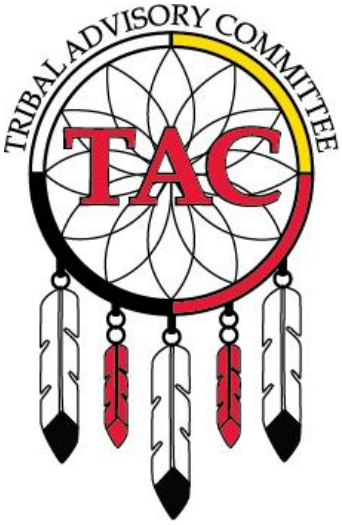

Department of Health and Human Services
Centers for Disease Control and Prevention
Agency for Toxic Substances and Disease Registry

8th Bi-annual Tribal Consultation Session

February 2, 2012
Executive Summary

Acronyms

ABCS	Aspirin, Blood Pressure, Cholesterol, and Smoking
AI/AN	American Indian/Alaska Native
ATSDR	Agency for Toxic Substances and Disease Registry
CDC	Centers for Disease Control and Prevention
DHAP	Division of HIV/AIDS Prevention
HHS	Health and Human Services
HIT	Health Information Technology
IHS	Indian Health Service
I/T/U	IHS/Tribal/Urban
NCBDDD	National Center on Birth Defects and Developmental Disabilities
NCEH	National Center for Environmental Health
NIHB	National Indian Health Board
OSTLTS	Office of State, Tribal, Local, and Territorial Support
SPDI	Special Diabetes Program for Indians
STDs	Sexually Transmitted Diseases
TAC	Tribal Advisory Committee
TB	Tuberculosis

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The U.S. Department of Health and Human Services (HHS), Centers for Disease Control and Prevention/Agency for Toxic Substance and Disease Registry (CDC/ATSDR), held its 8th Bi-annual Tribal Consultation Session on February 2, 2012, at the CDC Headquarters in Atlanta, Georgia. With a shared goal of engaging in true and effective consultation, CDC/ATSDR senior staff and Tribal leaders and representatives discussed policies, programs, and strategies that impact American Indians/Alaska Natives (AI/ANs) with the hope that open, continuous, and meaningful consultation will lead to the elimination of health disparities faced by Tribes. This meeting immediately followed the Tribal Advisory Committee (TAC) meeting on January 31 – February 1, 2012.

The 8th Bi-annual CDC/ATSDR Tribal Consultation Session began with Mr. Chester Antone, Councilman, Tohono O'odham Nation and TAC Co-Chair, providing the opening blessing. After brief self-introductions by Tribal participants, Judy Monroe, Deputy Director, CDC and Director, Office for State, Tribal, Local, and Territorial Support (OSTLTS), introduced CDC/ATSDR Director Tom Frieden.

Dr. Frieden informed the group that the CDC's mandatory funding remains fairly reliable, although funds are at real risk of further reductions in the future. He said State and local level funding are seeing reductions, with some programs having been eliminated. In terms of funding to Indian Country, Dr. Frieden indicated that a quarter million dollars goes to Tribes—a 16 percent increase between FY 2010 and FY 2011.

Noting that heart disease and stroke are the leading killers in the U.S., with rates of heart disease being higher for AI/ANs, Dr. Frieden discussed the Million Hearts initiative. He explained that this new effort aims to prevent one million heart attacks and strokes over the next 5 years (from January 1, 2012 to January 1, 2017). Dr. Frieden provided the group with statistics on heart disease and strokes and he noted the role of the ABCS (Aspirin, Blood Pressure, Cholesterol, and Smoking) in helping to reduce them. Key components of the program are community prevention and clinical prevention. In terms of community prevention, the initiative primarily targets the reduction of sodium and trans fat, as wells as distinguishing between commercial versus traditional tobacco use. For clinical prevention, the campaign will focus on the ABCS, health information technology (HIT), and clinical innovations in care delivery.

Turning his discussion to chronic diseases, Dr. Frieden indicated that Dr. Ursula Bauer, Director, National Center for Chronic Disease and Health Promotion, CDC, directs grants to address chronic diseases, including Community Transformation grants. Specifically, he noted that nine Tribes were

awarded a total of $7 million to focus on chronic diseases. Dr. Frieden also discussed the problem of prescription drug abuse in the U.S., stating that 1 in 20 people (in 2010) reported non-medical prescription drug use in the past year—with AI/ANs having the highest ration of prescription drug use of all groups.

