

Shiprock, New Mexico



Building Partnerships for Health Disparity Research

November 15th, 2011 & February 4, 2013



March 29, 2012

Dear Colleagues,

Thank you for contributing to an exciting dialogue on "Building Community Research Partnership for Reducing Health Disparities" on Tuesday, November 15, 2011. The University of New Mexico, NM CARES Health Disparities Center's Community Engagement Core appreciates your time and contributions to making this a successful experience.

We hope you will join us in our efforts to seek out new and strengthen existing research relationships to conduct meaningful and applied research to promote health and well being for all New Mexicans. Thus, as a participant in the November dialogue, we are inviting you to become part of a community of researchers and to formally apply to be an Intercultural Health Disparity Scholar. The scholars are selected based on their commitment to reducing health disparities, promoting cross-cultural relationships, and developing intervention strategies that bridge community-based with science-based knowledge. Some of the benefits of being an Intercultural Health Disparity Scholar include:

- Support to attend the National Health Disparity 2012 Joint Conference with NMPHA held at the Crowne Plaza Hotel in Albuquerque, New Mexico on April 26-28, 2012;
- Support to attend the National Health Disparity 2013 Joint Conference with NMPHA to be held at the Hyatt Albuquerque Hotel in Albuquerque, New Mexico on April 18-19, 2013;
- Eligibility and support to participate in a 2-day long training in Community-Based Participatory Research in your community; and
- The opportunity for you and your colleagues to receive technical assistance and resources on topics (i.e. grant-writing for the National Institutes of Health, best practices and culturally congruent interventions for health promotion, translation research into policies) and to develop or adopt practical tools for putting community participatory research principles into practice and policy.

We look forward to following-up with you regarding key recommendations you made which you will find summarized in the attached minutes from the meeting. Additionally, we will continue to sponsor training and networking opportunities as part of our NM CARES Health Disparity Center.

Again, thank you for your participation in the training and look forward to working with you.

Sincerely,

Lisa Cacari Stone
Nina Wallerstein
Clarence Hogue Jr.
Lucinda Cowboy
Alison McGough-Madueno

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Dialogue As A Tool

Information was presented by Dr. Lisa Cacari-Stone, Director of Community Engagement Core/NM CARES Health Disparities Center, on why dialogue is important for doing research with communities. She mentioned the center's goals in building community-academic partnerships for engaging in health disparity research based on intercultural leadership, trust, guiding principles, and mutual terms and conditions of agreements.

Research in communities has come a long way from the abuses inflicted mostly on America's minority populations. Practices by researchers are now studied, reviewed and approved by regulating bodies such as an **institutional review boards (IRB)**, also known as an **independent ethics committee** or **ethical review board**. These committees have been formally designated to approve, monitor, and review biomedical and behavioral (social science) research involving humans.

A brief history of research in the United States was presented where communities and ethnicities have been abused, misinformed and misled in their role and participation in research.

Before 1974 and the creation of IRB committees most research was conducted with little thought to the people involved and used minorities as guinea pigs.

Examples of research abuse among communities:

- 1932-1972 Tuskegee Syphilis Experiment
- 1890-1930 immigration policies

Post 1974:

- Parachuted onto communities by pulling data and not sharing results with communities
- No investment back to the communities
- Research for the sake of research or research objectives that don't match the needs of communities

- 1990-1992—Havasupai Tribe \$50 M lawsuit against Arizona State University for misuse of blood samples

UNM's vision:

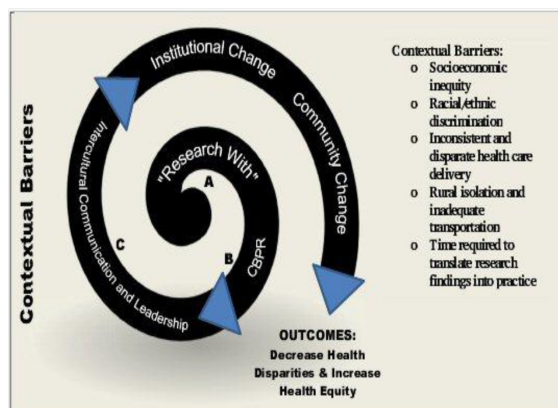
- Community-Based Participatory Research (CBPR) model working with communities to inform, provide solutions for family wellness, culture and language preservation/restoration.
- Increase access to care
- Training of new researchers from racial ethnic & other under-represented communities
- The University of New Mexico Health Science Center (UNM HSC) is growing and is recognized as the national leader in research with communities.
- UNM HSC continues to work on collaboration efforts externally with Community Organization and internally with Faculty and students.



