

# Community Based Participatory Research as a Path to Equity: Role of Research Teams, Researcher Identity and Mentorship

Nina Wallerstein, DrPH

Professor and Director, Center for Participatory Research  
University of New Mexico Public Health Program

Visiting Professor, San Francisco State University

1<sup>st</sup> Annual Victor J. Schoenbach Health Disparities Keynote Lecture

33<sup>rd</sup> Annual Minority Health Conference  
UNC Gillings School of Global Public Health

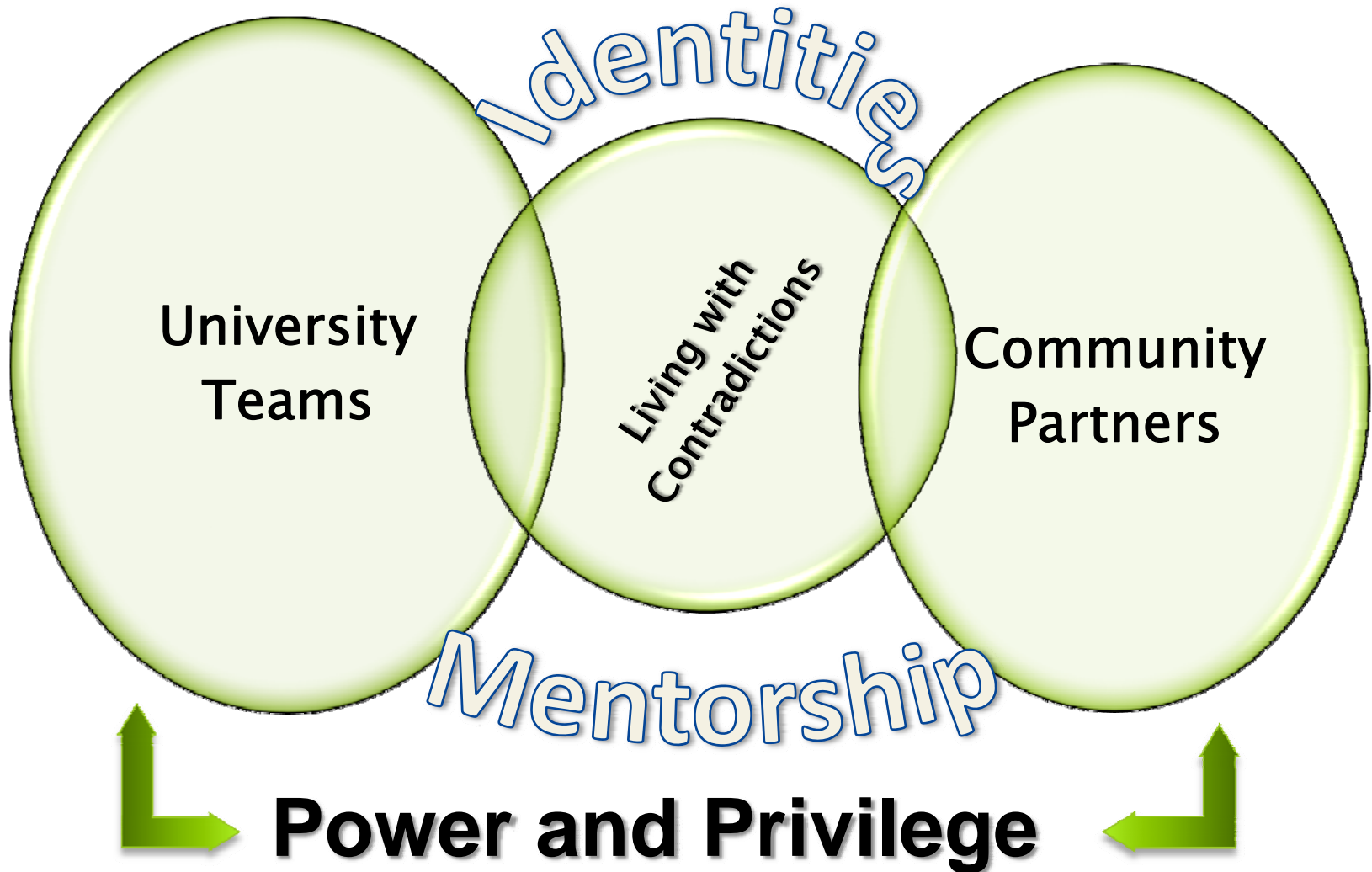
February 24, 2012

# CBPR on the Rez: Reflections on the Rocks

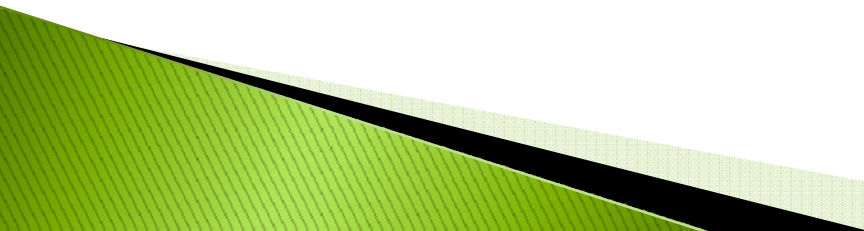
- ▶ CBPR as Translational Science
- ▶ Reflections on CBPR Identity
- ▶ Reflections on Mentorship
- ▶ Living with Contradictions in Research Partnering