On a more positive note, Dr. Frieden acknowledged that AI/ANs have a positive history of doing immunizations, an extremely cost-effective public health intervention. He commented that immunizations have led to dramatic reductions in vaccine preventable diseases among AI/ANs, commenting that health insurance plans are required to cover all routine recommended immunizations at no cost to the patient under Health Care Reform. Additionally, Dr. Frieden said the CDC is working to support adult vaccinations at I/T/U [Indian Health Service (IHS), Indian, and Tribal] facilities. In closing, Dr. Frieden said the goal of the CDC is to improve the health of all populations and to eliminate health disparities; to that end he said he looked forward to addressing the concerns of Tribal Nations.

Following Dr. Frieden's remarks, Tribal leaders and representatives asked for support for the Special Diabetes Program for Indians (SPDI); a literature review of cancer in Natives; a tracking sheet to ensure follow-up on issues raised during consultation; Grade 13 positions in the Office of State, Tribal, Local, and Territorial Support (OSTLTS); additional funding for HIV; timelier distribution of vaccinations; direct funding to Tribes; and protection of Indian programs from budget cuts.

Throughout the day, Tribal leaders and representatives heard from CDC Center Directors. Specifically, the following presentations were made:

Dr. Ursula Bauer, Director, National Center for Chronic Disease and Health Promotion, CDC, discussed Community Transformation grants; the potential of mentorship programs for Tribes; and a potential new program called the Coordinated Chronic Disease Prevention Program. Discussion following Dr. Bauer's presentation focused on the need for funding to small Tribes; building a structure for Tribes to share information and provide mentorship to one another; support for the Traditional Foods Program; a need for paper companions to web-based information; and the need for training and technical assistance to Tribes, especially concerning the grants process.

Dr. Coleen Boyle, National Center on Birth Defects and Developmental Disabilities (NCBDDD), provided an update from the NCBDDD, noting it is the newest center at CDC and is congressionally mandated. With a focus on individuals with disabilities, assuring healthy pregnancies, and preventing developmental disabilities, the Center is working with State Health Departments and would like to reach out to Tribal Nations. Dr. Boyle's presentation addressed the Center's Pulmonary Embolism Initiative; work with non-malignant blood disorders; efforts to target Hispanics' corn based diets; as well as efforts in autism and other neurologic disorders, among other items. Regarding work with Tribes, Dr. Boyle said the Center had previously focused on healthy pregnancies regarding alcohol use and is trying to implement screenings and brief interventions for women that exceed the daily recommendations for alcohol. Follow-up discussion to Dr. Boyle's remarks centered on requests for data specific to AI/ANs.

Dr. Beth Bell, National Center for Emerging and Zoonotic Infectious Diseases, provided an update from that Center, saying it deals with issues ranging from vector born infections, to food borne

illnesses, to quarantine systems. As part of her remarks, she highlighted a pilot study, The Neighborhood Pilot Project, involving spay and neutering as a vehicle to manage Rocky Mountain Spotted Fever. Following her remarks, Tribal participants requested more information on the Neighborhood Pilot Project; inquired about the FDA's role in dealing with wisteria; and asked for assistance in brokering Tribes relationships with State and local health departments.

Dr. Jonathan Mermin, Director, Division of HIV/AIDS Prevention, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, CDC, discussed IHS partnerships with Tribal communities in terms of addressing HIV/AIDS. Noting that 1 in 200 people in the U.S. that live with HIV is AI/AN, he said the Division of HIV/AIDS Prevention began a new strategic direction that is focused on health equity and reducing incidence. He said they try to distribute resources in alignment with the epidemic, but realize some communities need extra resources and therefore more is given to Native Americans because it's a significant public health issue. To that end, he referenced increased collaborations with IHS under the new national strategy—with $1 million going to IHS for the expansion of some of its HIV programs.

Lisa Neel, Program Analyst, HIV Program, IHS, provided the group with an overview of HIV in Native communities and she shared various CDC-generated statistics. Notably, she said 26% of AI/ANs (in 2009) living with HIV were estimated to be unaware of their status; compared to Whites, AI/AN men and women both have higher diagnosis rates; and following diagnosis AI/ANs with full blow AIDS don't survive as long as compared to other groups. Ms. Neel said IHS is refocusing on treatment and prevention for AI/ANs to stop these trends, including an expanded national HIV testing initiative. Other efforts cited included pilot projects aimed at improving care; media projects geared toward youths; and various collaborations.

