American Indian/Alaska Native Health Research Advisory Council (HRAC)
Washington, DC Meeting
March 18, 2010

HRAC Tribal Delegates and Alternates

- Judith Bender, Aberdeen Area Proxy
- Emily Hughes, Alaska Area Delegate
- Tim Gilbert, Alaska Area Alternate
- Norman Cooeyate, Albuquerque Area Delegate
- Kathy Hughes, Bemidji Area Delegate
- Kristal Chichlowska, California Area Proxy
- Jessica LePak, National Congress of American Indians Proxy
- Elizabeth Neptune, Nashville Area Delegate
- Madan Poudel, Navajo Area Delegate
- Roselyn Begay, Navajo Area Alternate
- Cara Cowan Watts, Oklahoma Area Delegate
- Violet Mitchell-Enos, Phoenix Area Alternate
- Chester Antone, Tucson Area Delegate

Federal Attendees

- Wendy Perry, Agency for Healthcare Research and Quality
- Sue Clain, Assistant Secretary for Planning and Evaluation
- Ralph Bryan, Centers for Disease Control and Prevention
- Ileana Herrell, National Institutes of Health
- Wilbur Woodis, Office of Minority Health
- Sharon Folgar, Office of Intergovernmental Affairs/Tribal Affairs
- Kimberly Romine, Intradepartmental Council on Native American Affairs
- Dawn Houle, Indian Health Service Office of Tribal Self-Governance
- Lyle Ignace, Indian Health Service
- Yvonne Maddox, *Eunice Kennedy Shriver* National Institute of Child Health and Human Development
- Lisa Kaeser, *Eunice Kennedy Shriver* National Institute of Child Health and Human Development

Speakers

- Rose Weahkee, Ph.D., Indian Health Service
- Shiva Singh, Ph.D., National Institute of General Medical Sciences
- Alan Guttmacher, M.D., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development
- Kathy Etz, Ph.D., National Institute on Drug Abuse
- Stacey Ecoffey, Office of Intergovernmental Affairs

Meeting Minutes

- A quorum was reached, thus results from meeting are considered official.

Opening Session

- Invocation by Chester Antone.

- Opening Remarks by HRAC Co-Chairs Cara Cowan Watts and Kathy Hughes and OMH Special Assistant on Native American Affairs, Wilbur Woodis.

Agency for Healthcare Research and Quality

1. Updates from Wendy Perry

- Wendy Perry informed the group that AHRQ looks at items such as how healthcare is delivered, patient safety, how to improve the quality of care, HIT, etc. She reported there were a large number of grant announcements tied to Comparative Effectiveness Research (CER) although it's now being called Patient Centered Research. She urged HRAC to get the word out in Native communities so AI/ANs will apply as the amount of money they received for this purpose is large.

2. Discussion and Next Steps

- Wendy said to come to AHRQ with ideas even if it doesn't tie to a specific grant announcement. They can also help provide technical assistance for grants.
- Wendy will send the Program Brief link and any grant announcements that come out.

Office of Assistant Secretary for Planning and Evaluation

1. Updates from Sue Clain

- Peggy Halpern has retired, so Ansalan Stewart will be the new Alternate to HRAC.
- They are a staff division that advises the Secretary on policy development. ASPE's research budget is only 2 million and they do not provide grants. Their major impact is that they are part of the Secretary's Budget Council. ASPE chairs the Internal Legislative Team and Sue chairs the Indian Legislative Team.
- ASPE does occasionally succeed in getting money for AI/AN research but it has to be tied to the Secretary's priorities. For example, they collaborated with SAMHSA to conduct a study looking at an AI/AN Suicide Prevention Hotline. This can be downloaded at http://aspe.hhs.gov/hsp/09/aian-suicidepreventionhotline/index.shtml.
- She also helps to get studies of the broader population to include American Indians and Alaska Natives. For example, with the Healthy People User Study, they surveyed 102 Tribes and had 51 respond. The study is located at: http://aspe.hhs.gov/health/reports/09/userstudy/index.shtml.
- They are currently working on a project looking at preventative health screening measures including behavioral health screening such as depression, etc.
- Sue will provide a copy of the Secretary's Strategic Plan when it is available.