Intercultural Community-Based Participatory Research Model

Guiding Framework

The guiding framework and model below describes how the community and institutional changes can happen while overcoming barriers (i.e. discrimination, socio-economic inequity) when the research relationship and processes are built upon principles of Intercultural Partnership and Community-Based Participatory Research. This framework aims to increase capacities of institutions and communities to work together and conduct mutually beneficial research that Reduces Health Disparities and Increases Health Equity.



A - Research with Communities

In order to move towards institutional and community change, dialogues between academic and community members are needed. The focus of the on-going dialogues should be on “how” we shift our thinking about doing community research from using an “on/in” approach to a “with” modality. The figure above illustrates a continuum of research that occurs between universities and communities from “doing research-on,” “to doing research-in,” with final movement towards “doing research-with.”



B - Community-Based Participatory Research (CBPR)

CBPR is described as supporting “collaborative, equitable partnerships in all phases of the research.” This is achieved through a co-learning and capacity building process among all partners. All research findings and knowledge gained is shared with all partners. CBPR involves a long-term process and commitment from both Researchers and Community. Source: Israel et al. 2003, pp. 56-58.

C - Intercultural Communication and Leadership

- Include cultural diversity at the center of how things are conceptualized and implemented across research projects.
- Expand the definition of community and research partners to Intercultural Allies who mutually advocate for each other to guarantee community voice and perspective in the outcomes relating to the elimination of health disparities.
- Intercultural Allies are trusted individuals.
- Be aware of and help equalize power differentials between community experts and the research institution.
- Both partners step into a mediator role “for the community but not against the institution.”
- Engage in intercultural communication

ANTICIPATED OUTCOMES

This framework aims to increase capacities of institutions and communities to work together and conduct mutually beneficial research that **Reduces Health Disparities** and **Increases Health Equity in New Mexico.**

Group Expectations: Why are you here today?

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Learning Objectives: Introduce the concept of Intercultural communication and skill building.

Expectations:

The group compiled a list of expectations for the training as well as a number of expected discussion topics listed below.

- Leadership Training
- Gain Communication Skills
- Value of Partnership
- Making Collaboration Meaningful
- Study Data Translation



Guest Speaker for RCFW's monthly event

Building partnerships through effective Communication


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Discussion of Positive and Negative Research Experience- Deep Listening Activity

Two questions were posed to the group for discussion

1. *In your experience what have been the barriers to doing research in your community?*
2. *What are facilitators/ideas for improving research to reduce Health Disparities?*

The participants were divided into smaller working groups for discussion. Each was assigned to answer both questions. After fifteen minutes the groups reconvened for debriefing. The following table lists the comments from the group at-large. The exercise in deep-listening allowed participants to be heard both as a group and as individuals. Positive and negative experiences faced by participants were validated by others in the group setting.

Barriers	Facilitators
<ul style="list-style-type: none">● Not Enough Time● Historical Lack of Trust● Provider- Rapid Turnover in Community, no continuity● Funding Availability● Communication- Language Barriers (Not Utilizing English & Navajo)● Limited/Delayed Feedback to Community● Researchers don't return information to community● Difficult IRB Approval● Costs Associated with Research● Lack of Family Involvement- Breakdown of Communication w/in families● Lack of Support in work/community setting from peers, co-workers, supervisors● Methodological Issues- Length, Incentives● Use of Heavily Academic	<ul style="list-style-type: none">● Community Friendly Language☑ Use Stories to Connect● Educate Community on Research Process and how it is part of our everyday lives● Tie in Cultural Values● Promotion of Community Strengths● Identification of How Research is Already Occurring in the Community● Connection to Community Issues● Involvement in Community Beyond Research Activities● Identify Community Relevant Issues that Lead to Disparity 

Principles & Approaches To Research Partnerships

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Community Based Participatory Research: Identifying practices and actions that can promote effective collaboration around research.

The participants learned the process of Community Based Participatory Research known as CBPR. Presented by Nina Wallerstein and Clarence Hogue, the group reviewed the principles of CBPR.

