

# Department of Health and Human Services Centers for Disease Control and Prevention (CDC) Agency for Toxic Substances and Disease Registry (ATSDR) Tribal Consultation Advisory Committee (TCAC) Meeting November 18–19, 2008

# **Executive Summary**



On Tuesday, November 18, 2008, the meeting of the Tribal Consultation Advisory Committee (TCAC) met at the Desert Diamond Casino and Resort in Tucson, Arizona. The meeting was chaired by Linda Holt.

On Wednesday, November 19, 2008 the TCAC and meeting attendees went on a site visit to the Tohono O'odham Nation.

#### Tuesday, November 18, 2008

Ms. Holt reviewed the agenda for the November 18 - 19, 2008 TCAC meeting. There were no additions or corrections to the agenda.

#### **Motion**

Mr. Robert D. Moore, District Three Council Representative, Rosebud Sioux Tribe, moved to approve the November 18-19, 2008 TCAC agenda. Vice Chairwoman Kathy Hughes, Oneida Business Committee, seconded the motion. The motion passed unanimously with no abstentions.

## **Consideration of July Meeting and Subsequent Conference Call Minutes**

Ms. Holt reviewed the Action Steps and notes from the July 29–30, 2008 TCAC Meeting in Hollywood, Florida.

With the assistance of TCAC and the National Indian Health Board (NIHB), CDC reached out to tribal leaders nationally for increased involvement and engagement at the November Consultation meeting.

CDC shared and distributed the FY 2007 Al/AN Budget Portfolio with TCAC and tribal leaders on February 28, 2008, and will distribute the FY 2008 Al/AN Budget Portfolio on November 20, 2009. An ongoing TCAC project has been to identify how tribes can expand funding opportunities and access to CDC programs. CDC must implement its Tribal Consultation Policy

to increase tribal access to CDC resources. TCAC will help CDC understand tribal needs and cultural values. TCAC meetings and Tribal Consultations will be held in Indian Country in order to meet with area tribes and determine their needs.

Minutes and recommendations from TCAC meetings will be available to all tribes. They are posted on the CDC Office of Minority Health and Health Disparities (OMHD) and on NIHB's web page. The Area Health Boards can be helpful in sharing this information with tribes in their areas. TCAC and NIHB will help in informing and advising Tribes about the progress made in two and one-half years of Tribes and CDC working together to increase understanding, collaborations, and resource allocations to address public health issues in Indian country.

TCAC will discuss and clarify how it will conduct business for the next year and TCAC will determine strategic priorities and goals and a roadmap for accountability. NIHB will assist TCAC Co-Chairs in arranging and implementing area ambassador visits by contacting Executive Directors of Area Health Boards.

CDC / OMHD will develop briefing books for TCAC members and other tribal leaders regarding CDC for each TCAC Meeting. The CDC / OMHD webpage includes handouts and notes from each TCAC meeting.

TCAC requests an opportunity to receive information about CDC's Aging Program and Network and about how CDC is collaborating with the HHS Administration on Aging (AoA) and the Indian Health Service (IHS) to maximize resources and services available to Native Elders and tribal communities.

TCAC requests an update on the CDC Public Health Alert process and how tribal organizations are connected.

CDC should develop a tribal training center and utilize a clearinghouse approach so that best practices being developed in CDC collaborative work with tribes can be reproduced in other new program areas of tribal importance. Technical assistance is needed in the public health arena to help tribes implement these programs at the local level.

#### **Discussion Points:**

- NIHB can act as a resource gatherer for best practices in public health and can also bring tribal programs funded by CDC to the NIHB Annual Consumer Conference.
- Institutionalization of how CDC work with tribes needs to occur. Tribes are beginning to understand the role that CDC can play in their communities, tribes need to know that CDC continues to be committed to increasing and strengthening partnerships and collaborations.
- CDC and NIHB could work together to create training modules and programs of CDC and its various resources and projects. The orientation session provide to the TCAC needs to be expanded and repeated so the education received by TCAC members is provided to others from Indian country. The training program could be mobile and used at different conferences.
- Budget Subcommittee members should concentrate on delivering a strong presentation at the next HHS Budget Consultation and the CDC Tribal Consultation Session to CDC. They should advocate for fewer line-items in the CDC budget, and potentially discuss advantages of having a AI/AN line item.

## Motion

Mr. James Crouch, Executive Director, California Rural Indian Health Board (CRIHB), moved to approve the Action Steps (minutes) of the July 2008 meeting. Mr. Chester Antone seconded the motion. The motion carried unanimously with no abstentions.

Ms. Holt then turned to the meeting notes from the conference call held on September 17, 2008.

A TCAC logo will be created to help people become familiar with the work that Indian Country does with CDC. Designs will be publicly solicited through NIHB. TCAC will choose the top three designs by electronic vote. A face-to-face vote on the top three choices will take place at the February 2009 TCAC meeting. TCAC members will speak with their local artisans about creating a logo. Because TCAC is a national organization representing all areas of Indian Country, the logo should have a broad base of applicability.

Regarding a CDC cooperative agreement evaluator, NIHB will send the contractor their scope of work for the cooperative agreement with CDC so an comprehensive evaluation can occur. The contractor will be conducting surveys and key informative interviews.

#### Motion

Ms. Kathy Hughes moved to approve the minutes of the September 2008 Conference Call. Mr. Chester Antone seconded the motion. The motion carried unanimously with no abstentions.

Ms. Holt turned to the October 20, 2008 Conference Call Meeting minutes. Finalizing TCAC meeting dates through May 2009 was discussed.

There was discussion regarding the frequency of TCAC teleconference calls. Based on attendance, it was suggested that they not hold monthly conference calls, but move to a structure of less frequent calls with more participation.

