Implementing, Disseminating, and Measuring Community-Based Participatory Research Interventions to Reduce Health Disparities

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My Research Story

- Freirian Popular Educator (1970s -- )
- Empowerment Intervention Research: 1980s--
  - Adolescent Social Action Program/Youth Link/ Y.E.S.
- Community Based Participatory Research: 1990s --
  - Participatory Evaluation of Healthy Communities/ Health Councils in N.M. and Latin America (PAHO)
  - New Mexico CBPR Tribal Research: Family Listening
  - National Healthy Native Community Fellowship
  - Social and Cultural Capital Assessments in tribes
  - Natl. Cross-Site CBPR Process & Outcomes
  - CTSC Community Engagement Director, UNM
  - Health Disparities Center Associate Director, UNM
My Starting Points: CBPR

“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).
Outline

- Challenges within Translational Science
- Definitions and Principles of CBPR
- A Research Story of Implementing Interventions: Empirical and Cultural Evidence
- Evaluation and Measurement of CBPR
- Benefits of CBPR and Self-Reflexivity
Challenge of Health Disparities

“The real challenge lies not in debating whether disparities exist, but in developing and implementing strategies to reduce and eliminate them.”

—IOM Committee Chair

Social determinants of health → ? → Health outcomes
Challenges in Bridging Science to Practice

Challenge of bringing evidence to practice
- Moving from efficacy to effectiveness trials
- Internal validity focus insufficient for translational research
- External validity: Implementation/Role of context

Challenge of what is evidence? /knowledge?
- Empirically-supported vs.
- Culturally-Supported/Culturally-Centered/Indigenous
- Evidence-Based Practice vs. Practice-Based Evidence

Challenge of one-way translation orientation

Challenge of colonizing methodologies
Challenge of Research History: Tuskegee Syphilis Experiment

"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

Peter Buxtun, a former Public Health Service employee.
Challenge of Recent Mistrust

**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.
CBPR Definition

“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)
What it is and What it isn’t

CBPR is an orientation to research

- Changes the role of researcher and researched

CBPR is **not** a method or set of methods

- Qualitative and quantitative
- Epidemiology and intervention research

CBPR is an applied approach

- Goal is to influence change in community health, systems, programs, or policies
Continuum of Community Based Research: N.M. CARES Health Disparities Center
CBPR Principles

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

Israel et al, 1998 and 2008

CBPR/TPR Principles for Tribes

- Tribal systems shall be respected and honored
- Tribal government review and 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
Within the Field: Our Challenges

Need to ask: What is our purpose?
- Utilitarian vs. World View? (E. Trickett, AJPH, 2011)

For community intervention research:
- Reality of complex community interventions
- What multiple designs can we use?
- What teams do we need to contextualize social epidemiologic data?

Tension between what is contextual and what is generalizable: (specific “form” versus “function/”processes) 
- Hawe et al, 2004/ LW Green
Within the Field: Our Challenges

Researcher-Community Relationships

- Nuances of participation
- Power and privilege: Who sets the research agenda?
- Historical and current research abuse/racism
- Specific university and research team reputation and community relationship
- Challenge of research team having necessary skills and values (cultural humility, listening, patience)
- Challenge of individual vs. community benefit
- Challenge of academic vs. community needs
Jemez Pueblo
- Less than an hour North of ABQ

Ramah Navajo
- Two hours West from ABQ
Jemez Pueblo: CDC Grant, 1999-2003

• Purpose: to better understand community strengths/ cohesions for health, & identify cultural measures
  • Qualitative Approach - over 60 key informants: Interviews/ FG

Ramah Navajo: NARCH, 2001-2005

• Purpose: to identify capacities and what keeps tribal members healthy
  • Quantitative Approach - ~250 Community Profile

• Findings: Concerns:
  • Loss of Culture/ Language
  • Communication: Elders/ Youth

CBPR Process

• Tribal Advisory Committees
• Co-developed instruments
• Trained interviewers
• Co-conducted interviews
• Co-analyzed data

Results:
Community Reports
2003 JAPH Publication
Community Profile
2011 HEB Publication
Family Listening Program Funding & Collaboration


• Purpose: To create intergenerational prevention program for 3rd to 5th graders, parents, and elders

  --Adapt evidence-based life-skills Anishinabe curriculum.