Key Principles of CBPR

1. Acknowledges community as a unit of identity.
2. Builds on strengths and resources within the community.
3. Facilitates a collaborative, equitable partnership in all phases of research, involving an empowering and power-sharing process that attends to social inequalities.
4. Fosters co-learning and capacity building among all partners.
5. Integrates and achieves a balance between knowledge generation and intervention for the mutual benefit of all partners.
6. Focuses the local relevance of public health problems and ecological perspectives on multiple determinants of health.
7. Involves systems development using a cyclical and iterative process.
8. Disseminates results to all partners and involves them in the wider dissemination of results.
9. Involves a long-term process and commitment to sustainability.

Israel, B. A., Eng, E., Schulz, A. J., & Parker, E. A. (2005). Introduction to methods in community-based participatory research for health. In B. A. Israel, E. Eng, A. J. Schulz & E. A. Parker (Eds.), *Methods in community-based participatory research for health* (pp. 3-26). San Francisco, CA: Jossey-Bass.

Guiding Principles for Decolonizing and Indigenizing Research

1. Reflection

True partnerships begin with reflection upon the privileged statuses from which most partners operate and the emotionally difficult task of acknowledging the pain of Native communities and developing empathy.

2. Respect

Research partners must value and prioritize indigenous epistemologies, knowledge, cultural protocols, and healing practices.

3. Relevance

The community should contribute to defining research problems and strategies, which should respond to their own self-identified needs and concerns.

4. Resilience

All aspects of the research must acknowledge the community's strengths and resilience.

5. Reciprocity

The partnership should be collaborative and mutually respectful with knowledge exchanged in both directions.

6. Responsibility

Research partners are obliged to enhance community capacity to conduct Indigenous and Western research, disseminate research findings in culturally meaningful ways, and anticipate the implications.

7. Retraditionalization

Traditional knowledge and methods must be actively integrated into the formulation of the research questions and the process of scientific inquiry.

8. Revolution

Research partners and community members must actively seek to decolonize and indigenize the research process to transform science as well as themselves, their communities, and the larger society for the betterment of all.

Walters, K.L., Stately, A., Evans-Campbell, T., Simoni, J.M., Duran, B., et al., (2009). "Indigenist" collaborative research efforts in Native American communities. In A. R. n (Ed.), The field research survival guide. (pp. 3-26). New York, NY: Oxford University Press.



Discussion of Core Values

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Learning Objectives: Developing a Community Voice:

Identify core values and principles present in partnerships; understand how these shape values , shape the research process.

The group was divided into smaller groups for discussion. The participants were assigned to answer the following two questions.

1. What are some of your CORE VALUES that would shape how you approach working in research partnerships?
2. What are you most concerned about?

The following table consists of six Core Values identified by the participants along with components specific to each value.

Value	Components
Respect	<ul style="list-style-type: none"> ● Establish Safe Environment ● Cultural Sensitivity (Local Facilitators Aid in Building Relationship) ● Agree to Disagree (Respect Differences) ● Culture/Traditions <ul style="list-style-type: none"> - Flexibility - Humility - Bidirectional Support
Listening	<ul style="list-style-type: none"> ● Equality- Believing each person has contribution
Ownership	<ul style="list-style-type: none"> ● Mutual decisions around Data/Information Use and Next Steps/Application of Research ● Create Mutual Goal/Shared Vision ● Shared Resources (Researcher < -- > Community) ● Equitable Commitment ● Time Frame, Follow Through, Follow Up- Understanding of expectations in each activity/area
Communication Compassion Trust	<ul style="list-style-type: none"> ● Concise ● Consistent ● Clear ● Translate to community friendly or common Verbage ● Humanness; Validation and Accountability ● Humility, Co-Learning Patience; Appreciation of ● Bi-directional support; openness/honesty

Discussion of Core Values

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Learning Objectives: Developing a Community Voice

(continued)

The following table consist of concerns about partnerships identified by the participants.

