Participatory Research to Promote Shared Leadership Toward Maternal and Child Health and Emotional Wellbeing: Lessons Learned and Future Directions to Promote Health Equity.

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Acknowledgements

Conceptualizing the Problem

Increasingly large numbers of children are affected by childhood traumatic stress

By the time children in the U.S. turn 18:

- 62-68% of U.S. children are exposed to a potentially traumatic event (PTE)
    - Over 50% are exposed to two or more PTEs
    - 41% experience clinically relevant impairment
    - 12% meet criteria for Acute Stress Disorder
    - 16% meet criteria for Post Traumatic Stress Disorder

Maternal health and wellbeing impact risk and resilience for child health and wellbeing

Beginning in the perinatal maternal health and wellbeing impacts immediate and lifelong risk for negative health outcomes

Many mothers and children experience negative outcomes associated with the fundamental causes of racial discrimination and poverty

Maternal mental health impacts how children experience and process potentially traumatic events

Residing in a rural area increases the risk for experiencing inequities in health and wellbeing for mothers and children

Community based participatory research (CBPR)

GOALS

- Active partnerships
- Sustainability
- Generates rich knowledge
- Equitable progress

CHALLENGES

- Power and privilege
- Community consent
- The role of research in social change
- Community's ownership of the project

Brief Experiential Exercise

Things You Like Best About Yourself

1.

2.

3.

4.

5.

Things You Like Least About Yourself

1.

2.

3.

4.

5.

Robeson County, NC

- Rural

- Median Income: $32,407

- Majority-minority community

- Health inequities:
  - 15% of mothers experience postpartum depression
  - Infant mortality rate = 14 per 1,000 live births
  - Highest reported death rate for infants 28 days to 1 year in NC
  - 83% of mothers receive Medicaid
  - 64% receive WIC
  - 68% are unmarried
  - 18% report smoking during pregnancy
  - American Indian Mother fare worse than other racial/ethnic groups

Robeson County, NC

Mothers Improving Pregnancy and Postpartum Health Outcomes Through stOry Sharing (MI-PHOTOS)

The Community Advisory Board

Objective

- MI-PHOTOS' aim was to listen to mothers' stories and develop an understanding of their challenges and strengths related to having and raising infants and toddlers in their community. MI-PHOTOS focused on building foundational knowledge to advance sustainable social change and health equity for rural mothers and children

PhotoVoice

A participatory approach in which academic researchers and community members work together to build a deep and genuine understanding of the community's experience through photography.

PHOTOVOICE

1. Uses photography to engage community members as co-investigators
2. Juxtapose realities to construct new knowledge about how the community issue is part of a system of power and authority
3. Reach influential advocates with this new knowledge to generate action steps to effect change

Photovoice Session Prompts

1. What are the daily challenges of being pregnant and a mother in this community?

2. Where do mothers get stress and support in this community?

3. What do mothers in this community need?

4. What is the most important issue for you since you learned you were going to have a child?

5. What can we do to help mothers in this community?

RESEARCH

S – What do you _see_ here?
H – What is really _happening_ here?
O – How does this relate to _our_ lives?
W – _Why_ does this concern, situation or strength exist?

NEW KNOWLEDGE

DISSEMINATION

E – How can we become _empowered_ through our new understanding?
D – What can we _do_?

CHANGE

Liebenberg, L. (2018). Thinking Critically About Photovoice: Achieving Empowerment and Social Change. _International Journal of Qualitative Methods_.

