

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

Community and Scientific Advisory Council Bi-annual Meeting
November 5, 2010, 12:30 to 4:30 P.M.
Best Western Rio Grande Inn, 1015 Rio Grande Blvd. NW
Albuquerque, NM 87104
Tel. (505) 843-9500

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EXECUTIVE SUMMARY

On November 5, 2010 the New Mexico Center for Advancement of Research, Engagement & Science on Health Disparities (NM CARES HD) convened the first bi-annual meeting of the Community and Scientific Advisory Council (CSAC) at the Best Western Rio Grande Inn in Albuquerque, New Mexico. The purpose of the meeting was to welcome the sixteen members of the CSAC and key partners from the NM CARES HD and to achieve the following objectives:

- Introduce the CSAC with NM CARES HD's vision, values, goals and affiliated partners.
- Discuss and identify challenges and opportunities for building mutually beneficial partnerships with community groups to develop, implement, and sustain effective strategies to eliminate health disparities among Native American, Hispanic/Latino and other marginalized communities in New Mexico.
- Review and discuss the CSAC's leadership and advisory roles to the NM CARES HD.

Following this initial meeting, the role of the CSAC is to meet twice a year with the NM CARES HD (the Center) leadership in order to provide on-going guidance on the Center's operations, work of the cores and research projects and scope of work for strengthening community engaged research for reducing health disparities.

Greetings and opening remarks were delivered by Rob Williams, MD, MPH, and Lisa Cacari Stone, PhD. The general message shared by Dr. Williams was one of optimism and encouragement to utilize the CSAC as a venue to voice community concerns and provide guidance on the development of the NM CARES HD. Dr. Cacari Stone's opening questions to the group was 1)"What is the change we are looking for? 2) How can we move from a deficits framework of racial/ethnic disparities to one that focuses on assets and life opportunities for better health? And 3) Can we create this change by working together for the common good?

Next, Richard S. Larson, MD, PhD provided a brief overview of the health disparities research efforts being undertaken by the University of New Mexico Health Sciences Center (UNM HSC). Dr. Larson highlighted the work of the UNM Clinical and Translational Science Center (CTSC) and other initiatives aimed at matching community needs through intervention planning and implementation. He also highlighted the growing network for Community Based Participatory Research (CBPR) at UNM and the current efforts to increase the institution's capacity for community-based solutions for reducing health disparities in New Mexico (see Appendix F).

Next, Dr. Cacari Stone, and Dr. Wallerstein, introduced the purpose of the NM CARES HD and outlined the components and cores of the P20 grant. The presentation focused on New Mexico's growing health disparities and how the NM CARES HD's goal is to be a vehicle for change for shifting from conducting research "on communities" to a modality of conducting research "with communities." Conducting health disparities research "with" communities is a more promising approach for eliminating health disparities and promoting opportunities for meaningful community participation through careful listening and translation of research into results-based programs and policy interventions. This presentation also provided an overview of the basic principles of CBPR intercultural communication and conflict resolution as the guiding principles for the afternoon's discussions (see Appendix G).

Following this presentation a short discussion took place during which Roberto Chené, MA, inter-cultural consultant, posed the overarching question of How do we get from research "in" communities to conducting research "with" communities? To get to this larger question, the following three questions were addressed in the small groups:

- 1. What are the facilitators to "with"?
- 2. What are the barriers to "with"?
- 3. What outcomes would be different if our research adopts a "with" modality?

The CSAC and NM CARES HD members discussed the facilitators, barriers and outcomes from using a CBPR minded "with" approach to health disparities research. Across all groups, the CSAC emphasized the need to include the community as an equal partner in the research process. The focus was on capacity building in the community to allow for a more coordinated approach to CBPR that brings community members on board with all phases of research from question development to project implementation to allow for more meaningful research to be conducted. Additionally, the discussion emphasized the need to address fragmentation in the community and institution to generate a more efficient and successful use of resources and funding. A concern highlighted during this portion of the discussion was how to eliminate

current institutional practices that prohibit support for community. The two most important issues discussed were reforming tenure and promotion and strengthening intrainstitutional relationships, coordination, data sharing and communication. A need for increased minority faculty participation was also discussed and cited as a route to strengthening connections and relationships with marginalized communities.

The CSAC emphasized the need to include the community as an equal partner in the research process.

The meeting adjourned with the following suggestions on next steps for building mutually beneficial partnerships with community groups through the development of the NM CARES HD:

- 1) To develop two-way communication between the institution and communities of New Mexico is imperative to the success of the NM CARES HD;
- 2) To assess and change institutional practices which will be the basis of an institutional assessment conducted by the CEC to identify the limitations and strengths already present in the institution;
- 3) To assure continued feedback from CSAC members through meeting participation as an integral strategy to maintaining the community focus of the NM CARES HD; and
- 4) To develop an appropriate assessment that will begin the movement towards healthier research relationships between the University of New Mexico and New Mexico communities.



SUMMARY OF THE COMMUNITY SCIENTIFIC ADVISORY COUNCIL BI-ANNUAL MEETING

Purpose of Meeting and Introductions

The first bi-annual NM CARES HD Community and Scientific Advisory Council (CSAC) meeting brought together the key partners to engage in a dialogue about how to build a Health Disparities Research Center that would strengthen the bridge between the communities of New Mexico experiencing poor health outcomes and the University of New Mexico. There were three primary objectives for this meeting as follows:

- To introduce the CSAC with NM CARES HD's vision, values, goals and affiliated partners.
- To discuss and identify challenges and opportunities for building mutually beneficial partnerships with community groups to develop, implement, and sustain effective strategies to eliminate health disparities among Native American, Hispanic/Latino and other marginalized communities in New Mexico.
- To review and discuss the CSAC's leadership and advisory roles to the NM CARES HD.

The CSAC is comprised of 16 members, eight associated with UNM leadership and research, and eight members representing various organizations (clinicians/providers, community members, policy makers, consumers) from the broad geographic and demographic diversity of New Mexico. The primary functions of the CSAC are to advise the NM CARES HD leadership on facilitating the planning and implementation of its development and operation; review and advise on the progress in achieving its specific aims; engage with the Community Engagement Core and NM CARES HD leadership in assessing barriers and developing solutions for effective academic-community engaged efforts; and provide evaluations as appropriate to the group.



(Pictured from left to right: Dr's. Lisa Cacari Stone, Richard Larson, Nina Wallerstein, and CSAC members Harriet Yepa-Waquie, Roxane Bly, and Dr. Arthur Kaufman)

The Partners' Voices

Next, the partners were asked, "Why does it matter for you to attend today?" This question fostered a common understanding of why the members of the CSAC and NM CARES HD team felt it was important to attend the meeting (see Appendix L for complete list of responses). Five commonly shared purposes were to:

- 1) Make sure that the community's perspective was represented and that there was a strong emphasis on relationship building and understanding the community people;
- 2) Build better collaborations between the departments within the institution that are studying health issues from different perspectives, i.e. clinical, mental health, and behavioral health;
- 3) Move away from managing disparities to a more in-depth look at the underlying causes and address the social determinants of health in New Mexico's communities;
- 4) Continue working together because this group represents the key players that will make the changes that are needed to happen; and
- 5) Understand the richness of cultures, languages and traditions of New Mexico's diverse communities and build our work on it.

"This group represents the key players that will make the changes that are needed to happen." CSAC Member

Health Disparities Research at UNM Health Sciences Center

Dr. Richard S. Larson, Vice President for Research, UNM HSC, provided a presentation on current research activities within the HSC (see Appendix F for power point slides). Dr. Larson expressed his optimism in the growing support for public funding of the institution's growing research enterprise at UNM while other universities are experiencing a decline in funding, as well as a decline in federal funds. This growth also has sustained jobs within the private industry in NM. Dr. Larson talked about some of the accomplishments of the health disparities research enterprise which focuses on increasing education and capacity, building collaborations both externally and internally, working with community organizations and faculty and students, getting the opportunity to be recognized as a national leader in health disparities research, and creating a partnership and growth through the Clinical and Translational Science Center (CTSC).

Dr. Larson continued to speak about two CTSC program goals that would assist with institutional transformation – emphasize and support clinical and translational research through organizational change, and accelerate progress of medical discovery to improvement of health care and health outcomes. He shared some of the benefits of having the CTSC be part of the UNM HSC. One of the important benefits is coordinating use of resources of CTSC with other projects to engage in community based research to improve community health. He sees that the NM CARES HD can work very closely with CTSC to meet similar goals and objectives around improving research methods and approaches. Dr. Larson concluded his presentation in describing the steps we need to take in matching research activities to community needs. This is a bi-directional process that values both the community and institutional needs.

Challenges and Opportunities for Community Engaged Research

Dr. Lisa Cacari Stone, Assistant Professor at UNM HSC Department of Family & Community Medicine and Senior Research Fellow with the RWJF Center for Health Policy at UNM, began her presentation by stating the vision and goal of the center, which is to research causes of and solutions to health disparities (see Appendix G for power point slides). She spoke about the measurement of health disparities at three levels: 1) disparities in health status which focuses on differences in health conditions and outcomes: 2) disparities in healthcare which focuses on differences in the preventive, diagnostic and treatment services offered to people with similar health conditions (i.e. the lack of access); and 3) disparities in life opportunities which focus on differences in education, literacy, housing, social support, and environmental conditions (e.g., violence, poor air quality, and inadequate access to healthy foods).

Dr. Cacari Stone then shifted her focus on the challenges to opportunities of what we could do to change our situation. She explained that if we were to focus our efforts more on serving as change agents, providing education and leadership training, and moving to multi-level interventions (community, systems and policy), we would position ourselves better in reducing disparities.

The University of New Mexico and the State of New Mexico have a tremendous opportunity through the P20 grant, NM CARES HD - New Mexico Center for Advancement of Research, Engagement and Science on Health Disparities. Dr. Cacari Stone provided more background of the P20 grant which has a total budget of \$7.1 M for five years. She explained that there are four cores and two projects that make up the entirety of the grant. The four cores are administrative, research, training/education, and the community engagement. The two identified projects are the Mescalero Project and the Alcohol/Substance Abuse Project. The CSAC is part of the administrative core, as well as the consultants, and other UNM partners. The goals of each of the cores are spelled out in the Appendix G and the faculty and staff that are leading each of the cores are described in Appendix C. The community engagement core team will be working closely with the CSAC and HSC leadership on developing the strategic plan for the grant which would include creating effective strategies that enhance the partnership between the community and the institution.

Community Based Participatory Research and Guiding Principles

Dr. Nina Wallerstein, Professor, UNM HSC Department of Family & Community Medicine, then transitioned the focus of the meeting to present some foundational knowledge and understandings around community based participatory research (CBPR), see Appendices G, H, and I for additional information. The definition she provided for community based participatory research is a 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 disparitiesⁱ. She presented this information in preparation for having the audience members begin a dialogue on how do we shift our thinking about doing community research from using an "on/in" approach to a "with"

modality. Figure 1 below illustrates a continuum of research that occurs between university's and communities from doing research on, to in to with.

Figure 1



Next, Dr. Wallerstein talked about some of the challenges for doing health disparities research shown in Figure 2 below. Much like Dr. Cacari Stone's presentation, Dr. Wallerstein shifted her focus from challenges to opportunities. The opportunities that she presented are in the form of principles that help guide the way the institution and the communities can work together. There were three sets of principles that she shared – CBPR Principles, Principles for Tribes, and Principles for Intercultural Partners. The principles had some common values and the ones that

were most apparent are mutually beneficial partnerships and reciprocity. Dr. Wallerstein also shared the Intercultural CBPR model, for conducting health disparities research with communities which is illustrated in Figure 3 (also see in Appendix I). This model depicts how the needed community and institutional changes can happen when it is built upon a foundation of CBPR guiding

"Research matters only if we can translate it ." Lisa Cacari Stone

principles. Additionally four strategies for doing effective community based participatory research were presented (see Appendix H). To emphasize that a major component of successful CBPR is making a meaningful connection with the communities and taking the research findings back to the community, Dr. Cacari Stone stated, "research matters only if we can translate it."

