Seeking
8. Problem Solving
9. Recognizing Types of Anger
10. Managing Anger
11. Being Different
12. Positive Relationships
13. Building Social Support
14. Making a Commitment & Presentation of Projects
CBPR Conceptual Model

Improved **Outcomes** can be linked to effective partnership practices, including:

- Changed policy environments
- Greater partnership and project sustainability
- Shared power relations in research
- Community/social transformation & improved health

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**Figure 1. Family Listening/Circle Program Conceptual Model**

**Risk Factors**
- **Child:** Behavior Issues, Academic Problems
- **Family:** Ineffective Parenting, Alcohol Abuse/Use
- **Community:** Alcohol Access, Substance Norms

**Family Listening/Circle Program**
- History, Language & Values: Cultural Stories
- Cognitive Behavioral: Communication, Self Efficacy, Problem Solving, Prevention Messages, Anger Management
- Empowerment: CAPs, Commitment

**Psycho Social Outcomes**
- **Child:**
  - Family & School Attachment
  - Self Confidence & Leadership
- **Family:**
  - Warm & Supportive Parenting
  - Communication with Parents & Elders
- **Community Empowerment:**
  - Cultural & Community Participation
  - Community Service & Action

**Health Outcomes**
- **Child:**
  - Alcohol & Substance Initiation & Experimentation
  - Anxiety & Depression
  - Resiliency
  - Social Adjustment
- **Family:**
  - Alcohol & Substance Abuse/Use Norms

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**Outcomes**

**Intermediate**
- Policy Environment
- Sustained Partnership
- Empowerment
- Shared Power Relations in Research
- Cultural Reinforcement
- Individual/Agency Capacity
- Research Productivity

**Long-term**
- Community Transformation
- Social Justice
- Health / Health Equity

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Adapted from Wallerstein et al, 2008 & Wallerstein and Duran, 2010
Participatory Data Collection:

- Develop instruments with community advisory board members (greater validity)
- Train community interviewers, survey data collectors, focus group facilitators
- Job opportunities for community
- Enables better response rate
- Issues of confidentiality
- Community partners provide important mentorship and guidance
CBPR Conceptual Model
Adapted from Wallerstein et al, 2008 & Wallerstein and Duran, 2010

Participatory Data Analysis:

- **Role of University expertise**
  - Statistical programs (Quant/Qual)
  - Present data in useable form for interpretation based on community’s request

- **Role of Community expertise**
  - Provide insight on measures (process & outcome evaluation)
  - Provide interpretation of importance that only possible if from locality (local research team/ advisory committee)
  - Protection of community
  - Provide important mentorship and guidance

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**Outcomes**

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- Community Transformation
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Adapted from Wallerstein et al, 2008 & Wallerstein and Duran, 2010
Facilitator observations after each session

Journals by the children after each session

Pre/Post/Post-Post Tests of Parent and Child
- Program families
- Comparison families

360 evaluation: Three open-ended questions at end of program:
- To parents and child about each other
- Any changes in family, in child, in parent
Culture (Kids and Adults)

- “It felt good it was fun and important to learn about our people” - Child
- “I learned how the long walk started and ended” - Child
- “I felt good when he as talking about the ancestors that all ancestors did all those things” - Child
- “We learned about our ancestors and elders, their history.” - Children and Adults
- “That our culture and tradition are important for our people of this community and they continue to participate in any cultural/traditional activities.” -- Adult
- “Clan, value in family and language” -- Adult
If I drink as a teenager, it could cause me problems later in life.

There are plenty of ways for people like me to have a say in what our school does.

I can refuse a ride home with an older friend or family member who has been drinking.

All questions statistically significant (p-values <0.05)

“I will just say no to them and walk away and if someone said it to me again I will tell the teachers” – Child

“I learned about the step model and about how to calm down your anger” – Child

“Be nice, stay calm, don't be mean to your parent right, don't hit anything” – Child
**Vision:** Native Communities Realize Their Own Vision of Wellness

**Mission:** Building Leadership and Sharing Resources to Promote Native Community Wellness

HNCF develops and supports teams of change agents to lead creative wellness strategies in Native communities. Native Teams from across the country gather three times a year for intensive learning that is hands-on, collaborative and grounded in Native cultural and spiritual teachings.

[www.hncpartners.org](http://www.hncpartners.org)
HNCF Theory of Change Logic Model

**Individual Changes**
- Leadership & Transformation of Individuals

**Team Changes**
- Increased Ability of Teams to Work Together and in Their Communities

**Strengthened Community Capacity Change**
- Increased Capacity of Community Wellness Groups to Make Change

**Community Changes**
- Healthy Policies and Practices
- Effective Interventions
- Increased Resources
- Increased Partnerships
- New & Improved Programs
- Community Participation
- Language & Cultural Capacities
- Wellness & Community Capacities
- Communication & Dialogue

**Health Status Changes**
- Socio-Economic Changes

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“I feel more confident about my ability to share what I have learned with my peers, supervisors and community. I know that I am an integral part of my community and that I can make a ripple in my community.”

“The fellowship experience was wonderful. It came at a time in my life that I really needed it. It made me a better person and gave me tools to make my world a better place. Thank you so much to everyone that had a part in making this happen for me.”
Hypothesis of Pilot Case Study

1. The activities resulting from the HNCF will increase social cohesion and social capital of the community leading to better health and well-being of the community.

2. The activities resulting from the HNCF will increase cultural connectedness leading to better health and well-being of the community.