Re-activation of Budget and Tribal Preparedness and Emergency Response (TPER) Subcommittees: The two Subcommittees could include representatives recommended by TCAC members, and subject matter or technical experts from their Tribes, Health Boards or EpiCenters.

The November TCAC meeting and Biannual Consultation were also discussed.

#### **Motion**

Roger Trudell, Chairman, Santee Sioux Tribe of Nebraska, moved to approve the minutes of the October 20, 2008 Conference Call, with the above noted correction. Lester Secatero, Chairman, Albuquerque Area Indian Health Board, seconded the motion. The motion carried unanimously with no abstentions.

## **Area and National Organization Reports**

Aberdeen Area Roger Trudell, Chairman Santee Sioux Tribe of Nebraska

Issues in the Aberdeen Area include:  Suicide Hepatitis C Drug use on reservations Gang activity Alcohol abuse Infant mortality Smoking Accidental death from a number of causes, including poor roads and driving under the influence of alcohol or drugs Cancer, especially given that tribal health facilities are not always able to reach out to provide annual and semi-annual checkups and screenings; facilities are often understaffed
Alaska Area Tim Gilbert Alaska Native Tribal Health Consortium (ANTHC)
Priority issues in Alaska include:  Unintentional injuries Tobacco use disparities Sexually-transmitted infections (STI) Cancer prevention and control Obesity prevention and control, especially in pediatric populations Suicide
The Alaska Area would welcome assistance from CDC regarding creative health messaging using new technologies.
Albuquerque Area Lester Secatero, Chairman Albuquerque Area Indian Health Board
Concerns in the Albuquerque area include:  Diabetes Alcoholism Loss of Native language and culture Bad roads
Bemidji Area Kathy Hughes, Vice Chairwoman Oneida Business Committee Bemidji Area concerns include:  Communication, especially given turnover among Health Directors Funding and resource allocations: CDC must continue to fund all tribes across the United States at adequate, long-term, consistent levels iabetes Obesity Cardiovascular Disease Cancer, as annual testing is not regularly conducted
☐ Meningitis

	Important needs include: Infrastructure development Community capacity Access to healthcare Health statistics and data collection Consistent funding for preparedness The lack of a Health Board
James	rnia Area s Crouch, Executive Director ornia Rural Indian Health Board (CRIHB)
	is engaged in three major efforts: CDC-funded tobacco control work Injury prevention Emergency preparedness
	rns in the California area include: Accident prevention, particularly ATV and bicycle accidents, seatbelt use, and child safety seats Adolescent obesity Access to individual identifiers to build data sets
Micha	ille Area el Cook, Director d South and Eastern Tribes
	health issues for the United South and Eastern Tribes include: Resource allocations: Funding should not go to states, but directly to tribes Public health preparedness and emergency response Government-to-government relationships, including IHS's role in the federal emergency management process Data access, especially in the area of trending Environmental public health, particularly safe water Obesity
-	o <u>Area</u> Freddie o Health and Social Services Committee, NIHB
	The need for a ban on smoking in public facilities, except in gaming facilities Traditional healers have few apprentices Solid waste management The large population of wild Navajo horses

	Encouraging Indian students to go to college
Linda	nd Area Holt, Council Member of the Suquamish Tribe woman, Northwest Portland Area Indian Health Board (NPAIHB)
	es and concerns in the Portland Area include: Establishing local MOUs with VA facilities to care for Native veterans Long-term care criteria American Indian Recovery (AIR), an alcohol recovery program Facilities to care for those suffering from alcohol and drug addiction, especially youth. Tracking cancer in reservations Exercising the pandemic flu plan Tribal conferences on immunization and emergency preparedness Issues related to the Canadian border, particularly with methamphetamine from Mexico A child safety seat project Project Red Talon, a STD/HIV program Rapid HIV testing for tribes
Chest	on Area er Antone, Councilman no O'odham Nation
	n area concerns include: Suicide Alcoholism Drug abuse Public health issues associated with the drug trade across the Mexican border, such as raising children with incarcerated parents and proper immunizations for the children STD epidemic Prostitution Data sharing agreements and collaborations Changing the negative perception of research in order to benefit from it Combining expertise from different agencies in HHS to address problems in Indian Country
Rober Distric Rosek	Service Tribes It D. Moore It 3 Council Representative It 4 Council Representative It 4 Council Representative It 5 Council Representative It 5 Council Representative It 5 Council Representative It 5 Council Representative It 6 Council Representative It
	nal Congress of American Indians (NCAI)
South	West Area Vice President, NCAI  NCAI is working on a number of bills related to Indian Country  NACI's transitin plan includes recruiting tribal people to serve in positions in the new administration