Figure 2

CHALLENGES

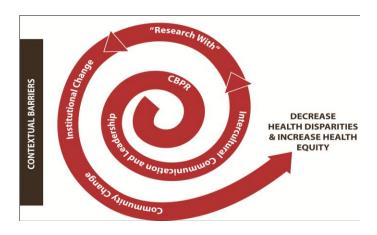
- Challenge of bringing evidence to practice
- Challenge of what is evidence
- Challenge of institutional barriers
- Challenge of lack of systematic input from communities of color on health disparities priorities and concerns
- Challenge of lack of responsibility back to communities and dissemination of findings from community perspective
- Challenge of sustainability of programs
- Challenge of lack of public trust and suspicion of research

OPPORTUNITIES

Relying on three sets of guiding principles and the Intercultural model can place more focus on the unique strengths of both the communities and the institution when determining effective interventions and strategies.

- CBPR principles
- Principles for Tribes
- Principles for Intercultural Partners
- Guiding Intercultural CBPR Model

Figure 3



A Group Dialogue on Research "In" Communities to Research "With" Communities

Following Dr. Wallerstein's presentation, Roberto Chené, MA, Community Consultant, facilitated a group discussion to get feedback on the primary question - **How do we get from research "in" communities to conducting research "with" communities?** The meeting participants were divided up into five groups to discuss three key questions that would help address the primary question. The three questions were as follows:

- 1. What are the facilitators to "with"?
- 2. What are the barriers to "with"?
- 3. What outcomes would be different if our research adopts a "with" modality?

Each participant was given a worksheet to record their notes. The groups dialogued for about forty five minutes. Next, they were asked to have a volunteer from the group to report out on one of their outcomes to the question of "what outcomes would be different if we conduct research with communities?" Each groups' responses were captured in a summary format that are included in Appendix N. All the group worksheets were collected and these responses were compiled into one document (see Appendix O).

The following five main themes were synthesized from the rich group discussions. These themes are correlated with the barriers, facilitating strategies and the outcomes of using a "with" modality (see Appendix M).

Themes for Action

- 1. Coordinate Intra-Institutional Communications
- 2. Address the Institutional Practices Barring Community Support
 - 3. Make the Community an Equal Partner
 - 4. Eliminate Rather Than Manage Health Disparities
 - 5. Identify Best Practices
 - 6. Increase Minority Faculty

1. Coordinate Intra-Institutional Communications

When dealing with a large institution like the University of New Mexico there is a tremendous need to coordinate communication across disciplinary silos. When communication is not taking place in an efficient, consistent, and timely fashion fragmentation can arise. Communication is especially important in the case of UNM to create a bridge between the research and efforts taking place on north campus at the Health Sciences center and all that is being undertaken on the main campus. A lack of interdisciplinary communication and sharing of research findings may have attributed to the current lack of understanding of CBPR principles that has consequently limited the institutional buy-in and standardization of utilizing these principles when researching with communities. Fostering bi-directional communication between disciplines and a careful assessment of current research efforts and possible points of collaboration will clear the way for collaborative research. A suggested approach to breaking down communication barriers and disjunction would be institutional forums to start dialogue on how to better communicate between departments and disciplines. Organizing and instituting a coordinated approach will make way for the development of a unified disparities minded agenda to eliminate the negative health outcomes seen throughout minority communities in New Mexico.

Theme	Barriers	Facilitating Strategies	Outcomes
Coordinate Intra- Institutional Communications	 Minimal Interdisciplinary Communication Incomplete understanding of CBPR→Lack of institutional buy in Traditional Research Model-Inflexible procedure and timelines Fragmentation between HSC and Main Campus 	 Communicating in a bi-directional manner Assessing and identifying overlaps or intersections within the institutions current research efforts Conducting forums to dialogue about possible solutions 	Collaborative Research

2. Address the Institutional Practices Barring Community Support

Fragmentation of research efforts creates a complex barrier to the institution providing the necessary support for successful CBPR. Fostering an overarching buy-in for changes in communication and research sharing practices will give way to increased coordination, communication and respect between the institution and communities. Open communication will create a more responsive network of resources that are in tune with the specific needs of each community researching with the institution thus creating an increased institutional capacity for community support.

Theme	Barriers	Facilitating Strategies	Outcomes
Address the Institutional Practices barring community support	 Fragmented research efforts Established research incentives→Inadvertently discourage community based research Deficient incentives for faculty conducting/participating in community based research 	 Propagating widespread Institutional buy-in to support sustainable change to research approach/faculty requirements Improving Interdisciplinary communication Improving institution wide understanding of CBPR principles and positives of community based research Increasing faculty use of CBPR principles and engagement in community based research 	Improved institution/community relationship and improved health outcomes specific to community Shift from doing research "in" to "with" communities

3. Make the Community an Equal Partner

A key component of doing successful research "with" communities must involve an equal balance of power and participation between the community and the institution collaborating on the project. To make way for successful and equal partnerships the institutional members must make an effort to understand how communities define their social and health issues. Communities give different meaning to their health and lived experiences which comprise cultural and spiritual ways of knowing different than "western" science. For instance, one CSAC

"For instance, diabetes programs are always concentrated on nutrition; it encompasses more, the earth, the sky, everything."
Beverly Becenti-Pigman

member explained the importance of how communities perceive chronic diseases differently than medical definitions: "diabetes programs are always concentrated on nutrition; but it encompasses much more, it includes the earth, the sky, everything." Other examples supported the importance for academic partners to invest time to recognize and embrace the social meanings and cultural assets and practices of communities. A greater understanding of the

community and its members combined with respectful listening are key facilitators to building more equitable lasting partnerships necessary for successful research with communities. Taking the time to build a strong and respectful relationship opens the lines of bi--directional communication, increases the research capacity of the community partners and creates an equal

partnership with the institution. All three actions will yield long-term sustainable impacts to decrease health disparities.

(Dr. Tassy Parker is shown speaking as Dr. Steve Adelsheim looks on)

Theme	Barriers	Facilitating Strategies	Outcome(s)
Make the Community an Equal Partner	Use of preconceived research questions not applicable to participating community Researcher notion of knowing it all-no willingness to get to know/understand community Translation Issues (language, cultural, contextual, technical/scientific terminology) Inflexible IRB process not conducive to community ownership/participation	 Investing time up front to build relationship with community by gaining understanding and appreciation of all its members and components Respectfully listening to community and understanding community definitions of issues Providing opportunity for bidirectional communication on community needs Partnering community and institutional core values Recognizing and utilizing existing community strengths, social structures and current research efforts Training community to actively participate in research process, propagate community ownership 	Community will be the force directing research questions and efforts: Question Development ↓ Sustainable, community specific impacts ↓ Increased community capacity

4. Eliminate Rather Than Manage Health Disparities

The NM CARES HD overarching goal is to begin moving from just researching the problems or managing health disparities to a proactive research approach towards finding solutions and eliminating disparities. This shift towards elimination will be most aptly achieved by fully understanding how social determinants are contributing to health outcomes in communities and using this understanding as a tool and vehicle for sustainable change within communities. In addition, increasing the community stakeholder support will also have a positive impact of sustaining the efforts to reduce and eliminate health disparities.

Theme	Barriers	Facilitating Strategies	Outcome(s)	
Eliminate Rather Than Manage Disparities	Absence of institutional willingness to address tough questions/issues arising from community based projects Unreasonable institutional expectations of community	Utilizing the understanding of social determinants causing health disparities as a tool to change health outcomes Continuing to address tough	Increased involvement and support of stakeholders within the community and institution in addressing the interventions that will have the most impact in reducing	
	based research efforts	issues/questions as they arise	or eliminating health disparities	

5. Identify Best Practices

The NM CARES HD has the opportunity to reflect and assess existing projects undertaken with communities in order help researchers determine what is working and those practices that are not working. A thorough assessment of research conducted with communities through the NM CARES HD will allow for the identification of best practices common to the projects and the eventual development of a widely applicable framework for CBPR to foster community ownership in future projects.

Theme	Barriers	Facilitating Strategies	Outcome(s)
Identify Best	Ignoring community needs	 Investing time to learn about 	Creation of Framework to
Practices	 Not investing in relationship building with community Discounting results of current research/project efforts in community 	the community and to identify and compile information on what is/has worked	foster community ownership and enhance development of other CBPR projects

6. Increase the Minority Faculty

The cultural diversity found within the faculty of the University of New Mexico is a major contributor to what makes the institution so unique. Embracing this diversity and encouraging the participation of minority faculty will be a key element in sustainable success for the NM CARES HD. Improving the capacity of minority faculty to participate and conduct health disparities research and CBPR projects will assure that the community voice is better represented because of the shared experiences that faculty of color have with New Mexico's communities. Additionally, encouraging and providing institutional incentives for the sharing of cultural knowledge on the part of faculty will improve community capacity. This could be achieved by developing stronger relationships between community members and academes based on a respectful understanding of social and cultural practices, structures and current community norms.

Theme	Barriers	Facilitating Strategies	Outcome(s)
Increase the Minority Faculty	No communication with recruitment of main campus faculty	 Increasing advertising of Disparities Center and Research Efforts on main campus Recruiting more minority faculty Building research and overall capacity of minority faculty 	Improved Relationships with Communities: Voice of community will be heard because faculty are from the communities Improved Capacity of Minority Faculty: Increased sharing of cultural knowledge and experience → Improved community capacity

CSAC's Recommendations and Guidance on NM CARES HD Activities

In the last part of the meeting, Dr. Robert Williams, Principal Investigator of the P20 grant, presented the following questions to the CSAC members and all others present including UNM faculty and staff members. He also shared a handout that listed the specific aims of the grant and the progress made in each area, see Appendix P.

- What is your assessment of the progress to date in achieving aims and are there any suggestions?
- What comments on development and function are there so far of the NM CARES HD cores/projects?
- What recommendations are there on integration with other research centers at UNM?
- How is the NM CARES HD is aligned with the health disparities research priorities of both UNM and the broader community?
- What should be the priorities for pilot project funding?
- How effective have the initial community engagement efforts been and what should be the next steps?



(Dr. Williams is shown here and Alison McGough-Maduena is sitting to the right in background)

"The center could be the driving force to change the institutional structure and remove barriers to health disparity research."

CSAC Member

The feedback received from the CSAC on the NM CARES HD addressed and focused on two key areas, institutional structure and reduction of health disparities. One CSAC member summarized these key areas by saying, "the center could be the driving force to change the institutional structure and remove barriers to health disparity research," (see Appendix Q for a complete summary of recommendations).

Under institutional structure, the CSAC members expressed that the University has a good opportunity to build its capacity in doing health disparity research with communities by engaging more minority faculty as well as other faculty from other disciplines university wide. Involving more faculty from across the University and having researchers working synergistically will result in less fragmentation and more sharing of resources. Facilitating and ensuring this coordinated effort could be one of the major functions of the NM CARES HD.

Reducing disparities was also discussed passionately. There was a unified concern that the Center should not become another center that only manages disparities. A critical part of reducing and eliminating health disparities is placing emphasis on building a mutually beneficial relationship with communities. What this involves is gaining an understanding of the community constituencies, learning their needs as well as finding out what resources, including ongoing research efforts, are available. Knowing this will help the institution understand how to better assist with building the community's capacity and how to support those needs from a strengths-based approach. Being transparent will help initiate having more open dialogues on health disparities with the communities. Furthermore, effective communication will be fostered through

having mutual respect and will eventually result in great action to address community concerns. The need for building a mutually beneficial relationship was poignantly stated when a CSAC member said, "great action has been seen when a community need is voiced and addressed by an institution, especially when the institution can be in tune with the community and builds the most appropriate and beneficial relationships."

Finally, reducing disparities is also about knowing how efforts can be sustained over a long period of time.

"Great action has been seen when a community need is voiced and addressed by an institution, especially when the institution can be in tune with the community and builds the most appropriate and beneficial relationships."

CSAC Member

Getting the buy-in from the University to support the research findings and building political will are some key strategies that can support communities sustain their efforts.

Meeting Evaluation

A few CSAC members indicated it would be helpful to have a copy of the grant to know what is contained in it to be able to provide more informed feedback. Dr. William's handouts on the grant's specific aims did provide some tangible data about some of the progress made thus far.

Attendance was favorable, of the thirty-four individuals invited thirty-one were in attendance, and only one CSAC member did not attend. Eleven people or 32% completed a meeting evaluation form. Three questions related directly to the meeting objectives were asked to evaluate meeting objectives. The questions were framed using a likert scale where a "1" response was strongly disagree and a "5" was strongly agree. The first question about understanding the NM CARES HD's vision, values, goals and affiliated partners, 45% rated a 4 and the next highest was 36% rating a 3. For the second question about understanding the challenges and opportunities for building mutually beneficial partnerships, 54% rated a 5. Regarding the third objective about understanding the CSAC's leadership and advisory roles to the NM CARES HD, 63% rated a 3. However on another question related to understanding their role as a CSAC member, there was a tie between a 3, 4, and 5 rating at 27%. A fully compiled evaluation summary including opinions to the open ended questions is provided as Appendix K.