Dr. Donna McCree, Associate Director, Division of HIV/AIDS Prevention (DHAP), National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, CDC, discussed the national strategy that was released in July 2010, a comprehensive plan for addressing HIV in the U.S. Strategy targets for 2012 are to reduce HIV incidence; increase access to and quality of care; and reduce HIV-related disparities. She said the DHAP provides support to State, local and community HIV prevention programs with funding and technical assistance; and tracks the epidemic and success of programs; among other things. Dr. McCree shared key components of the High Impact Prevention approach; and she said a pamphlet is available online. Additionally, she said the CDC, IHS, and HHS OS are directed to consult with Tribes to develop and implement approaches to address HIV/AIDS. In closing, Dr. McCree posed and heard responses to the following questions:

- **How should the public health community frame the discussion about HIV/AIDS in the Native community?**

    - Provide education about HIV/AIDS and where it comes from.
    - Share facts about transmission.
    - Fund Health Boards to educate the community.
    - Focus on specific populations, but also on a safe sex message.
    - Solicit the assistance from those with the most influence in a community.
    - Talk about it in the context of Native history.
    - Frame the discussion locally.

- Talk about the issue as part of a broader overall wellness conversation.
- Address transmission of the disease through drug use for AI/ANs.
- Take a holistic approach to wellness.
- Involve medicine people in the community and validate Native views.
- Don't emphasize that the disease is prevalent among poor people.
- Don't focus on sexual activity; it's taboo in Native communities.
- Involve those infected and let them tell their testimonies.

- **What are the obstacles to continuity of care, i.e., testing, linkage to and maintenance in care, in Native Communities?**

  - Confidentiality issues.
  - Clinics not following or not having a policy, which deters people from getting tested.
  - Community health departments do outreach and talk about HIV/AIDS in the clinic, but education must be age appropriate.
  - Care in the clinic specific to infectious diseases is provided, but for HIV positive people they often choose to seek treatment outside the clinic.

- **How should the High Impact Prevention approach to HIV prevention work in Native Communities?**

  - Use global incentives.
  - Routinely offer HIV tests.
  - As for Natives input; effort should be community-driven.
  - Peer-to-peer education, counseling, and interventions are effective.
  - It's time for full-scale collaboration with CDC and Tribes.
  - Tribes need technical assistance to build their own capacity.

Dr. Christopher Portier, Director, National Center for Environmental Health and the Agency for Toxic Substances and Disease Registry (NCEH/ATSDR), discussed the issue of environmental public health. He said the ATSDR was created by the Superfund law circa 1985. Charged with going to Superfund sites to see if people are being affected, he said a community can ask for an assessment of toxins in the community. Dr. Portier told the participants that the National Center of Environmental Health has national programs that look at evidence linking environmental exposures to health and then creates programs to address them. He also indicated that there is an environmental health lab at NCEH. Next, Dr. Portier shared organizational changes he made in ATSDR, saying he saw a need to focus efforts on a community level. Notably, he said he's considering developing a 5-year strategic plan; he is elevating the Office of Tribal Affairs; and he will increase focus on education and outreach. Dr. Portier also indicated that regional offices for ATSDR will increase staff, including health educators and community involvement specialists. Regarding the budget, he said it has been a tough year with a $27.2 million decrease for NCEH. He said ATSDR saw a minor drop in its budget ($.5 million). With the Lead Poisoning and Prevention program virtually eliminated, he said other lines remain the same. As part of his presentation, Dr. Portier discussed the Navajo Nation Birth Cohort Study involving mining and milling on Navajo and abandoned uranium mines and the subsequent contract award in 2010. He discussed the Asthma Control Program—which aims to prevent attacks, hospitalizations, and death. Before closing, Dr.

Portier provided information on a national bio-monitoring program (which will produce a national report on 350 to 400 chemicals); discussed the importance of environmental justice; and shared information about Health Understanding grants. Tribal leaders and representatives expressed concern related to the impact of budget cuts on prevention programs; sustainability and follow-up of the Navajo Nation Birth Cohort Study; and the impact of fracking on Tribal lands.