Centers for Disease Control and Prevention

1. Updates from Ralph Bryan

- Dr. Bryan discussed the items provided in the packet of materials including the new organization of CDC. They have a new Associate Director for Science, Dr. Harold Jaffe, who has returned to CDC. Dr. Judy Monroe was just announced as the new

Director for the Office of State, Tribal, Local and Territorial Support. "Tribal" was added into the name after discussions at the CDC Consultation in January.

- Dr. Bryan reported that they are seeing more frequent AI/AN focused Quickstats or ones that include AI/ANs with other populations. There are several that will be included in upcoming issues of the weekly MMWR at: http://www.cdc.gov/mmwr/.
- There is also a new Indian Health Surveillance Report on Sexually Transmitted Diseases prepared by CDC and IHS. This is available online or you can request a hard copy from Dr. Bryan.

2. Discussion and Next Steps

- Cara mentioned that she wants to see CDC involved in the Superfund sites. Has EPA and CDC been working together? Tracy Ching King from the Billings Area originally brought this issue up. Ralph said that the Agency for Toxic Substances and Disease Registry (ATSDR) would be the agency responsible for this issue. Dr. Bryan is not sure what they've done in Montana, but if there are specifics he would be happy to follow up. Annabelle Allison is the Tribal lead in that office. Cara plans to elevate the Superfund site issue this year.
- Madan Poudel said they are interested in a Uranium Comprehensive Study at Navajo Nation.

Office of Minority Health

1. Updates from Wilbur Woodis

- The Office of Minority Health (OMH) is in the Office of the Secretary, Office of Assistant Secretary of Health. They are a minority health office, but it is a small office. OMH does have grants working with EpiCenters to try to improve community health profiles. They are funding 10 EpiCenters with small grants and these will be completed in the next few years. Other AI/AN projects include the Healthy Indian Country Initiative and the Indian Country Meth Initiative. There is a small project for HIV/AIDS that will fund 5-6 communities with small grants and grant announcements will be out soon.

National Institutes of Health

1. Updates from Ileana Herrell

- NIH is unique in that they have 27 Institutes and Centers, 24 of which have grant making authority.
- The National Heart Lung and Blood Institute has been conducting the Strong Heart Study since 1988 and it is the largest study with American Indians.
- The National Cancer Institute is looking at ways to improve colorectal cancer screening for Lakotas and breast cancer screening in the Bemidji Area. The Diné College has a research initiative for scientific enhancement where they are coordinating with the Mayo Clinic.

- The National Institute of Neurological Disorders and Stroke is working with 9 other NIH Centers and Institutes to support a Native American High School Summer Program at Harvard.
- Through the NIH Loan Repayment Program, in 2007-2008 they supported 29 AI/AN researchers.
- There is an American Indian Health Web Portal that is sponsored by the National Library of Medicine. It is located at: http://americanindianhealth.nlm.nih.gov/contact.html
- The Arctic Health Site is sponsored by the National Library of Medicine and maintained by the University of Alaska Anchorage. It can be found at: http://www.arctichealth.org/

2. Discussion and Next Steps

- Elizabeth Neptune asked where they were at in the process with the NARCH proposals. Shiva Singh replied that they are reviewing them right now and asking the Institutes to take a look to see which ones they can fund. They will make their decisions and send out recommendations to IHS.
- Dr. Herrell will email the slides from the Resource Day at the HHS National Tribal Consultation that NIH presented on how to apply for NIH grants along with other reports, consultation letter, and associated urls and web portal that were discussed.