Themes

- "A mom community": MI-PHOTOS as a Social Support Group

- "We can't hardly make it": Community & Family Dynamics

- "They Do Everything": Professional Support Programs

"A mom community": MI-PHOTOS as a Social Support Group
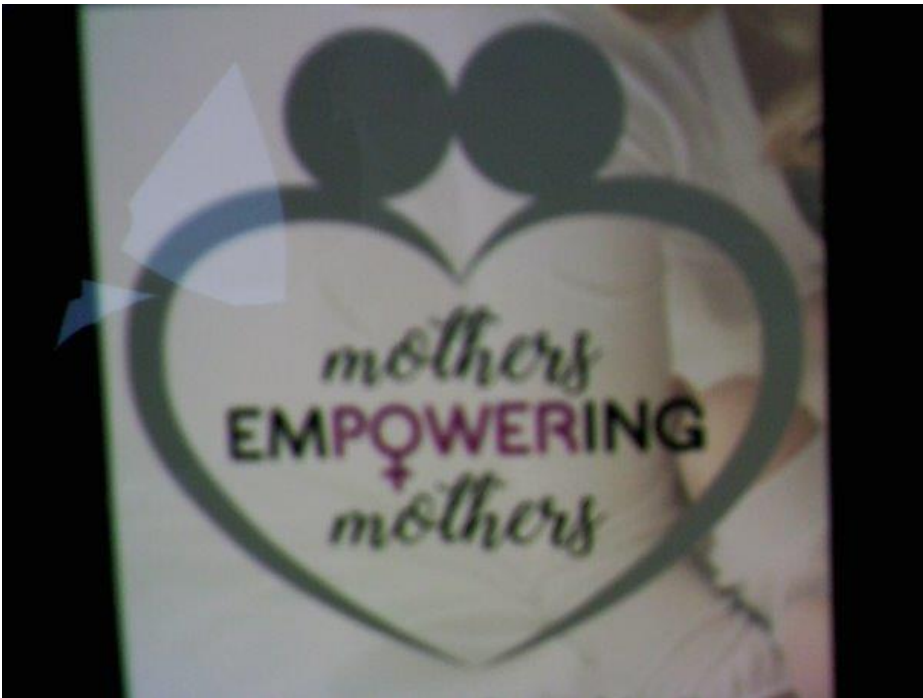
"I mean something like...where we can get together and express [how] we feel so somebody else can hear us, so somebody here knows how we feel...maybe somebody needs to take a stance so we can actually put something into action here."

"A mom community":
MI-PHOTOS as a Social Support Group

"These girls are working, they're going to school, while we – some of us have been dealt a bad hand...I want people to be aware that...our area is all types of people here, as well as we were a diverse group of moms...at the end of the day, we're all raisin' our children...with the best means that we possibly have... I think that's important for people to recognize and then see - 'but these were the challenges they were faced with, we still came out on top."

"We can't hardly make it": Community and Family Dynamics

"They don't have nothing around here for our kids to do"

"Kids who are going through problems, like a recreation center…like it would be nice to have kids who are going through trouble…something to stabilize them."

"We can't hardly make it": Community and Family Dynamics

"We all know how it is to be a struggling mom, you know, the dryer breaks down, you have to use coat hangers, constantly have to clean up."

"We can't hardly make it": Community and Family Dynamics

"My step-father and my mother [are] a big huge support in my life... My mother...took me back in her wing because she know, she been through it before, my step-father, he has been such a huge support, helping me take care of [my daughter]."

"[My daughter's father] was the only person that I really depended on and now I have to do everything by myself."

"They Do Everything": Professional Support Programs

"Yes, this is…my support. I mean, I've still got my partner, but these people basically are my support…I can talk to them about my husband, but you can't talk to your husband about your husband…my [nurse] has…helped me through so much, with school, with being a first-time mom…it's difficult…trying to find support here."

Nurse-Family Partnership
Helping First-Time Parents Succeed®

HEALTHY START ROBESON

"They Do Everything": Professional Support Programs

"After that support's gone, then what? What are you supposed to do?"

"Why isn't there one place to go where [people can] share all this information? Like why do we have to dig, dig, dig, dig?"

"They Do Everything": Professional Support Programs

"I like my nurse and I talk to her about stuff, but I know…where I can stop, like…if I feel depressed, because they ask you, like, are you depressed?…I know you can't talk to them about it…I'm not 'bout to tell you this and then you go from here and then have to go through all this other mess because they're gone say, 'well you might not be good for your child if you're depressed.'"

Takeaways

- Multi-faceted social support

- Mental health stigmatization

- Bridging peer, professional, and confidential support

Lessons Learned Initiating Community Based Participatory Research in Partnership with a Diverse, Rural Community

Exploratory, Qualitative Case Study

Autoethnography: Initiating CBPR
- Benefits
- Challenges
- Paradoxes

Triangulation
- Data
- Researchers

Member checking

Self-reflection
- Writing
- Discussion

Content analysis of notes and minutes
- Project meetings
- Community stakeholder meetings
- Gatekeeper meetings
- Community Advisory Board Meetings
- Community cultural events

Themes

- Rejecting the Disparities Lens – focuses on the harm of approaching and defining communities based on disparities
- "One Step Forward, Two Steps Back" – related to the challenges of pacing and engaging the community
- "Nothing about us without us" - focused on hearing messages coming from the community
- "From vs. Of vs. In the community" - focused on the challenges of identifying the community, stakeholders, and the identified population;
- "Identity Matters" - focused on cultural humility, navigating racial/ethnic differences, and working from an "outsider" versus "insider" perspective;
- "Building Trust on the Edges" - related to the process of building the basic knowledge and presence in the community required to move forward with CBPR.

