# Centers for Disease Control and Prevention (CDC) Agency for Toxic Substances and Disease Registry (ATSDR) Tribal Consultation Advisory Committee (TCAC) Rapid City, SD

# April 2-4, 2008 DRAFT MINUTES

Members Attending	Area/Agency Represented	Areas Not
Represented	• • •	Alaska
Linda Holt, co-chair	Portland	Phlockix
Jefferson Keel, co-chair	(Oklahoma) NCAI	Phoenix
Roger Trudell	Aberdeen	Bemidji
Lester Secatero	Albuquerque	Billings
Brenda Shore	Nashville	
Chester Antone	Tucson	
Rhonda Farrimond	TSGAC	
Robert Moore	DST	
Jerry Freddie	NIHB (and spoke on behalf of Navajo)	

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NIHB Staff
Helen Canterbury
Stacy Bohlen
Lawrence Shorty
Colette Keith

Mike Snesrud
Dr. Stephanie Bailey
Annabelle Allison
Dawn Satterfield
Tim Hack

Other Guests

Elaine Dado, NPAIHB
Kerri Lopez, NPAIHB
Vanessa Tibbitts
Stacey Ecoffey, DHHS, IGA
Jacqueline Left Hand Bull

Corey Smith

Ed Clairmont, Rosebud Sioux Tribe

Jody Zephier, Yankton Sioux Tribe

Greg Zephier, Yankton Sioux Tribe

Tim Joaquin, Tohono O'Odham Nation

Bridget Caniff, NPAIHB

Art Zimiga

Rob Runnels

Favian Kennedy

Christine Reinke

Adeola Jayeola

Bridget Caniff, NPAIHB
Karen Reifel, Rosebud Sioux Tribe
Ronald Valandra, Rosebud Sioux Tribe
Skyla Two Eagle, Rosebud Sioux Tribe
Alvina Wells, Three Affiliated Tribes
Beverly Hall, Three Affiliated Tribes

Randolph Runs After, Cheyenne River Sioux Tribe Arlene Blackbird, Cheyenne River Sioux Tribe

#### DAY ONE – Wednesday, April 2

#### **Opening Prayer and Introductions**

Jefferson Keel opened the day with introductions at 8:30 AM. Robert Moore provided a blessing for the participants.

## **Approval of Outstanding 2008 Meeting Minutes**

Motion made by Robert Moore to move minutes review until later. Motion Seconded by Lester Secatero. By consensus, it was decided to move minutes until later on the agenda.

Review of meeting agenda.

**Mike Snesrud,** introduced Dr. Stephanie Bailey, Chief of the Office of Public Health Practice. Dr. Bailey will be in attendance today and through mid-day tomorrow to enable her to participate in the site-visit to Pine Ridge. Please engage her in dialogue.

#### **Review of Tribal Consultation Sessions and Meetings 2008**

**Lawrence Shorty,** stated that NIHB will have the report of entire transcripts available from the February 28<sup>th</sup> Consultation Session soon. He reviewed the issues identified from the evaluations.

**Linda Holt**, shared a comment made to her about the Consultation Session, was that it was nice but how will it benefit tribes? How will CDC review the testimonies provided and work with tribal governments to address concerns stated. She stated that TCAC needs to review the Consultation minutes from 28<sup>th</sup> and the NIHB written report of the testimonies, consider critical issues raised by tribal leaders, and then determine how to frame these recommendation to CDC senior leadership on behalf of tribes. When reviewing minutes and report, TCAC needs to strategically consider the prioritization of AI/AN public health needs to CDC.

**Lawrence Shorty**, shared that NIHB is working with CDC to track and inventory all recommendations made and CDC response to those recommendations on a quarterly basis. This inventory will be posted on NIHB's website and distributed to area health boards so more tribal leaders are made aware of TCAC action steps and interactions between Indian Country and CDC. NIHB is working on behalf of tribes to increase access to CDC resources.

**Linda Holt**, directed participants to page 4, last page of evaluations. For homework, she directed members to review minutes and evaluations of the meetings to guide discussion

of how TCAC can outline future TCAC Meetings and guide TCAC in identifying a more strategic approach to maximizing TCAC time and outcomes. .

**Robert Moore**, introduced himself and stated that he is representing the Direct Service Tribes here during this meeting and consultation. He said that during the HHS consultation, there was a concern raised that when county statistics are used to support state block grant funding and other federal awards made to states, resources seldom filter down to initiatives supporting tribes and AI/AN populations.

**Linda Holt**, said that is something she has been pushing CDC to look at and assume a greater role in assuring that CDC resources going to states actually can be documented to benefit tribes. She encouraged Tribes to bring examples forward of when their tribes have attempted to work with states around program initiatives funded by CDC. CDC has stated that as part of their Tribal Consultation Policy, they have a role to facilitate the dialogue and partnerships to be more inclusive of AI/AN tribes.

**Robert Moore,** said Homeland Security compels states to do outreach and engagement of tribes. This has not seemed to increase access for the tribes or for tribes to know and understand what federal agency they need to talk to regarding a specific public health emergency preparedness (PHEP) activity. He wondered if CDC could facilitate the dialogue more with states, especially in relation to PHEP and pan flu programs.

**Linda Holt**, raised again the issue that tribes be eligible to receive PHEP funds directly rather than dollars going to states. It has continues to be an issues when federal dollars go to the state and the manner states implement for engaging tribes being left up to each state's discretion. She emphasized the need for tribes to have access to the PHEP dollars. Linda also raised the need to talk more with the COTPER/DSLR in relation to the upcoming state PHEP continuing applications that DSLR receives. Linda requested for the TCAC to continue to be more involved in content of the division's program guidance going out to states and in reviewing letters of consensus DSLR receives from tribes or the area tribal health boards. She has understood from her dialogue with carious tribal leaders that it is AI/AN state employees who are writing the letters of concurrence rather than a tribe or the area health board. She thinks some states have been sliding underneath the radar and thereby having no accountability for how they are or aren't engaging tribes.

**Robert Moore**, brought before the TCAC an issue related to CDC diabetes funding. He distributed an article that had just been printed in a Denver paper. It stated that a Denver PhD student received a 4.2 million dollar CDC grant to work on diabetes with AIs. He is wondering,

why such a large sum of money went to individual student? Also, what kind of consultation was done with tribes by CDC guiding this effort as any work with diabetes certainly impacts AI/AN? Tribes are at the will of federal agencies and the OMB. If this work funded is ineffective, it potentially could be a detriment to tribes. Robert raised the idea of how critical it was for CDC to discuss how tribes might help in this effort, both with the grantee and the student's effort. He cited as an example of tribal capacities, a Rosebud initiative in diabetes effort. Rosebud is looking at Behavioral Health areas and

have developed their own approach. This approach does not necessarily fit under "western model" but feels it is an approach that will work effectively. CDC, universities, and PhD students need to know that there are nuances in tribal communities that need to be a part of this study.