Finally, members suggested the following changes to the next meeting including to 1) identify core values that will help drive the work of the CSAC; 2) bring in students to observe the process; 3) invite other representatives of other marginalized populations; and 4) most importantly, to have the next meeting in a community setting.

Moving Forward

The first CSAC meeting provided a good opportunity to discuss the challenges and more importantly the opportunities of the NM CARES HD. This meeting was an important first step towards building a support system based on mutual collaboration and shared opportunity for doing research "with" communities to reduce and eliminate health disparities. The CSAC members are key players for making this shift and will continue to be a base for expanding the advocacy network for systems change.

As we move forward together, the success of the NM CARES HD will depend largely on the creation of mutually beneficial partnerships between the UNM and New Mexico's diverse communities. These partnerships should foster transparent and honest communication as well as promote dialogue that is built on mutual respect and shared values and vision for change. Under the NM CARES HD, the UNM is charged with conducting an internal assessment to determine what are the barriers and facilitators to conducting research with communities. The CSAC is a core advisory partner in helping develop and use this assessment for future strategic planning towards systems change.

W.K. Kellogg Community Scholar's Program (2001)

APPENDIX A

Meeting Agenda



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

A center to research the causes of and solutions to health disparities in New Mexico

Funded by the National Institute of Health's Center for Minority Health & Health Disparities, 2010-2015

I. Community and Scientific Advisory Council Meeting Agenda

II. November 5, 2010

Best Western Rio Grande Inn 1015 Rio Grande Blvd. NW Albuquerque, NM 87104 Tel: 505-843-9500

Purpose of Meeting

• To convene the first meeting of the Community and Scientific Advisory Council (CSAC) which is tasked with advising the NM CARES HD's development and operations.

Objectives

- To introduce the CSAC with NM CARES HD's vision, values and goals and affiliated partners.
- To discuss and identify challenges and opportunities for building mutually beneficial
 partnerships with community groups to develop, implement, and sustain effective strategies
 to eliminate health disparities among Native American, Hispanic/Latino and other
 marginalized communities in New Mexico.
- To review and discuss the CSAC's leadership and advisory roles to the NM CARES HD.

Noon-12:30	Networking Lunch
12:30-12:45	Welcome: Robert Williams, Director, NM CARES HD Opening Remarks-"Moving from Disparity to Opportunity": Lisa Cacari Stone, Director, Community Engagement Core, NM CARES HD
12:45-1:15	Introductions & Icebreaker: Facilitated by Roberto Chené
1:15-1:25	Overview of Health Disparities Research at UNM Health Sciences Center: Richard S. Larson, HSC Vice President for Translational Research
1:25-1:45	Overview of NM CARES, Challenges & Opportunities for Community Engaged Research in New Mexico:

	HD
1:45-2:45	 CSAC & NM CARES HD Discussion: Facilitated by Roberto Chené, Consultant, Southwest Center for Intercultural Communications Focus Questions How do we get from research "in" communities to research "with" communities? What outcomes would be different if our research adopts a "with" modality?
2:45-3:00	Report Back: Facilitated by Roberto Chené and Nina Wallerstein
3:00-4:30	CSAC Review and Discussion of Roles & CSAC Guidance on NM CARES HD Activities: Facilitated by Rob Williams and Lisa Cacari Stone
4:30	Adjournment

Lisa Cacari Stone & Nina Wallerstein, Associate Director, NM CARES

APPENDIX B

CSAC and NM CARES HD Biosketches



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

III. Biosketches

Community and Scientific Advisory Council

Linda Armas is President and co-founder of De Colores which showcases, promotes and develops the best of Hispanic art, music, dance, literature, and leadership. She also serves as President of the Southwest Center for Linguistic & Cultural Competency which addresses language access in health care environments and chairs the Hispano/Latino Health Advisory Council for the UNM Health Sciences Center and the School of Medicine. Ms. Armas worked for a major health care organization in New Mexico for over 20 years in operations management and administration. She teaches medical terminology and interpreter training to health care and social service employees and as a university course in various colleges and universities. She also contracts with the New Mexico Department of Health to provide state wide bilingual language training. Over the years, she studied the impact of health disparities and developed and implemented programs that address the special needs of culturally distinct populations. Aside from New Mexico, she has presented her programs on cultural competency and women's studies in Spain at the request of the Spanish government's hospital system and in several US Army installations throughout Germany at the request of the US Department of the Military. Her efforts also include language access advocacy, lobbying for state wide language programs and the creation of laws to govern language access in health care.

Beverly Becenti-Pigman is Chair of the Navajo Nation Health Research Review Board. Throughout her extensive career, she has been involved in a number of Tribal government committees regarding health including the National Tribal Steering Committee on Injury Prevention. Ms. Becenti-Pigman has also had experience working directly with local Tribal governments systems as the past Secretary/Treasurer for the Kayenta Chapter and as the Judge (retired) for the State of Arizona, Navajo County.

<u>Laura Gómez</u> JD, PhD is Professor of Law and American Studies at the University of New Mexico. Her educational background includes an B.A from Harvard in Social Studies (where she was a Harry S Truman Scholar), an M.A. and Ph.D. in Sociology from Stanford University (where she had a National Science Foundation Graduate Fellowship), and a J.D. from Stanford Law School. Following law school, Gómez clerked on the Ninth Circuit Court of Appeals for Judge Dorothy W. Nelson. Before going to Stanford, she worked as a legislative aide to U.S. Senator Jeff Bingaman. Before joining the UNM faculty in 2005, Gómez spent 12 years as Professor of Law at UCLA (where she also was appointed in the Sociology Department). She was a co-founder and the first co-

director (with Jerry Kang) of UCLA's Critical Race Studies Program, the first specialized program of study on race and law in any U.S. law school.

Arthur Kaufman, MD, is vice president for UNM Health Sciences Center office of community health. Dr. Kaufman's specialties are Family Medicine and Internal Medicine. He is board certified in both. After graduating from State University of New York Downstate Medical Center, he completed an Internal Medicine residency at St. Vincent's Hospital in New York. He served in the Indian Health Service in South Dakota and in New Mexico before coming to UNM. Dr. Kaufman joined the Department of Family and Community Medicine in 1974. His primary interests are in creating innovative education and service models to address community, indigent, rural and population health needs. He is currently the Vice President for Community Health at the UNM Health Sciences Center.

Richard Larson, MD, PhD is Senior Vice President for Research at UNM's Health Sciences Center and Senior Associate Dean for Research at the School of Medicine. Dr. Larson manages the research endeavors at the Health Sciences Center and also maintains an extramurally funded laboratory developing a variety of biotechnologies, including diagnostic devices and imaging tests. Recently, he led the successful effort to obtain a Clinical and Translational Science Award for the UNM Health Sciences Center. In 2006, he and his collaborators at UNM and Sandia National Laboratories were awarded the Chief Scientist Award for their hand-held bio-agent sensor from the Defense Intelligence Agency. Recently, this hand-held detector was selected by R&D Magazine as one of the top products of 2010. Dr. Larson is extensively involved in supporting and initiating several commercial ventures in New Mexico. He currently has commercial partnerships with Senior Scientific, Adaptive Methods, and Sandia National Laboratories. He is a member of the Board of Directors for the National Center for Genome Research and TriCore Reference Laboratory—New Mexico's 12th largest company— where he has been involved in founding, operating and governance for more than 11 years.

<u>Tassy Parker</u>, PhD, RN is Assistant Professor of Family and Community Medicine and Co-Director of the Mental and Behavioral Health Center for Native American Health at the University of New Mexico Health Sciences Center – School of Medicine. Dr. Parker is also a Research Scientist with the UNM Center on Alcoholism, Substance Abuse, and Addictions. A medical sociologist and registered nurse, Dr. Parker is an enrolled member of the Seneca Nation and lived on her tribal Territories in Western New York for 40 years. Dr. Parker has two NIH-funded research projects to examine the role of psychological distress and other mental health problems as risk factors for American Indian maternal alcohol use and mental health risk factors associated with obesity in American Indian children and their families. Dr. Parker is a founding member of the national Native Research Network and a current member of its Board of Directors.

<u>Shari Roanhorse-Aguilar</u> is Deputy Bureau Chief, Long-Term Services and Support, Medical Assistance Division for the NM Human Services Department. She is the former Tribal Liaison for the NM Medicaid program and Indian Health Care at both state and national levels. She has worked directly with Tribal leadership among the 22 New Mexico Indian Tribes and Pueblos and the Indian Health Service on health care disparities among Native American recipients.

<u>Valerie Romero-Leggot</u>, MD is Vice President for Diversity at the University of New Mexico Health Sciences Center, Associate Dean of the School of Medicine Office of Diversity and Associate

Professor in the Department of Family and Community Medicine. Her office promotes the racial, ethnic, geographic, and socio-economic diversity in the Health Sciences Center and develops a variety of opportunities to address key issues in diversity. One of her major duties is to provide a forum for discussing issues concerning underrepresented and disadvantaged populations.

<u>Delores Roybal</u> is the executive director of Con Alma Health Foundation. Prior to Ms. Roybal being named Executive Director of Con Alma, she held positions as Program Director, of the Santa Fe Community Foundation, and Executive Director, of Women's Health Services. She has been active in the nonprofit sector and in philanthropy for many years at the local, national, and international levels.

Alice Salcido, MPH is the Probate Judge for Doña Ana County. Ms Salcido has extensive experience in administration and public service, including four years as Chief Deputy County Treasurer in the mid-1960s. Most recently, she served as interim director of the New Mexico Department of Public Health's Border Health Office. She also has 18 years of experience as district coordinator for U.S Senator Jeff Bingaman, advising him on a wide range of border and health issues.

Beverly Singer, PhD is Tewa and Diné from Santa Clara Pueblo, New Mexico. She is an award-winning documentary video producer whose concern is indigenous community wellness. Active in producing and writing about indigenous films, she is an Executive Board Member of the Independent Television Service (ITVS) and author of Wiping the War Paint Off the Lens: Native American Film and Video (2001) published by the University of Minnesota Press. She is an Associate Professor of Anthropology and Native American Studies and Director for the Institute of American Indian Research at the University of New Mexico. She received her Ph.D. in American Studies from the University of New Mexico, M.A. in Social Service Administration from the University of Chicago, and documentary film training from the Anthropology Film Center in Santa Fe, NM.

Roxanne Spruce Bly is the Founder and Coordinator of the Native Healthcare Council of New Mexico and a member of Laguna Pueblo. She is currently a member of the American Indian Health Advisory Committee. She is a lobbyist and an advocate for the Health Care Reform and was formerly the Director of Health Action New Mexico.

Alfredo Vigil, MD is Cabinet Secretary of the New Mexico Department of Health. He is also Professor of Family Medicine at the University of New Mexico. Dr. Vigil is a graduate of UNM's School of Medicine and performed his family practice residency at UNM as well. He is a Fellow of the American Academy of Family Physicians and the National Public Health Leadership Institute at University of North Carolina. Dr. Vigil has 30 years of extensive clinical and management experience specializing in family medicine, geriatrics, emergency medicine and reproductive health issues. He has worked in private practice, community health centers, hospitals and other non-profit organizations. For five years prior to his current position, he was chief executive officer of El Centro Family Health, a non-profit primary care organization in Española.

Harriet Yepa-Waquie, MSW is Director of the Albuquerque Service Unit Diabetes Education Program with Health Heart Project. She has worked as a community research partner from Jemez Pueblo with the UNM Master of Public Health CBPR research team for the past ten years. She has been involved with the Native American Family Intervention Project which is a Community Based

Participatory Research Process as the tribal organizer. Ms. Yepa-Waquie has also been involved with the Jemez Pueblo: Built and Social-Cultural Environments and Health. She has many experiences working with the Native American communities especially with the Diabetes Programs. She received her MSW from U.C. Berkeley School of Social Welfare.

