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Creating A Culture of Equity & Engagement at Academic Health Centers: A Case Example of the NM CARES Health Disparities Center Presentation to the NM CARES Health Disparities Center May 20, 2014

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Background

- Health inequities are a national and state problem.
- Research can improve health and eliminate inequities by informing and testing solutions that work.
- Community participation in research strengthens the study design and translation and application of findings.
- Yet, there are many challenges to effective partnerships:
 - i.e. Legacy of mistrust and ethical abuse of people of color in studies or lengthy timelines to build partnerships
- Recognizing these challenges, the National Center of Minority Health Disparities invests in Health Disparities Centers in order to enhance relationships between academic institutions and racial/ethnic communities.

New Mexico Context



 UNM HSC seeks to be the lead in the nation in reducing health disparities by the year 2020.

- 58% of New Mexico's populations are racial ethnic minorities (48% Latino, 4.8% Native American, 3% African American, 2.3% Asian).
- These same populations suffer the most adverse health conditions (i.e. diabetes, obesity, drug overdoses) and lack access to social resources to achieve good health (jobs, housing, education, health care).
- As a minority health serving institution and beneficiary of public tax dollars, UNM HSC/UNM is obliged to align institutional research efforts with external needs of local communities.

Purpose

- Previous research on Community Based Participatory Research projects have often looked "externally" to principles and best practices that occur in the community.
- At the time of our literature review there had been no study conducted to assess the "internal" institutional culture, structural barriers and organizational actions needed to foster conducting research *with*, rather than on communities.
- To address this gap, the NM CARES HD Center (CEC) conducted an internal assessment of institutional facilitators and barriers to "community engaged" health disparities research.

Conducting Research with Communities





The aims of the study were to assess the:

- UNM HSC organizational barriers and facilitators, including those which reflect differentials of power, privilege, and race, to bi-directional health disparities research with communities; to
- <u>Range of approaches</u> to community engaged or partnered health disparities research; and to
- Promising practices for conducting community engaged or partnered health disparities research.

Methods

pilot study data collection

Study participants were selected on the basis of their experience with community engaged research.

Sampling & Data Collection

- N= 21 Interviews (Nov 2011-August 2012)
- Purposive sampling
- 3 types of stakeholders: leaders/ administrators, researchers community advisory members engaged with health disparities research from 2006 to 2012
- Semi-structured interview guides created for each group
- Community and Scientific Advisory Committee (CSAC) provided feedback and recommendations to refine the guides
- Data collection protocol & informed consent procedures approved by UNM HRRC (ethics review); application submitted to Navajo IRB; delays in official approval resulted in dropping Navajos from sample

Data Analysis

- Interviews were digitally audio-tape and professionally transcribed
- Data analysis used NVivo software
- Team coding
- First cycle codes-by question level
- Second cycle codes-emerged by patterns and themes
- Categorized themes into three interrelated areas; developed a cognitive map to understand the integrated schema:

a) Relational

b) Contextual

c) Structural

Development of Interview Guide

We drew from various scholarly works to inform the development of the interview questions including:

- CBPR for Health (Minkler & Wallerstein, 2008)
- Reconstructing the Landscape of Health Disparities Research: Promoting Dialogue & Collaboration between Feminist Intersectional & Biomedical Paradigms (Weber, 2006. In Gender, Race, Class & Health: Intersectional Approaches)
- Decolonizing Methodologies: Research & Indigenous Peoples (Tuhiwai Smith, 2002)
- Rethinking Racism: Toward a Structural Interpretation (Bonilla-Silva Source: American Sociological Review, Vol. 62, No. 3, 1997, pp. 465-480)
- Organizational Climate and Culture (Rousseau, 2011. In *Macro-Organizational Factors)*

The CEC consulted with members of the NM CARES HD Community and Scientific Advisory Committee (CSAC) for feedback and recommendations to refine the interview questions.

Sample Questions

Five Categories Questions:

- 1. Your own research experience
- 2. Broader research at UNM HSC
- 3. Context of your research
- 4. Institutional context
- 5. Promising practices and approaches

Sample researcher question

- 1. Could you describe briefly your experience with health disparities research at UNM in New Mexico?
- 2. How do you define health disparities research?
- 3. How would you describe the current state of health disparities research being conducted at the UNM HSC?