Linda Holt, stated that TCAC was not informed about this funding opportunity from CDC and certainly one like this should have been circulated. TCAC should be made aware of funding opportunities like this, ideally being consulted early in the planning process to be able to suggest verbage in the development of the program announcement. TCAC and the tribes continue to ask CDC to inform them of funding opportunities in advance and as they become available. To allow them as much time as possible to write competitive applications. Many tribes still are not able to utilize grants.gov to be appraised of these opportunities, what additional could CDC do to inform them. She also raised the issue of how many stream universities, like the University of Colorado, get funded to do work with tribes when tribes applying for the same funding do not. She also raised the issues about the University of Colorado using tribal data they have secured without the tribes' permission for work under this grant.

**Robert Moore,** said he understands that CDC is trying to "get biggest bang for the buck" but is that the best way to more effectively partner with tribes and develop culturally relevant approaches.

**Jefferson Keel,** said that is a pattern in past several years throughout federal government not just CDC. NIH, etc. The large universities, state health departments, and health care organizations are tied into the government systems so they get an email notice of the funding opportunity when tribes and tribal organizations do not. Universities, like the U of Colorado get the information, apply for the grants and are awarded those without tribal consultation or concurrence. Dollars that often are set aside for each racial and ethnic population end up going to non-Native institutions who have full-time grant writers and who write applications to 'benefit AI/ANs' but are not. He felt it was almost insulting.

**Robert Moore**, said that this is exactly his point. In the Great Plains, we have our own universities, (Tribal Colleges and Universities), and collect and keep our own data, etc. We could do this work, we could own it from the tribe, not have it be down by a non-native institution using data the HIS has collected on us and uses without our explicit permission.

**Jefferson Keel,** said with regard to assuring tribal input into the process, that the TCAC and tribal leaders want Stacy Ecoffey, IGA to help assure that tribes are consulted up front in the planning stage and that tribes get the information about all funding opportunities. It seems we have reached a point, where tribes need a centralized point-of-contact and place where they can go to for information, maybe NIHB. All tribes need to have access to this information in a timely manner and federal agencies like CDC, need to consult with us per the HHS and their agency tribal consultation policies. On another note, Jefferson raised the need of IGA to get involved with all the HHS agencies to assure that the panel review committees that read and review applications need to have

AI/AN professional. If these panels are the one that are ranking and recommending to divisions who should be funded and who should not, tribes need to be assured that what a applicant is writing in their application is factual. AI/AN representation is essential to the process.

**Robert Moore,** asked who owns that data that is acquired by a grantee relative to a particular tribe or tribes? If you go to CDC archives you will see AI/AN related information inappropriately having been used, used without permission of the tribe. This is great opportunity for TCAC to become involved in research activities with CDC.

Linda Holt, communicated some tribes and tribal organizations have had concerns with the University of Colorado in other federal funded grant projects and what they actually wrote in their application they were going to do. She and others express concern regarding use and ownership of tribal data collected through tribal diabetes program funded with resources from IHS. Linda indicated that the Area Health Boards and individual tribes and have tried unsuccessfully to get this diabetes data in a uniform manner. She issued caution about CDC working with mainstream universities to do public health practice without the endorsement of the tribes themselves. Endorsement by IHS doesn't pass as tribal endorsement, as IHS is just another federal agency. Another issue continues is why tribes are not eligible for all CDC funding opportunities. We've got SAMHSA to assure eligibility, CDC needs to assure that tribes are eligible for any grant that state is eligible to apply to receive.

**Robert Moore**, challenged the TCAC to request more information about this large diabetes award going to the University of Colorado. Tribes want something that will be useful for all of Indian Country, not just an individual doctoral student.

**Linda Holt**, asked Mike to find out the history behind this award and get the information to answer the many questions and concerns voiced by TCAC members.

**Mike Snesrud,** said she will immediately check with the Division of Diabetes and PGO to find our more specifics about this award. CDC has many grants out, so she doesn't recall this one in particular but will get the information requested. CDC has just begun the journey of consulting and working with tribes. CDC has made commitments and are implementing activities and actions to work more effectively with tribes. Prior to the this last year, when CDC hosted it's first Biannual tribal Consultation, CDC often were not allocated much time at the HHS regional and national consultation meeting agendas. Primarily this was because many tribes were unaware of the potential resources and expertise CDC had to offer. As a result of the implementation of the CDC Tribal Consultation Policy and the establishment of the TCAC, more tribes are now becoming aware of who and what CDC has to offer. We all need to remember that tribes have been educating, working, and partnering with HIS for many years to get things to where they are today. CDC has now willing stepped forward and desires to do more with tribes to address public health needs in Indian Country. Through the TCAC we are having some important discussions that need to be carried by you back to other tribes. We need TCAC, Area Health Board, Tribal Epicenters, and NIHB to help in enhancing

communications and disseminating information. Consultation needs to focus on the dialogue and collaborative planning. Testimonies are necessary because tribal leaders articulate specifically what the issues are but it is in the discussion between us that will allow and assist us to develop and implement steps that take us to new levels in had we work together to address health disparities and health status. CDC has worked for many years to establish relationships with states and academic universities, now we are putting efforts to establishing relationships with tribes also. At the February Consultation Session we provided charts and graphs to you relative to CDC and to tribes. We intended to continue to make our budget allocations to Indian country more transparent. Please know that as of FY 2007, all tribes and tribal organizations are eligible to apply for any funding opportunity unless congressional language provided to CDC with funding states limited the eligibility to only states. In the case, where congress has mandated or earmarked dollars that only states can apply to receive, some national program office such as the COTPER/DSLR and the NCIRD/Immunization Services Division have developed stronger language and accountability for how states receiving CDC dollars need to assure tribes will benefit in documentable ways from those resources. Where this may seem inadequate, please understand that CDC desires to get more needed resources and services to AI/ANs.

During this past FY, CDC developed an inventory of TCAC recommendations provided to CDC, this inventory was distributed to you previously and is posted on the NIHB website. The intent of this inventory is that it can be used as a tracking tool for you to help CDC in monitoring our response to your recommendations. It can and should be updated as the TCAC develops and submits new recommendations to CDC. In addition, Mike shared OMHD is developing internally within CDC a Center Leadership Council Execution Plan that will assist and enable more broad based and coordinated response to TCAC recommendations.

**Robert Moore**, again brought attention back to the CDC funding going to the University of Colorado and asked that this specific case be a test scenario for tribes and CDC. TCAC has identified concerns about this new CDC funding initiative and wants to receive answers back to questions raised. Robert offered that there are many large DSTs and other tribes doing excellent work in diabetes areas. Their experience and expertise would be a benefit to this study/project.

**Mike Snesrud**, committed to identifying which operating unit is connected to this funding and engage them in responding to TCAC concerns and questions. She also encouraged individual TCAC members to bring additional concerns to CDC's attention at any time and not to feel they had to wait until a TCAC meeting to do so.