# **National Indian Health Board (NIHB)**

Jerry Freddie

Council Delegate, Navajo Nation

	NIHB has added new staff members and is moving to increase and strengthen relationships with federal agencies such as CDC and SAMSHA in addition to IHS and CMS. Tribal leaders specifically expressed the need to have a CDC day and focus at the NIHB Annual Consumers Conference in addition to the Public health Summit.
	NIHB tracks legislation and works with other Indian organizations
	NIHB encourages young people into public health fields through its Public Health Summer Fellowship and other CDC training opportunities.
	The NIHB Board has done strategic planning and updated its plans. This should be shared with the TCAC and CDC.
	nal Indian Health Board (NIHB)
	e Hillsberg
	r Program Manager for Public Health Programs, NIHB
	Raven Murray is a new staff member at NIHB
u	NIHB supported the TCAC meeting in Hollywood, Florida on July 28–30, 2008 which included presentations from the interns of the Morehouse School of Medicine Public Health Fellowship Program, a program that they hope to replicate
	The NIHB Annual Consumer Conference was held in Temecula, California in September, 2008
	A new initiative for NIHB is the Public Health Accreditation Program
	On April 22 and 23 of 2009. NIHB will host a Public Health Summit in Oklahoma City, Oklahoma. The theme will be "Tribal-State Relocations and Foundations for Public Health." Proposals to address topics on public health issues or programs at the state or local level are encouraged.
	The Healthy Indian Country Initiative (HICI) is a collaboration with the Association of American Indian Physicians to support preventive health activities with thirteen tribal
	organizations. The Centers for Medicare and Medicard Services (CMS) Tribal Technical Advisory
	The Centers for Medicare and Medicaid Services (CMS) Tribal Technical Advisory Group (TTAG) held its third quarterly face-to-face meeting at the National Museum of American Indians in Washington, D.C., in early November 2008.

## **Tribal Self-Governance Tribes** Jefferson Keel, Chairman **Tribal Self-Governance Advisory Committee**

Ms. Holt read the report from the Tribal Self-Governance Tribes.

#### **Discussion Points:**

- There was concern that states and counties with AI/AN tribes and or high AI/AN populations within their jurisdictions often utilize statistical information that portray and states the high disparities and needs, and yet, when award is made, few to no resources are allocated to tribes and tribal organizations to meet those needs.
- CDC must be strengthened the language in new program announcements and program quidance in continuing applications of current awards to states, to hold states and academic institutions more accountable for engaging tribes in planning and implementation of public health activities done with CDC resources.
- The Public Health Accreditation Task Force has had two meetings. The value of accreditation lies in tribes' ability to determine for themselves the best measures or standards that are appropriate for their public health needs. Accreditation will also allow

tribes to improve and build their public health response as they exercise sovereignty in how public health programs are delivered.

The membership of TCAC includes primary and alternate representatives that are nominated by Area Health Boards. If a TCAC member is not able to attend a meeting, then arrangements should be made for alternate representation.

## Working Lunch: CDC's Healthiest Nation Initiative and Healthy Nations Alliance

## **Healthy Nations Coordinating Council National Center for Health Marketing Centers for Disease Control and Prevention**

Ms. Julia Smith presented an update on CDC's Healthiest Nation Initiative. The Alliance for the Healthiest Nation aims to create and spark a nationwide movement to make the United States the Healthiest Nation. The Alliance now includes approximately 100 organizations from all sectors of society. They are working toward a committed vision that values health, prioritizes prevention, and protects from emerging threats. The organizations in the Alliance work together to create a national commitment to the optimal health of every person.

The Alliance is guided by five basic principles, which are to help the grassroots grow and work with diverse partners; engage in conversation that changes focus from the absence of illness to understanding what will create and maintain health; coalesce voices, convene information, and convene partners to provide the roadmap for the initiative; make it easy to make the right choice. Healthy options should be easily available; and measure what matters and to redefine what it means to be healthy.

<del>-</del>	A 11'	1 41	41 .					
IhΔ		acke throo	things	of individuals 1	and	organizations that	ot chanca	to ioin.
1115		aoro 1111 <i>c</i> c	: umua	OI IIIUIVIUUAIS (	ann	UTUALIKATUULIS IITA	11 いいいろこ	ICO ICONTA

	Speak out
□ '	Walk your talk: Take just one action to improve your health and serve as a model for
	positive health behavior in your home, community, school, or workplace
	Share your successes

A Leaders-to-Leaders Summit will be held in Washington, D.C. on May 27-28, 2009. This Summit will assemble a broad spectrum of leaders to link together, leverage assets, and lead to actions to improve the health and longevity of our world and its citizens.

#### **Administrative Matters**

## **Confirming Dates for Quarterly TCAC Meetings**

In order not to conflict with other meetings, the next TCAC meeting will take place the week before February 17-19, 2009 in Albuquerque, New Mexico. This meeting will be held simultaneously with an American Indian/Alaska Native pandemic influenza public engagement meeting.

The dates of the next meeting in Atlanta, Georgia, which include a Tribal Consultation, are to be decided in the middle of January. Because of the transition to a new administration, scheduling

will shift forward about 45 days, so the HHS Budget Consultation will not take place in March as usual, but in April, and all HHS regional consultations will be shifted as well. The CDC Director, National Center Directors, and key programmatic staff should be in attendance at the TCAC and Consultation Meeting in Atlanta.

The subsequent quarterly TCAC meetings for 2009 will be held in Alaska the week of August 4-7<sup>th</sup> and in California at a location yet to be decided on December 14–17, 2009.

#### Reactivation of the PHEP and Budget Subcommittees

The Subcommittees will be chaired, or co-chaired, by TCAC members. The work of the TCAC will depend on the ability of these Subcommittees to organize and move agendas related to these focus area ahead. Via email, TCAC members will be asked to nominate technical experts from their areas to serve on the Subcommittees, or to volunteer to participate themselves.

#### **Budget Subcommittee:**

The Budget Subcommittee will include a senior-level staff person from CDC's Financial
Management Office (FMO) to serve as the SME and OD/FMO point of contact.
The data will help them prepare for the National Budget Consultation and the CDC Tribal
Consultation in Atlanta.
The goal of the Budget Subcommittee is to analyze and impact CDC's budget.
The Budget Subcommittee will analyze information provided by CDC regarding the
allocation of resources to benefit AI/AN tribes and make recommendations to CDC about
their budget planning, formulation and allocations.