# How does Power and Privilege from our Identities affect CBPR Research?



# My Research Story

- ▶ Paulo Freire Popular Education (1970s -- )
  - ▶ Empowerment Research (1980s --)
    - Adolescent Social Action Program with Native and Latino Communities, YouthLink, Women to Women
  - ▶ Community Based Participatory Research: 1990s
    - Participatory Eval. NM Healthy Communities/Councils
    - PAHO Participatory Evaluation in Latin America
  - ▶ CBPR Research with Tribes
    - National Healthy Native Community Fellowship
    - New Mexico CBPR Intervention Tribal Research
  - ▶ National CBPR Process & Outcomes Research
- 

# My Starting Points

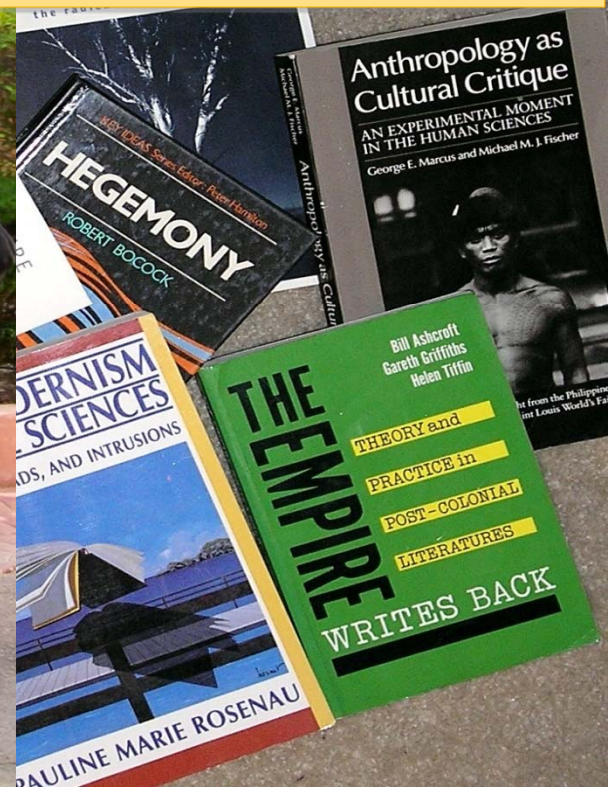
- ▶ “For apart from inquiry, apart from the praxis, individuals cannot be truly human. Knowledge emerges only through invention and re-invention, through the restless, impatient, continuing, hopeful inquiry human beings pursue in the world, with the world, and with each other.”
- ▶ Without a sense of identity, there can be no real struggle...”

— [Paulo Freire](#), [\*Pedagogy of the Oppressed\*](#)





## ACKNOWLEDGEMENTS



# Challenge of Inequities

Inequities widening dramatically

Reducing inequities central to both:

Social Epidemiology

CBPR / Community-engaged intervention research

**Social  
determinants  
of health**



**Health equity  
outcomes**



# Challenge of Translational Science

- ▶ 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.
  - Cultural- / Community- / Practice-Based Evidence
- Challenge of Scientific Knowledge Production Itself
  - Reinforcing Unidirectional Translation

Challenge of Research Abuse and Mistrust





# 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



Tuskegee Institute



Peter Buxtun, a former Public Health Service employee.

# Challenge of Public Health History

## Development of a Health Education Program\* Navajo Indians

EDNA A. GERKEN, C.P.H., F.A.P.H.A.

*Supervisor, Health Education, Office of Indian Affairs, Department of the Interior,  
Washington, D. C.*

A PRESENTATION of some practical procedures in the development of a health education program, drawn from experiences with a group of American Indians, the Navajos, may be of interest to those concerned with child health. These experiences are significant because, in dealing with primitive people, it is necessary to disregard everything but the most basic fundamentals and, therefore, needs and relationships are more clearly perceived than in programs dealing with a more complex culture.

being sold in every trading post. Substituted for the natural foods formerly eaten, their use contributes to malnutrition and dental caries. Automobiles and improved roads are bringing closer contact among family units on the reservation, facilitating the spread of communicable diseases and increasing the need for modern methods of sanitation to control this.

Cultural factors also contribute to the health problems here. The people, for example, believe that disease is caused by the spirits.

Lack of health knowledge and skills, particularly in regard to the care of infants and children is another factor contributing to high morbidity and mortality rates. Medical and nursing

- ▶ Health Education and the marginalization of culture
- ▶ Native agency and voice erased
- ▶ Calls for collaboration with everyone, except Navajos...

# Challenge of Current Abuse

## **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.



# Community Based Participatory Research (CBPR)

“ 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



NM CARES Health Disparities Center, 2011

# Community Based Participatory Research as Opportunity

- ✓ Can we use CBPR partnership opportunities and *research spaces* for:
  - ✓ Regaining research trust
  - ✓ Co-construction of knowledge:
    - ✓ academic and community knowledge
  - ✓ Purpose of promoting equity and social justice
- ▶ Need Accurate and Valid Data
- ▶ Need Constituents to Demand Change

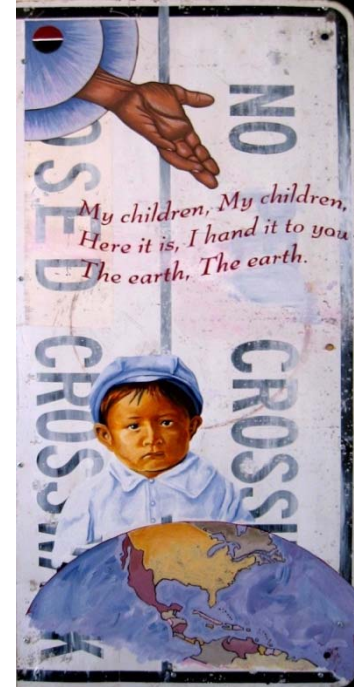
What is role of research teams and researcher identities for effective partnering for change?