National Institute of Drug Abuse

1. Presentation by Kathy Etz, Ph.D.

- Dr. Etz is the Chair of the AI/AN Coordinating Committee at NIDA. NIDA Priority Areas are Prevention Research, Treatment Interventions, and Medical Consequences. They currently fund ten NARCH programs that support data collection, research training, and infrastructure development.
- NIDA has four Clinical Trial Networks that transfers science out to the Native communities. There are Nodes all across the United States.
- There is a NIDA AI/AN Researchers & Scholars Workgroup whose purpose is to educate the public, students, health practitioners and researchers on addiction, develop research concepts, assist AI/ANs in the grant application process, and enhance research competency to name a few.
- The NIDA AI/AN Mentoring Program for Substance Abuse Research is a nation-wide mentoring program designed to train and support the career development of AI/AN researchers in substance abuse and addictions research.
- There are a few upcoming activities that might be of interest to HRAC: Blending Addiction Science and Practice: Evidence-Based Treatment and Prevention in Diverse Populations and Settings occurring on April 22-23 in Albuquerque, New Mexico; and NIDA/NIAAA Meeting on AI/AN Substance Abuse: The State of the Science/NIH Grant Development Workshop: Technical Assistance for Tribal Based Participatory Research occurring on October 5-7 in Rockville, Maryland.

Eunice Kennedy Shriver National Institute of Child Health and Human Development

1. Updates by Alan Guttmacher, M.D.

- Dr. Guttmacher, Acting Director of NICHD, provided a brief overview of the *Healthy Native Babies Project* which is focused on Sudden Infant Death Syndrome risk-reduction. He provided a handout describing the project's materials that have been developed, the train-the-trainer sessions that were held, and briefly discussed the upcoming outreach and dissemination phase of the project.
- He provided an overview of the National Children's Study. He was aware of HRAC's concern about AI/ANs not being part of the study, but to try and sample this population would be very expensive.

2. Discussion and Next Steps

- Tim Gilbert raised the issue of infant mortality being extremely high in Aberdeen and Alaska. Dr. Guttmacher responded by saying that this is not an ideal study to look at infant mortality if that's the real question. Scientifically, there is a better way to go about it. Dr. Guttmacher said he would not be opposed to doing this study if the HRAC could provide the funding.

Indian Health Service and Suicide Prevention Efforts

1. Presentation by Rose Weakhee, Ph.D.

- IHS conducted a literature review search over a ten year period and only twenty-two publications were found regarding suicide in the AI/AN population.
- Based on Chandler and Lalonde, University of British Columbia, "First Nations communities that succeed in taking steps to preserve their heritage, culture, and work to control their own destinies are dramatically more successful in insulating their youth against the risks of suicide."
- The National Tribal Advisory Committee provides recommendations on behavioral health. Currently, they are working on two huge plans – Suicide Prevention Strategic Plan and Behavioral Health Strategic Plan.
- The Annual IHS Behavioral Conference will be held on July 26th in Sacramento, California.

National Institute of General Medical Sciences

1. Presentation by Shiva Singh, Ph.D.

- Dr. Shiva Singh provided an overview of NIGMS and about the creation of the NARCH Program. In 1999, Leo Nolan (IHS) and Dr. Clifton Poodry (NIGMS) organized a roundtable discussion to find out the need and how NIH could respond to health disparities among minority populations. The NARCH Program was created as a result of this discussion. The three main goals of the NARCH Program are: capacity building; research; and training. NARCH funds go directly to Tribal partners and they subcontract with other institutions so the Tribal community is in

charge of the research. They are currently at NARCH VI. Research itself is based on topics that have been prioritized by communities and there are seventeen active NARCH Centers.

- Dr. Singh discussed a few programs for minorities:
    - The Research Initiative for Scientific Enhancement (RISE) is a student development program for minority-serving institutions. Tribal colleges participating include: Diné, Salish and Kootenai, and Haskell.
    - The BRIDGES Program provides support to institutions to help students in Associate's or Master's degree programs. A number of institutions partner with them like the University of New Mexico.