  --Within cultural values, norms, beliefs as directed by tribal partners.
Four Year CBPR Plan

**Years One & Two**
- Develop Tribal Research Team
- Explore Possibility of Adapting Anishinabe Curriculum
- Conducted Focus Group Discussions
  - Elders, Parents, Service Providers, & Youth

**Years Two & Three**
- Co-created Tribal Curriculum
- Co-created Evaluation & Process Tools

**Years Three & Four**
- Piloted Tribal Curriculum with 11 Families
- Conducted Evaluation (Outcome & Process)
  - Analysis and Dissemination of Results
Co-Creating an Intervention

Empirically-Supported/Evidence-Based Intervention:

- Whitbeck et al., Listening to One Another Curriculum: Cultural messages more lasting/delayed alcohol experimentation

Culturally-Supported*/-Centered Interventions**

- What would make this centered in the tribe?
- How do we benefit from indigenous knowledge yet not intrude or co-opt for our purposes?

*G. Hall, 2003; **M. Dutta, 2007
Family Listening Project

1. Welcoming
2. Family Dinner
3. Our Tribal History
4. Our Tribal Way of Life
5. Our Tribal Vision
6. Community Challenges
7. Communication & Help Seeking
8. Recognizing Types of Anger
9. Managing Anger
10. Problem Solving
11. Being Different
12. Positive Relationships
13. Building Social Support
14. Making a Commitment
Family Circle Program Evaluations

- Facilitator observations after each session
- Journals by the children after each session
- Pre-Post Test Interviews of Parent and Child

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

“I want to work on saying, just NO! I’m not that kind of person so I want to learn how to say no!”

“When my sister gets me mad I will stop and tell her not to get me mad. Then I will stop and walk away. Then my problem will be solved.”

“Sometime I am shy. It is not effective because I should say what I want and be confident so they can understand me”.

Outcomes: Culture (Kids & Adults)

↑ I am proud to be from my tribe.

“I felt good when he as talking about the ancestors that all ancestors did all those things”  --Child

“It felt very good because I finally learned about our culture”  --Child

“I am grateful that I’m learning our way of life.  I want for me & my family to learn as much as we can.”  --Adult

“That our culture and tradition are important for our people of this community and they continue to participate in any cultural/traditional activities.”  --Adult
Family Circle Program Extended

In Jemez, Dept. of Education took over 2nd implementation/trained new facilitators (2009)

Jemez Departments of Education and Health and Human Services adopted for Summer Youth Program Traditional Days:

150 kids, age 7-14 (2011)

Program now being owned, sustained and re-worked by tribe
RezRIDERS
NI DA R34 TO START 2012

Extreme Sport: Appeal to High Risk and Tradition
Cultural Mentors in Cultural Environments
Indigenized Cognitive Behavioral Curriculum
Community Action Projects
RezRIders Logic Model

**Project Context (Inputs)**

**Partnership**
- Long-term partnership: Community Based Participatory Research (CBPR) approach
- Research questions, design & approach: Tribally Driven
- RezRIders responds to Tribal needs & culturally congruent

**Tribal Research Team**
- Culturally connected mentors
- Representation of Tribal departments, programs & government
- Presence of Traditional Jemez Leadership

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**RezRIders Curriculum (Intervention: ES+Cognitive Behavioral)**

**Snowboarding & Core Values**
- Youth-driven Core Value development, discussions & mentorship opportunities - (A)(B)
- Participants bond, with dialogue & traditional knowledge exchange - (A)(B)

**White Water Rafting & Optimism**
- Optimism exercises & discussions involve flow of knowledge through an ecological framework – (A)(B)
- Mentors build upon bonding & learnings; working towards meaningful Community Action Projects - (A)(B)

**Rock Climbing & Self Determination**
- Individual & team oriented problem solving reinforce self determination & support - (A)(C)
- Mentors facilitate experience towards community responsibilities & stewardship - (A)(B)

**Community Action Projects & Empowerment**
- Projects reflect issues from Tribal youth perspective - (A)(C)
- Projects are obtainable & pragmatic; offer direct community benefit through service approach - (B)(C)

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**Intermediate Outcomes (Psycho-Social)**

**Individual Psycho-Social Factors - (B)**
- Self Esteem & Self Efficacy
- Self Regulation
- Leadership & Self-Determination
- Optimism & Hope

**Group Psycho-Social Factors – (A)(B)(C)**
- Pro Social & Positive Peer Networks
- Within Program Peer Connections
- Outside Program Peer Connections

**Community Social Factors - (A)(B)(C)**
- Youth & Adult Bonding
- Family Relationship
- Empowerment
- Collective Efficacy
- Political Efficacy
- Community Efficacy
- Community Awareness
- Traditional Tribal Knowledge