"Building Trust on the Edges": The Harm of Approaching Communities with a Disparities Lens

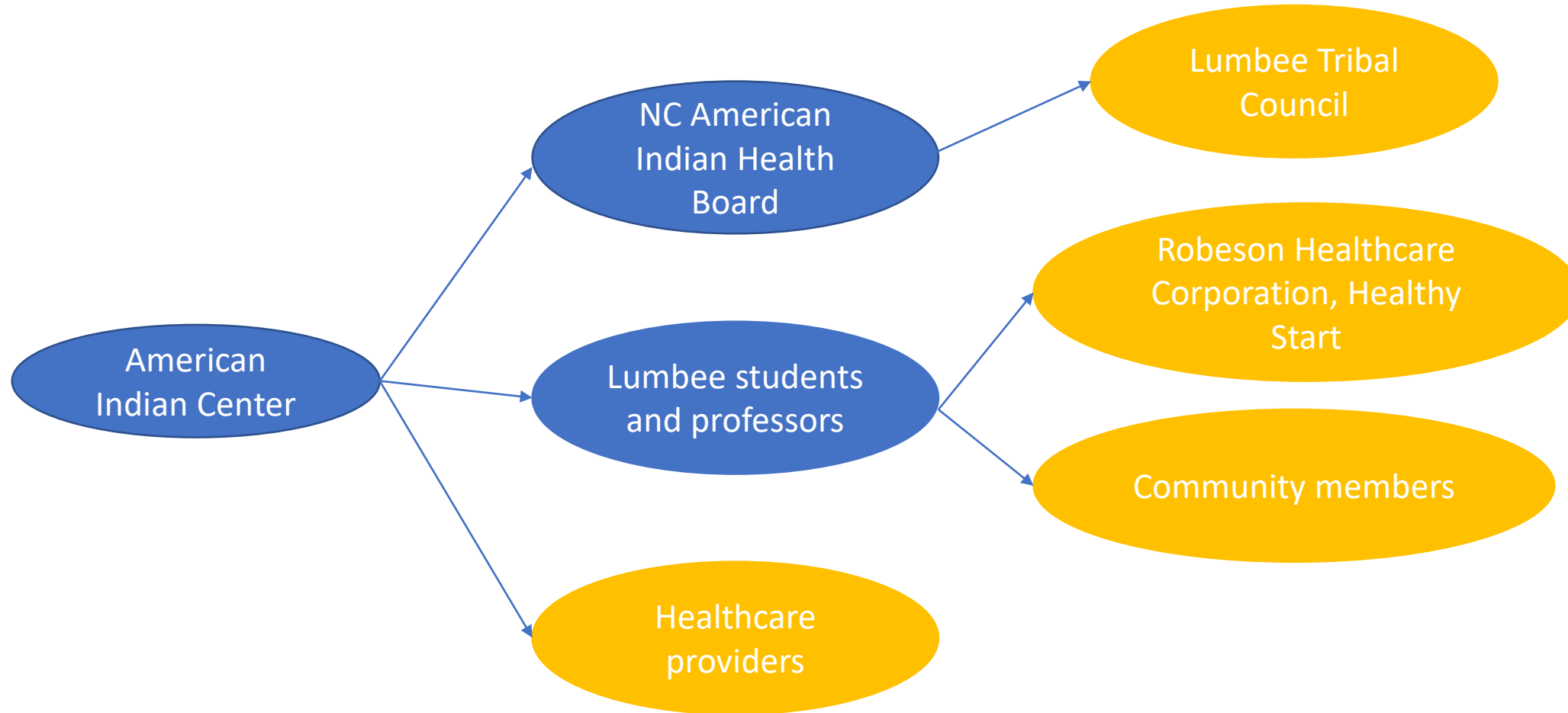Understanding Perinatal Health Experiences Among **Native American Indian Mothers** in rural NC

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Understanding Perinatal Health Experiences Among **Mothers** in rural NC

Community – University History

"One step forward, two steps back"