#### Tribal Preparedness Emergency Response (TPER) Subcommittee:

ш	The Tribal Preparedness Emergency Response Subcommittee has held several
	conference calls.
	In the past, they have worked with COTPER DSLR and CPHP Project Officers as well
	as some State PHEP Program Directors.

## Suggestions and Approaches for CDC Budget Opportunities

Michael Franklin **Financial Management Office (FMO) Centers for Disease Control and Prevention** 

Michael Franklin explained the federal budget cycle and process. Planning for each fiscal year begins eighteen months to two years before the fact. Therefore, in February of 2009, planning will be underway for the 2011 budget. The planning process at CDC begins in January or February. Engagement with CDC partners should begin at this time. The Office of Management and Budget (OMB) sends its guidance to HHS in the spring, and HHS submits it to CDC. The Coordinating Centers of CDC then respond to the guidance. At this point, there is a "window of opportunity" to work with CDC partners regarding the budget. By the fall, OMB responds. Congressional Committees then review budgets from all agencies. This process takes place in January or February. OMB has approved the Congressional changes by July. In September, the President should be able to sign the Appropriations Act; however, the signing rarely takes place in September. In this case, the budget goes into a Continuing Resolution in order for the government to keep operating. Because budgets are shrinking, tribes need to help CDC plan and prioritize according to their long-term needs. Additionally, tribes should make their wishes known at the Congressional level and use their power and influence to impact congressional decisions. There are many other groups competing for dollars, as CDC only has a set amount. Congress has the power to make congressional decisions regarding how dollars are provided and expectations regarding how the HHS and CDC will be responsive to those directives.

## **CDC/ATSDR FY 2008 Resource Allocations: American Indian/Alaska Native Programs** (Preliminary Report)

The preliminary report of the CDC/ATSDR resources committed to programs that benefit American Indian/Alaska Native populations and communities was summarized according to organizational and disease-specific programs and by defined funding categories.

Funding allocation categories include intramural, extramural, awardee, or indirect funding. These figures include all funding categories, including grants, cooperative agreements, resource allocations, and grants to states that benefit tribes. The total American Indian/Alaska Native funding for FY 2008, including Vaccines for Children (VFC) was \$108,080,000. Non-VFC funding was \$43,816,183, or 41% of the total funding. This represents an increase from FY 2007.

VFC funding level decreased, as all of CDC's budget decreased. Not including VFC, Chronic Disease Prevention and Health Promotion programs comprised the highest percentage of American Indian/Alaska Native total funds. Including VFC, most funding to tribes was through indirect means. Without VFC, 52% of the funding allocation was via American Indian/Alaska Native awardees. The amount of funding to tribal awardees appears to have increased by about \$1 million, which is a trend in the right direction. Indirect funding to tribes in the amount of \$1.4 million that does not include VFC funds is figured according to population-based estimates sent by the states as well as figures generated by the National Center for Health Statistics. American Indian/Alaska Native funding represents 1.2% of CDC/ATSDR's FY 08 budget, which is parallel with FY 2007. Overall, American Indian/Alaska Native allocations increased by 8%. The final analysis of the budget will include maps to illustrate the number of tribal awardees, the locations of tribal awardees, the amount and categorical reason for the award. This information will be displayed in GIS maps by state and IHS Area.

#### **Discussion Points**

- Because so much of CDC's funding is spoken for via line items, TCAC should inform and engage other tribes and tribal organizations and collectively communicate tribal priorities and recommendation about their needs at the Congressional level to "untie" some of those "strings" and increase allocations to tribes based on evident need and disparities.
- CDC has a unique responsibility to Al/AN tribes as part of the Federal Trust Responsibility that the United States government has to each sovereign nation in this country. Every agency within HHS must meet that obligation to provide adequate healthcare for tribal members. If the federal government has to take resources away from a foreign country, then tribes will advocate for that, as the United States government's responsibility is to make its nation whole and well before spreading limited resources throughout the rest of the world.
- It is important to determine the actual numbers of tribal members that are served by indirect funding. If resources are going to states based on population estimates that include American Indian/Alaska Native populations, then the states and CDC should be accountable for those resources going to those populations.

- States need to document whether these indirect funds are effectively benefiting AI/AN populations. If not, then CDC needs to hold states more accountable and increase the finding going directly to tribes. Tribes should request a larger percentage of the CDC/ATSDR budget in categorical areas having greater disparities in Al/AN population...
- It was clarified that the figures shared by CDC in the FY AI/AN Portfolio in the indirect funding category are chiefly comprised of VFC funds (National Immunization Program) and funds used by the National Center of Health Statistics, which are allocated using censusbased population data. No other indirect funding going to states is counted.
- Tribal communities are among the most under-counted groups by the Census in the country. If funds are distributed according to Census statistics, then the numbers of tribal populations served need to be more accurate.
- It was recommended that a series of budget development workshops or seminars was recommended. This series could help everyone involved in the process of advising on the budget to understand how the budget is put together.
- Only about 15% of CDC's total budget is not earmarked by Congress. Tribes have a great deal of power to influence CDC's budget.
- It would be helpful to learn for tribes to understand what drives the budget formulation and where tribes can fit in with other populations. Tribal communities share common problems with other populations, and they could find resources from other directions.
- States are often not held accountable for funds awarded to them because of need and disparities evident in American Indians/ Alaska Natives tribes and population. States do not engage the tribes in any substantial manner, they do not distribute any of the resources to the tribes, and they are falsifying reports that go back to CDC that documents activities implemented. Tribes have a right to see these reports and have access to the funds.
- Tribal communities should not have to go through states for money that is granted based on need and disparities of their population.
- In the case of COTPER funds (DSLR & SNS) which are granted to states, states need to have concurrence and signature of the Chief Officer of the Area Tribal Consortia and/or tribes in their jurisdiction. Tribes should be able to see what activities the state said they were going to doing to involve and engage tribes. Some states are beginning to do this, but many are not.
- Direct funding to tribes is important, and tribes need to make plans and be more assertive in advocating and affecting public health legislation to be more directive to CDC. When congressional legislation is written, it should specifically include tribes as eligible grantees and/or the intent to assure tribes and Native populations do benefit from resources and programs.
- Public Health Emergency Preparedness money must have more accountability. When a disaster or emergent situation happens. CDC should demand that states clarify how tribal nations within the disaster area are being helped.