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**Outcomes (Long Term)**

**Individual Level**
- Use and/or Abuse of Alcohol & Other Substances
- Depression Symptomology

**Group/Peer Level**
- Knowledge, Awareness, Beliefs
- Mentor & Peer Connections
- Negative Influence

**Community Level**
- Changes Within Local Agencies
- Diffusion of RezRIders

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**Measures, Data Collection**

**Quantitative Pre/Post**
- 1. Depression Scale
- 2. ATOD Scale
- 3. Coping Scale
- 4. LOT-R Scale
- 5. Hope Scale
- 6. Gratitude Scale
- 7. Wiggins Empowerment

**Qualitative**
- 1. Participant/Mentor Dialogue & Reflection Summaries
- 2. Tribal Photo-Voice Project
- 3. Interviews (Parents, Program, Leaders)

**Process Instruments**
- 1. Mentor Activity Logs
- 2. Mentor Activity Assessment
- 3. Tribal Process Instruments (CBPR)

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**Theory Base:**

(A) Indigenous Theory - Culturally-Grounded Adult & Youth Co-learning Environments
(B) Social Learning Theory - A Dynamic Interplay of Beliefs, Values & Expectancies
(C) Empowerment Theory - Provides opportunities for Pro-Social & Community Connection
How Do We Evaluate CBPR?

- Evaluate grant: intervention outcomes
  - Cultural-Centeredness/Sustainability

- Evaluate partnership processes:
  - Collaborative processes/power sharing

- Evaluate systems/intermediate outcomes of benefit to community:
  - Policies/Practices/Programs
  - Community Capacity/Empowerment

- Evaluate effectiveness in reducing health disparities
“Research for Change”
Cross-Site Multicultural CBPR
NARCH V Grant (2009-2013)

Purpose: To identify facilitators and barriers to effective CBPR across diverse populations and settings, and to advance the science of CBPR to reduce health disparities

Partners:
- National Congress of American Indians Policy Research Center (S. Hicks/M. Villegas as PI)
- University of Washington (B. Duran, co-PI)
- University of New Mexico (N. Wallerstein, co-PI)

Funding: Pilot: NI MHD
NARCH V: NI GMS, NI DA, NCRR, NCI, OBSSR (with Indian Health Service)
Specific Aims:

1. Describe the variability of CBPR processes and outcomes across partnerships

2. Describe and assess the impact of governance across AI/AN and other communities of color

3. Examine associations among group dynamic processes and CBPR outcomes (culturally-centered interventions, community capacities, policies/practices), under varying diverse contexts

4. Identify promising practices, tools, and future research agenda for the field of CBPR
Multi-Year Study Design

- Created CBPR Process on all Levels of Grant:
  - Scientific Community Advisory Committee
  - Scientific Subcommittees
  - Virtual Community of Practice of CBPR Sites
- Define Universe of CBPR Projects
- Develop Case Studies (originally projected 8)
  - 5 by Nov. 2011; 1-2 more
- Internet Survey Instrument Design for ~330 sites
  - To be launched Nov. 2011
  - Key informant interviews to verify data (15 min): PI
  - Community Engagement survey (30 min): 4 partners
CBPR Conceptual Logic Model


**Contexts**
- Socio-Economic, Cultural, Geography & Environment
- National & Local Policies/Trends/Governance
- Historic Collaboration: Trust & Mistrust
- Community Capacity & Readiness
- University Capacity & Readiness
- Health Issue Importance

**Group Dynamics**
- **Structural Dynamics:**
  - Diversity
  - Complexity
  - Formal Agreements
  - Real power/resource sharing
  - Alignment with CBPR principles
  - Length of time in partnership
- **Individual Dynamics:**
  - Core values
  - Motivations for participating
  - Personal relationships
  - Cultural identities/humility
  - Bridge people on research team
  - Individual beliefs, spirituality & meaning
  - Community reputation of PI

**Relational Dynamics:**
- Safety
- Dialogue, listening & mutual learning
- Leadership & stewardship
- Influence & power dynamics
- Flexibility
- Self & collective reflection
- Participatory decision-making & negotiation
- Integration of local beliefs to group process
- Task roles and communication

**Intervention/Research Design**
- Intervention adapted or created within local culture
- Intervention informed by local settings and organizations
- Shared learning between academic and community knowledge
- Research and evaluation design reflects partnership input
- Bidirectional translation, implementation & dissemination