**Stacy Bohlen**, said NIHB will do what they can to support these efforts. She is wondering if this was an earmark from Congresswoman Diana DeGette's office. Stacy communicated that without saying the words, this is talking about SDPI that flows out of IHS. NIHB is concerned about who did or did not give IRB approval. She committed to look into this today with Kelly Acton. She expressed that it should be a requirement of any research project in Indian Country to have tribal IRB approval. Indian Country now

has Tribal Epicenters and the capacity to do this work. The issue of block-grants and tribal set-asides continues to be brought up. Tribes continue to state clearly that they would like federal resources going directly to them rather than states as states continue to use AI/AN health disparities within their states to demonstrate needs and get funding and then not design any documentable activities that show tribes benefitting from or getting any resources. She recommends that NIHB do a white paper on this.

**Robert Moore**, said another issue is how states report out statistics. States identify and report out data and statistics by county but not by tribes. Most importantly, Robert wants the message to be clear, that federal agencies working with states need to collect and report data that is more specific to tribes. He is assuming that TCAC would also want to be certain that this work move forward but TCAC wants to be involved in these discussion through its relationship with CDC.

**Lawrence Shorty**, shared he in previous positions has worked with research institutions. Recently at the end of March, there was CDC research conference where participants were discussing data ownership. He understood that it was stated that data collected by universities is owned by them. Lawrence will follow up on this and potentially at another upcoming TCAC meeting, the membership can requests to hear more from CDC Research unit and stakeholders.

**Linda Holt,** said that TCAC should get information on all grants CDC allocates to tribes or to states and universities whose scope of work includes tribes and Native populations.

**Lawrence Shorty,** directed TCAC members to the session in their booklets that contains all the testimonies presented at the February CDC Session.

**Linda Holt**, asked group to review those tonight and plan to discuss them at the next TCAC quarterly meeting. TCAC began discussion of when and where next TCAC meetings should be, whether to have quarterly meetings or less frequency, and where will meetings be hosted and held?

TCAC again requested PGO training to be scheduled to occur at either the NIHB Public Health Summit, the next TCAC Meeting, and at all CDC Consultation Sessions. Mike will bring this request back to PGO and get at least one training scheduled for this FY.

**Jefferson Keel,** said it would be important to latch on to other conferences that are going on and piggy back with them. He said, "Let's go where the Indians are!" Further discussion occurred that members needed to think more about this, and for right now, determine where the July 29-30<sup>th</sup> meeting would be held.

**Jefferson Keel**, welcomed Dr. Bailey and afforded CDC time to provide some updates.

**Mike Snesrud**, introduced Dr. Bailey stating that Dr. Bailey directs an important office whose works is of importance to tribes. Dr. Bailey reports directly to CDC Director, Dr. Gerberding.

**Dr. Bailey**, said fortunately for her, the Office of Minority Health and Health Disparities is being realigned to be in the Office of Public Health Practices. She communicated the important role of the CDC Senior Tribal Liaisons so that tribes know there is one office and official points-of contact when tribal entities are calling into CDC with questions. She is wants to understand who the tribal stakeholders are what existing structure is there to communicate and share information between CDC and the tribes. She communicated she had seen the AI/AN Portfolio that had been shared with the TCAC and other tribal leaders at the Consultation Session. She raised the questions, "How do we effectively use what we have and know to leverage the agency for the right results". She shared that this kind of financial transparency is just know being made available to tribal leaders. Tribes need to know that in any given year there are at least 17,000 transactions going out of CDC. CDC has only a finite amount of money; sp we must be strategically smarter in where we are investing to get the most impact. CDC is talking with many stakeholders to determine what results we want together and how we more effectively use these monies. No one entity, including CDC can solve all public health problems. CDC therefore has chosen to collaborate with many partner and influence, leverage, and create strategic vision together so we can collectively address public health needs. Dr. Bailey said she understood that tribes have a government to government with the federal government. Tribes should attend CDC strategic planning sessions and be a visible and known entity. There needs to be a "meaty" discussion between CDC and tribal leaders. She stressed that this discussion needs to be thoughtfully planned so it isn't just another "meeting" and the timing of when this occurs is critical. She also said that: access to information (data) is critical, tracking effectiveness of current funded programs is important, and that she is planning a tour of Indian Country. She communicated that she is open to dialogue and suggestions from the TCAC. She prioritized the need to remember the importance of public health practice as a focus and how she would commit to have CDC engage and include tribal health departments representatives in discussions and site visits to county and states.

**Roger Trudell,** said if Dr. Bailey could be present for any extended period of time, she would see that when tribes gain ground, they loose funding. Roger also shared that it is necessary to try and understand why it is that AI/AN tribes in the Aberdeen Area experience disparities greater here than in any other part of country.

**Dr. Bailey**, asked group to create a strategic framework for dealing with disparities. The framework would be vetted throughout Indian Country. She explained that things work in cycles. It is not enough just to leverage health agencies, but must also leverage agriculture, commerce, and any area where policies are made.

**Jefferson Keel,** said disparities exist because we have allowed them to grow. Part of the problem is funding but the problem we have in this country is that we don't know what problems exist in our own backyard. If you look at poverty, look at all the factors that are

tied to it and the health disparities in this country. Jefferson spoke about politicians who come to Indian Country. This TCAC needs to look at how to shape federal policy changes. All of HHS and its agencies need to understand how the policies and procedures of IHS affect tribal members.

**Dr. Bailey**, said your urgency is our urgency. What are the common policies in your community? We must partner, we must be collaborative and strategic as possible.

Linda Holt, said she agrees with discussion about the University of Colorado and CDC's needs to start owning up to what they say they are going to do - CDC should have consulted with tribes in relation to this 4 million dollar grant. Also, I have been made aware by several of Tribal CCC Program Managers that there is a National Policy and Practice Summit coming up in Chicago in May. Apparently, State CCC Program Mangers are invited but not Tribal CCC Managers. In that Tribes have been working to build relationships with states, why are Tribal Program Mangers not invited to this? Linda shared that she had read a chain of emails from Phyllis Rochester, Branch Chief from CDC's Division of Cancer Prevention and Control, explaining situation. Question as to why CDC would support this as it seems to be in opposition to their expressed efforts to have CDC-states-and tribes working collaboratively; so why exclude tribes when talking policy?

**Dr. Bailey,** responded that now that the TCAC has brought the issues to TCAC, we will move ahead with finding answers and talking with tribal leaders as we go forward.

**Ed Clairmont,** said tribes rely on the federal government for funding and that the government should honor the government-to-government relationship.

Robert Moore, said Linda has excellent point. He would challenge CDC to take the concerns presented - the State Policy Summit and 4.2 million dollar grant situation and see what kind of resolutions can happen now with both Mike and Dr. Bailey using and considering perspective from TCAC. He suggested that CDC use the opportunity to shape the study to see what diabetes is in Indian Country and the State Policy issue, use it as another opportunity for CDC to leverage its relationship with national partners and states to facilitate more intentional involvement with tribes in establishing partnership with tribes. Robert noted that States have acres and acres of olive branches but no one has planted a tree. Maybe CDC could plant the tree between state and tribes.