# Our Team Inquiry

- Literature on Identity and Positionality
- Team Panel: UNM CBPR 2011 Institute:  
INDIGENOUS AND CRITICAL METHODOLOGIES
- Ongoing Reflections on our Research



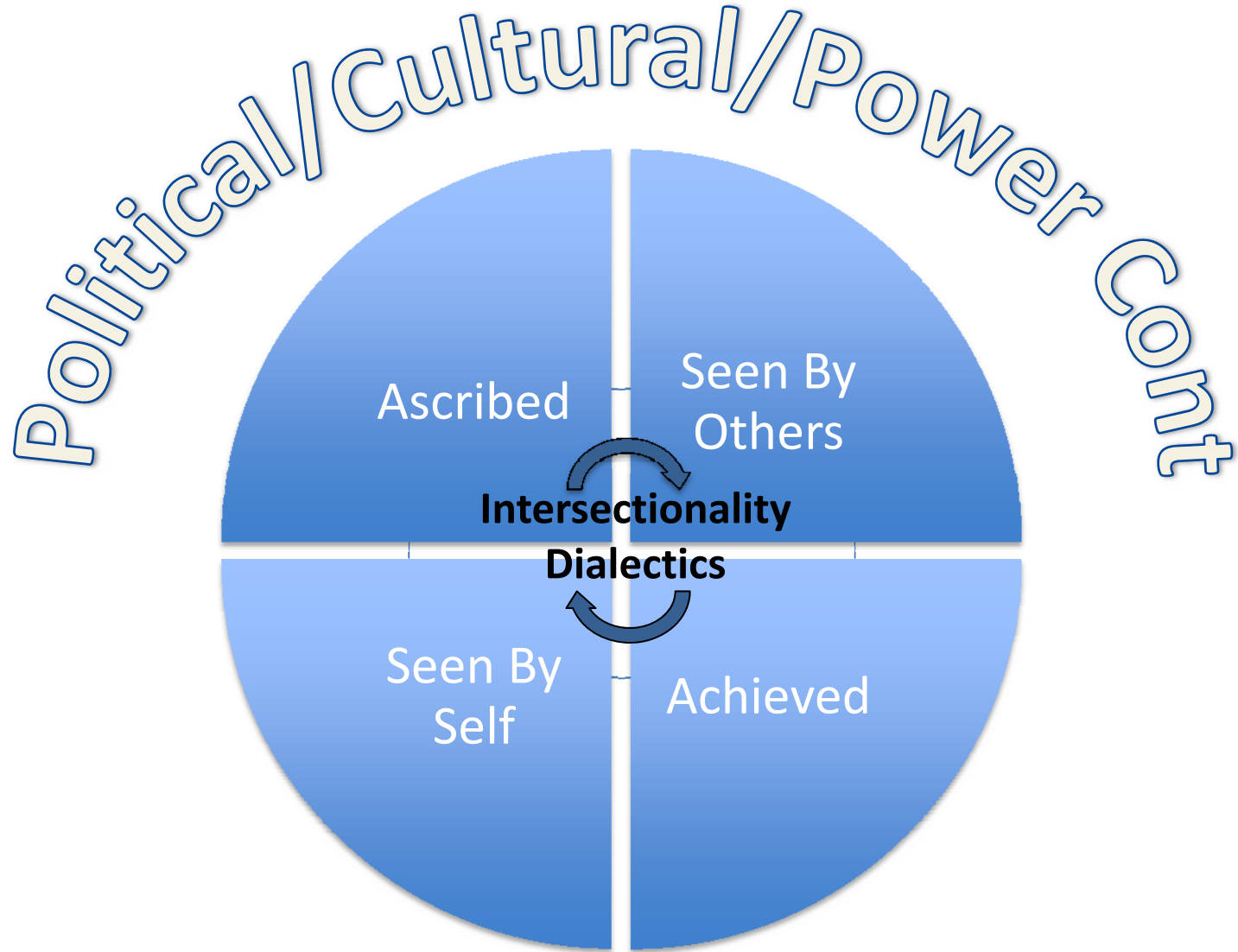
How do we perceive the role of our identities in doing CBPR ?

How do we perceive the role of mentorship?

What motivates each of us to work in the team?

What has kept us connected and wanting to continue with the team?

# Research Identities in CBPR



# University Institutional Contradictions in Creating a Diverse Team

- ▶ Democratic Team
  - ▶ Privilege to be an Academic:
  - ▶ Freedom of Voice/  
Value of Diversity
  - ▶ Expectation that my  
voice is heard
  - ▶ Hierarchy of Universities
  - ▶ University Norm of  
Objective Inquiry/  
Standard for how to do  
Science
  - ▶ Scholars of color often  
not experience being  
heard / outsiders-within
- vs



# Research Contradictions of Power and Privilege based on Identity

- ▶ Positions of Power between Researchers and Researched
- ▶ Processes of Research: Decision-making, etc.
- ▶ Representation and Writing : Who has Voice

Diane Wolf, Feminist Dilemmas in Fieldwork, 1996

- Access to Knowledge: who has access to what knowledge?