With the new administration and the possibility of new CDC leadership, TCAC should make a strong recommendation to CDC that the percent of its total budget for AI/AN programs should be doubled.

# Updates from CDC in Response to TCAC Recommendations

CAPT Snesrud provided updates on CDC responses and actions to TCAC recommendations, stating that the most important overarching TCAC recommendation is for CDC to continue to fully implement its tribal consultation policy. This policy primary purpose of this policy is to increase tribal access to CDC resources and programs. All other actions flow from this policy. Dr. Bailey, Chief of the Office of Public Health Practice, is advocating with the Executive Leadership Board and the Center Leadership Council of CDC to assure that appropriate leadership does respond in a timely manner to TCAC recommendations. There is a flowchart that shows how CDC is systematically responding to TCAC recommendations.

CDC's COTPER Division of State and Local Readiness public health emergency preparedness (PHEP) and CCID/NCIRD/ISD immunization services (VFC/317) programs have implemented guidance to state awardees requiring tribal engagement/partnerships. This same standardized language will be used by the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) in all their new cooperative agreements. These three are large programs have set a precedent across CDC as an example for other programs to follow. The language is specific and direct regarding tribal eligibility and engagement.

Several of the key categorical programs within Chronic (Cancer, Diabetes) and NCHHSTP (DHAP) regularly offer trainings to their project officers about "how to work more effectively with tribes". OMHD has approached OWCD about standardizing a training for all project officers to increase their competencies in working with tribes, although no requirement is in place to mandate training.

Regarding competitive applications, CDC programs are ensuring that when funding opportunity announcements target tribal communities and tribal applicants, the best objective review panel possible is assembled. In situations when funding announcements are broader, the objective review panels should still include members who are savvy and knowledgeable about Indian Country.

Regarding monitoring and tracking where tribal recommendations have influenced CDC priorities to enhance tribal access to CDC resources, CDC is working to be transparent about where dollars are going in Indian Country. Discussions with FMO about guidelines to allow tribal stakeholders to provide input into the CDC budget formulation process will continue.

CDC is working with NIHB and other partners to disseminate information about CDC funding opportunities and how to obtain technical assistance in the application process.

A CDC-wide American Indian/Alaska Native strategic plan has not yet been created, but there is strong support for the concept. This plan will be re-visited after the transition.

CDC will continue to offer a formal orientation to tribal leaders at least once a year. There is support for the establishment of an Office of Tribal Affairs within the Office of the CDC Director (OD). There is a need for a succession plan for two senior tribal liaisons to institutionalize these positions within the agency, and assure progress in making the agency responsive to its Tribal Consultation Policy continues.

#### Motion

Mr. Moore moved that TCAC request the new administration to establish an American Indian/Alaska Native-specific office within the OD/CDC. Mr. Trudell seconded the motion.

#### Motion

Mr. Moore amended his motion to include the recommendation that tribal persons should be identified who can move into positions currently held by Dr. Ralph Bryan and CAPT Mike Snesrud. Mr. Trudell seconded the motion. The amended motion carried unanimously with no abstentions.

Changes to the TCAC Charter were reviewed to reflect the changed role of TCAC. CDC's PGO notified OMHD that it was not appropriate for funds from the NIHB Cooperative Agreement be used to do logistics and administrative tasks associated with the TCAC (the work of CDC). For this reason, an outside contractor who fulfills this role with other Agency Advisory Committees was contracted. It was noted that TCAC could have discussed and voted on the suggested revisions of the TCAC Charter via a conference call earlier.

## **CDC Program Updates**

CDC's Division of Violence Prevention's Activities on Suicidal **Behavior Prevention Among American Indians and Alaska Natives** 

**Alex Crosby National Center for Injury Prevention and Control Division of Violence Prevention** 

Dr. Crosby addressed the group about the National Center for Injury Prevention and Control (NCIPC) and its Division of Violence Prevention's activities regarding suicidal behavior prevention among AI/ANs. In the area of problem description and surveillance, they are using the National Violent Death Reporting System (NVDRS). The NVDRS combines death certificate data with data from law enforcement; from the medical examiner or coroner; and from the toxicology lab or crime lab.

In the area of evaluating programs, the Division of Violence Prevention has developed a partnership with the Substance Abuse and Mental Health Services Administration (SAMHSA). The G.L. (Garrett Lee) Smith Memorial Act provides funding for a number of tribal suicide prevention activities, and the agreement with SAMHSA provides for evaluation of the prevention programs. The work focuses on the promotion of protective factors, connecting them with the cultural history of tribes.

Another important collaboration is with the Area Tribal Epidemiology Centers. The Division routinely conducts conference calls with the EpiCenters to provide technical assistance on injury-related issues (e.g., assessment, research, programming, applying for grants) and to facilitate communication and collaboration between the Centers and CDC about their activities. The Division has collaborated with IHS and a tribal reservation in the Midwestern United States in response to a cluster of adolescent suicide. In addition, as suicidal behavior in certain populations is tied to health disparities, the Division intends to address those disparities. The Division is working with several programs at CDC and in other federal agencies two look at suicidal behavior among adolescents in two specific populations: American Indian/Alaska Natives and Latinos. They will bring together an expert panel to examine problems related to adolescent suicidal behavior and to identify recommendations for where federal agencies and local communities can take action.