HRAC Discussion

1. Update and Next Steps

- Cara asked for an update on the status of Data Sharing Agreements that was assigned to the Portland and Alaska areas. Tim Gilbert informed the group that they recently had a conference call. He said he would draft a summary of what was discussed and send out to the HRAC. As a result of the call, they realized that their issues are more on a local level than national.
- Dr. Bryan attended the CDC Tribal Consultation that was held in January of this year. Data sharing was discussed and issues with IHS and data sharing between states and EpiCenters were among the discussions. He informed the group that there is a workgroup looking at these issues very closely.
- Dr. Bryan also discussed The Tribal Epidemiology Subcommittee of the Council of State and Territorial Epidemiologists (CSTE) which includes representatives from CSTE, the offices of several state epidemiologist, and Directors of each of the Tribal Epidemiology Centers (TECs). The Subcommittee, through CSTE, commissioned a legal review of barriers to data sharing with TECs in selected states – results of this review will be presented at the annual CSTE conference in Portland in June 2010.
- Violet Mitchell-Enos mentioned the need to discuss data ownership as this is still a big issue. Dr. Bryan informed the group that there is an existing NCAI resolution on data ownership.
- Cara asked if NCAI could arrange a side meeting during the Rapid City, South Dakota Research Conference. Cara suggested that NCAI share with Tribes what they've already done, other available resources, and could point out technical assistance for putting in place Institutional Review Boards (IRBs). She asked if Puneet Sahota and Sarah Hicks from NCAI would follow-up with Dr. Ileana Herrell about technical assistance for grants.
- Cara also noted that there has never been a concerted literature review and perhaps one should be done. Dr. Bryan said the University of New Mexico (UNM) Health Database could help in this respect. He suggested that looking five to ten years back would be a good start. He reminded the HRAC that UNM presented at an HRAC meeting several years ago and Sarah Hicks also presented so she might be a good point person. OMH and HRAC can reach out directly to the library.

- Cara asked what the Federal government has funded. Dr. Bryan said that this is different and would require going thru all the grant offices, which would be laborious but would be good to put on the radar.
- Cara wrapped up the discussion and reiterated the next steps that need to occur. A conference call needs to be arranged to discuss issues and concerns with data sharing so the HRAC can be fully informed when we speak to Federal staff about these concerns.

Office of Intergovernmental Affairs

1. Update by Stacey Ecoffey

- The Regional Tribal Consultations are occurring from March – May. With the President's mandate from November, HHS is looking to improve the overall consultation process with Tribes.
- A Tribal Federal Work Group will review all the comments received on the Tribal Consultation Policy, the National Tribal Budget Consultation, and the regional consultations. At the end of April they will request nominations. During the summer, recommendations will be made and then this group will end.
- A Secretary's Tribal Advisory Committee will be set up like the current advisory committees. They have not developed a charge yet or started getting into any details. They plan to send out a request for nominations in August. Fifteen to eighteen members will be selected from across the country. They will then develop a charter and then create an agenda on issues they would like the Secretary to focus on.
- HRAC's charter will need to fall into place soon before the development of the Secretary's Tribal Advisory Committee. IGA has not taken a harsh stand on this, but it needs to happen soon and it must be in compliance with FACA.
- Stacey apologized that the HRAC never received a letter back from the Secretary regarding the request for a meeting. She informed the group that the Secretary will not meet with individual advisory committees, but would meet with all the co-chairs hopefully at the beginning of June.

12th Annual National Tribal and Budget Consultation Session

1. Update

- Cara provided an update from the consultation and the topics she discussed during the session. She discussed topics such as: the need for oversampling; NCS design and the possibility of a parallel study; increase IHS health providers and researchers; behavioral health/suicide prevention; focused funding on NA research; data sharing; and Superfund sites.

2. Discussion

- Governor Cooeyate brought up the fact that Tribes don't have their own expertise to create IRBs.

- Violet Mitchell-Enos suggested that a Native American IRB be created for all Native American communities. She suggested talking to Federal partners about funding such an effort.
- Cara mentioned the need for IHS IRBs to be strengthened.