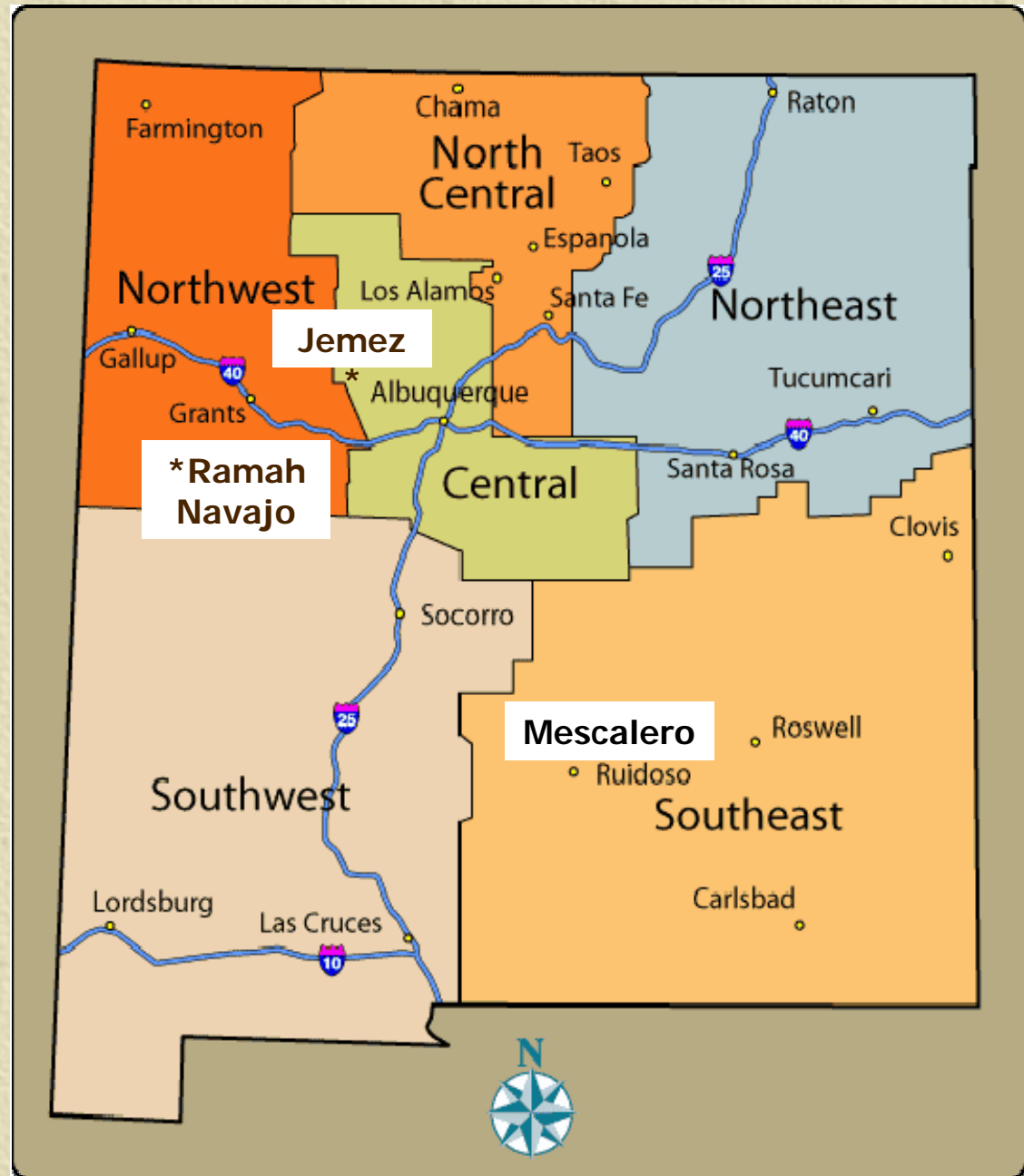
## Jemez Pueblo

- Less than an hour North of ABQ



## Ramah Navajo

- Two hours West from ABQ



# Family Listening Program

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





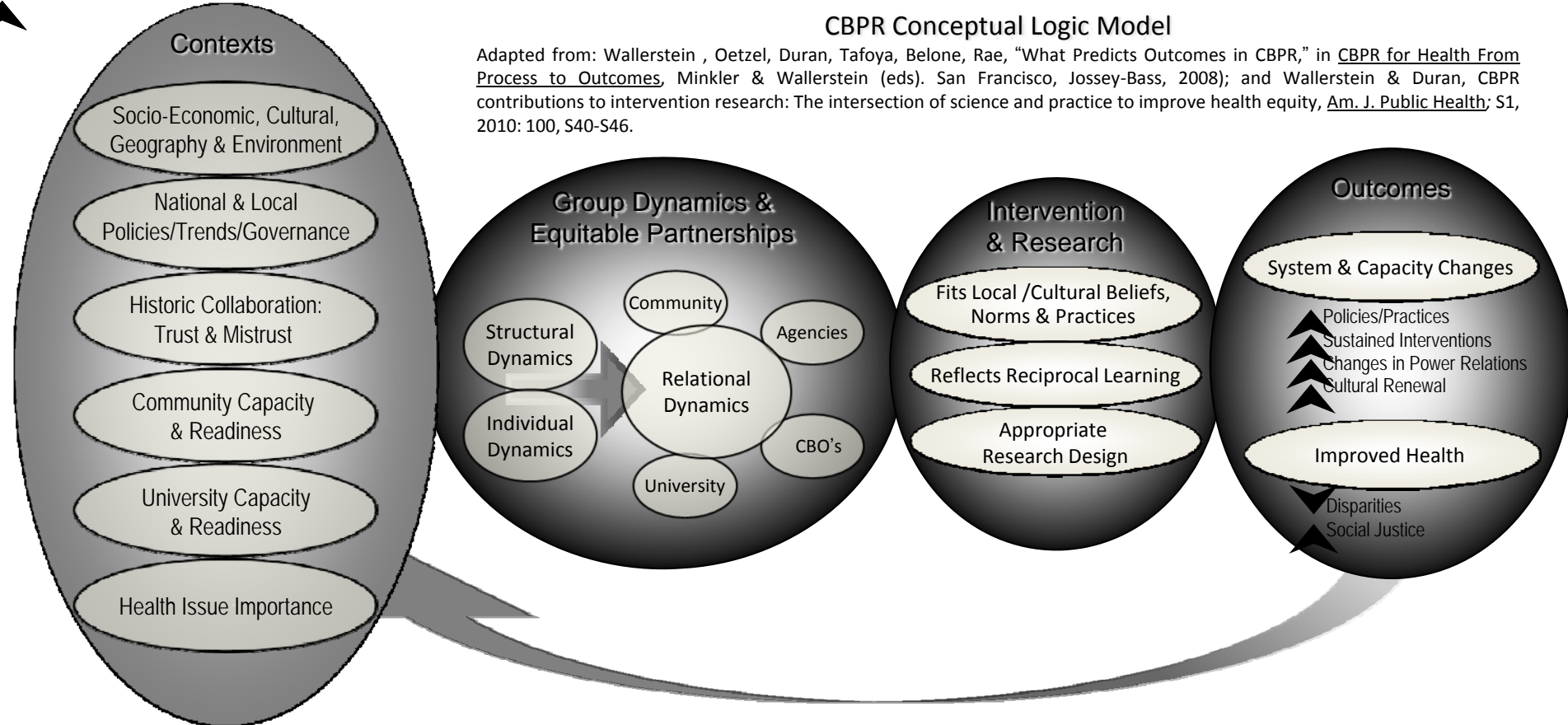
# “Research for Improved Health”

## Study of Community–Academic Partnerships

- ▶ **Funding:** NIH: NARCH V: 2009–2013
- ▶ **Partners:**
  - National Congress of American Indians Policy Research Center
  - University of Washington and University of New Mexico
- **Aims:** To advance science of CBPR to improve equity
  1. Describe 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
  4. Identify promising practices and tools

# CBPR Conceptual Logic Model

Adapted from: Wallerstein , Oetzel, Duran, Tafoya, Belone, Rae, "What Predicts Outcomes in CBPR," in CBPR for Health From Process to Outcomes, Minkler & Wallerstein (eds). San Francisco, Jossey-Bass, 2008); and Wallerstein & Duran, CBPR contributions to intervention research: The intersection of science and practice to improve health equity, Am. J. Public Health; S1, 2010: 100, S40-S46.