Larry Alonso, Traditional Foods Project Lead, Native Diabetes Wellness Program, Division of Diabetes Translation, National Center for Chronic Disease Prevention and Public Health Promotion, provided background information on the Traditional Foods Project, slated for 2008-2013. Given the anticipated conclusion of the Traditional Foods Project, Mr. Alonso asked the group its thoughts about the possibility of a new project. Originally funded for 11 partners, he said money from IHS increased the number of partners to 17, including Alaska. Grantees focus on things such as harvesting, planting, and traditional fitness activities. Mr. Alonso said the program has brought about community transformation in the way of more healthy decisions and has afforded the sharing of data on traditional foods, social supports, and traditional forms of exercise. Additionally, he said the project has shown that small communities, when funded, can demonstrate quick, significant impact. With consideration being given to another iteration of the project, and Traditional Foods programs being woven into Community Transformation grants, Mr. Alonso asked for ideas regarding future iterations of the project. Consultation participants expressed concern about the sustainability of programs after the funding cycle; asked for technical assistance in writing food policies; and recommended that the connection between the Traditional Foods Program and reauthorization of SDPI be promulgated. As a result of the discussions, Stacy Bohlen agreed to have NIHB draft messaging on behalf of Tribes pertaining to their support of the Traditional Foods Program; and Lemyra DeBruyn, on behalf of the Native Diabetes Program, agreed to provide Stacy Bohlen with aggregate data pertaining to the Traditional Foods Program.

The remainder of the day's agenda was dedicated to hearing testimony, recommendations, and concerns from Tribal leaders. Testimonies were provided by the following:

- Rex Lee Jim (for the Navajo Nation)
- Lester Secatero
- J.T. Petherick
- Chester Antone
- Stacy Bohlen (for NIHB)

Details on the testimonies, as well as other agenda sessions, are provided in the 8th Bi-annual Tribal Consultation Session Meeting Summary. Highlights of the testimonies are provided below.

- Request for direct funding to Tribes.
- Need for increased cancer screenings in Indian Country.
- Request for funds for Tribes to develop education materials on the SDPI.
- Tribes need direct access to State and IHS data.
- There is a need for health surveillance disease systems.
- Additional funds are needed to address health disparities.
- Medicaid Feasibility Study funding is needed for study design, timeline, and cost analysis.
- CDC Tribal liaisons should visit Tribes.

- Training is needed for Community Specialist staff.
- Funds and technical assistance is needed at the grassroots level.
- Address mining and its effects on ground water.
- Hold grants that benefit Indians harmless from budget cuts.
- Across all grant agencies, examine if the Grants Office will accept evaluators from Indian programs who know the community. Will they be deemed credible?
- Re-consider what you consider "credible" data. Tribes might have successes that are measured differently. Continue to increase capacity of non-Tribal organizations.
- Invest more in Tribal public health systems.
- Request that CDC supports Tribes at the same level as local and state governments.
- Identify direct funding mechanisms to address States' lack of coordination with Tribes.
- CDC needs to consolidate infectious communicable disease funding, such as HIV, TB, and STDs.
- Expand support for chronic diseases.
- Support reauthorization of SDPI using the success stories from the Traditional Foods grants.
- Review previous consultation minutes because many issues raised today are embedded in those testimonies, e.g., water contamination and comingling of funds.
- CDC should do a literature review and produce results on the extent of cancer in the Native American community.
- Create more innovation opportunities with Tribes.
- Additional staffing is needed in the Tribal Support Office at Grade 13.
- CDC needs to hold States accountable for CDC resources.
- NIHB suggests CDC provides States with guidance for working with Tribes.
- CDC needs to ensure that its funding is included in Tribal communities.
- Request that CDC track action items from meetings, and include a synopsis of the actions.
- NIHB requests documents/presentations for all agenda items for all future meetings, with ample time for Tribes to discuss the information and plan for next steps.
- Request that information/action items be posted on the CDC website, updated monthly, and shared with NIHB.

On behalf of Dr. Frieden, CDC, and staff in the gallery, Dr. Monroe thanked the Tribal leaders for their testimonies and participation. The meeting adjourned with Councilman Antone providing a closing prayer.

Action Items:

- Delight Satter agreed to set up a conference call for Tribes to brainstorm how to conceptualize the idea of mentorship and the sharing of information among themselves, per Ursula Bauer's request.

- Ursula Bauer agreed to coordinate with Stacy Bohlen to get her staff to attend the Tribal Health Summit (scheduled for May 2012, in Oklahoma) to present on grants-related topics.

- Coleen Boyle agreed to get AI/AN-specific information to J.T. Petherick on structural malformations, autism, and other developmental disabilities, as applicable. She will also include national survey data.

- Beth Bell agreed to ask Dr. Jennifer McQuistin to send Chester Antone information on the Neighborhood Pilot Project.

- Stacy Bohlen agreed to have NIHB draft messaging on behalf of Tribes pertaining to their support of the Traditional Foods Program.

- Lemyra DeBruyn, on behalf of the Native Diabetes Program, agreed to provide Stacy Bohlen with aggregate data pertaining to the Traditional Foods Program.

- Delight Satter and Dr. Gregory Holzman agreed to follow-up on the request for CDC to have a form to track Tribal concerns.