It was recommended that the Division include a youth on this expert panel.

#### **Quarantine Regulations**

Dr. Bryan and representatives from the Division of Global Migration and Quarantine (DGMQ), present via telephone. They presented the update on new proposed guarantine regulations. which are in the review and approval process with HHS and OMB.

The Public Health Service Act granted the Secretary of HHS the authority to quarantine individuals. Within that authority is the ability to apprehend, detain, and conditionally release individuals. The purpose of this authority is to prevent the introduction, transmission, and spread of communicable diseases within the United States. The Secretary of HHS delegated that authority to CDC, and the Director of CDC passed the authority to the DGMQ. The purpose of updating the quarantine regulations is not only to bring them up to date with modern technology, but also to codify current procedures. Over 500 comments were received when the updated regulations were published in the Federal Register. For the past three years, the Division has worked with state, local, and tribal health authorities and conducted tribal consultations. The proposed changes clarify a number of jurisdictional issues in Indian Country.

The transition of government will likely delay the publication of the final regulations, but when the date of release is known, CDC will advise tribal leaders.

#### Office of Smoking and Health (OSH) Video Presentation

"Nathan's Story -The Impact of Secondhand Smoke on an American Indian Tribal Casino Worker." Produced by CRIHB Tribal Support Center

CAPT Snesrud directed the group's attention to the handouts in Tab Seven of their Briefing Books, noting that a number of CDC programs wanted the opportunity to provide updates about their program activities with and for Indian Country. The Office of Smoking and Health (OSH) presented to TCAC at the July 2008 meeting, and they sent a staff person and a video to share.

## **Cancer Prevention and Control Update**

## Gary Gurian, Senior Program Officer for C-Change **Active Member of the National Cancer Partnership**

Dr. Gurian presented information about the National Partnership for Comprehensive Cancer Control (CCC) and C-Change, explaining that C-Change is a national cancer collaborative with non-partisan membership. It includes 130 leaders representing 150 private, public, and nonprofit organizations. C-Change's mission is "to leverage the expertise and resources of its members to eliminate cancer as a public health problem at the earliest possible time." They work collectively to address policy and practice issues. The strategic focus areas of C-Change are to accelerate cancer research; improve access to the full continuum of cancer care services; and support state, tribe/tribal organization, territory, and Pacific Island Jurisdiction comprehensive cancer control efforts.

C-Change has integrated its efforts into the National Partnership for CCC, using some of its resources to assist in the funding and management of leadership institutes and policy and practice summits convened in conjunction with the national partnership. The National Partnership's mission is to advance CCC. Similar to C-Change, the Partnership works to leverage member organizations' resources and coordinate expertise to support CCC efforts. The National Partnership represents a unique collaboration among twelve national cancer organizations. It also includes liaisons and designated representatives from the Pacific Island Jurisdiction CCC Coalitions and Programs and from the American Indian/Alaska Native Advisory Workgroup. Initiatives are funded through CDC and also through the organizations that make up the national partnership. The National Partnership Strategic Plan for 2008-2012 includes strategies to help advance American Indian/Alaska Native CCC coalitions, programs, and efforts.

The Partnership plans to convene an American Indian/Alaska Native CCC Policy and Practice Summit in the Summer of 2009. This Summit will be modeled after the State CCC Policy and Practice Summit in May 2008. It is designed for American Indian/Alaska Native CCC coalitions and programs to inform national partners about policy and practice issues that need to be addressed to help advance CCC. The Summit is also designed for AI/AN Coalitions to identify areas and issues that they need to collectively address to advance CCC within their jurisdiction. The Partnership's strategic plan includes a 2010 "Mega CCC Leadership Institute." State, territories, tribes/tribal organizations, and Pacific Island Jurisdictions will all be invited to this Institute. The CCC National Partnership will continue to leverage its financial and staff resources and coordinate cancer expertise to collectively support CCC.

## **Ena Wanliss, Assistant Director for Program and Policy Information Division of Comprehensive Cancer Control**

Ms. Wanliss presented the group with activities of the Division of Cancer Prevention and Control (DCPC), which has worked with a number of tribes and tribal organizations as partners in the national breast and cervical cancer early detection program. The National Breast and Cervical Cancer Program provides free or low-cost breast and cervical cancer screening and diagnostic services to low-income, uninsured, or underinsured women. Their tribal partners include eight tribes and tribal organizations in the lower 48 states. Since the program's inception, approximately 52% of women screened through the program were of racial or ethnic minority groups, and five percent were American Indian/Alaska Native women. In Fiscal Years 2003-2007, Native American and Alaska Native organizations provided 84,606 Pap tests and 44,786 mammograms to 52,582 unique women. A total of 241 breast cancers were detected; 13 invasive cervical cancer cases were detected; and 468 high-grade, pre-cancerous cervical lesions were detected.

The Program makes significant contributions beyond providing screening, such as providing health education. States are required to coordinate activities with the tribes located within their boundaries. The Comprehensive Cancer Control (CCC) Program provides seed money, structure, and support for developing and implementing CCC plans. The CCC program assists states, tribes, and tribal organizations in developing, implementing, maintaining, and integrating the evaluation of cancer control programs. Seven tribal organizations are currently funded under the CCC program. The program is unique because each CCC program is unique. The Tohono O'Odham began the planning phase of their CCC program in July 2007.