## Contexts

- Social-economic, cultural, geographic, political-historical, environmental factors
- Policies/Trends: National/local governance & political climate
- Historic degree of collaboration & trust between university & community
- Community: capacity, readiness & experience
- University: capacity, readiness & reputation
- Perceived severity of health issues

## 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 & communication

## Intervention

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

## Outcomes

### CBPR System & Capacity Changes:

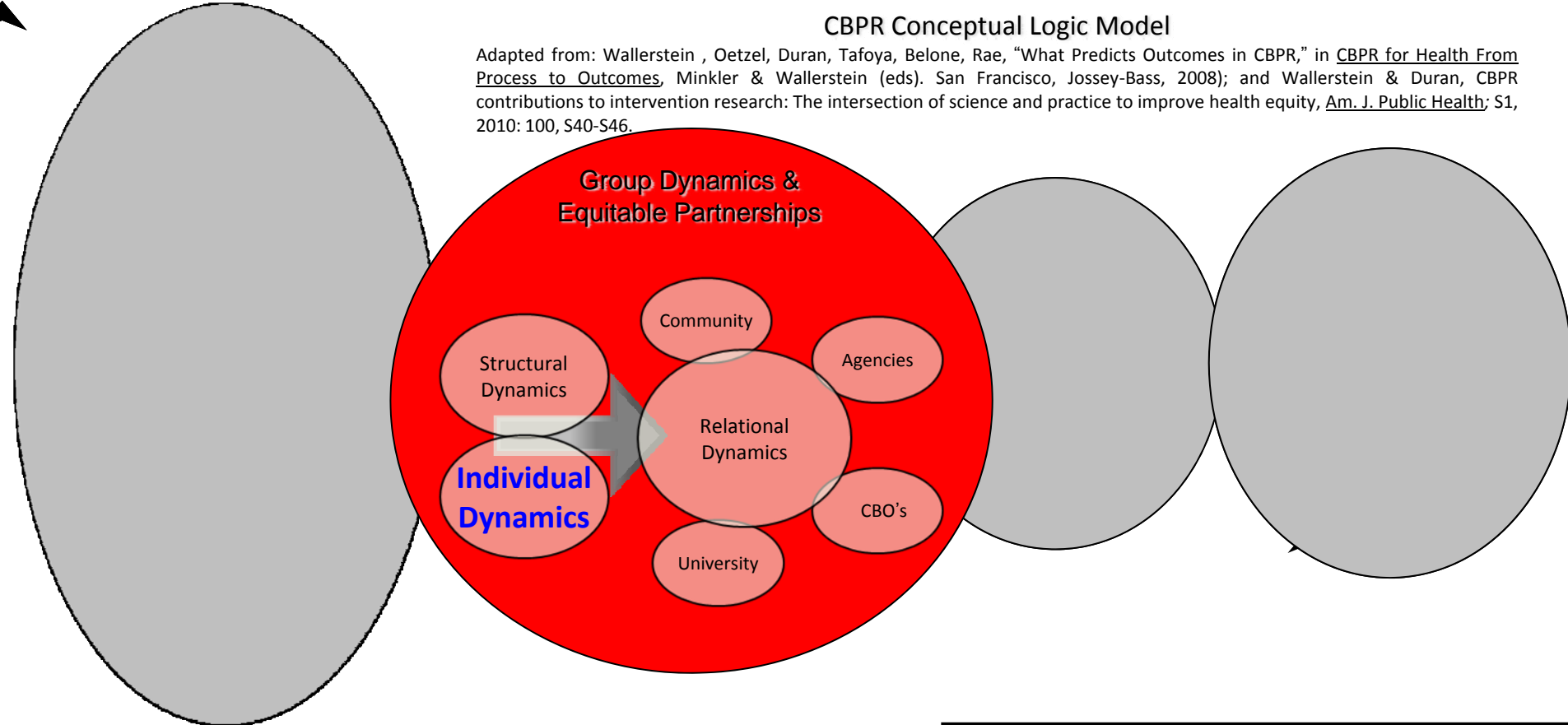
- Changes in policies /practices
  - In universities & communities
- Culturally-based & sustainable interventions
- Changes in power relations
- Empowerment:
  - Community voices heard
  - Capacities of advisory councils
  - Critical thinking
- Cultural revitalization & renewal