**Dr. Bailey,** responded that the Consultation Session in February was a beginning. These feelings and situations happens to black communities as well. After the Consultation Session, she has begun to contact various people regarding CDC's work with states in relation to racial and ethnic communities. She validated that this is a true perception that is going around in Indian Country with regards to their relationship with states and that at a minimum, CDC needs to use the long term relationships established with states to assist them in being more inclusive of Indian Country.

**Mike Snesrud,** said CDC has heard concerns expressed and now needs the opportunity to make some phone calls and find out what's going on with these two situations.

**Dr. Bailey,** said we need to know all of the major programs and the AI/AN portfolio so we can use increased knowledge to prevent situations and not react as this does not work.

**Jefferson Keel**, said he appreciates the commitment from Dr. Bailey.

**Dawn Satterfield**, said she doesn't know where these program dollars for diabetes came from and that she already has made some phone calls to begin tracking the situation. Dawn provided an update on the Division for Diabetes Translation, Native Diabetes Wellness Program (NDWP). She played a DVD animation of the Eagle Books, with a Lakota voice over of the characters explaining that the template was there for them to use to adapt to their local community. They are also exploring doing podcasts recordings. The NDWP continues work on a new series of Eagle Books for middle-school aged children featuring the original characters and some new faces, as well. They continue to work with NIDDK at the National Institutes of Health, the IHS Division of Diabetes Treatment and Prevention, and the eight tribal colleges and universities who are creating a science based culturally appropriate curriculum, K-12, focusing on type 2 diabetes. Implementation testing that is expected to be rolled out later this fall. Dawn distributed copies of the Sam English three poster images to celebrate *Diabetes Talking Circles*, Community Health Representatives (CHRs), and American Indian participants of the Diabetes Prevention Program and other diabetes studies with the Traditions of Gratitude series. The NDWP is planning a community driven distribution "celebration" campaign in 2008 with other partners, which will honor and celebrate the role CHRs have played in diabetes prevention activities across Indian Country. Dawn asked, "Please join Mr. Eagle and friends to share the Eagle Book stories with children everywhere". Single set of books: CDCINFO www.cdc.gov and bulk supplies: Public Health Foundation at http://bookstore.phf.org\* and IHS (for tribal programs) at http://www.ihs.gov/MedicalPrograms/diabetes/resources.

**Roger Trudell**, encouraged tribal leaders and others to remember and mention how critical CHR's are to the health care system in tribal communities.

**Robert Moore,** asked about funding for the eagle books. **Dawn Satterfield**, responded that NDWP in past FY got a million dollars from IHS that they matched to make the Eagles Books available to all tribal communities.

**Jody Zephier (Yankton Sioux Tribe)**, said CHR's are often frontlines when it comes to diabetes prevention.

**Roger Trudell,** introduced the Aberdeen Area Tribal Chairmen's Health Board staff to give a luncheon presentation of their work.

**Christine Rinke,** gave power point presentation on Aberdeen Area Maternal Child Health Data.

**Favian Kennedy**, gave power point presentation on Aberdeen Area Smoking Data.

**Corey Smith,** gave power point presentations on Informatics and the Comprehensive Cancer grant.

**Adeola Jaiyeola**, provided an overview of Northern Plains Tribal Epicenter, highlighting their Comprehensive Cancer Program work, NARCH grant, and Diabetes projects.

**Jacqueline Left Hand Bull**, gave update on other AATCHB initiatives.

#### LISTENING SESSION: NCEH/ATSDR Environmental Public Health

**Jefferson Keel**, introduced Tim Hack, Deputy Associate Director and Senior Strategic Engagements, Office of Policy, Planning & Evaluation, NCEH/ and Annabelle Allison, Office of Tribal Affairs Coordinator.

**Tim Hack**, gave power point presentation on Climate Change Workshop.

**Linda Holt,** asked Tim if we could get result of the report that came out of the Climate Change Workshop. **Tim Hack**, said he would get a report and presentation materials to TCAC.

**Annabelle Allison**, introduced herself. She is the new Office of Tribal Affairs Coordinator for NCEH/ATSDR. She shared that she has experience in doing data collection and working with radon and indoor air and a background in environmental health programs with tribes.

Greg Zephier, (Yankton Sioux Tribe), asked about chronic illnesses and its link to mold standards.

**Annabelle Allison**, responded that any mold is bad mold but that you can mitigate the negative impact by reducing moisture. **Tim Hack**, added that mold is number one issue to come across their desk.

**Greg Zephier,** asked about the federal role in bomb clean up sites. **Tim Hack**, said one of their initiatives is bomb cleanup sites. Tim indicates that these activities have not evolved to their full capabilities the way they could to meet the needs of Indian Country.

**Rodger Trudell**, said at Region VII consultation there was discussion on several EPA and environmental issues. One of the concerns at Santee is the high rates of Cancer, they wonder about the linkages to these hazards as they are directly down wind from atomic energy plant in Canada. Another concern is that the tribe does not know how they have been experimented on as a people. (Sterilization of tribal women, etc.) What are long term effects of atomic energy, etc.?

**Tim Hack**, said that they do bio-monitoring in the lab. They test for 200 plus chemicals in blood and urine, and the health effects. That data could be stratified and analyzed more specifically.

Robert Moore, said with regard to climate change, that the rivers on the Plains, Oglala Aquifer, etc., average level of water is decreasing. That is major issue for the Nations in the Plains. Some communities are getting water for the first time ever from Mini Wiconi Water Project. He commended Tim for elevating the Office of Tribal Affairs to the OD of the Coordinating Center. That shows that CDC is beginning to institutionalize the government-to-government relationship of CDC to tribes to address the needs prioritized by tribes and brought to the agency. Tribes need to do some assessments so we can identify people for you in Indian Country to work with regarding these issues.

#### TRIBAL CONSULTATION SESSION

**Lawrence Shorty,** opened this session of the TCAC Meeting as a time for TCAC members and other tribal leaders to provide comments and discuss with CDC needs and issues related to chronic diseases.