The inter-agency agreement with IHS facilitates and enhances collaborative relationships and partnerships between states with American Indian/Alaska Native populations that conduct comprehensive screenings. DCPC monitors the progress of all states in developing plans to specifically address to Al/AN women for breast and cervical cancer screening.

CDC will continue to leverage its partnerships to increase access and resources, helping to facilitate and assist program work with tribes and Native communities. CDC will assist with the implementation of Tribal Consultation policies and support workgroup activities around comprehensive cancer control and provide technical assistance to expand tribal linkages to the breast and cervical program and the CCC program.

## **Day 1: Meeting Wrap-Up**

It is concerning that the Navajo are not seeking healthcare until their health problems have escalated.

The ability of tribal health institutions to diagnose chronic diseases is limited. Al/AN tribes should demand better equipment and updated, larger tribal facilities if they are going to address cancer. More resources need to be allocated to public health prevention activities in order to prevent Cancer and other chronic diseases disproportionately affecting Al/AN populations.

Training of healthcare professionals is a concern. The state of tribal healthcare facilities affects retention and recruitment of healthcare professionals on Indian reservations. Insurance coverage in Indian Country is basic.

Many Indian children are obese and diabetic. TCAC should find collaborators to see that new research and increased resources are available for public health prevention programs and strategies that have worked in AI/AN communities.

Many Indians with cancer could be cured by surgery and other innovative treatment programs, but without resources and with outdated healthcare facilities on the reservation, these interventions often are not possible.

When research is conducted with American Indian people, the results should be shared with them to make it useful. Tribal communities need help understanding prevention, primary care, and other health ideas, but in their own language and terminology.

TCAC would like to see that information from national public health conferences be shared with tribal health staff and leadership at "mini-conferences" in TCAC members' regions.

## Wednesday, November 19, 2008

# Site Visit: Tohono O'odham Nation Tour

International Border Visit
San Miguel Community Building

Councilman Tom Joaquin Tohono O'odham Nation, "Desert People."

Councilman Joaquin presented to the group on issues facing the Tohono O'odham people, explaining that the Tohono O'odham Nation is comprised of 2.8 million acres of land. It includes 75 miles of international border between the United States and Mexico. Currently, the Border Control is building a vehicle barrier and fencing on the border. Ancestral lands of the Nation extend across the border into Mexico, and the Nation includes nine communities with over 1500 members in Mexico. Those members come across the border to receive services such as healthcare, financial assistance, education assistance, and other aid.

When the vehicle barriers were constructed, the Nation advocated for three traditional crossing points that are specific to tribal members. Tribal ID cards allow them to come across the border at those points. The Nation has traditional sites in Mexico, where members make pilgrimages and conduct ceremonies. Because of the increase in violence from drug cartels in Mexico, they have been forced to halt some of the pilgrimages. Many dangers face illegal immigrants from Mexico who cross the border into the United States and onto Tohono O'odham lands. Local Indian health services often incur costs for providing services to these illegal immigrants.

There is a great deal of illegal activity the border, including trafficking of human cargo and drugs. Along the border, there are "staging areas" where illegal immigrants wait to be picked up and brought into the United States. The "staging areas" are littered with their cargo, such as water bottles, backpacks, clothing, and other items, including vehicles. The trash poses environmental concerns and damages the vegetation and land. Every year, the monsoon season brings flooding. There is a need for assistance both for flooding evacuation and for cleanup of environmental hazards in the groundwater. Mexico military incursions are also a concern. Nation members cannot be sure whether the armed men are Mexican military guarding the border, Mexican drug cartels disguised as military, or Mexican military that are working with the drug cartels. Because of increases in drug activity and violence, there is stress on people living along the border. The stress leads to behavioral health issues associated with living in fear.

They are thankful for their local law enforcement, which works with the Border Patrol to assist with the ongoing violence problems. Drug busts occur with tribal members and non-tribal members who come onto the Nation to assist drug cartels and in moving human cargo. They are seeing an increase in methamphetamine trafficking, and the meth finds its way to other tribal communities, towns, and areas all over the country. The Nation does its best to assist the Department of Homeland Security (DHS) in the name of saving its people.

The border construction includes a vehicle barrier and three types of fencing. The first type restricts vehicle traffic. The Nation will never agree to a wall-type fence because of the relationship that they have with their members and aboriginal lands on the Mexican side of the border. The Nation is sensitive to vegetation and animal migration in the area. Water issues are also a concern on the Nation. Water is an environmental issue and it also affects people's health and well-being.

Additional comments were offered by: Verlon Jose, Chairman of the Tohono O'odham Legislative Council Marla Kay Henry, Chairwoman, Chukut Kuk District Geneva S. Ramon, Chairwoman, Gu Vo District. Stanley Cruz, Chairman, Pisinemo District. Mr. Felix Anton, Elder and Spiritual Leader of the Tohono O'odham Nation

Trash on Nation lands also presents a danger to the cattle. Transportation for Nation members to receive health services is a concern. In addition, long distances in the District mean that response to emergencies takes a long time. Border tensions affect the Tohono O'odham

people mentally, with emotional distress and related health issues. Border tensions also affect the people physically, as their traditional hunting practices and ceremonies often cannot be performed for safety reasons or because they are interrupted by the Border Patrol. Ceremonies are performed for the community, and if they are not done, then the community's health suffers. With the vehicle barrier's construction, foot traffic has increased, and drug smugglers have hideouts near Nation communities.