Participant Breakdown

The CEC team conducted key informant interviews with the following type of stakeholders:

- Community-engaged investigator/researcher
- UNM leader/administrator
- Community partner involved in one of the Health Science Center Community advisory boards or task forces

There were a total of 21 interviews
42% Community-engaged academic researchers
29% UNM leaders
29% Community advisory members

In our selection of interviews, there were also a few that refused to participate in the study based on their personal reasons and some that did not respond.

Key Findings: Major themes and sub themes



Finding 1: Organizational Climate & Culture

Culture of Money

 Community needs and priorities often take a "back seat" to funding pressures and institutional deadlines.

"This is **our culture** here. Many times we're so used to funds that we're driven—the work that we do is driven by the funding that we get. That kind of has an impact on being creative and innovative. Oh, no, you cannot do that because this is what the grant requires. We always talk about not working in silos or not being so fragmented, but we still do it because of our funding." – *Researcher*

"I feel that the university and the research, they need to really know, really, really know and assess what are the needs that this community, this state, has, and instead of reacting to where the money is, really look at how do we find—do research so that research can guide where the money should come from. They need to be more proactive in guiding the whole process." – *Community Advisory*

Finding 1: Organizational Climate & Culture

Values- University vs. the Community

- Institutions were seen as valuing funding, resources, publications, and research projects based on funding guidelines.
- Community values emphasize community needs, priorities, health concerns and how the funding and research projects will benefit the community.

"I think that so much of this, when you talk about the privilege and you think about it in an institution, and you think, well, what does an *institution value*? If you really look at what it values, you look at what has received resources and what has received money.....I guess resources is the word—resources in terms of personnel and financial." -Leader

Finding 1: Organizational Climate & Culture

Power and Privilege

- Power and privilege creates a disconnect between the university and communities.
- Leadership was perceived as hierarchical and not interacting with communities.
- University maintaining control, power and ownership, rather than allowing the community to share the power.

"The university does not... well, it shares power until it begins to be uncomfortable. Then it's not willing to share power." -- Leader "...We need to put the power and titles aside & really deal with people as human beings....Second, because this is a small university or if it was a bigger university, there are certain players in the university who have power. They can exploit that power & everybody knows it." – Leader

Finding 2: Community Engagement & Relationship Building

Historical Mistrust

 Historical mistrust was named as a legacy of previous research harms. Lack of community benefit was recognized by both researchers and leaders, as the context that is still salient for current research efforts. Also expressed was the concern that many researchers were not aware of the culture of the communities they are working with.

"Many of our research leadership, they don't understand how long it takes to develop a community, to build trust, to meet with them, to truly form a bond with community. They want to go in and get their data and get out, or get their blood samples and get out. It's the problem what we've had forever with the lack of trust from communities."-Researcher

Finding 2: Community Engagement & Relationship Building

Commitment

 Lack of Commitment was seen as a challenge from researchers who were oriented towards building their careers rather than prioritizing work with communities. Most researchers see a challenge to commitment to communities, such as the time it takes to build partnerships.

> "You don't know what the intensions are of the researcher. Again, it goes back to that are you here for your tenure promotion, are you here to get more funding for your center, are you here to publish and be in that journal, or are you here because you are very concerned about this issue and you wanna make a difference? I think in terms of historically, that mistrust has been there." -*Researcher*

Finding 2: Community Engagement & Relationship Building

Community Involvement

Working with communities was perceived as a process of university, researchers, leadership, faculty needing to get to know the community they want to work with rather than seeing them as research project. The question is how to recognize the richness in communities with their culture, tradition, language, environment, and family and bring those into the research process.

"—but also sometimes we don't think as much about community harms in research. I think we often think about *a more biomedical model that focuses on individual harms in the conduct* or involvement in research, and potentially that is an area, I think, that needs—where there is dialogue and understanding, that we need to change that perspective, but that it's not acceptable to ensure the lack of harm to an individual, but yet harm the reputation or somehow stigmatize a community. Again, that's part of that historical legacy of working with tribes and other communities, certainly, not just tribal communities, but where there needs to be further attention." - *Researcher*

Finding 3: Policies

Funding & Resources

Resources need to support sustaining community engaged scholarship efforts. The work involved with community engaged scholarship is much more labor and resource intensive and so the funding mechanisms and cost categories that need to be in place go beyond your traditional forms of research.