#### **Presentation of Area and National Organization Reports**

#### Navajo Nation: Jerry Freddie

Mr. Freddie distributed an area report and introduced Dr. Patricia Nez. Dr. Nez is a Navajo Nation medical doctor working in health research. He said NIHB has been a good advocate for Navajo Nation. Navajo Nation has consultation with HHS and attended and participated in Tribal consultation with a lot of federal agencies. commended NIHB staff and the trend developing with CDC to enhance communications, including frequent TCAC conference calls. Consultation with CDC is focused on public health. There is need for technical assistance in the public health area so that tribes are able to implement these programs at the local level. Solid waste management is a huge problem, conservation of water resources, and the inadequate number of Native public health professionals and researchers that can come forth. We know what our issues are and desire to work with all the other people who commit to work with us. Slide presentations are excellent. We need people to take information and to adapt in a manner than is comprehensive but translatable to our Native people. Bar graphs are a good way to display information. He thinks the information being shared is excellent information, but it needs to be interpreted in Navajo. Stability and continuity in CDC leadership is imperative for work to continue. With regards to funding, if there are good programs that are currently funded, they should retain funding. Maybe CDC needs to look a developing a tribal training center and utilize a clearinghouse approach so that the 'best practices that are being developed in CDC work with tribes' can be mimicked in other new program areas of tribal importance. It makes sense that the TCAC to help to disseminate this information once it is collected and maintained on a website. Once the information is

readily available, we can individually by diversify it as we determine it needs to be to fit with our tribes or areas. Need compilation of best practices in public health, national homeland security issues etc. For the most part we don't have the infrastructure to operationalize and maintain these programs, we need to establish infrastructure in our communities. Some tribes, in terms of homeland security are more prepared than others with regard to emergency preparedness and mitigation plans. Mr. Freddie mentioned earlier there are federal and state documents but in order to have them filter down to grass roots people, these plans need to be in hands of local leadership so that the tribal leadership can review them and determine what needs to happen. This is a recommendation we can make. When we were hosted by CDC in Atlanta in February and visited the DEOC, emergency operations center, how many tribes have something like it? He thinks that this capacity building effort would be another very important use of resources. Epi centers are now in all areas so better use and coordination of states and CDC with them could definitely be beneficial to tribes in emergency preparedness activities including vaccine stockpile issues. Tribes have concern about how they receive information and stockpile medication in an emergency, who is the gatekeeper for this information at the tribal level. He would like to have a listing of all CDC funded programs going to tribes in all 12 areas. He feels that it is important for CDC to hear highlights but also to receive written reports from each area of priority public health needs. His report compliments Evelyn Acothley's report. He thanked all for attending meeting.

## **Aberdeen Area: Roger Trudell**

- Lupus
- Hepatitis C (from the needle)
- Behavioral Health

#### Yankton Sioux Tribe (addition to Aberdeen Area report)

- Yankton Sioux Tribe has 8000 members (4500 live on rez)
- Prevention is their priority
- CDC vision is healthy people but in Indian Country our health is threatened by our daily lives
- Physical health of Indians affected by poverty. (commodities, etc.)
- Nutritional Education (convenient stores stay open late to capture food stamp market)
- Child safety belt initiatives
- USDA Food Stamp Program
- Buffalo Diet and Historic Tribal Diets were much more healthy for our people

#### Robert Moore (addition to Aberdeen Area report)

- USDA Food Program
- EBT cards you can purchase unhealthy foods
- Preventive rather than reactive medicine

#### Ron Valandra (addition to Aberdeen Area report)

• Suicide grants

- Rosebud and Pine Ridge and Cheyenne River will coordinate IRBs
- Land Based Treaty Tribes issues(Aberdeen Area and Navajo Nation)

#### Randolph Runs After (addition to Aberdeen Area report)

- CDC initiatives regarding environmental justice
- NIH involvement
- Centers for excellence in environmental health
- Super Funds/Brown Fields
- Mercury poisoning
- Environmental Justice grant
- Air particulate grants
- Uranium in Cheyenne and Moreau Rivers
- Water levels are down

## Alaska Area: No Report

#### Albuquerque Area: Lester Secatero

- Health Disparities
- Diabetes
- Fitness interest
- Staffing needs a dentist now
- SAMHSA grants
- Alcohol
- Burial Practices and traditional Medicine

## Bemidji Area: No Report

#### **Billings Area: No Report**

## Oklahoma Area: No Report

#### **Brenda Shore: Nashville Area**

- Diabetes
- Hypertension
- Alcohol/substance abuse
- Injury Prevention (car accidents)
- Elders (Long Term Care)

#### Jefferson Keel: Oklahoma Area

- Methamphetamines
- SAMHSA treatment program grants
- Aftercare programs age appropriate
- CHR's

#### **Phoenix Area: No Report**

## **Portland Area: Linda Holt**

- Echo all of the disparities
- Epi center
- Alcohol abuse
- Post Traumatic Stress Disorder
- Money should come directly to tribes not from states

#### **Tucson Area: Chester Antone (Distributed a one pager)**

- Diabetes Studies
- Suicide
- Alcohol and substance abuse
- Climate Change
- Alcohol
- Challenges to Spirituality
- Public Health Task Force

#### **Direct Service Tribes: Robert Moore**

- DST emphasis on govt to govt relationship
- Contract Health Dollars
- Strong Preventive health (like the children's books presented earlier)
- DST meeting June 21<sup>st</sup> in Albuquerque

## **Tribal Self Governance: Rhonda Farrimond**

- echoes what other have said
- April meeting of TSGAC, all are invited to attend.

**Tim Hack**, said animal control program is ENSVED

**Jefferson Kee**l, said thank you to CDC. Bottom line is tribal beneficiaries are the Native people who need resources from IHS, SAMSHA, NIH, CMS, CDC etc. It is imperative that there is greater coordination across the department. Jefferson introduced Stacey Ecoffey (Oglala Lakota), Principle Advisor, HHS/OS Office of Intergovernmental Affairs, DHHS.

Stacey Ecoffey, said she is excited about CDC and its TCAC coming to Pine Ridge. Stacey has been in her position for a year and definitely wants IGA to get more involved in TCAC. DHHS is largest government agency in executive branch. CDC is one of 11 agencies that fall under them. After hearing the discussion about tribal leaders concerns about the recent CDC award to the University of Colorado and the issue Linda Holt brought up about Tribal CCC Program Mangers being invited to the National Cancer Partners Policy Summit, Stacey offered several ways to address the situations. There is a clear and obvious need to have agencies within DHHS to start talking and partnering and the need for the HHS to be able to look at better ways to assure Tribes have access to the resources of all of its agencies. HHS and CDC staff can't lobby. To some degree they

are caught in middle, Congress determines by authorizing language to which agency the resources are allocated to and who in some cases is eligible. In relation to the states, if it is determined by Congress that the resources go to states, then the agency needs to adhere to this. Agency Advisory committees are great way to address the state issue. Six years ago we didn't have any advisory committees. On other end, all of us recognize that in the near future we are going to have whole new slate of people in administration. This opportunity to get CDC leadership and the TCAC out in Indian Country for consultation sessions, we have to use the opportunity. She welcomed TCAC members to her homelands.

**Robert Moore,** introduced Ellie Wicks who works in Senator Tim Johnson's Western South Dakota office. He introduced representatives from Senator John Thune's office and Representative Stephanie Herseth Sandlin's office. He praised Stacey for being at HHS.