3. The activities resulting from the HNCF will increase the presence of positive healthy policies/practices/programs leading to better health and well-being of the community.
# Case Study Design and Methods

<table>
<thead>
<tr>
<th>NOVEMBER (10’) – JANUARY (11’)</th>
<th>FEBRUARY – JULY (11’)</th>
<th>AUGUST - SEPTEMBER (11’)</th>
<th>OCTOBER (11’) – APRIL (12’)</th>
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</thead>
<tbody>
<tr>
<td>Literature Review &amp; Instrument Development</td>
<td>National Committee</td>
<td>Local Committee</td>
<td>Instruments &amp; Recruitment</td>
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<tr>
<td>How does the HNCF contribute to community health/wellness?</td>
<td>National Alumni Advisory Committee</td>
<td>Community 1 &amp; Community 2</td>
<td>1. Focus Groups</td>
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<tr>
<td></td>
<td>Provided oversight on instruments and process</td>
<td>Local Community Advisory Team (LCAT)</td>
<td>a) Local Coalition</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>b) Community members</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>c) Youth &amp; Elder Groups</td>
</tr>
<tr>
<td>Literature Review</td>
<td></td>
<td></td>
<td>2. Interviews</td>
</tr>
<tr>
<td>*Social Cohesion</td>
<td></td>
<td></td>
<td>a) Tribal Leaders</td>
</tr>
<tr>
<td>*Cultural Connectedness</td>
<td></td>
<td></td>
<td>b) Program providers</td>
</tr>
<tr>
<td>*Policy/Program Changes</td>
<td></td>
<td></td>
<td>c) Community members</td>
</tr>
<tr>
<td>Draft Instruments</td>
<td></td>
<td></td>
<td>3. Questionnaire</td>
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<tr>
<td>* Focus Group guide</td>
<td></td>
<td></td>
<td>a) Community members</td>
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<tr>
<td>* Interview guide</td>
<td></td>
<td></td>
<td>b) Program providers</td>
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<tr>
<td>* Questionnaire</td>
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**Cultural Core Values and Connectedness**

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>9. It is important for my children and other future generations to speak our native language.</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>10. I want to learn more about our native language and culture.</td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>11. I know where to find knowledge on our Native language and culture</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

- Strongly agree: 70%
- Agree: 60%
- Neither agree or disagree: 30%
- Disagree: 10%
- Strongly disagree: 10%

It is important for my children and other future generations to speak our native language: 70%
I want to learn more about our native language and culture: 60%
I know where to find knowledge on our Native language and culture: 50%
### Strengths, Concerns, Recommendations

<table>
<thead>
<tr>
<th>Strengths</th>
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<tbody>
<tr>
<td><strong>A. Cultural Teachings and Workshops</strong></td>
</tr>
<tr>
<td>- Traditional storytelling and different topics and they are interesting</td>
</tr>
<tr>
<td>- Play a big role in that more people have a chance to hear about cultural things</td>
</tr>
<tr>
<td>- Learnings are on parenting skills, cultural skills, and traditional values.</td>
</tr>
<tr>
<td>- I think it is nice they actually do have workshops – we listen to their talks and really is informative</td>
</tr>
<tr>
<td>- They bring a lot of the stuff for families, topics basically on families and people like it.</td>
</tr>
<tr>
<td>- I would say ¾ of the responses have to do with learning Navajo culture, language, and tradition, those are things people are asking for</td>
</tr>
<tr>
<td>- The committee is pretty active and engaged.</td>
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<table>
<thead>
<tr>
<th>Concerns</th>
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<tbody>
<tr>
<td><strong>A. More Collaboration</strong></td>
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<tr>
<td>- I feel there is like different groups all over the place, they don’t even work together. Why is that?</td>
</tr>
<tr>
<td>- There is no connection right now getting all those to follow out on that one idea, they all kind of want to do their own thing</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Change/Recommendations</th>
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<tbody>
<tr>
<td><strong>A. Building Partnerships</strong></td>
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<tr>
<td>- I like what someone said, “To be someone outside the box is to strategize thinking” When you ally with someone what you strategize with wanting to be partners with them – it has to be win-win, if we’re going to partner with them they also have to win with us</td>
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</tbody>
</table>
Learnings: Example of how data was shared back with youth

### Sense of Community

<table>
<thead>
<tr>
<th>Statement</th>
<th>% of People Agreed</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am proud of the community I live in.</td>
<td>65%</td>
</tr>
<tr>
<td>I feel accepted in my community.</td>
<td>30%</td>
</tr>
<tr>
<td>I feel a strong sense of responsibility for my community.</td>
<td>10%</td>
</tr>
<tr>
<td>Most people in this community are trustworthy.</td>
<td></td>
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<tr>
<td>Most people in my community try to be helpful to each other.</td>
<td></td>
</tr>
<tr>
<td>Traditional activities bring people together regardless of conflicts in the community.</td>
<td>50%</td>
</tr>
</tbody>
</table>

Rate the statements from: "Strongly Agreed" to "Strongly disagree"

- I feel accepted in my community.
- Most people in this community are trustworthy.
- Most people in my community try to be helpful to each other.
- Traditional activities bring people together regardless of conflicts in the community.
Questions??

Special Thanks to Our Community Tribal Research Teams:

• Navajo; Pueblo; Apache
• Healthy Native Communities Partnership and all the Fellows
• UNM Team: Lorenda Belone, Nina Wallerstein, Rebecca Rae, Anslem Omeh, Gill Woodall, Orrin Myers