William Wiese, MD, MPH is Professor and former chair of the Department of Family and Community Medicine at UNM. Dr. Wiese co-founded the Master of Public Health Program and directed the Area Health Education Center Program. He also served as Chair of the School's Curriculum Committee through the period when it adopted the then innovative problem-based medical curriculum. He left the School of Medicine to direct the Public Health Division in the New Mexico Department of Health (1997–99). He returned to the School in 2002 as the founding director of the Institute for Public Health. The mission of the Institute is to improve health status and reduce health disparities through collaborations within the Health Sciences Center and with external partners. Dr. Wiese has served nationally on the U.S. Preventive Services Task Force and the Council on Linkages between Academia and Public Health Practice. He has been Associate Director for the Robert Wood Johnson Foundation Center for Health Policy since its inception in 2007.

Cheryl Willman, MD is an internationally known leukemia researcher and Director and CEO of The University of New Mexico Cancer Center, the Official Cancer Center of the State of New Mexico. The UNM Cancer Center received designation as a National Cancer Institute (NCI)-Designated Center in 2005 and was ranked as one of "America's Best Cancer Hospitals" by U.S. News & World Report in 2006. The 85 oncology physicians, 120 researchers, and more than 500 staff of the UNM Cancer Center are dedicated to providing outstanding cancer treatment, conducting world class research, training the next generation of cancer healthcare professionals, and delivering community outreach programs throughout New Mexico's urban, rural, and tribal communities. The UNM Cancer Center provides care for more than 7,600 cancer patients each year in 85,000 patient visits, nearly 50% of the adults and virtually all of the children in New Mexico affected by cancer. More than 50% of these patients are ethnic minorities, primarily Hispanic and American Indian.

In her research, Dr. Willman focuses on finding the causes and the cures for patients affected by leukemia. She is the Director of Leukemia Research Programs and Correlative Science Laboratories for the National Cancer Institute's Children's Oncology Group and Southwest Oncology Group. Her own UNM laboratories, supported by over \$16 million in funding from the NCI and the Leukemia & Lymphoma Society, receive leukemia samples from the majority of children and many adults in the United States. She has published more than 160 scientific articles in prestigious journals and several books and reviews. She leads a consortium of investigators from UNM, Sandia National Laboratories, and the Fred Hutchinson Cancer Research Center who are applying advances from the Human Genome Project to improve leukemia diagnosis and discover new and more effective drugs and therapies. In the past three years, Dr. Willman and this UNM/Sandia team has filed six new patents on their discoveries.

Consultants

Roberto Chené, MA holds a BA in Philosophy, an MA in Pastoral Theology, and has done postgraduate work in Social Welfare Policy at Brandeis University. He is the director of the Center for Intercultural Leadership Training and Conflict Resolution in Albuquerque, N.M. He is deeply rooted in the Chicano-Latino community and has taught "Cross-Cultural Education" and "Latinos and Public Policy" at the University of New Mexico. He consults with many organizations in Multicultural Organizational Development and is currently working with two major religious organizations as they initiate programs to eliminate institutionalized racism. He has conducted trainings, presentations, and lectures throughout the US and has worked in Mexico and South Africa. Roberto is motivated by his deep commitment to transform relationships of dominance into relationships based on equality. He is currently working on a book of reflections and lessons gleaned from his more than thirty years of practice in the building of multicultural community.

Spero Manson, PhD is Distinguished Professor of Public Health and Psychiatry in the Schools of Medicine and Public Health at the University of Colorado. He is Director of the Center for American Indian and Alaska Native Health Disparities (funded by National Center on Minority and Health Disparities), Director of the Center of Excellence for Elimination Disparities (funded by the Centers of Disease Control and Prevention), and former Director of the Center on Native Elder Health Disparities (funded by the Agency for Healthcare Research and Quality). He is nationally known for his research and leadership in behavioral and mental health of Native Americans.

Glenn Flores, MD is Professor of Pediatrics and Public Health and Director of the Division of General Pediatrics, the Judith and Charles Ginsburg Chair in Pediatrics, and the Director of the Academic General Pediatrics Fellowship at UT Southwestern and Children's Medical Center Dallas. He is a former Robert Wood Johnson Generalist Physician Faculty Scholar and a former Robert Wood Johnson Minority Medical Faculty Scholar.

NM CARES HD CORES

Administrative Core

Rob Williams, MD, MPH is the Principal Investigator/Director of New Mexico Center for Advancement of Research, Engagement & Science on Heath Disparities, Director of the Administrative Core, Professor of Family and Community Medicine, Director of Research Involving Outpatient Settings Network, and Director of the UNM component of Native American Research Center for Health (NARCH) He has held a variety of clinical and research management positions throughout his career, and his research and publications have centered on the themes of translation of research into practice and health disparities. He worked for 8 years on the Navajo Reservation, a year for the Peace Corps/UNM in Western Samoa, 8 years at an inner city community health center, and for a year in a periurban South African community.

Nina Wallerstein, DrPH is Professor in the Department of Family and Community Medicine, and was the founding Director of the Masters in Public Health Program at the University of New Mexico until 2007. She currently is the Director of the Center for Participatory Research, Institute

for Public Health, Vice President's Office of Community Health; Director of Community Engagement and Research of the Clinical Translational Science Center, and Senior Fellow in the Robert Wood Johnson Foundation Center for Health Policy at UNM. She received her DrPH and MPH in Community Health Education at the School of Public Health, University of California, Berkeley. For over 25 years, she has been involved in empowerment/popular education, and participatory research with youth, women, tribes, and community building efforts. She is the coeditor of Community Based Participatory Research for Health, 2nd edition, 2008 (with Meredith Minkler); co-author of Problem-Posing at Work: Popular Educator's Guide; and author of several other health and adult education books and over 100 articles and book chapters on participatory intervention research, adolescent health promotion, alcohol and addictions prevention research, empowerment theory, and popular health education. She has worked in Latin America with the Pan American Health Organization in participatory evaluation of healthy municipalities and communities, and in development of empowerment and health promotion trainings. Her current research interests focus on community capacity and health development in tribal communities, culturally appropriate translational intervention research, and community based participatory research processes and outcomes.

<u>Dennie Jones</u>, MD, FACP is Professor of Medicine in the Division of Hematology and Oncology and Associate Professor in the Department of Internal Medicine at the University of New Mexico. He is also the Medical Director for the Clinical Protocol and Data Management/Medical Informatics Shared Resource of the University of New Mexico Cancer Center.

Miria Kano, MA is the Senior Program Manager for the New Mexico Center for Advancement of Research, Engagement and Science on Health Disparities (NM CARES HD) and the Research Involving Outpatient Settings Network (RIOS Net). Ms. Kano has conducted long term ethnographic work in three New Mexico counties with people seeking behavioral health services for severe mental illness and chronic substance abuse, as well as with members of the lesbian, gay, bisexual, and transgender community. She is a doctoral candidate in the Department of Anthropology.

<u>Lindsay O'Connell</u>, **BFA** in Digital Communications and Graphic Design. She is the Administrative Assistant for New Mexico Center for Advancement of Research, Engagement & Science on Heath Disparities and Research Involving Outpatient Settings Network, and is currently pursuing her Masters degree in Health Education with a community focus.

Research Core

Steven P. Verney, PhD is the Director of the NM CARES HD Research Core, and Associate Professor and Associate Chair for Graduate Education in the Department of Psychology at UNM. An Alaska Native (Tsimshain), he is an accomplished and well-respected Native American faculty member who has a history of collaboration with faculty in the Health Sciences, Arts and Sciences, and Center for Alcoholism Substance Abuse and Addictions.

Robert Rhyne, MD Co-Director, Research Core is the Vice Chair of Research and a Professor in the Family and Community Medicine Department at UNM. He is co-founder of the practice-based research network in New Mexico, Research Involving Outpatient Settings Network (RIOS Net). He has 25 years of experience in primary care, has been PI and co-investigator on numerous National

Institute of Health funded projects, and has conducted research in Community Oriented Primary Care, community-based medical education as well as on Complimentary and Alternative Medicine (CAM) use in Hispanic communities in New Mexico.

<u>Victoria Sanchez</u>, **Dr PH** is Assistant Professor in the Master of Public Health. She coordinates the Community Health Concentration track and teaches the program planning and social/cultural theory courses. She has a long-standing interest in understanding health behaviors within the broader contexts of family, cultural, community, and societal norms. Her research interests span substance abuse prevention, community capacity building, coalition effectiveness, participatory planning and evaluation processes with public health departments, and qualitative methodologies to understand community change.

Betty Skipper, PhD is a Professor and Associate Chair in the Department. She received her Biostatistics Ph.D. from Case Western Reserve University in Ohio. She has been Department faculty since 1967. She currently teaches Epidemiology Data Analysis and is a mentor for medical student research projects. She has published numerous articles in peer-reviewed journals and is involved in many of the Department's research projects. She directs the Biostatistics Unit in the Department.

<u>Charles North</u>, **MD** is Professor of Family and Community Medicine. He graduated from the University of Pittsburgh School of Medicine, completed Family and Community Health residency and Masters of Science in Family Medicine and Community Health at the University of Minnesota. He worked on the Hopi Indian Reservation for seven years and retired from the Indian Health Service and Commissioned Officer Corps of the USPHS after 31 years. He is a co-founder of RIOS Net and started the family medicine site at IHS. His interests include Native American health, integration of public health and primary care and practice improvement.

Jennifer Averill, PhD, RN is an Associate Professor of Nursing whose clinical background spanned medical-surgical, oncology, hospice, home health, school health, critical care, public health, rural health, and transcultural populations (including migrant health and NM Indian health), prior to completion of her PhD in Nursing at the University of Colorado Health Sciences Center in 1997. Currently her research focuses on rural and multicultural populations (especially elders), Community-Based Participatory Research (CBPR), critical ethnography, and interdisciplinary (research) collaboration with the UNMHSC Clinical Translational Science Center (CTSC). She has taught a variety of subjects in Colorado and New Mexico for all levels of nursing students (ADN through PhD). Currently she teaches nursing theory for both MSN and PhD students, rural and cultural health for PhD students, and qualitative research techniques. Jennifer is active in the International Institute for Qualitative Methods, Western Institute of Nursing, American Public Health Association, American Nurses Association, Sigma Theta Tau International, and is a grant reviewer for the National Institutes of Health (NIH) in CBPR. She and her husband enjoy trail riding (they have horses), hiking, and other outdoor activities, and she has a special interest in writing original poetry.

Research Training and Education Core

<u>Matthew Borrego</u>, **PhD, RPh, is** Director of the Research Training and Education Core. Dr. Borrego is also Associate Professor of Pharmacy Administration at the University of New Mexico. Dr. Borrego's current research interests center around two major areas, pharmacy education and

health outcomes research. Ongoing studies include the measurement of teaching, pharmacy education and interdisciplinary education related outcomes. Studies in the health outcomes area include applied pharmaco-economic evaluations, health related quality of life studies and general health outcomes studies. Dr. Borrego also has a growing interest and is conducting preliminary studies in issues related to cultural competence in providing health care services, health and pharmaceutical policy and the health status and access to care of minority (especially Hispanic) populations.

Deborah Helitzer ScD, is Co-Director of the Research and Training and Education Core. Dr. Helitzer is a Professor of Family & Community Medicine; the Assistant Dean for Research Education at the School of Medicine, and Director, Research Education, Training and Career Development of UNM's CTSA. Through her relationships with Native American communities all over the southwestern US, Dr. Helitzer has enhanced community capacity and helped communities to answer their own questions about health disparities. Over the last 20 years, she has collaborated with content experts to conduct community-based and health services participatory research on the following topics: Cancer, Diabetes, Adolescent Risk Taking, Adverse Childhood Experiences, Obesity, HIV/AIDS and TB, Malaria, Immunizable Illnesses, Childhood Diseases, and Agricultural Injury. She is a faculty member at both of the AAMC Women in Medicine programs and has just recently completed her ELAM fellowship. The currently funded research on women faculty development continues the theme of capacity building in her research, her expertise in program evaluation and qualitative research, for all of which she is nationally renowned.

Community Engagement Core

Lisa Cacari-Stone, PhD is Director of the Community Engagement Core is Assistant Professor with the Department of Family and Community Medicine and Senior Research Fellow with the Robert Wood Johnson Center for Health Policy at UNM. She has been a national recipient of the W.K. Kellogg Doctoral Fellowship in Health Policy Research at the Heller School of Social Policy and Management, Brandeis University, where she received her doctoral degree in 2004. From 2005 to 2008, she served as an H. Jack Geiger Congressional Health Policy Fellow for Senator Edward M. Kennedy with the Committee on Health, Education, Labor and Pensions. During that time, she also was a W.K. Kellogg Scholars in Health Disparities Program and Alonzo Yerby post-doctoral scholar at the Harvard School of Public Health. Dr. Cacari's research explores the influences of border migration, and social policy upon health as well as the role of community engagement in developing interventions that might reduce those health disparities. She teaches two courses, "Health Policy Politics and Social Equity" and "Border, Migration and Latino Health" for graduate students in health and social sciences.