Tenure and Promotion

Current tenure and promotion criteria need to align better and support the efforts of faculty researchers involved with community engaged scholarship/research. While scholarly products are important in meeting the academic goals of UNM, they are not always aligned to community needs and priorities.

Finding 3: Policies

Quote

"The barriers are the existing tenure and promotion guidelines. I think it makes it when you're doing this kind of work, it makes it more difficult to publish quickly because you're publishing with co-authors and— I'll give you an example, I have written two articles with community partners on different projects and it's been—both took a long time. Both took, I don't know, from beginning to end, maybe a year each because we did it in a collaborative way. It was really fascinating, and I loved doing it, but that's—but it's also a slower process. I think what defines success here is definitely a barrier." – *Researcher*

Discussion Points

- Culture and organizational climate within academic settings is critical for setting the tone on whether or how community-engaged and health disparities research is supported including "how" behaviors are incentivized through grant writing, tenure and promotion and advancement of staff and faculty as key leaders in the university.
- Often the values underlying this climate such as individualism or "investigator driven research" conflict with community values that promote collective values such as group driven research questions and collective ownership of data.



Linda Helton

Discussion Points - continued

- As the need for community engaged research increases to support interventions that will truly address what the communities want, there has to be more support for researchers interested in community engaged scholarship.
- Issues of time commitment, in building partnerships, in co-analyzing and co-publication with community members, surfaced over and over.
- Giving community engaged scholars the same value as basic science scholars was also another key concern impacting the need to change the tenure and promotion criteria.



Recommendations from study data

- Improve communications and trust through intercultural dialogue and conflict resolution skills development and undoing racism trainings (building allies)
- Prioritize engagement initiatives by place-based focused efforts
- Include CBPR and CeR as part of the IRB policies and practices

- Adopt and amend institutional policies on promotion and tenure by redefining scholarship to value community engaged research
- Revise current organizational structures for grants development to allow for increased flexibility for resource sharing and outreach activities with communities

Recommendations from presentation participants 2014 NMCARES/NMPHA Joint Conference on Health Disparities.

- Conduct a larger survey in communities; look at parallel demographics.
- Replicate study on Main Campus.
- Secure funding for follow-up study.
- University and community collaboration on educating funders on ways to best serve community priorities.

Recommendations from inter-department presentations

- Collaborate with other UNM departments doing similar research.
- Work with Office of Diversity, NMCARES, and NAACHW towards development of "joint report."
- Collaborate with Dr. Monica Kowal to expand study to main campus.
- Provide additional information on number of participants/interview questions, etc.
- Is work primarily academic involvement? What percentage was community involvement, participation?
- Conduct a separate pilot of community members.
- Have report reviewed by community members for bi-directional support. Take back to interviewees for review.
- Limited pilot: look for funding for larger study.

Recommendations from inter-department presentations - continued.

- Consider how to present findings to HSC leadership.
- Create interest group to draft policy recommendations
- Create think-tank group
- Collaborate on findings report for more weight.
- Create action steps: who is audience; who can move on actions steps. "If you were to do this, what would happen?"
- Present to NAACHW
- Disseminate and translate findings into recommendations for organizational "culture" change

Next Steps: Review and Dissemination

- ✓ NM CARES HD Center
- ✓ CSAC (preliminary key findings)
- ✓ HSC Office of Diversity
- Community Partners/Stakeholders (on-going)
- UNM HSC/UNM Leadership:
 - Office of Community Health (HEROS, NAACHW, Centers of Excellence (Hispanic, African American)
 - Office of Diversity & Equity
 - RWJF Center for Health Policy
 - ✓ Community Engagement Initiative/Carnegie Efforts
 - Center for Native American Health
 - Southwest Hispanic Research Institute
 - Vice Chancellor of Research



Questions & Answers

Community Engagement Core



New Mexico Center for Advancement of Research, Engagement and Science on Health Disparities