- Pacing mismatch

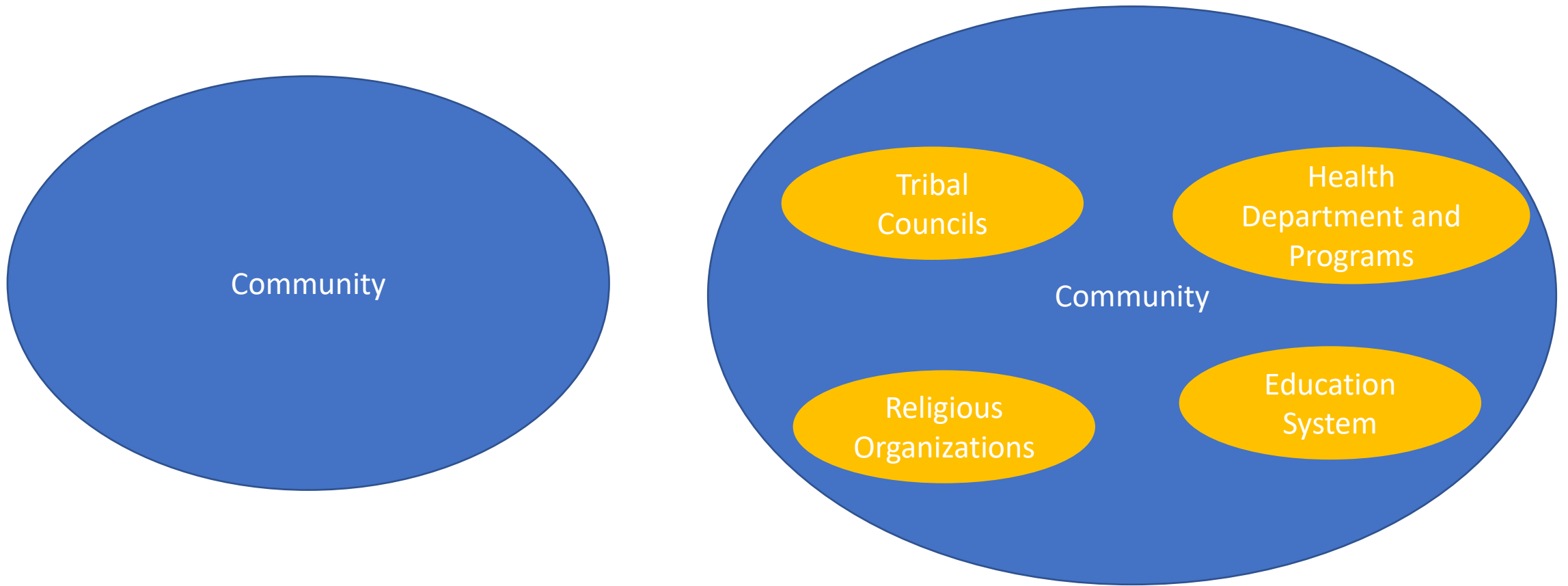- Doctoral/Graduate Students

- Deadlines, funding, and momentum

"From" Versus "Of" Versus "In" the Community

Nothing About Us **Without** Us is For Us

- Incorporation of the community

- Benefits to the community

Identity Matters – Power Dynamics

Facilitating Community Engagement

- Examine existing relationship with the community

- Identify who to work with
  - Key Informants
  - Cultural Insiders

- Develop a strategy

- Be flexible

- Be patient

Discussion and Recommendations

- Early partnership and engagement with community members

- Awareness and transparency of researchers' positionalities

- Co-creating research topics and questions

- Integrating a CBPR approach into research methods

Current Projects

Community Voices

- Mixed Methods Study of Mothers and Service Providers

- Individual surveys, qualitative interviews, and focus groups with mothers who are pregnant or mothering infants and toddlers and the providers who serve them

- Inform the co-creation (with the community) of an intervention to meet unfilled needs for rural pregnant mothers and mothers of young children grounded in the strengths and needs of the community

Whole Robeson Together

Whole Robeson Together

Goal 1: Develop study methods and a support group intervention to increase maternal health and emotional wellbeing in pregnant mothers and mothers of infants and toddlers in Robeson County that is culturally acceptable and feasible.

Goal 2: Test the feasibility of the support group methods including delivering the intervention to pregnant mothers and mothers of young children, recruiting and retaining mothers, and measuring changes in maternal health and wellbeing, to ensure the support group is acceptable and addresses the needs of mothers in the community.

Goal 3: Develop an implementation and sustainability plan for the intervention.

Thank You

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