### Health Outcomes:

- Transformed social /econ conditions

## CBPR Conceptual Logic Model

Adapted from: Wallerstein , Oetzel, Duran, Tafoya, Belone, Rae, "What Predicts Outcomes in CBPR," in CBPR for Health From Process to Outcomes, Minkler & Wallerstein (eds). San Francisco, Jossey-Bass, 2008); and Wallerstein & Duran, CBPR contributions to intervention research: The intersection of science and practice to improve health equity, Am. J. Public Health; S1, 2010: 100, S40-S46.



- Core values
- Motivations for participating
- Personal relationships
- Cultural identities/humility
- Bridge people on research team
- Beliefs, spirituality & meaning
- Community reputation of PI

# Impact of my identity on New Mexico Research

## Contradictions of My Identity and history:

Authority & Power means Responsibility/

Accountability: in research & community benefit

Reputation of PI Matters

Resources and Brokering in Community/Show Up

## Subject to Tribal Sovereignty:

Community Authority/Ownership of Research

Respect Community Knowledge (what is shared with  
me, with bridge team members, or not shared)

Challenge University Policies/Practices





# Researcher Identity in National CBPR Study

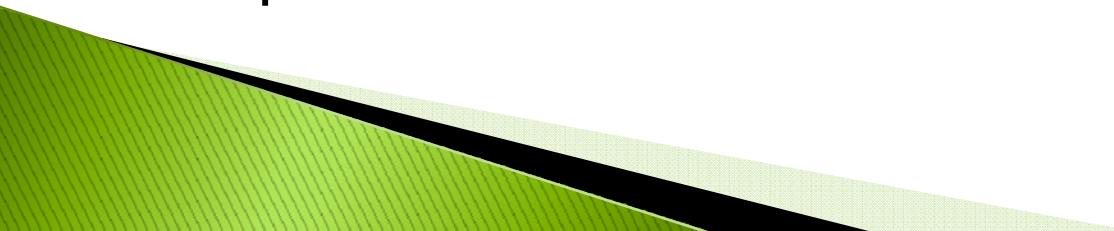
## Impact on Case Study Teams (Who)

- How we divided ourselves for different sites
- Role of PI: Important to show respect by showing up
- “Bridge people” critical

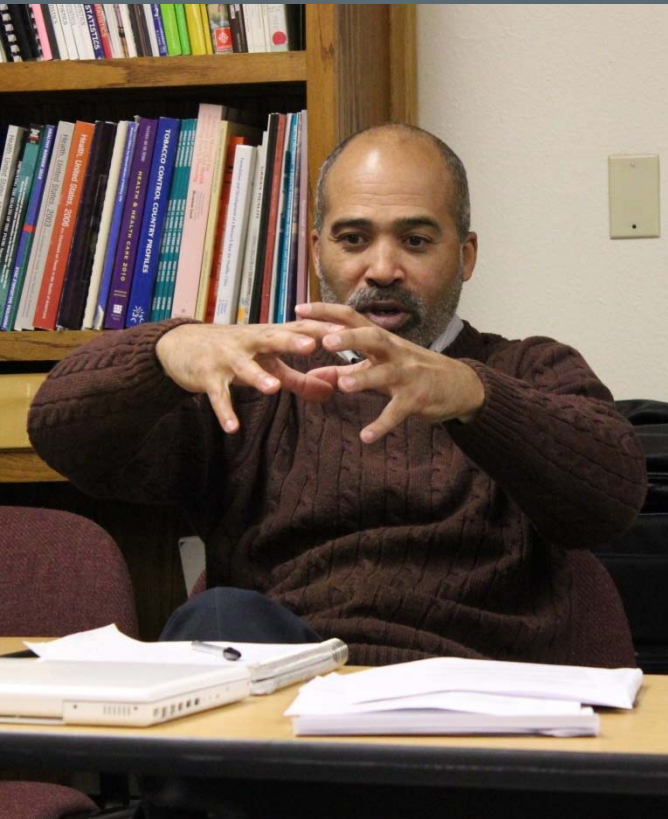
## Impact on Research Fieldwork/ Data Collection