<u>Nina Wallerstein</u>, **DrPH** (see bio above) is Co-Director Community Engagement Core see administrative core.

Clarence Hogue Jr., BA is a Navajo/Diné from Fruitland, New Mexico and currently resides in Albuquerque. Clarence received his Bachelor of Arts in Speech Communications from Brigham Young University. He has been working in the youth development field for the past ten years and has been supporting youth program development in Native communities in the southwest region of the U.S., including school based and community based programs. Clarence has also worked for his tribe supporting community and economic development projects. He consults with various

organizations, i.e. school, state agency, non-profits, and provides project coordination and training services. Clarence has a strong interest in working with grassroots community initiatives and would like to pursue and focus his next career around health advocacy for Native peoples and other underserved populations. Clarence will be working on the CEC team as the Project Research Coordinator.

Lucinda Cowboy, BA is the Native American Liaison for the Community Engagement Core. She is also currently the Native American Community Outreach Specialist with UNM RIOS Net and the project coordinator of a research project examining best practices for recruiting and retaining minority population and has coordinated the research project for barriers for colorectal cancer screening. Lucinda is a member of the Navajo tribe and is originally from ChiChilTah which is located about 30 miles south of Gallup, New Mexico. She has extensive experience with community outreach as a health educator and prevention specialist geared towards diabetes and substance abuse prevention. Her current role as community outreach specialist allows her to engage and build partnerships with various groups and organizations in the Native American communities. She is currently providing the RIOS Net project results to various groups such as the Indian Health Service Health Boards, the Navajo Nation Chapter Houses, the Pueblo Health Councils and other Native American Coalitions. She enjoys interacting with the communities and receiving valuable feedback about research projects. Lucinda has lived in Albuquerque for the past 7 years and is happily married with one daughter. She is currently pursuing her Master's Degree in Health Education.

Angelica Solares, MCRP currently serves as community outreach specialist and project coordinator for the Department of Family and Community Medicine's practice based research network, RIOS Net. She holds a Masters in Community and Regional Planning from the University of New Mexico. Before joining the Department of Family and Community Medicine, she worked in the public sector and non-profit organizations both in New Mexico and California where she worked with disenfranchised communities, especially low-income Hispanic families.

Alison McGough-Madueña, BS born and raised in Albuquerque, New Mexico. Graduated in 2005 from Rio Rancho High School and moved to Tulsa, Oklahoma to attend the University of Tulsa. Alison received a Bachelor of Science degree in Exercise and Sports Science with a minor in Biology and Pre-Med studies from the University of Tulsa in December of 2009. While in Tulsa became involved in a number of local non-profit organizations including the Day Center for the Homeless and interned at the Indian Healthcare Resource Center of Tulsa. Through membership in the Delta Delta Delta national sorority was able to help with the launch of the Reflections Body Image program and participate in a number of philanthropy events for St. Jude's Children's Research Hospital. Enjoys traveling and the outdoors and while a student at TU was privileged to serve on a mission team in Malawi, Africa. Has a special interest in HIV/AIDS prevention and intervention programs. She is currently a student in the Masters of Public Health program with a concentration in Epidemiology.

Research Projects

Research Project One: Substance Abuse and Primary Care

Andrew Sussman, PhD is the Principal Investigator of this project. Dr. Sussman is also Research Assistant Professor in the Department of Family and Community Medicine. He is a medical Community and Scientific Advisory Council Meeting

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anthropologist and has been with Department of Family and Community Medicine since 2003. He received his Ph.D. in Cultural Anthropology and a Masters in Community and Regional Planning from the University of New Mexico. Dr. Sussman conducts much of his research with RIOS Net, the Departmental practice-based research network. He has expertise in qualitative research methods, formative assessment and process evaluation. His work focuses on patient-provider communication, clinical decision making and health disparities in the primary care setting. Dr. Sussman also teaches Qualitative Research Methods in the Masters of Science in Clinical Research Program.

Victoria Sanchez, DrPH (see above bio) is Co-Investigator of this project.

Kamilla Venner, PhD is Assistant Professor in the Department of Psychology at the University of New Mexico. Her training and research interests have centered on substance abuse problems and recovery with an emphasis on Native Americans. Her work has involved testing the cross-cultural applicability of addiction models developed with predominately Angle male samples.

Robert Williams, MD (see above bio)

Jacque Garcia, BA, is Project Coordinator for Research Project One, was born and raised in Albuquerque, New Mexico. She received her Bachelor's of Arts in Psychology and Spanish from the University of New Mexico and is currently a graduate student in the University of New Mexico Master of Public Health program. As a new addition to the New Mexico Health Disparity Center, she will be coordinating research for the study that involves reducing disparities in substance use screening and treatment, directed under Andrew Sussman, Ph.D. Jacque's career goals stem from her interests in reducing health disparities in her home state of New Mexico. She is also interested in international health and has done public health and medical outreach in Mexico, El Salvador, and Kenya.

Research Project Two: Mescalero Apache Suicide Intervention

Richard Hough, PhD is the Principal Investigator of this project and is Research Professor of Psychiatry at UNM. Dr. Hough is a nationally known psychiatric epidemiologist and mental health services researcher. He has been the principal investigator on a number of NIMH and SAMHSA funded research projects that have examined such topics as life stress and mental disorder in El Paso, Texas, and Ciudad Juarez, Mexico; the prevalence of mental disorder and services use in Mexican American populations in Los Angeles; the prevalence of behavioral disorders in youth in public sectors of care; and the effectiveness of interventions for persons with serious mental illness. He was an investigator on the National Vietnam Veterans Readjustment Study that established the first solid estimates of the prevalence of PTSD in Vietnam veterans. Currently, he is responsible for developing behavioral health services research in the CRCBH at UNM and is involved in a wide array of NIMH, SAMSHSA and RSA funded projects related to behavioral health care in New Mexico.

Maria Yellow Horse Braveheart, PhD is Co-PI for the project and Associate Professor for the Center for Rural and Community Behavioral Health (CRCBH) on the Department of Psychiatry at UNM. She was formerly an Associate Professor at Columbia University School of Social Work and a member of the Hispanic Treatment Program, a clinical intervention research team at New York State Psychiatric Institute. Dr. Brave Heart is an affiliate of the Columbia Population Research Center, focusing on immigration of Indigenous Peoples from Latin America, and a faculty affiliate of the Institute for Latin American Studies. Currently, Dr. Brave Heart's projects include identifying

key cultural components of collective trauma, grief, and loss among Indigenous Peoples of the Americas, to inform clinical intervention research. This work builds upon Dr. Brave Heart's Historical Trauma and Unresolved Grief Intervention, recognized in 2001 as an exemplary model in SAMHSA's Center for Mental Health Services special minority initiative, through a Lakota Regional Community Action Grant on Historical Trauma. Dr. Brave Heart developed historical trauma and historical unresolved grief theory and interventions among American Indians, which have become internationally recognized. In 1992, she founded the Takini Network, a non-profit organization devoted to community healing from Indigenous intergenerational massive group trauma. Dr. Brave Heart is expanding her work with reservation populations in the United States and Canada to include Indigenous and Mestizo populations from Latin America.

Steven Adelsheim, MD is a child psychiatrist. Currently, he is professor of Psychiatry, Family/Community Medicine, and Pediatrics at the University of New Mexico Health Sciences Center. He is also a consultant to the New Mexico Behavioral Health Purchasing Collaborative through the New Mexico Department of Human Services (HSD). He is the former School Mental Health Officer for the New Mexico Department of Health. Dr. Adelsheim is a nationally recognized consultant in the field of school mental health, working with many city, state, national and federal programs. He has served for the last four years as the co-chair of the Committee on Schools of the American Academy of Child and Adolescent Psychiatry. In 2005, he received the AACAP's Irving Phillips Award for significant contributions to the field of prevention of mental illnesses in children and adolescents. He holds a bachelor's degree from Harvard College and an M.D. from University of Cincinnati College of Medicine.

<u>Deborah Altschul, PhD</u> is a psychologist who is a faculty member at the University of New Mexico Department Of Psychiatry's Center for Rural and Community Behavioral Health. Her research is largely focused on examining the connection between behavioral health disparities, cultural competency, consumer outcomes, and evidence-based practice. Dr. Altschul works closely with the state's Behavioral Health Purchasing Collaborative helping to develop a sustainable, culturally competent behavioral health infrastructure. She is the research and evaluation director of two federally funded grants supporting infrastructure development of behavioral health services in two tribal communities, several federally-funded grants developing infrastructure for the State's behavioral health system, and a legislatively-funded project to expand services to veterans and their families. Prior to working in New Mexico, Dr. Altschul worked at the University of Hawai'i Mental Health Services Research, Evaluation, and Training Program where she was the head of the Consumer Assessment Team, aimed at involving individuals with serious mental illness in study design, data collection, analysis, interpretation, and report writing. Dr. Altschul was also the Cultural Competency Specialist on two federally-funded grants focused on EBP implementation and statewide infrastructure development. She completed a postdoctoral fellowship with the National Association of State Mental Health Program Directors aimed at improving racial and ethnic disparities in mental health services.

APPENDIX C

Contact Information



<u>New Mexico Center for Advancement of</u>
<u>Research, Engagement & Science on</u>
<u>Health Disparities</u>

IV. Contact Information

Community and Scientific Advisory Council

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NM CARES HD CORES

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Appendix D

CSAC Roles & Functions



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

A center to research the causes of and solutions to health disparities in New Mexico. Funded by the National Institute of Health's Center for Minority Health & Health Disparities, 2010-2015

Role and Functions Community and Scientific Advisory Committee (CSAC)

Membership

- The CSAC is comprised of 8 members associated with UNM collaborative research, service and education leaders and 8 members representing various (clinicians/providers, community members, policy makers, consumers) from the broad geographic and demographic diversity of New Mexico.
- The CSAC builds in part on members from existing community advisory councils at UNMHSC, but will continue to develop new alliances as needed to bridge culturally and practice based knowledge with science in order to maximize the joint impact on reducing health disparities.

Meetings

• CSAC will meet twice a year in the community with the Center leadership and meetings will be tightly focused to enable useful and critical feedback to community engagement and the work of the cores and research projects.

Functions

- Advise the NM CARES HD leadership on facilitating the planning and implementation of the NM CARES HD's progress in achieving its specific aims, development and operations including:
 - Development, function, and integrative usefulness of the several cores
 - Balance and synergy with other research centers at UNM
 - Alignment with the research priorities within both UNM and the broader community that pertain to health disparities
 - Quality and relevance of the research with respect to disparities
 - General priorities for funding of pilot projects, and
- The CSAC will engage with the Community Engagement Core and NM CARES HD leadership in assessing barriers and developing solutions for effective academiccommunity engaged efforts including:
 - Advise on the design of the institutional-community assessment of the barriers
 and facilitators for conducting health disparities research with communities (Year
 1);
 - Review of the findings of the institutional assessment, which will help determine the CSAC's five year objectives (Year 2);
 - Assist in translating finding into an academic-community strategic plan for conducting health disparities research;

• Annually, the CSAC will review community priorities and reformulate its objectives and action strategies in order to provide guidance on innovative ways to enhance collaboration and communication among university and community partners.

Initial Progress and Challenges of the NM CARES HD

Progress

- Initial startup and staffing despite short notice of funding
- Support/partnership from the Center contributed to successful funding of 5 year NIH study of medical decision-making as contributor to disparities
- Submission of supplemental grant application to create partnership with NARCH and to expand CBPR expertise and activities in support of disparities research
- In-kind support for .25 FTE Native American faculty disparities researcher from Office
 of Community Health (working to get in place committed in-kind support for
 Hispanic/Native American faculty disparities researchers from Department of Family
 and Community Medicine and Department of Medicine)
- In-kind support for disparities pilot projects distributed by the Clinical and Translational Science Center (working to get in place committed in-kind support for disparities pilot projects from Office of Community Health and Cancer Center)
- Evaluation retreat and plan development

Challenges

- Timing of grant funding
- Limited time commitments

APPENDIX E

Working Perspective for Intercultural Partners: Guidelines for Effective Communication

The implementation of one of our key objectives, namely, the transformative approach of Community Based Participatory Research (CBPR) to cultivate scientific knowledge generated from research partnering with community groups to develop, implement, and sustain effective strategies to eliminate health disparities and inequities among Native American, Hispanic/Latino and other marginalized communities in N.M., will require us to make a paradigm shift in how we often think about cultural diversity.