Concerns		
Buy In	<ul style="list-style-type: none">•	Is research worth it for community?
Orientation of Research Group	<ul style="list-style-type: none">•	Action towards outcomes
	<ul style="list-style-type: none">•	Productivity
	<ul style="list-style-type: none">•	Setting of Priorities
Cost	<ul style="list-style-type: none">•	Financial
	<ul style="list-style-type: none">•	Human Resources



Guest speaker for RCFW's monthly event

Learning Objectives: Developing a Community Voice

(continued)

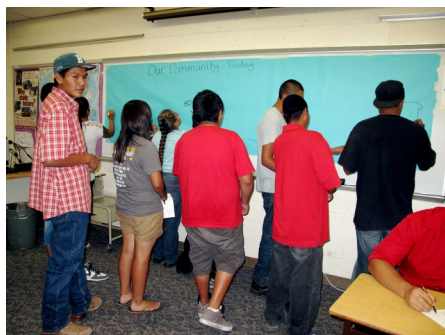
As part of the debriefing discussion more questions around working with researchers were raised by the participants. The following questions were addressed:

A. Using core values and principles discussed, what agreements need to be in place for a healthy research relationship to form?

- **Honorarium**- Community appropriate. (Ex: Gas Cards)
- **Formal Resolution**- Written agreements that provide narratives of community issues, concerns and expected outcomes, provides evidence of community support. Formalizes collaborative efforts.
- **Leadership**- Establish bi-directionality between university and community.
- Use of **Intercultural Model**- Learn from one another, Listen, Accept one another, be willing to make mistakes and to continue to move forward.
- **Timeline**- Mutual consensus and documentation of proposed timelines and responsibilities of each involved party
- **Mentorship/Incorporation of Navajo Students**- Utilize Native students in research process in university and community setting
- Utilization of **Peer Educators** at all Stages of Research Process

B. What are the terms and Conditions that need to be established around research ?

- **Student Support**- Creation of support network and groups for Native students, empowerment/ reminders to “speak up”
- **Leadership**- Create accountability within the University to build faculty of color
- **Trust**- Practical, Proxy Forms and Humility in interactions
- **Commitment**- Presence through entire process and in all activities



RCFW youth interaction

Identifying community needs

After an intensive day long seminar participants were ready for next steps. Below are some concrete steps for communities, researchers and institutions to reflect and act upon:

A. Research Area Ideas:

Family Unity

Suicide

Parenting Skills

B. Community Need Areas:

Evaluation of Current Programs

Data Analysis/Translation

Data Collection



C. Activities to support efforts to address issues and needs in community

i. Presentation on health disparities at community conferences

December

June- Youth Conference

ii. Matching students to community project for Data Analysis Co-learning Practicum

Present meaningful data back to community

iii. Work with Navajo Area Suicide Taskforce (Chinle) to track and evaluate program impact

iv. Explore funding for current/future projects (Ex: NARCH VII)

v. Family Listening Project- Bring to Shiprock

vi. IHD Scholar Team

Recruitment

(Pyn, Miranda, Karen and Evangeline) interested in participating

Connect to Current Project?

Leadership

Allocate resources to bring team to April Conference (NM CARES HD)

vii. Connect to ongoing work

NM CARES HD- Linking resource to connect community to institution

Add research capacity to current projects in community

Plus/Delta allowed the participants to voice any areas of concerns or give comment on what worked well during the convening and what improvements could be put in place for further gatherings. By encouraging participants to reflect on “what worked well” and “what could work better” while the experiences are fresh in their minds, this activity served as feedback for the groups future activities and development.

+	Δ
Stories help us make the connections	Clearer about what training is going to cover in advertising
Focus on teaching more about the role of research & partnering with community members	Increase tribal leadership presence at future trainings in this area
Timeline of HD research	Use more community language, utilize Navajo and Tribal focused visuals in presentations
Offered tools for strategic activity planning	
Expertise	
Incorporation of academics and community members *Clarence and Lucinda were effective facilitators, connected to community	
Visual presentations, color, set up	



As part of the evaluation, participants were given a Pre/Post test. Results are shown in the column to the right. Five questions were asked in the evaluation. Following are answers provided that reflect the groups' responses.

A. Please briefly describe your experience with community-engaged (or partnered or participatory) research:

Participants reported having a role in research in the following capacities: Tool Translation, Recruitment, Survey, Data Gathering, Community Evaluation, Networking, Program Implementation, Collaborating to address needs w/grants.

Two participants reported never having a formal role in research, with one also stating that they realized they may have had an informal role in the process after today's training

B. Did today's training meet your expectations? Why or why not?

The majority of participants reported that the training did meet expectations and also reported gaining a more in depth perspective of one or more subjects covered throughout the day.