- Impact on what we heard/access to knowledge

## Impact on Data Interpretation/Representation

- Impact on what and how we can interpret
  - Impact on ownership of data and co-publication
  - Impact on action
- 

# Team Voices: Identity



Michael Muhammad



Greg Tafoya

Dr. Lorenda Belone

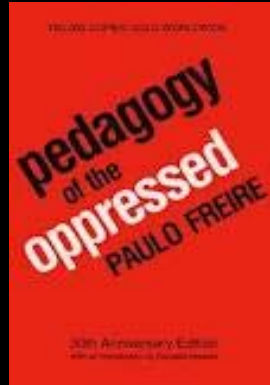


# Current Attacks on Culture and Identity

Mexican–American  
Studies suspended:  
Tucson, AZ

7 banned books:

- Pedagogy of the Oppressed by Paulo Freire



- Chicano! History of Mexican–American Civil Rights Movement by F. A. Rosales



NATIVE NEWS NETWORK

12-year old  
Menominee Seventh  
Grader Suspended for  
Saying "I Love You" in  
her Native Language



Connecting Native American Voices

# Traditional Mentorship in Research

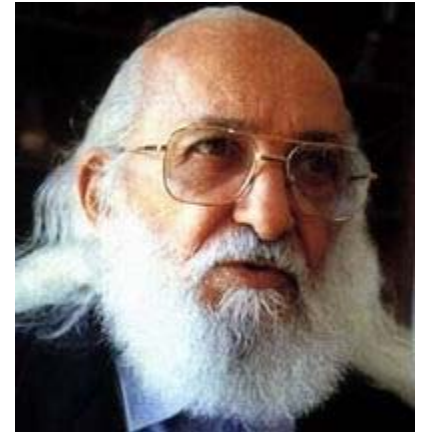
- A personal developmental relationship in which a more experienced or knowledgeable person helps a less experienced or less knowledgeable person
- Mentoring is informal transmission of knowledge, social capital, and the psychosocial support perceived by the recipient as relevant to work, career, or professional development.



# My History of Mentorship

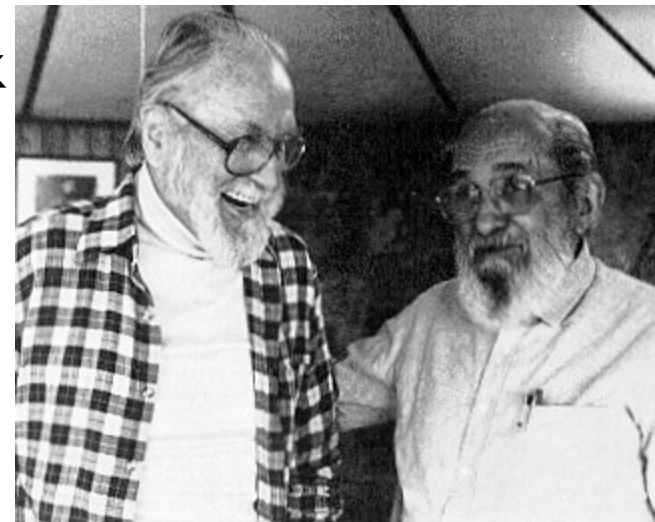
## ► Distant Mentors: Paulo Freire and Myles Horton

- Listening and Dialogue
- Participatory Learning
- Social construction of knowledge
- Self and collective reflection



## ► UNM School of Medicine:

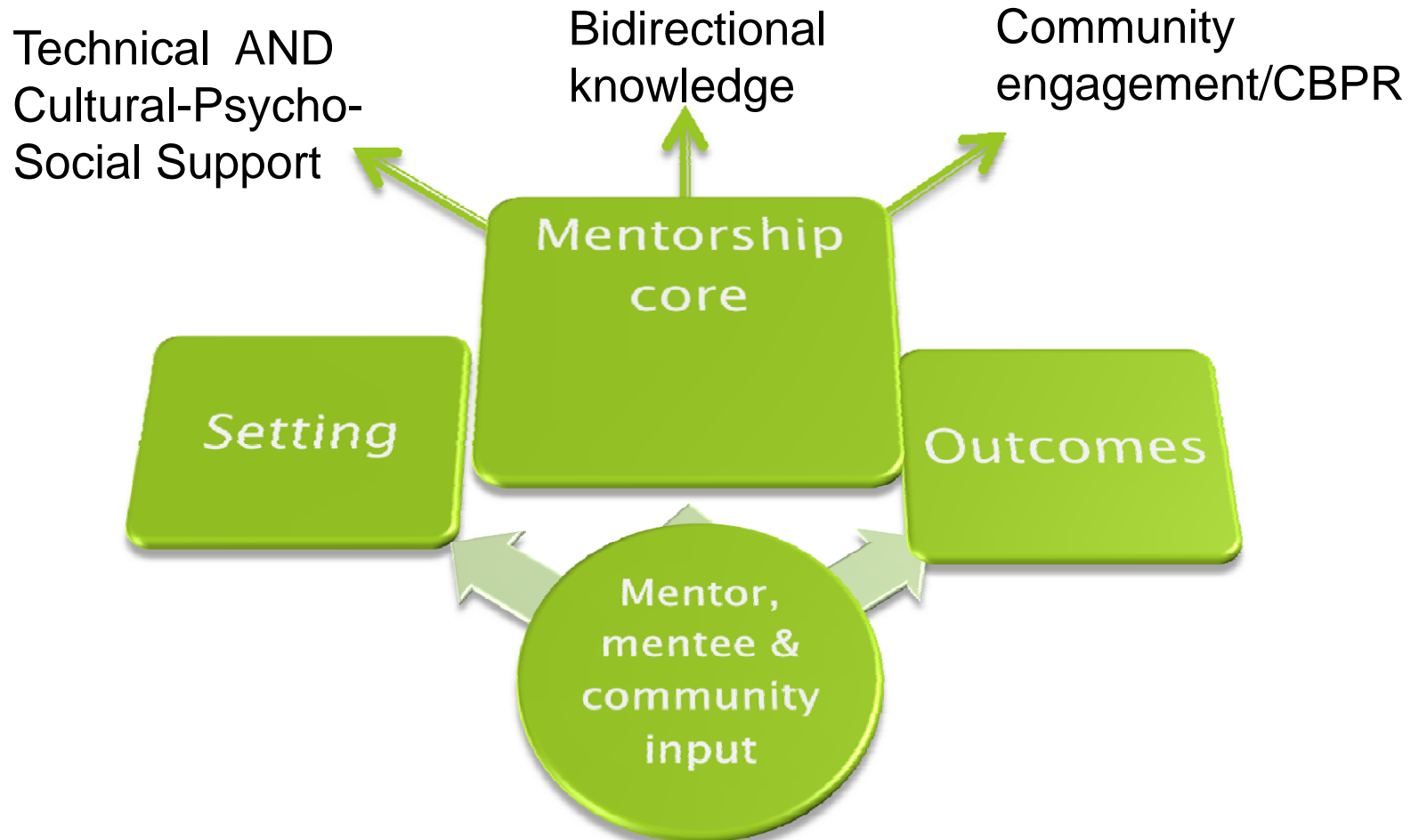
- Senior colleagues who had my back
- Colleagues of color
- Southwest Addictions Research Group (SARG)