A common practice is to approach cultural diversity as an "add on" a factor to pay attention to if funding and time allow. For the purposes of this project it is imperative that the inclusion of all cultures be at the center, at the heart, of how things are conceptualized and implemented. The point of this working perspective is to say that, not only must we build mutually beneficial partnerships with key community groups but that those partnerships be established in the paradigm of Intercultural Allies who mutually advocate for each other and find creative ways to guarantee that the community voice and perspective is included and integrated and sustained in the outcomes to eliminate health disparities.

The work of the Community Engagement Core(CEC) recognizes research that clarifies that community participants are the contextual and cultural experts in their own environments, capable of co creating an improved health status and quality of life. Community engagement in research and public discourse about science is a critical component of this co creation.

Intercultural Partners: Common Characteristics

Develop a cross-cultural ally connection based on mutual trust and knowledge of each other's cultural reality.

Have a shared knowledge of the power differential between the institution and the community. Both partners take a mediator role. This role is defined as "for the community but not against the institution".

Intercultural partners collaborate to find ways to ensure that the relationship between the community and the research institution does not degenerate into the stereotypical "all rhetoric and no credibility" pitfall.

Reciprocity and responsiveness is the magic ingredient which enables true cross-cultural relationships to succeed. Mutual understanding between the community and the research institution must result in actual changes, otherwise the legacy of distrust and antagonism will quickly reassert itself.

If the community representatives feel that they have to work too hard to be understood, or feel that only an angry voice will get attention, the relationship can quickly disintegrate. The cultural competence and ability of the research institution to hear (in the profound sense of that word), collaborate and act in partnership can transform and sustain the partnership.

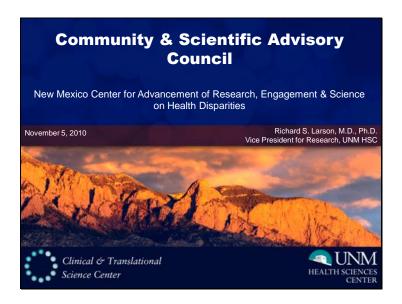
Mutual appreciation is another magic ingredient for intercultural partners. The practice of diversity asks us to "allow" the other to transform us. Working in an intercultural paradigm, if it's mutual, should feel mutually enriching.

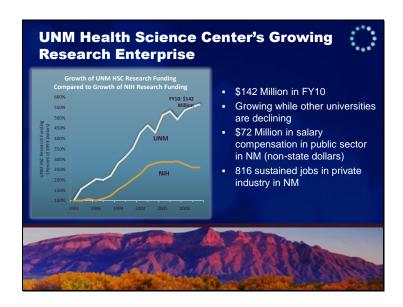
Intercultural partners are practiced in "conflict transformation". This means that inevitable differences or conflicts are often an opportunity for enhancing trust and understanding. The key is in the willingness to work out the differences. The expectation of conflict is part of the transformative perspective.

Roberto Chené, M.A. Director Intercultural Leadership Training And Conflict Resolution 1112 Calle del Ranchero NE Albuquerque, NM 87106 505-262-0264 Fax 505-255-0577 Cell 505-238-8031

APPENDIX F

Power Point-Overview of Health Disparities Research at UNM HSC by Dr. Larson

















APPENDIX G

Power Point- Overview of NM CARES HD and Barriers and Facilitators to CBPR by Dr.'s Wallerstein and Cacari Stone

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

Community and Scientific

Advisory Council Meeting (CSAC)

November 5, 2010

Presented by: Lisa Cacari Stone, PhD & Nina Wallerstein, DrPH

Best Western Rio Grande Inn, Albuquerque, NM





Why are we here?

Purpose

Convene the first meeting of NM CARES HD CSAC.

Objectives

- Introduce the CSAC with NM CARES HD's vision, values and goals and affiliated partners.
- Discuss & identify challenges and opportunities for building mutually beneficial partnerships with community groups to develop, implement, and sustain effective strategies to eliminate health disparities
- Review & discuss CSAC's leadership and advisory roles to the NM CARES HD.



Vision & Goal: A center to research <u>causes</u> <u>of and solutions to health disparities</u> in NM. Funded by NIH, Center for Minority Health & Health Disparities, 2010-2015.



Challenge: Health Disparities

Disparities in <u>health status</u>-differences in health conditions and in health outcomes: and

Disparities in <u>healthcare</u>-differences in the preventive, diagnostic and treatment services offered to people with similar health conditions, lack of access.

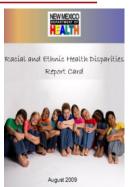
Disparities in <u>life opportunities</u> that affect health-differences in education and literacy, housing, social support, and environmental conditions (e.g., violence, bad air quality, and inadequate access to healthy foods).

Source: J. Geiger, Health Disparities: What do we know? What do we need to know? Why we need to know? What should we do? Chapter 9 in Gender, Race, Class & Health by A Schulz & L. Mullings.



Challenge: Disparities in Health Status

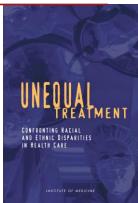
- Hispanics had the worst rates on 4 indicators (teen births, chlamydia, adults 65+ not receiving a pneumonia vaccination, drug induced deaths).
- American Indians fared the worst on 7 indicators (prenatal care, diabetes deaths, overweight among youth, pneumonia & influenza deaths, motor vehicle deaths, youth suicide, alcohol related deaths).
- African-Americans fared the worst on 4 indicators (infant mortality, adult obesity, HIV/AIDS, homicide).
- Whites had the highest rates on 3 indicators (suicide, individuals with diabetes not receiving preventive services, pertussis).
- Asian/Pacific Islanders had the highest rate on 2 indicators (hepatitis B and smoking).



Challenge: Disparities in Health Care

- Access-Lack of insurance coverage, health care providers and to preventive and specialty services
- Quality of care-Disparities consistently found across a wide range of disease areas and clinical services
- Disparities are found even when clinical factors, such as stage of disease presentation, co-morbidities, age, and severity of disease are taken into account
- Disparities are found across a range of clinical settings, including public and private hospitals, teaching and nonteaching hospitals, etc.

Smedley, B., Stith, A., and Nelson, A. "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care." Institute of Medicine (2002).



Challenge: Disparities in Life **Opportunities**

- UnemploymentNon-Hispanic White 4.0%
- Hispanic 6.9%
- Native American 6.2%
- African American 8.2%

Percent Persons Living in Poverty 18-64 Yrs

- non-Hispanic White 6.9%
- Hispanic 11.8% Native American 14.7%
- African American 11%
- Asian American 6.6%

Under 17 Yrs

- non-Hispanic White 2.1%
- Hispanic 9.3% Native American 10.7%
- African American 12.4%
- Asian American 3%
- Education- High School Diploma or more (25 years +)
 Non-Hispanic White 22.4%
- Hispanic 30.2%
- Native American 32.5% African American 26.4%
- Asian American 20.5%

Homeownership- Owner Occupied Units

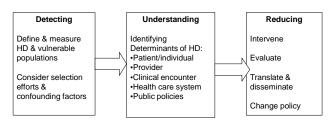
- Non-Hispanic White 72.5%
- Hispanic 67.9% Native American 62.3%
- African American 44.9% Asian American 65.1%

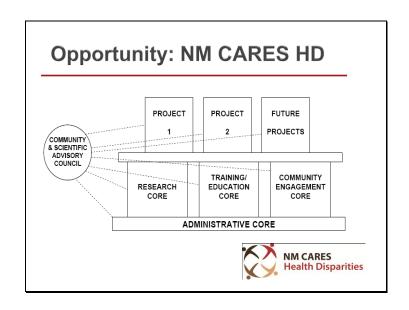
Source: U.S. Census Bureau, 2009 American Community Survey

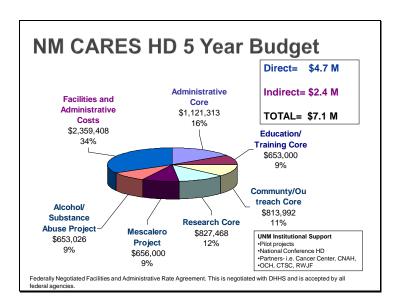


BUT, what if?...Moving from **Disparity to Opportunity**

- Serving as a change agent
- Providing education and leadership training
- Moving to multi-level interventions (community, systems & policy)







Administrative Core (\$1.1 M)

- · In-kind resources
- · Community and Scientific Advisory Council
- Consultants
- · Collaboration with UNM partners

R. Williams, D. Jones, N. Wallerstein



Research Core (\$827K)

The goal of the Research Core is to support and foster innovative research to address and improve health disparities in Hispanic and American Indian communities.

- Technical Support
- Research Clusters: groups to develop new ideas and methods for specific areas of health disparities needs

S. Verney, R. Rhyne, V. Sanchez, C. North, J. Averill, B. Skipper

Technical Support

- Materials Library
- Direct and external consultation with technical experts
- Provide training relevant to investigator's development

Research Clusters

- CBPR and Decolonizing Methods
- Race/Ethnicity and Health Equity
- Mixed and Novel Methodologies
- Translation of Research into Policy and Practice



Research Training/Education Core (\$653K)

- Goal interdisciplinary education to expand the number of persons working with the community in research on solutions to health disparities
- M. Borrego, D. Helitzer

- Faculty Mentorship Model
- Community Researcher Mentorship Model
- The Triad Mentorship Model (Combined Faculty and Community Researcher Mentorship Models)



Community Engagement Core (\$814K)

- Create authentic partnership between researchers and community constituencies for defining disparities research agenda
- Assess barriers/facilitators community engagement; action strategies to enhance trust & partnership
- Intercultural health scholars and summer institute
- Translate/disseminate findings to change practice/policy
- L. Cacari-Stone, N. Wallerstein, C. Hogue, L. Cowboy, A. Solares, A. McGough-Madvena

- Community and Scientific Advisory Council
- Community Liaisons
- Case studies of community research to identify barriers/facilitators
- Work with CSAC, HSC leadership on strategic plan
- Intercultural health disparities scholar team
- Summer institutes



Research Projects

- Alcohol/Substance Abuse Project (653K)
- Reduce prevalence of substance use disorders through intervention to increase screening and brief treatment in primary care
- CBPR mixed method study of barriers/facilitators in RIOS Net practices/communities
- Create and pilot test flexible interventions to increase screening/ intervention based on initial findings
- A. Sussman, V. Sanchez, R. Williams, K. Venner

Mescalero Project (\$656K)

- Apply CBPR methods to develop and test a method for screening for serious mental and behavioral health problems in adolescents in Native American community
- Pilot test intervention to reduce prevalence of these problems and of suicide
- R. Hough, S. Adelsheim, D. Altschul, CRCBH



What Next? Moving from doing research "in" to conducting research with communities.

ON IN WITH

CONTINUUM OF RESEARCH

Challenges for Health Disparities Research: The Promise of CBPR

- Challenge of bringing evidence to practice
 - Moving from efficacy to effectiveness trials
 - Internal validity focus insufficient for translational research
 - External validity: Contextualization/Implementation process
- Challenge of what is evidence
 - Empirical Evidence from the Literature
 - Practice and Culturally-based Evidence/Indigenous theories, norms, practices
- Challenge of institutional barriers
 - One-way translation orientation
 - Fragmentation of researchers
 - Institutional racism



Challenges for Health Disparities Research: The Promise of CBPR

- Challenge of lack of systematic input from communities of color on health disparities priorities and concerns
- Challenge of lack of responsibility back to communities and dissemination of findings from community perspective
- Challenge of sustainability of programs
- Challenge of lack of public trust and suspicion of research



Opportunities-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."

Source: W.K. Kellogg Community Scholar's Program (2001)



Opportunities-CBPR Principles

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

Source: Israel et al, 1998 and 2003



Opportunities: Principles for Tribes

- Don't plan about us, without us
- > All tribal systems shall be respected and honored,
- Tribal government review and approval prior to implementation
- 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

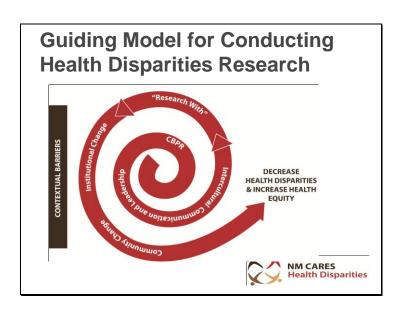
Source: Turning Point Collaboration for a New Century of Public Health, Spring Forum 2001, NACCHO,W.K.K Kellogg, Robert Wood Johnson Foundations; (1) Manson SM, Garroutte E, Goins RT, Nez Henderson, P.. 2004; Norton IM, Manson SM. 1996.