New HRAC Research Recommendations

1. Discussion and Next Steps

- Regarding HRAC recommendations – Send out last year's submission and response. Then decide on next steps. Pat Parker from NAMS recommended that we prioritize those recommendations if they have not changed.
- Cara asked if NCAI could do a Tribal Leader Alert to encourage participation at regional consultations and to testify about HHS accountability if no feedback on testimony.
- Dr. Bryan urged that it was important to figure out who has the responsibility to respond. Is it OMH or the Executive Secretarial level?
- The Secretary never received our letter that was sent requesting a meeting. The group decided we should send another letter since the first was never received.

Sustainability of HRAC

1. Discussion

- Kathy Hughes commented on not seeing HRAC getting into proposed projects and reviewing and providing input. HRAC typically only hears about completed projects. She would think that would be a task for HRAC, but is not sure where to go since there are so many agencies within HHS. Is there a clearinghouse at HHS for all research?
- Dr. Bryan raised this concern last year and noted that this year the request to CDC for support of the HRAC is undergoing close scrutiny, they had to fight to maintain support. It's hard to point to concrete examples of policy changes that have been made on account of HRAC. What is the value added? HRAC got off to a slow start and has really progressed. The big question is: what are CDC and other OPDIVs seeing in terms of returns on their investments?
- Pat Parker from NAMS mentioned the research report and the fact that this is the first advisory committee to provide a report that represents agency research pertaining to AI/ANs. Dr. Bryan said the Annual Report is a step in the right direction. He posed the question of how has it changed the way HHS departments work or what's the impact?
- Wendy Perry said she would like to see other agencies getting involved in HRAC.
- Madan Poudel asked about the charter and if the HRAC needed to change its mission or primary functions. Dr. Bryan read the primary functions and said that a lot of our discussions go outside of these specified functions. We talk about support for research in Indian Country, but it doesn't seem to fit within the three primary functions.

- Wendy Perry was disappointed that the only area that had any large contributions to the Discussion Guide survey was Alaska. Dr. Bryan suggested the need to have priorities that are ranked from an advisory committee. Wendy Perry said the priorities that we have seen in the past few years like cancer, diabetes, etc are too broad. Dr. Bryan said the HRAC needs to be more specific, such as, barriers to colon cancer screening, Tribal delivery vs. IHS delivery, etc. HHS is already doing research in the broad areas of cancer, obesity, etc. So, it would help to know what we are not doing that would be important to Tribal communities. Tim Gilbert asked if they were suggesting that HRAC undertake the Discussion Guide survey again to ensure HRAC support by Federal partners. Dr. Bryan said the HRAC should be doing it because the group can use the information to come up with priorities.
- Chester Antone mentioned the high level recommendations like NIH developing a consultation policy, but not program specific recommendations. Dr. Bryan said there is a difference between process and priorities.
- Next Steps: Email and then make phone calls with co-chairs to set plan for priorities. Look at testimony, recommendations, discussion guide, and top three priorities. Send group simple email with priorities and the original survey.

Action Items

1. IHS Committee Members – there are none for the FCC and there are no plans to include one – reproduce another letter.
2. Data Sharing/Infrastructure – Jim Crouch
3. Resend letter to the Secretary.
4. Superfund sites – Cara will develop something to push out for more involvement. Cara will need Dr. Bryan's assistance.
5. Access to data and data sharing agreements – have Sarah Hicks call Dr. Bryan.
6. FACA Compliance
7. Cara would like to see a list of things in writing for each agency. They are:
    a. Research fellows
    b. Grant announcements
    c. Status on HRAC testimony and any input from your agency (It was presented during the AHRQ breakout session but applies to all agencies.)
    d. Any status of Tribal Consultation results, or the outcomes of this. Please get this out to us electronically.
8. Next HRAC Quarterly Call –Tuesday, June 29th at 1pm CST.

HRAC November Meeting Video Highlights

- Pat Parker, NAMS, shared several video clips from the November meeting that NAMS produced.

Co-Chair Vote

- The HRAC reached a quorum and voted to keep Cara Cowan Watts and Kathy Hughes as co-chairs for the HRAC.
- Cara said the HRAC will re-evaluate this decision in the next six months or so. If you would be interested in being a co-chair, please let us know.