**Jefferson Keel**, also recognized Stacey for her efforts and leadership and expressed appreciation.

Mike Snesrud, gave update from the COTPER/Division of State and Local Readiness, Office of Smoking and Health (OSH), and the Division of Adolescent and School Health (DASH). She shared that the continuation application for Tribal Support Centers has been posted on grants.gov. The due date posted is June 2, 2008. This will serve as the non-competing continuation application for Year 4, as well as the interim progress report for Year 3. The American Indian Adult Tobacco Survey Implementation Manual has been completed and is in the clearance process. This manual will assist tribes in fielding their own tribal-specific American Indian Adult Tobacco Survey, providing information on protocols, training interviewers, budgets, and the like. Janis Weber, contracted OSH staff, will provide additional training on evaluation and logic models. She will also provide analysis of evaluation data collected by the Tribal Support Centers during the first two quarters of FY 2007-2008 and provide training on how these data can inform and improve program. DASH has for the first time ever tribes made tribe as eligible applicants for their recent funding opportunity. Three tribes were funded directly (Cherokee Nation, Winnebago, and Nez Perz) Funding is made available to monitor critical health-related behaviors among high school students through implementation of the Youth Risk Behavior Survey (YRBS), enable schools to implement effective policies and practices to prevent and reduce sexual risk behaviors among students that contribute to human immunodeficiency virus infection, and enable schools to implement coordinated school health programs.

Mike also gave a brief response to the issue raised earlier by Co-Chair, Linda Holt, about the CCC Program. CDC partners with 10 other national Partners to collaborate on comprehensive cancer control activities. For the past year plus, the national partners have been planning a policy summit. The National Cancer Partners determined that this upcoming Summit would be an opportunity for the states to come together and discuss issues as they related to the states with the intent in the near future they would host a similar Summit for the tribes. This was a decision that all the partners made. CDC doesn't control this group nor are resources from them sponsoring this Summit. She

communicated that she would continue to connect with Phyllis Rochester and other leadership from the Division of Cancer Prevention and Control (DCPC) to find out more facts and to communicate that TCAC and the Tribal CCC Program Directors were not happy with the decision to exclude them from a policy meeting about CCC. Preliminary information collected seems to indicate that this situation needs further exploration to understand what actually happened and to see how a better outcome could be realized. Mike communicated that she will engage the DCPC and the C-Change who has the lead for planning of this upcoming Summit and get back to the TCAC with more information. Mike also explained that there has been a AI/AN Advisory Committee to the National Partners that has been together for the past year and that it was intended that a representative from this group attend. She will also talk with the DCPC Tribal Liaison to determine if this Advisory Committee was involved and aware of the meeting and be prepared to report back to the TCAC at an upcoming TCAC conference call.

**Kerri Lopez**, said that as a tribal CCC Program Director, she has questions about this Advisory Committee in that she wonders how the membership was chosen as to her knowledge there are none of the funded CCC Program Directors on the Committee and no communications system set-up to share information.

**Linda Holt**, stated that her concern is the apparent disregard for what the Tribal Consultation Policy states. If tribes will be affected by the CCC policies being discussed at the Summit, then they definitely should be invited to attend.

**Stacey Ecoffey,** agreed and said she doesn't understand why the state directors and not the tribal are invited. The collaborative dialogue can not occur without the tribes participating.

**Mike Snesrud**, encourage all to understand that neither CDC staff nor the C-Change alone are making the decisions. CDC is not funding the Policy Summit and what seems important here is what CDC has communicated to other partners about our commitment and role with tribes in honoring our policy.

**Stacey Bohlen,** asked if C-Change gets federal funding.

**Mike Snesrud,** said she doesn't know a lot about them and if they do get federal funding. She will contact the Director of C-Change and get him involved in the response back to TCAC.

**Jefferson Kee**l, said the basic problem is that we are talking about a federal policy issue here. If tribal governments aren't consulted then tribal governments do not have a stake in any of these meetings. He understands that CDC may not be the decision maker but it also occurs to him that Tribes don't have to participate either. It seems that if tribes are purposely being excluded, then it borders on a civil rights issue. We can dig into this and make it something it is not. What we really need to do is to see where this originated and what we should do once we have the facts. TCAC needs to focus on what we can do to improve the relationship and increase the communication between the tribes-states-CDC-

and other national cancer partners. We could involve others like the National Association of State Legislators or the National Governors Association as appropriate and necessary. Another reality is that this committee has is that we need to talk with CDC. Their funding that is going to the states for CCC needs to engage and benefit AI/ANs. It is good that they have also funded tribes directly, but when CDC is talking with states and other partners, we (tribes) want to be included in those conversations. We are at point where we need meaningful input, not non-Natives talking about AI/ANs, we are past that and tribes need to be participating fully for ourselves. He would like to see CDC's official response.

**Mike Snesrud**, thanked the TCAC for bringing these issues to CDC. It certainly seems as if there have been some missed opportunities for communicating with tribes, errors made up front. She can't speak for DCPC, but she certainly will find out the "facts' and get back to TCAC.

**Lester Secatero**, asked what Mike's role is with Dr. Gerberding.

**Mike Snesrud**, responded that the Director of OMHD, is Dr. Williams, who reports now to Dr. Bailey who reports directly to Dr. Gerberding. The TCAC, is a high level advisory committee to the agency and Dr. Gerberding and she is the designated federal official for this advisory committee and one of the two senior tribal liaisons who are the designated points-of-contact for CDC activities with AI/AN tribes.

**Dr. Bailey**, said there are going to be some changes. Perhaps by looking at the feasibility of creating a CDC Office of Tribal Affairs to be better able to honor the government-to-government relationship so it can be in more a direct line of accountability. CDC will be response to specific issues raised prior to the next meeting.

**Linda Holt**, said we are making recommendations to CDC but this goes beyond CDC and their relationship with states and their relationship with other federal and national partners. The agency needs to answer back.

**Kerrie Lopez,** shared that all the Tribal CCC Program Directors have been talking together and are drafting a letter to the DCPC.

**Dawn Satterfield,** said regarding 4.2 million dollar grant, the press release distributed by Robert Moore was totally wrong. She has contacted her division, IHS, and CDC will get back to the TCAC in the near future. She specifically has talked with Dr. Kelly Acton and will assure that TCAC hears answers to their concerns and a commitment to address any additional concerns regarding this.

#### DAY TWO - Thursday, April 3

Charter Bus Trip to the Pine Ridge Indian Reservation in South Dakota – graciously hosted the TCAC and CDC staff.

#### DAY THREE – Friday, April 4

Jefferson Keel opened the meeting with a prayer.

Jefferson Keel, said it was a good opportunity to go to Pine Ridge yesterday. Stacy Ecoffey is a good example of how our own people can make life good for Indian people. He again recognized Stacey and her leadership and noted the pride Stacey Ecoffey does in whatever she does and her connection maintained to her tribes and Indian Country. The issues they are confronted with on Pine Ridge are universal to Indian Country; poverty, lack of water, sanitation facilities, etc. We have heard from the NCAI President, the words he spoke reminded him of other great leaders. People on outside of the reservation don't think the way AI/ANs do with regards to our culture. Jefferson stated that he would have liked to have spent more time there. The issues that affect Native people, like substance abuse treatment etc., is not only limited to reservations anymore. These same issues also affect Urban Indians and their health and wellbeing. He would like to see other programs like Headstart, Elder Care, Diabetes Prevention, STD/HIV Prevention etc. discussed during our consultation sessions. "People say our youth is our tomorrow, yet they are our today"! Today we have to do several things to conclude:

- 1) Look at TCAC and see which direction we want to go in our next meetings, etc. Chester has invited and requested we go to Tohono O'Odham Tribe in November. He would personally like to visit there, but will leave it up to TCAC for their decision.
- 2) Before we conclude this meeting, we need to have the next meeting determined, when, where and the agenda.