Opportunities: Principles for Intercultural Partners

- Make paradigm shift in thinking about cultural diversity to "inclusion at the center"
- Expand definition of partners to "Intercultural Allies"
- Build mutually beneficial partnerships
- Share knowledge and power
- Ensure authentic relationships
- Reciprocate and respond
- Listen and act based on deep listening
- Show mutual appreciation
- NM CARES Health Disparities
- Transform conflict to enhance trust

Source: R Chene, Consutant, Director of the Southwest Center for Intercultural Communication & Conflict Resolution, 2010



APPENDIX H

Handout- Strategies for Effective CBPR



NM CARES

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

A center to research the causes of and solutions to health disparities in New Mexico

Funded by the National Institute of Health's Center for Minority Health & Health Disparities, 2010-2015

Strategies for Effective Community Based Participatory Research

Wallerstein N, Duran B, Minkler M, Foley K.

"Developing and Maintaining Partnerships with Communities." In: Israel B A, Eng E, Schulz A J, Parker E A, eds. *Methods in Community-Based Participatory Research for Health*. 1st ed. San

Francisco, CA: Jossey-Bass; 2005: 31-51.

Four strategies have been identified as being useful in the development of community partnerships in CBPR. There is no sequence to the strategies as they can be used in conjunction with one another to develop and establish successful community partnerships and sustainable joint institutional structures.

Strategy 1: Reflect on Institutional/Community Capacities and Resources

Carefully assess resources and knowledge of both the participating community and research institution after thoughtful consideration of strengths, weaknesses, dangers or concerns that may be encountered.

Strategy 2: Identify most Appropriate Potential Partners and Partnerships within community

Identify/contact potential community partners keeping in mind practical, political, and personal implications that may be involved. Researcher must spend a considerable amount of time getting to know the community to develop the cultural humility needed to make mutually beneficial partnering choices.

Cultivate active participation of community members by minimizing existing community barriers to involvement (i.e. work conflicts, transportation, location accessibility)

Strategy 3: Negotiate or Reframe Ultimate Health Issue for Research

Initially reframe research questions within the context of partnership based on the community needs, concerns, strengths and resources.

Perform regular project assessments and make progressive shifts in research questions in response to careful consideration of cultural etiologies and mindfulness of community perspectives.

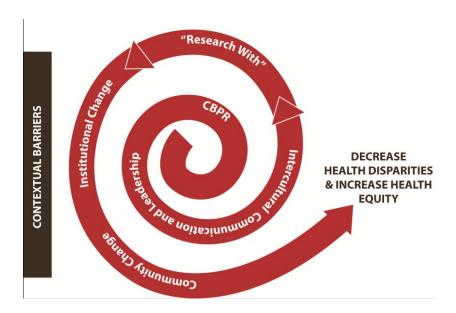
Strategy 4: Create and Nurture Structures to Sustain Partnerships through Constituency Building and Organizational Development

Develop new, collaborative institutional structures based on mutually agreed-upon principles that ensure cultural/community appropriateness and local ownership. Focus on the creation of sustaining partnerships and formation of community accessible research benefits.

APPENDIX I

Guiding Framework for Conducting Health Disparities Research with Communities in NM

INTERCULTURAL CBPR MODEL



CONTEXTUAL BARRIERS

- Socioeconomic inequity
- Racial/ethnic discrimination
- Inconsistent and disparate health care delivery
- Rural isolation and inadequate transportation
- Time required to translate research findings into practice

PRINCIPLES OF COMMUNITY BASED PARTICIPATORY RESEARCH

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 disseminated to all partners. CBPR involves a "long-term process and commitment."

(Israel et al. 2003, pp. 56-58)

- Cultivate sustainable partnerships
- Cooperate and collaborate
- · Foster bi-directional learning and reciprocal knowledge
- Incorporate community theories into research
- Develop interventions for diverse communities
- Create new systems and build local capacities
- Disseminate research and knowledge to all partners
- Commit to long term community relationships, research and action

Community and Scientific Advisory Council Meeting November 5, 2010 – Best Western Rio Grande Inn

- Redress power imbalances
- Increase health equity 2009:e1-e6)

(Wallerstein and Duran

Tribal Participatory (TPR):

- Seek tribal government approval for research, publication, dissemination
- Return data to the tribe
- Promote core values: trust, respect, self-determination, mutuality of interests, reciprocity

(Mason et al. 2004/Norton & Manson 1996)

Intercultural Partnership

- 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.
- Be aware of 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 based on:

Mutuality ⇔ Respect ⇔ Reciprocity ⇔ Authenticity ⇔ Trust ⇔ Collaboration

(Chené 2010)

ANTICIPATED OUTCOMES

Decrease in Health Disparities

Increase in Health Equity

APPENDIX J

Small Group Dialogues Worksheet

HOW DO WE GET FROM RESEARCH "IN" COMMUNITIES TO RESEARCH "WITH" COMMUNITIES?

FACILITATORS TO "WITH"	BARRIERS TO "WITH"	WHAT OUTCOMES WOULD BE DIFFERENT IF OUR RESEARCH ADOPTS A "WITH" MODALITY?

APPENDIX K

Evaluation Worksheet Summary



<u>New Mexico Center for Advancement of Research, Engagement & Science on Health Disparities</u>

V.

VI. Community and Scientific Advisory Council Meeting

VII. November 5, 2010

VIII. Best Western Rio Grande Inn - Albuquerque, NM 87104

EVALUATION – Compiled Responses

Please take a moment and fill out the following evaluation for this meeting. Your feedback is important.

Please rate each of the following statements by <u>circling</u> the appropriate number <u>on a scale of 1 to 5, with 5 being "strongly agree."</u>

being Strongly agree.		ongly agree			Strong Agree	•	Total Respondents
I understand the NM CARES HD's vision, values and goals and affiliated partners.	#	1	2	3 4	4 5	5 1	11
2. I understand the challenges and opportunities for building mutually beneficial partnerships with community groups to develop, implement, and sustain effective strategies to eliminate health disparities among Native American, Hispanic/Latino and other marginalized communities in New Mexico.	#	1	2 0	3 2	4 2	5 6	11
I understand the CSAC's leadership and advisory roles to the NM CARES HD.	#	1	2 0	3 7	4 2	5 1	11
4. The agenda was well planned and organized.	#	1 1	2 0	3 3	4 5	5 2	11
 I felt the advisory committee's opinions and feelings were understood and valued. Notes: understood and valued were circled with question marks 	#	1 2	2	3 1		4 5 2 5	11
6. As a result of this meeting, I understand my role(s) as a CSAC member.	#	1	2	3		4 5 3 3	11
I feel satisfied with what was accomplished at today's meeting.	#	1	2 0	3	4 5 4 2	NR 1	10

* no response

Please provide your opinion of the following questions.

- 8. How will the principles of CBPR and intercultural communication get us to do research "with" rather than "in" communities to reduce disparities?
 - Input and notes already provided
 - Focus on real community improvement
 - Continuing to have these discussions and bringing more perspectives to the council
 - I think to include or provide training and education to identified community members who will be your connection to the community to build from
 - There is a lot of work yet to do. We need to address the issues/concerns discussed
 - Principles well thought out
 - Hold colloquiums in the community that share research that employs CBPR involving health issues, politics of health care
- 9. What other principles or strategies need to be added?
 - AIM 2 providing training and a culturally centered mentorship model is key VP
 Office for Diversity goal. So is also expanding the number of Hispanic/Native
 American research faculty. Office of Diversity is interested in collaborations.
 - Build on existing community mechanisms
 - It would be great to include members of the project communities
 - Traditions, customs, beliefs, lifestyles, language, and what the university's thoughts and positions are
 - More integration with other groups within the university
 - Tran disciplinary approaches history of health disparities and politics of racism; culture (anthropology/sociology/political science); invite science community, they need to change their attitudes as well as health care providers
- 10. What do you think should be included in our next advisory committee meeting?
 - Core values
 - Specific project consideration and specific approaches with community
 - I think there were moments when your facilitator could have taken a more active role in managing group dynamics
 - Racism discrimination in relationship to health disparities
 - Bring in students to observe the process
 - A representative of newly immigrated Latino or person who works with that population
 - Meet in some unique communities

Thank you very much for you feedback and comments.

APPENDIX L

"Why it matters for members to be here?" – Discussion Summary

Responses from participants:

- To provide an indigenous perspective on the issue
- It's a social justice issue and we need to talk about social determinants of health
- To include the mental health-psychological perspective
- It has major impacts on clinical work
- Sovereignty and self determination implications cultural implications
- Focus on 'working with' communities approach
- Represent southern NM border health issues, reach out to all diverse populations
- Data access and indicators; teaching about cancer; sustaining an effort; synergies on how to deliver care the best way possible
- Substance abuse impacts on health
- Access to underserved areas; address social determinants; better collaboration and relationship; mobilize university's resource i.e. programs, depts.; let the community's health drive the work
- Why do disparities persist still amidst all the streams of funding coming in; reach out to the urban Native American community
- Community perspectives CBPR
- This group represents the key players to make the changes happen; bi-directional learning
- Research represents future solutions, a center focused on health disparities
- Knowledge can advance social change and the work needs to be meaningful

APPENDIX M

CSAC Meeting: Summary Matrix of Key Themes for Action

Theme	Barriers	Facilitating Strategies	Outcomes
Coordinate Intra- Institutional Communications	 Minimal Interdisciplinary Communication Incomplete understanding of CBPR→Lack of institutional buy in Traditional Research Model- Inflexible procedure and timelines Fragmentation between HSC and Main Campus 	Communicating in a bidirectional manner Assessing and identifying overlaps or intersections within the institution's current research efforts Conducting forums to dialogue about possible solutions	Collaborative Research
Increase Minority Faculty	No communication with recruitment of main campus faculty	 Increasing advertising of Disparities Center and Research Efforts on main campus Recruiting more minority faculty Building research and overall capacity of minority faculty 	Improved Relationships with Communities: Voice of community will be heard because faculty are from the communities Improved Capacity of Minority Faculty: Increased sharing of cultural knowledge and experience → Improved community capacity
Eliminate Rather Than Manage Health Disparities Make the Community an Equal Partner	Absence institutional willingness to address tough questions/issues arising from community based projects Unreasonable institutional expectations of community based research efforts Use of preconceived research questions not applicable to participating community Researcher notion of knowing it all-no willingness to get to know/understand community Translation Issues (language, cultural, contextual, technical/scientific terminology) Inflexible IRB process not conducive to community ownership/participation	Utilizing and fostering the understanding of social determinants as the cause of health disparities as a tool to change health outcomes Continuing to address tough issues/questions as they arise Investing time up front to build relationship with community by gaining understanding and appreciation of all its members and components Respectfully listening to community and understanding community definitions of issues Providing opportunity for bidirectional communication on community needs Partnering community and institutional core values Recognizing and utilizing existing community strengths, social structures and current research efforts Training community to actively participate in research process, propagate community ownership	

Identify Best Practices	Ignoring community needs Not investing in relationship building with community Discounting results of current research/project efforts in community	Investing time to learn about the community and to identify and compile information on what is/has worked	Creation of Framework to foster community ownership and enhance development of other CBPR projects
Address the Institutional Practices Barring Community Support	 Fragmented research efforts Established research incentives→Inadvertently discourage community based research Deficient incentives for conducting/participating in community based research 	 Propagating widespread Institutional buy-in to support sustainable change to research approach/faculty requirements Improving Interdisciplinary communication Improving institution wide understanding of CBPR principles and positives of community based research Increasing Faculty use of CBPR principles and engagement in community based research 	Improved institution/community relationship and improved health outcomes specific to community Shift from doing research "in" to "with" communities

APPENDIX N

<u>Compilation of Group Responses to the question – What outcomes would be different if our research adopts a "with" modality?</u>

Group 1 –Things get better and that there is real improvement. How can the center help and what changes can be made to the traditional research model. People should be trained to themselves and take ownership. Whatever is built and begun should be sustained.