One participant reported that the training did not meet their expectations but was better than they thought it was going to be and also stated that the day had showed them the need for strategic planning on the part of the community when engaging in research.

C. How could today's training support you in doing community-engaged (or partnered or participatory) research in your community?

Participants reported that the training could be used in their communities to generate a new community perspective of research and help their communities to realize the relevance of research. The training was also seen as a useful tool for gaining support and training their communities on how to identify research ideas and how to form more equitable research partnerships.

Pre/Post Survey Results

Participants reported an increased level of knowledge and skills around all objectives:

1. Identify components of an intercultural CBPR model that values doing "with" communities

PRE=1.88

POST=4

2. Describe how a space that promotes safety, bonding, and bi-directional intercultural learning can be established when working in a group

PRE= 2.5

POST=4.5

3. Understand the importance of listening to bi-directional partnership

PRE=2.25

POST=4.88

4. Identify the guiding principles and core values of Community Based Participatory Research (CBPR)

PRE=1.75

POST=4.375

D. Were there any discussion topics that needed more discussion time?

- Cultural Competency and Intercultural Collaboration
- Disseminating Information- How to reach community leaders
- Introducing HD Research and CBPR
- Identifying group priorities and needs to focus on when doing research
- Research Conditions and Agreements

E. What information could have been provided to aide your understanding of the presented topics?

- Clearer initial mission/goals for the training
- More information on the IHD Scholar Teams
- More Examples of disparities to get a picture of the meaning
- More stories to bring the lessons to life and connect them to nature

F. Other Comments:

- Enjoyed food/snacks
- Great Facilitation! Kept the day going
- Good setup, created opportunity for real dialogue
- Good use of stories



Moving Forward With Building Community Capacity for Health Disparities Research

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Restoring and Celebrating Family Wellness (RCFW) Committee

Meeting Summary: February 4, 2013

This summary is a continuation of the original dialogue held on November 11, 2011 and that identifies the key areas the academic - community partnership can focus on and where action plans can be further developed.

The University of New Mexico NM CARES Health Disparity Center and Center for Participatory Research attended the Restoring and Celebrating Family Wellness committee meeting on Monday, February 4, 2013 to discuss and identify ways of building partnership.

RESTORING AND CELEBRATING FAMILY WELLNESS COMMITTEE:

The Restoring and Celebrating Family Wellness (RCFW) committee consist of many different organizations, programs, community members and youth. They meet on a monthly basis and host monthly workshops/events in the community and host two annual conferences. The committee's initiative is to strengthen families and nurture positive changes in their communities.



RCFW Committee:

(programs/organizations represented)

Northern Navajo Chapters & Community Members/Volunteers

Office of Youth Development/
Shiprock Boys & Girls Club

Community Health Representatives/
Outreach

Department of Behavioral Health
Services

Dine' Ba'Hozho' Coalition

Social Services Family Violence
Prevention

Shiprock Health Promotion/Disease
Prevention

San Juan County Partnership

Teen Life Center

Department of Workforce
Development

The Healing Circle Drop-In Center

Shiprock Branch Library

Shiprock Law Enforcement

Family Roots & Wings

Navajo Health Education/HIV
Prevention

Shiprock Navajo Peacemaking

Public Health Nursing

Northern Dine' Youth Committee

Farmington Indian Center

Moving Forward With Building Community Capacity for Health Disparities Research *continued*

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A. Follow-up on New ways of working together: Bridging Resources

NARCH VII Grant Proposal

New ways of working together by identifying community needs was discussed at the initial dialogue held in November 2011. In response to the interest expressed by the RCFW committee members on Family Unity and Wellness, the NM CARES Community Engagement Core in collaboration with the Center for Participatory Research worked with the Healthy Native Communities Fellowship staff to submit the NARCH VII grant proposal (Native American Research Centers for Health). If funded, the Family Listening Project will be implemented in Shiprock. The Family Listening Project is a Community-Based Participatory Research approach on working with families integrating culture and tradition.



Shiprock, NM

Discussion on Family Listening Project

The coalition members in attendance expressed the busy schedules they have in implementing the Family Listening Project and the possibility of seeking other organizations that are a part of Restoring & Celebrating Family Wellness that might have time and interest (perhaps the Sisters in Circle, the Healing Circle Drop-In Center, or others). There is a slight chance that the NARCH VII might be considered for Shiprock and can be used as a pilot study.