**Action Item:** Jefferson requests that we know who the speakers will be significantly ahead of the Consultation Session based on priority public health issues. At our next TCAC Meeting, we need to look at response and progress made in the past year.

**Linda Holt,** said one of her specific goals is to increases Indian Country's knowledge and access to CDC so that all tribes can increase their relationships with CDC. Her concern is at this time, is that TCAC communicates recommendations to the agency and Dr. Gerberding but the TCAC doesn't here formally back from the agency. TCAC needs to get a response back from CDC and a status report. CDC needs to step up and meet their commitment to AI/AN Tribes. Yesterday was a wake up call for CDC about the need to get out to Indian Country. Cynthia Manuel, alternate to TCAC and on the NIHB Board of Directors, has communicated this need. She hopes the TCAC and CDC will come to Tohono O'Odham in the fall.

**Robert Moore**, said regarding the REACH U.S. grant. He is interested in knowing if TLDC was aware of this grant. **Linda Holt**, said there is a 4 pm conf call this afternoon regarding the grant.

Brenda Shore, said she and Buford are on TLDC. They have not heard of this.

**Robert Moore**, said our congressional delegation in South Dakota have been made aware of this grant and are concerned that it be tribally driven.

**Linda Holt,** shared that this is something that came up at the most recent TLDC Meeting when Portland Area questioned the CDC Cooperative Agreement with U of Colo. Apparently nothing was discussed with any tribal or IHS IRB as Portland brought the issue forward. Portland Area's main concern was data ownership. Spero Manson and Dr. Robideaux assured them that it would be protected. The concern related to this cooperative agreement awarded to UDC is that they are going to use tribal data for this scope of work of 4+ million.

**Robert Moore,** said gravity of this should be raised to a level beyond CDC.

**Mike Snesrud**, said this cooperative agreement came out of REACH US not the DDT. We need to look at original program announcement and engage Dr. Wayne Giles and other REACH staff who have been involved in this FOA. She recommended that CDC be afforded opportunity to get correct information before we speculate any further.

**Linda Holt,** said it was a competitive grant by CDC that results in no tribal recipients. She has a problem that, why should non-Native entities be awarded dollars to do work with AI/AN tribes and communities? At this point in the relationship with CDC, this doesn't seem right.

**Roger Trudell**, said he questioned the same thing back some time ago. He thinks this funding was related back to Senator Campbell and his work and influence as diabetes funding has been put out to the U of Colorado.

**Jefferson Keel**, said the real responsible partner is CDC, who let that grant allocation go forward. CDC needs to be held accountable. Dr. Gerberding needs to understand the gravity of this pending outcome of the facts. The other factor is the funding opportunity announcement itself and the CDC grant process. Jefferson raised the issues that if TLDC and Dr. are the tribal watchdogs, how did this get past Dr. Action? **Linda Holt**, said she strongly disagrees with that because Dr. Acton is not a tribal leader but rather a federal representative and staff person. Dr. Acton withheld info from TLDC and she fought us every step of way on this agreement. Tribal leaders need to talk to IHS Director about this.

**Mike Snesrud,** said that since this issue seems to involve several of the HHS agencies, it is important to keep Stacey Ecoffey, IGA involved. IGA needs to be kept in the loop. **Jefferson Keel,** said he and Linda will get together with Stacey and Laura Caliguiri, IGA Executive Director of IGA involved. **Robert Moore,** said Mike is right this has broader implications.

## **Robert Moore made the following Motions:**

1. To authorize TCAC chairs to draft letters to Bob McSwain at IHS and to Julie Gerberding at CDC to raise concerns regarding the grant and processes by which it was awarded. Motion Seconded by Roger Trudell. Motion carried unanimously.

- 1) To recommend and ensure that CDC through tribal consultation, do the following:
  - Develop Standards of Success for all grants
  - Expect clear outcomes as they affect AI/AN federal relationship with U.S. government.
  - Deficiencies be demonstrated as need
  - Data use be authorized by Area Indian Health Board governing bodies. **Motion Seconded by Roger Trudell. Motion carried unanimously.**

**Roger Trudell,** said it would be helpful if federal agencies reported to one place like to NIHB to send grant information to tribes.

**Stacy Bohlen**, said she checked on the grant to the University of Colorado. Media reports were grossly exaggerated. Spero Manson is the PI and the PHD student is part of his team. **Brenda Shore**, responded that the issue of the university using tribal data will still needs to be checked into. **Linda Holt**, said the TCAC still also need to clarify and enforce data ownership.

**Robert Moore**, asked at what point do tribes need to stand up to defend research by and for Indians. He raised the point- tribes now have great facilities, minds and wills to do the research and non-Native universities should be awarded these grants.

**Stacy Ecoffey**, stated that this ultimately is tied to the bigger issue of any and all research being done by HHS and it agencies. Tribes need to have collaboration across the department to assure that all agencies are looking to tribes to determine the research priorities rather than the agencies. The HHS AI/AN Health Research Advisory Committee (HRAC) will be meeting later this year to discuss this and other related issues. The HRAC will be meeting on a regular basis; CDC is one of the federal partners that will be advised by a tribal leader advisory board. Tribes can always bring issues of this to the individual agencies and IGA to oversee and assist with collaboration and resolution.

**Conference Call with Wanda King (CDC) -** Wanda King, gave update on Pandemic Flu continuation cooperative agreement awards. There were 175 applications. In mid April, DSLR will start panel reviews. DSLR thanked TCAC for the opportunity to have their project officers meet with the tribal leaders at the February TCAC Meeting. Since that time as a result of the meeting there has been:

- A Florida and Seminole tribal agreement
- Resolution of an issue raised by Eastern band Cherokee in relation to North Carolina
- Greater analysis of states submission of tribal health boards letters of concurrence.
- Guidance and language to states for the continuing applications has become stronger for what states need to do and document in relation to their work with tribes to make sure tribes are included in all preparedness activities.

Mike Snesrud, said she encourage TCAC members to more fully review this guidance language shared during Feb meeting and be prepared to recommend thoughts and

perspectives about it to DSLR staff. DSLR will be preparing regular updates and affording tribal leaders more opportunities to provide feedback and ask questions.

**Robert Moore**, asked Wanda about tribes being prepared in terms of public health emergency preparedness and capacity. One thing tribes are not fully aware of is federal response plan. CDC could be useful in educating tribes (Preparedness 101). He pointed out the FEMA curriculum as a framework for tribal governments. He helped author it, hoping to use it as a framework to help build and ensure tribal capacity. **Wanda King**, will take this back to CDC. **Brenda Shore**, said she is thankful Wanda is working with tribes on pandemic flu and readily available if tribes have questions. **Wanda King**, said thank you and that she will continue to have her and other team member be responsive to improving relationships.