# Southwest Addictions Research Group (SARG)

## Mentorship

Lopez-Viets et al, Academic Medicine, 2009



Culture & community as foundation

# Mentorship with UNM Team

- Ongoing reflection through long rural drives (laptop notes)
- Team longevity
- Believe people are “bigger” than they might believe (L.Moore)
- CBPR Model development and importance of identity in case studies
- Team: Up, Down, Co-Mentorship:
  - How we create Safety to question and be ourselves
  - Recognize structural barriers
  - Intentional co-mentoring
- Community mentorship



# Team Voices: Mentorship



Julie Lucero




Dr. Magdalena Avila



Greg Tafoya



# Reflections on CBPR Teams and Identity

- ▶ Purpose of CBPR Research: To facilitate knowledge development that changes social determinants/enhances equity and justice
  - ▶ --Need Accurate and Valid Data
    - Knowledge generated with community
    - Diverse team members critical
  - ▶ --Need Constituents to Demand Change
    - Internal within University
    - External within Communities and Society
    - Trust within partnerships important
- 

# Critical Reflective Trust

Lucero et al, 2012

Types of Trust	Defining Characteristic
<i>Critical Reflective Trust</i>	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.
<i>Proxy Trust</i>	Members of this partnership are trusted, because someone who we trust invited them, therefore we trust them.
<i>Functional Trust</i>	Members of this partnership are working together for a specific purpose and timeframe, but mistrust may still present.
<i>Neutral Trust</i>	We are still getting to know each other; there is neither trust nor mistrust.
<i>Unearned Trust</i>	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.
<i>Proxy Mistrust</i>	Members of this partnership are not trusted because someone who we do not trust invited them, therefore we mistrust them.
<i>No Trust</i>	Members of this partnership do not trust each other. It is likely that trust will not develop.


What is problem from each point of view?

What should be done from each point of view?

What can we do together?

Mohan Dutta

# Living with Contradictions

- ▶ Can't do CBPR in Indian Country without bridge team members, yet important PI role as outsider
  - ▶ Challenge power and privilege, yet benefit from it
  - ▶ Support community autonomy and capacity, yet university can re-colonize
  - ▶ Want to decolonize research and privilege community knowledge, yet danger of misappropriating cultural knowledge
    - ▶ Key: Intention and self-reflexivity, deep listening; belief in hybrid community and academic science
- 

# Deep Listening and Learning

- ▶ “Deep learning involves the whole body, blood and bone, not just the theoretical or cataloguing of insightful facts and analyses. Deep learning moves the feet to walk in a new way, moves the eyes to see from the new perspective won by that walking, and moves the hands to fashion the tangible world into a new image envisioned by the new seeing.”
- ▶ Moriarty, P, “Deep Learning for Earthquake Country,” 1993, Future of Prophetic Christianity: Essays in Honor of Robert McAfee Brown, Carmody and Carmody, (eds) Orbis Books, NY



# Humility and Gratitude

Self-reflexive of own positionality

Deep Listening to cultural perspectives of team

***“A life long commitment to self evaluation and self critique” to redress power imbalances”*** Tervalon & Garcia, 1998

Cultivate gratitude





# Many Thanks

## Center for Participatory Research Team, UNM

- Magdalena Avila, Lorenda Belone, Lisa Herrera, Julie Lucero, Michael Muhammad, Emma Noyes, John Oetzel, Rebecca Rae, Vanessa Simonds, Andrew Sussman, Greg Tafoya, Belinda Vicuna; and national NARCH Partners: Bonnie Duran, Emily Whitehat, Malia Villegas

## Community Partners from the Jemez Pueblo

- Kevin Shendo, Janice Tosa, Kristyn Yepa, Anita Toya, Harriet Yepa-Waquie, many others

## San Francisco State University

- Lisa Moore, Kathleen Gali, 2012 CBPR Class Students
- 