Moving Forward With Building Community Capacity for Health Disparities Research *continued*

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A. Follow-up on New ways of working together: Bridging Resources...continued

Funding sources at University of New Mexico

Other funding sources to consider if the Family Listening Project does not get funded by NARCH VII, in which the project will need to be modified and adapted based on funding.

- Clinical & Translational Science (CTSC) Pilot Grant - \$20,000- \$25,000
- Center on Alcoholism, Substance Abuse, and Addictions (CASAA) - \$20,000-\$25,000

Action Item:

Community Engagement Core in collaboration with Center for Participatory Research will follow-up with the coalition members to see if other committee members might be interested in the Family Listening Project.



B. Next Steps of Building Partnership for Health Disparity Research

ENGAGING

The Community Engagement Core is interested in building partnership by identifying a cohort of Intercultural Health Disparity Scholars to become partners in the creation, use, and dissemination of knowledge and enhancement of research to reduce health disparities.

Current organizations that have been identified include:

- Shiprock Health Promotion
- San Juan County Partnership
- Healthy Native Communities Partnership
- Sisters in Circle
- Shiprock Community Health Representative/Outreach

Other organizations/partnerships to consider that are also part of the RCFW committee include:

- Together Growing Our Dreams – Community Wellness
- Healing Circle Drop-In Center
- Youth Committee
- Dine’ Community Advocacy Alliance
- NNMC Parenting Class
- Family Roots and Wings
- Healthy Native Communities Fellowship
- Dine’ Bahocho Coalition



RCFW monthly event

Moving Forward With Building Community Capacity for Health Disparities Research *continued*

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B. Next Steps of Building Partnership for Health Disparity Research.....continued

BUILDING CAPACITY

The Community Engagement Core and the RCFW coalition members discussed ways of identifying community needs through training/education and research capacity building. Ideas on specific training/education and technical assistance needs were discussed.

Community Training/Education needs:

- Community-Based Participatory Research
- Historical Trauma –to include Dr. Larry Emerson
- Building Infrastructure for Grant Development and Management (include Grant Writing as needed)
- Health Disparity Research
- Qualitative Data Analysis (to align with Native American tradition of storytelling)
- Basic computer skills

Community Technical Assistance needs:

- Evaluation
Data has been collected for the past six years from the monthly workshops and conferences provided by the RCFW coalition. The coalition members expressed their interest in having NM CARES Health Disparity Center work with them on understanding the benefits of doing evaluation and the different ways to evaluate activities and programs. The following data has been collected:

- ◇ Sign-in sheets, registration forms
- ◇ Surveys
- ◇ Evaluation forms
- ◇ Workshop evaluation (plus, delta)
- ◇ Monthly workshop discussions on flip charts
- ◇ Case study produced by the Healthy Native Community Partnership

- Data usage
Coalition members expressed basic technical assistance needs on using excel for data collection and tracking. Also, ways of understanding and using research data.

Moving Forward With Building Community Capacity for Health Disparities Research *continued*

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PARTNERSHIP BUILDING

RCFW committee requested the NM CARES Health Disparity Center to provide presentations at the Summer Youth Conference to be held on June 25 & 26, 2013 in Shiprock. Ideas on presentations include:

- Health Disparities Research—What are “Health Disparities”, What is “Research”, link to educational and career paths in public health, research, etc.
- Qualitative Data Analysis- using the RCFW case study as an example through storytelling

C. NEXT STEPS

TIMELINE

Delivering community training/education and technical assistance request:

- March – April 2013 Technical assistance dialogue on evaluation of RCFW data
- ⇒ RCFW (Karen & Carmelita) & NM CARES Health Disparities Center: Research Core and Community Engagement Core will meet April 19, 2013
- April 17-19, 2013 NMPHA & NM CARES Health Disparities Center Conference
- ⇒ RCFW submitted an abstract and will be presenting on April 19, 2013
- May-June 2013 Training: Health Disparities Research and Qualitative Data Analysis
- June 25 & 26, 2013 Summer Youth Conference
- July – August 2013 Training: Community-Based Participatory Research



Guest speaker for RCFW's monthly event