## **Preparation for next Meeting:**

Discussion of next meeting dates/locations/agenda items:

- Next face to face meeting: July 28, 29 and 30<sup>th</sup>, 2008
- ➤ April 17<sup>th</sup> is next TCAC Conference Call will hope to include Dwayne Jarmen on Alcohol prevention, the discussion with DCPC and C-Change, and posting on CDC information on NIHB website for easy retrieval by TCAC members and their area health boards.
- ➤ Following July, the next TCAC Meeting and 2<sup>nd</sup> Biannual Tribal Consultation Session will be the week of November 17 20thh, 2008 at Tohono O'Odham (there will also be a NIHB Board meeting there at the time)

## Meeting Locations: (July)

➤ July – NIHB will facilitate with Brenda to arrange and plan for the Seminole Tribe in Florida to host the meeting

#### Agenda Items: (July)

- ➤ Tobacco How can cessation efforts be stepped up with more information from the CDC Tribal Support Centers
- ➤ PGO Training (consider doing a break-out at the NIHB Public Health Summit also)
- ➤ Report Back from CDC on issues raided by TCAC during this meeting and an update about all tribal awardees for FY 2008
- Debriefing on February Consultation

#### **Other Business:**

Discussion on preparation for next federal administration. There are navigational concerns on getting OMB participation in the field. May need to reactivate committee (financial strategies committee) to develop how tribes can impact CDC budget allocation process and increased resources through CDC.

Discussion on visit by Jefferson Keel and Linda Holt to Area Health Boards. Linda requested that area health board representatives determine which dates they would be available for a visit.

Discussion on communication and development of a CDC TCAC Meeting Book to educate tribes on what TCAC is about. This would be separate from cooperative agreement objection on development and communication of what is Public Health. NIHB could develop a video tool (like CMS video) for tribal leaders to have as tool.

#### Discussion on term limits:

• up to area health board to decide length of appointment of TCAC member

Discussion on strength of Indian people despite all of the adversity we have to deal with. Aberdeen Area representatives shared anecdotal story of Milk's Camp community on the Rosebud reservation in South Dakota. They were a prime example of being a "lost community" a result of their distance to adequate healthcare. Also other tragic history is Santee band execution of 38 Tribal leaders after Christmas in 1862. Treaties were established, not because people were afraid to fight anymore, they just wanted the people to survive.

**Linda Holt,** said we must get to issue of how the federal government assures and assists in holding their partner, the states, more accountable to be working with and engaging tribes. The states simply have to work and collaborate more with the tribes. She is passionate about getting federal government to live up to their obligations and commitments to tribes. We all need to learn and understand the different histories of tribes.

**Mike Snesrud**, said Milks Camp community is good example of developing case scenarios descriptions within a given area. She encouraged tribes to write up case scenarios and success stories so that we can all be better educated and learn from them.

**Linda Holt**, said she thinks it would have been nice to have had a video camera for next time we do site visit. **Chester Antone**, said yesterday we went to grave site at Wounded Knee. There was a lot of power there. It is a testament to our people. **Lester Secatero**, said he is hopeful that Dr. Bailey will spread the message back to CDC. **Linda Holt**, asked that Dr. Bailey plan to attend future TCAC Meetings and be prepared to share updates of CDC work with tribes.

Discussion on Tohono O'Odham Nation borders issue:

- Mike Snesrud will leverage partners at CDC and DHHS to look at the issue
- Would like to get Congressional people (SCIA) involved

Discussion on website updates:

- NIHB to archive information (for power point presentations, etc.)
- Budget Documents regarding TCAC
- Other applicable and relevant information

**Robert Moore**, gave closing prayer. Meeting adjourned at 11:34 AM.

#### **Action Items:**

#### National Indian Health Board

- Letter from Jefferson and Linda, TCAC Co-Chairs, to Tohono O'Odham Nation to formally accept their invitation to host the 2<sup>nd</sup> Biannual Tribal Consultation Session and quarterly TCAC Meeting on November 18-20<sup>th</sup>, 2008. Chester Antone requests NIHB to provide them electronically the final report of the testimonies from the CDC Tribal Consultation Session on February 28<sup>th</sup>.
- NIHB to assist TCAC Co-Chairs in arranging and implementing Area Ambassador visits by contacting Executive Directors of Area Health Boards to schedule.
- Develop Advance Consultation Book for tribes regarding CDC/TCAC (NIHB/CDC)
- Thank You Letter to Pine Ridge

## CDC

- Receive draft agenda from NIHB for July TCAC Meeting
- Put Annabelle Allison (ATSDR) on July agenda
- Review recommendations from January, February and now April TCAC Meetings to update Inventory, prepare progress report for July TCAC Meeting
- Follow up with Annie Fair (DCPC Tribal Liaison), Phyllis Rochester (Team Lead, DCPC, Partnership, Program, and Evaluation Team) and Carol Friedman (DCPC Branch Chief), and Tom Keen (Executive Director of C-Change, Lead Organizer for CCC National Policy and Practice Summit) regarding TCAC issues raised
- Follow-up with CDC REACH US Staff: Joe Maloney (Program Consultant with Tribal REACH Grantees), Sakeena Smith (REACH Team Lead), also Spero Manson (Professor and PI, University of Colorado Center of Excellence for Eliminating Disparities (CEED) Grant), Kelly Acton, (Director, IHS Division of Diabetes Treatment and Prevention), and Kelly Moore (Associate Director, CEED, AI/AN Programs at University of Colorado Denver) regarding TCAC issues raised
- Inform and invite Laura Caliguiri (Executive Director of OS/IGA) and Stacey Ecoffey (Principal Advisor for Tribal Affairs, IOS/IGA) about issues and TCAC desire to have them attend upcoming meetings and Consultation Session
- Prepare a listing of all CDC funded programs going to tribes in all 12 areas for FY 07 and FY 08 to-date.

#### Items for November TCAC Agenda

- Opportunity to receive information about CDC's Aging Program and Network. What CDC is doing to collaborate with AoA and IHS to maximize resources and services available to Native Elders and tribal communities?
- Consider a presentation about data ownership and CDC research for November TCAC Meeting. Explain how HRAC impacts coordination across HHS.
- Engage IGA and their Tribal Emergency Preparedness Initiative to clarify individual federal agencies various roles. Utilize the opportunity of meeting at TON to discuss border issues.
- Update on the CDC Public Health Alert Process and how tribal organizations are connected.
- Information about COTPER stockpile medications and knowing who in an emergency situation is the gatekeeper for this information at the tribal level.
- Update from COTPER/DSLR about new FY state plans and their implications to the tribes.

#### TCAC Recommendations

- CDC needs to look a developing a tribal training center and utilize a clearinghouse approach so that the 'best practices that are being developed in CDC collaborative work with tribes' can be mimicked in other new program areas of tribal importance.
  - o need for technical assistance in the public health arena so that tribes are able to implement these programs at the local level