Group 2 - Everything is shared and presented jointly between the communities and researchers. Resources need to be made available to community to create opportunity for them to achieve and improve their own health outcomes. Learning the process is also a resource that gets at outcomes. The center is better equipped to translate to other communities with other issues.

Group 3 - Communities are being invited to participate in the CSAC discussions and that meetings are taking place IN the communities. The tendency is to focus on issues first, widen the focus to bring out the community's strengths and help the community understand how to harness these strengths in the change process and give the community a voice. Gain understanding of how current health disparities are being dealt with by community members and use this information in the formulation of solutions and research efforts. Build relationships with the communities first, there is a period of learning and understanding and accepting strengths that need to happen first. Until a researcher understands the significance of cultural practices/teachings, for example traveling with a medicine bag, there will never be understanding of what the strengths and resources of a community are.

Group 4 – Respect is valued and is used as the foundation for the initiation of community based research. The education/communication must come ONLY until respect for the community has been established. There needs to be an understanding of cultural perceptions, beliefs, and societal structures. Use the NM CARES HD as an organizing entity/principle in the community. There are parallel activities happening and there is opportunity to co-invest in core functions. Seek out and understand role of competing programs/projects in a community and make an effort to coordinate the work around finding solutions to the disparities. Avoid community exhaustion by not duplicating efforts. Utilize the primary language spoken in the community to make sure communication is appropriate and respectful.

Group 5 – There is a coordinated effort among the researchers and them knowing their own strengths and what connections they have to resources i.e. services, education, helps to pull community together for increased cohesiveness. Use the institutions' experiences (UNM, DOH, and others) to assess their own barriers in working with communities. There are a lot of advisory committees. Span the gap between beliefs and practices being used and common to the community. Trust and understanding would help the research be more complete.

APPENDIX O

Compiled Responses From Small Group Dialogue Worksheets

- I. Facilitators to "with"-
 - A. Investing resources and time to develop relationship with community through open dialogue and respectful listening
 - B. Investing in the community to make sustainable changes to whole community. Looking beyond HD's, what strengths of the community can be reinforced to make research easier/more successful
 - C. Taking time to assess fragmentation in institutional efforts and how these can this can be mended for efficiency –Identify possible points of collaboration.
 - D. Understand broader context of problem. Framework should be based on issues specific to participating community.
 - E. Maintenance/Incorporation of two sets of core values (Community/Institution)
 - F. Bi-Directional Communication
 - G. Utilization of Communities Native Language
 - H. Utilization of existing community structures
 - I. Community=Partner vs. Project
 - J. Create buy-in by identifying and working with respected member of community.
 - K. Understanding of long term commitment to community required to make sustainable and impacting changes
- II.
- III. Barriers to "with"-
 - A. Weak community presence on CSAC-Bring in more community leaders to meetings
 - B. Funding-Always goes through the University-How can control be given to community?
 - C. Traditional Research Model
 - D. Community Readiness?
 - E. Disconnect between goals of Institution and Needs/Wants of community
 - F. Institution taking control of problem definition. Not listening to community.
 - G. Language differences, technical terms. Communication must be tailored to communities native language.
 - H. All knowing attitude of institution
 - I. Lack of flexibility-Time, Leadership
- IV.

- V. Outcomes to using a "with" modality -
 - A. Modification of western model or research to encourage the use of "with" models. Institutional policy changes (IRB, Incentive system for faculty etc.)
 - B. Recruitment of important community members and community "buy in" created necessary to form sustainable respectful relationships in communities of interest
 - C. People will be met in their community environment and concerns will be heard
 - D. Modifications to CBPR approach: Standardize asking community "How do we merge with current efforts and projects?"
 - E. Research will be shared/presented jointly by institution AND community
 - F. Researchers will be equipped to work in many different communities
 - G. Better outcomes- partnerships will make way for accurate and honest coassessment of issues and honest answers to research questions and stronger responses to projects
 - H. Resource Sharing between community and Institution
 - I. Community will drive research process
 - J. Community will be a PARTNER vs. a PROJECT
 - K. Best practices defined for creating sustainable projects/changes-Procedure for what happens after grant money is gone etc...
 - L. Process=Outcome → working definitions of overarching lessons and principles common to all center projects
 - M. NM CAREs HD will be a sustaining entity and used as an organizing principle to bring together

APPENDIX P

Progress In Achieving Specific Aims

Report to NM CARES HD CSAC 11/5/10

- Aim 1. Establish a multidisciplinary research center that advances the science of interventions to eliminate health disparities among Southwestern Native American and Hispanic communities.
 - Develop research to test interventions aimed at eliminating health disparities in these communities
 - Project 1 Focused on early identification and treatment of serious behavioral/mental health concerns in Mescalero, using CBPR; staffing
 - Project 2 Focused on increasing screening and brief intervention for substance use disorders in primary care, using CBPR; staffing
 - New RO1 Medical decision-making contribution to disparities and solutions
 - Staffing delays
 - Link with UNM programs in support of NM CARES HD goals
 - Ongoing meetings Cancer Center, Clinical and Translational Science Center, Office of Community Health, RIOS Net
 - Met with RWJ Center for Health Policy
 - No linkages with main campus programs
 - —Use systematic evaluation processes to continually improve the Center
 - Evaluation retreat to plan; followup in progress
 - Not yet operational
- Aim 2. Enhance the ability of UNM investigators to compete for NIH individual, disparity-related research grants.
 - —Provide critical research infrastructure to facilitate individual research projects
 - Available technical consultation, funding to support needed consultation
 - Limited consultation qualitative, statistical, clinical areas
 - Not yet being used sufficiently; lack of awareness
 - —Integrate NM CARES HD with UNM research resources
 - Ongoing meetings with CTSC, Cancer Center
 - No linkages with main campus programs
 - —Provide training opportunities and a culturally centered mentorship model that will increase the number of disparities researchers
 - Cataloging relevant current training in UNM
 - Planning for summer undergraduate disparities research interns
 - Initial planning for mentorship model
 - No undergraduate interns this summer due to timing of funding

- —Expand the number of Hispanic/Native American disparities research faculty
 - .25 FTE Office of Community Health
 - Troubleshooting 2.0 FTE commitments from Department of Family and Community Health and Department of Medicine
 - Challenges of matching funding and positions with availability of candidates
- Provide pilot project research funding in support of innovative disparities intervention research
 - CTSC funding for disparities research pilots awarded in excess of commitment
 - Office of Community Health, Cancer Center planning for pilot programs in early planning stages

Aim 3. Build a partnership, dedicated to research on health disparities, between UNM investigators and community residents in indigenous Native American and Hispanic communities.

- Strengthen communications processes in support of research on disparities
 - Award publicized through HSC public relations radio and TV
 - Presentations to UNM groups begun
 - No systematic communications strategy to increase awareness of problem of disparities and solutions
- Increase disparities research skills, awareness of activities, and partnership with community through a National Conference on Health Disparities
 - Planning beginning for first conference in Spring
- Expand community-based participatory research (CBPR) methods in health disparities research
 - Participation in CBPR seminar series
 - Submission of supplemental funding request to further build local expertise
 - CSAC meeting
 - No on-site community outreach yet
 - No partnerships with community groups

APPENDIX Q

CSAC's Recommendations and Guidance on NM CARES HD Activities

- 1. What is your assessment of the progress to date in achieving aims and are there any suggestions?
 - Not knowing what the grant entails makes it difficult to provide feedback on progress.
 - Challenges to recruiting ethnic minority faculty: Availability and how to move the institution towards recruiting and keep these individuals in the system as faculty members.
 - It appears as though there are no partnerships with community, raincloud group.
 - Nina asks: As a Center, how do we create an environment or structure that will eliminate the fragmentation and get "unstuck" or bring us all together around our disparities research agenda? (connections, relationships, knowledge)
 - Start today and move forward, we are not building a road but working to merge roads into a freeway. One person's fragmentation is another person's rich diversity.
 - i. Decide what questions is being asked and who is being asked? Approach and question will differ between communities. Use different "tools" for different communities
 - ii. How can we merge with current efforts in place in a community to decrease their disparities?
 - There are also different sectors to consider, specifically the non-profit sector and their vast resources. The layers and structure
 - Everyone is trying to keep up with what they are doing and there is not a designated entity to organize the defragmenting of efforts. A shift in institutional efforts should be made to bring together available resources and programs in the community.
 - i. The view of the community on specific issues should be gaged to assess if collaboration can improve effort to solve specifically targeted issue.
 - Emphasis is that we must understand where the need is for assistance in interfacing and collaborating.
 - Multiple small changes must be made. Great action has been seen when a community need is voiced and addressed by an institution, especially when the institution can be in tune with the community and build the most appropriate and beneficial relationships.
 - i. You must respond to all community calls and allow the community to be the driver of the research to address their specific needs.
 - ii. Requests must be shared between university partners and departments to familiarize everyone with communities to increase response time.
- 2. What comments on development and function are there so far of the NM CARES HD cores/projects?
 - It is fairly clear that the thrust of the programs so far are more about managing disparities as opposed to eliminating disparities. How can the center be an

- advocate for there being attention paid to the underlying social determinants of health disparities in NM?
- Request for assistance to develop an alternative to randomized control trials.
 Some cultures do not condone the approach of the unequal treatment of the control and intervention groups.
- Visibility of the center must be increased among faculty on north campus as well as main campus in order to bring a greater richness to the information being collected by the NM CARES HD center. Shift focus and begin to reach across campus to bring in the ideas and input of more faculty members. Ensuring that everyone that NEEDS to know will in fact know about the projects and center.
- With healthcare reform there is going to be a problem with healthcare among native Hispanics versus immigrant Hispanics. Efforts should be focused on exploring the new issues that may arise from this new and growing Hispanic population and work towards understanding and working to continue reform to address this new issue.
- Roberto- Commenting on multicultural institution dynamics- What tends to get lost is the uniqueness of each culture. The web of the institution causes a loss or dilution of this uniqueness. A creative separating or highlighting of the uniqueness of the ethnic minority scholars and the value of their different perspective or back ground must take place to allow the resource of their understanding to be accessed and incorporated into the greater knowledge of the institution. Open dialogue and careful listening must be a part of this highlighting.
- 3. What recommendations are there on integration with other research centers at UNM?
 - Center must prepare for questions of why other disparities (age, race, orientation) are not directly addressed by center. Specific disparities of communities must be understood, including the disparities of disenfranchised groups that may not be represented at meetings etc.
 - Address the limited access to primary care, what is causing the higher level of
 education to be partnered with greater % of those in poverty in rural ethnic
 communities. Understand the internalized consequences and effects of being a
 member of an ethnic minority group and how it can set an individual apart in a
 negative fashion.
 - The capacity to speak transparently about racism and discrimination is a skill that must be developed so the center's work is not seen as "pretend".
- 4. How is the NM CARES HD aligned with the health disparities research priorities of both UNM and the broader community?
 - The issues of what works/What interventions are most likely do decrease this
 condition of disparate health among ethnic minorities? Must be carved out to
 provide strategies and solutions at the national conference and other forums.
 - Why is the creation of a center being used when there are already so many centers existing on campus? Why not utilize this grant as a way to create a new approach or structure to the effort to solve the issue of health disparities. Why not redefine the word and how the work is done?

- Does the research have the buy in from the University to support the findings of the center? what will happen when the findings
- What are the options the center has to not get shut down when the research and projects get too risky?
- Where are we going to find the money to continue efforts of the center? How will the center provide aid to make the application of the new knowledge sustainable in communities?
- Organizational culture- Is the environment conducive to figuring out where to start and approach the problem of health disparity? How does the alternative or non-traditional research of community members and groups fit into the knowledge being accessed, valued and utilized in the process of creating the center?
- Political problems can arise that are aside from funding problems in regards to sustainability. Issue: Sometimes the evidence does not matter because the power structure that exists will not acknowledge it. What are the strategies that must be used to deal with the political reality that exists?
- The center could be driving force to change the institutional structure and remove barriers to health disparity research
- 5. What should be the priorities for pilot project funding?
 - Question 5 appears to be counterintuitive to the overarching goal of the center. It plans research without the communities input. Perhaps the question should be asking for suggestions of:
 - i. What mechanisms must be better in place to hear the needs of communities to shape research efforts and determine pilot projects?
 - Sometimes individuals start out as members of communities but with more work in research can be removed from communities but still have connections that must be utilize
- 6. How effective have the initial community engagement efforts been and what should be the next steps?
 - No specific data available