**Outcomes**
- System & Capacity Changes:
  - Policies/Practices
  - Sustained Interventions
  - Changes in power relations
  - Cultural Renewal
  - Improved Health
- Disparities
- Social Justice

CBPR System & Capacity Changes:
- Changes in policies/practices
  - In universities and communities
- Culturally-based & sustainable interventions
- Changes in power relations
- Empowerment:
  - Community voices heard
  - Capacities of advisory councils
  - Critical thinking
- Cultural revitalization & renewal

Health Outcomes:
- Transformed social/econ conditions
- Reduced health disparities
Cross-Site Accomplishments

- Conceptual model
- Literature review of measurement tools/constructs (Sandoval et al, 2011)
- Project code of ethics and integrity, protocols for student involvement, publications, communications
- Interactive Model on Web linked to instruments and to variables matrix/measures:
- Universe of CBPR Projects and Evaluation Metrics
Cultural-Centeredness Items

- To what extent does your project fit local/cultural beliefs, norms, and practices?
- How well did this project engage reciprocal learning?
- How appropriate was the research design for the partners in the project?
- To what extent was the community partner's knowledge, culture, and voices included in identifying the problem?

Dutta
## Trust Indicators

<table>
<thead>
<tr>
<th>Types of Trust</th>
<th>Defining Characteristic</th>
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<tbody>
<tr>
<td><strong>Critical Reflective Trust</strong></td>
<td>Trust, in this partnership, is at the place where mistakes and other issues resulting from differences (in culture; power) can be talked about and resolved.</td>
</tr>
<tr>
<td><strong>Proxy Trust</strong></td>
<td>Members of this partnership are trusted, because someone who we trust invited them, therefore we trust them.</td>
</tr>
<tr>
<td><strong>Functional Trust</strong></td>
<td>Members of this partnership are working together for a specific purpose and timeframe, but mistrust may still present.</td>
</tr>
<tr>
<td><strong>Neutral Trust</strong></td>
<td>We are still getting to know each other; there is neither trust nor mistrust.</td>
</tr>
<tr>
<td><strong>Unearned Trust</strong></td>
<td>Trust, is based on member’s title or role with limited or no direct interaction prior to this project. Examples of title or roles may include: a community outsider, a physician, or community organizers.</td>
</tr>
<tr>
<td><strong>Proxy Mistrust</strong></td>
<td>Members of this partnership are not trusted because someone who we do not trust invited them, therefore we mistrust them.</td>
</tr>
<tr>
<td><strong>No Trust</strong></td>
<td>Members of this partnership do not trust each other. It is likely that trust will not develop.</td>
</tr>
</tbody>
</table>
Recommendations for Research

Seek knowledge based on hybridity:
- Integrate Knowledge from both Academic Evidence and Cultural/Community Evidence
- Build on Community Strengths
- Build New Theories of Change

Pay attention to external validity and context of implementation/sustainability

Incorporate research on CBPR partnering

Pay attention to mutual benefits
Recommendations to Transform Research Academic Culture

- Expand to Community Engaged Scholarship
  - Develop tenure/promotion criteria on practice
  - Build CBPR/Community Engagement Centers and culturally centered support for faculty of color

- Build Diverse Teams:
  - to reflect ethnicity/culture of communities

- Protect Junior Faculty of Color
  - Limit committee work
  - Recognize burden to “represent” communities
  - Recognize difficulty of CBPR publication of data in short time frame for tenure and promotion
Recommendations to Assure Community Benefit

- Promote Community Capacity in Research
- Change Power Relations: data/$
- Create Shared Analysis and Reporting
  - Not “ventriloquism,” but multiple spaces so the lived experience of our partners can be heard and validated (Spivak 1990).
- For Outsiders: Return to CBPR principles: Show up; Be who you are; Listen; Social Justice (AJPH, Northridge, 2003)
- Assess impact on partnership/community capacity
Recommendations of Our Role: Self-Reflexivity and Cultural Humility

Be Self-Reflexive of Own Position and Characteristics: gender, age, education, race/ethnicity, sexual orientation, power and privilege

Embrace multiple cultural perspectives: the ability of team “to translate” matters

“A life long commitment to self evaluation and self critique” to redress power imbalances and “develop and maintain respectful and dynamic partnerships with communities” Tervalon & Garcia, 1998
Return to Listening

What is problem from each point of view?

What should be done about this problem from each point of view?

What can we do together?

Mohan Dutta