All of these concerns intertwine and affect the health of the Tohono O'odham people. Although there are problems on the border and in the Nation, there are good people in Mexico and in the United States. The most important way to support the O'odham land and people is to realize that people need each other. They need support not just from a few people or from one race, but from everybody. There is a misconception that because Natives have casinos, they are rich. On the contrary, they are "barely catching up," and they add their own dollars to the federal government's responsibility to address healthcare, education, and roads. Committees from the Nation work with federal agencies and Congress. They have made their needs known regarding roads, environment, health, and other issues. Collaborations are in place. There was discussion about border issues in Alaska and how all tribes can collaborate and network to solve problems.

#### **Tohono O'odham Museum and Cultural Center**

Bernard Siquieros, Administrator of the Tohono O'odham Museum and Cultural Center, addressed the group about the Center, which is a repository for all Tohono O'odham Nation treasures for preservation and education. It includes a library and archives, an Exhibit Hall, museum, and an Elders Room for use by the community. The site was chosen for its view and because of the variety of vegetation on the land surrounding it.

Mr. Felix Anton narrated the story of the Tohono O'odham tribal symbol, "The Man in the Maze." The Man in the Maze is the Elder Brother who created the O'odham. The Man in the Maze carries a staff, and power comes from this staff. Before we are born, we are given a Gift. We begin outside the Maze, and as we travel, our Gift emerges. Our life is the Maze, and the trail leads to the Man in the Maze.

The group enjoyed lunch on the patio and entertainment by a group of traditional dancers. Jaleen Wood, Miss Tohono O'odham Nation, offered remarks on her concerns about health issues in the Tohono O'odham Nation, especially diabetes among elders and youth.

2<sup>nd</sup> Biannual Tribal Consultation Session – November 20, 2008 Hosted by Tohonno O'odham Nation: Tucson, AZ

**Purpose:** These Consultation Sessions continue to demonstrate CDC's commitment and respect to honoring the federal trust relationship of CDC with Al/AN tribes in relation to the public health and safety of tribal nations. CDC strives to uphold the tenets of its Tribal Consultation Policy and strengthen relationships with Al/AN tribes. The TCAC Meeting and Biannual Tribal Consultation Session provided opportunities for formal government-to-government consultation between Tribal leaders and CDC senior leadership around several focus areas: Resource Allocations and Budget Priorities, Public Health Preparedness and Emergency Response, Epidemiology & Disease Surveillance, Environmental Public Health in Indian Country, and Obesity.

Meeting Attendees: November 20, 2009 - CDC's Tribal Consultation Session was attended by 42 tribal leaders, 55 other tribal leaders and professional designees from tribes and tribal organization, 46 CDC and other federal staff, and 15 staff from state health departments. Leadership from CDC's attending were: Office of Director/the Office of the Chief of Public Health Practice/Financial Management Office/ Procurement and Grants Office, National Center for Environmental Health, the Agency for Toxic Substances and Disease Registry, multiple leadership from the National Center for Chronic Disease Prevention and Health Promotion/Division of Nutrition, Physical Activity and Obesity/ Division of Diabetes Translation Native Diabetes Program/Office of Smoking and Health/ Division of Cancer Prevention and Control, Coordinating Officer for Terrorism Preparedness and Emergency Response and its Division of Strategic National Stockpiles, National Center for Injury Prevention and Control/Division of Violence Prevention, Coordinating Center for Infectious Disease/ Division of Global Migration and Quarantine, and National Cancer Partner/C-Change.

## **Summary of Action Issues presented during Consultation Session:**

- TCAC should have the opportunity to meet with the new CDC Director and other new members of upper leadership in order to establish a relationship with them and to continue the work that is being done.
- As a Committee, TCAC should have the opportunity to meet with Tom Daschle, the new Secretary for Health and Human Services, to enlighten him on TCAC's work.
- An initial recommendation was reinforced that CDC establish an Office of Tribal Affairs in the Office of the Director (OD) and that the OD respond in a timely and effective manner to TCAC's recommendations.
- ❖ TCAC supports keeping strong government-to-government relationships between Al/AN Tribes and the federal government (CDC) and the role and responsibility CDC has for facilitating its grantees (states) understand this relationship and assure that Al/AN tribes benefit from the resource awarded to states.
- The TCAC Budget Subcommittee will be re-established in order to effectively impact CDC's budaet.
- ❖ TCAC should continue to request direct funding for tribes and increases in funding allocations for American Indian/Alaska Native issues.
- States must be held accountable to ensure that CDC funds awarded to states are shared with AI/AN tribes. CDC should make it a policy and a priority that if resources directed toward tribal issues are awarded to an institution or entity that is not a tribal institution or entity, then those resources are awarded on the condition that the institution will collaborate with a tribe, tribal organization, or tribal entity.
- CDC should understand the significant ability of tribes to determine what works and is successful in Indian Country.
- Raising the health status of American Indian / Alaska Native people should be a main goal of CDC as an agency. With a new administration, it is imperative that CDC maintain its commitment to supporting the implementation of its Tribal Consultation Policy and being responsive to recommendations and issues raised during tribal consultations.
- The Navajo nation would like to explore opportunities for CDC direct allocation for emergency preparedness /response and pandemic influenza planning for the Navajo Nation. The Navajo Nation requests the creation of a site for the National Strategic Stockpiles/Receiving, Storing, and Staging in the central part of the nation to serve the rural and isolated area of northern Arizona.
- It is important for CDC to listen to the statements from tribes about the difficulties they have in accessing monies for preparedness activities that go to states as rationale demonstrating the need for these dollars to go directly to Al/AN tribes.
- All tribal leaders and CDC should remind the new administration of the United States' federal trust responsibility to AI/AN tribes.

- CDC needs to hold states accountable for cooperating with requirements regarding sharing resources with tribes. The requirements for states should be strengthened: if a state receives money from CDC based on population numbers that include Indian tribes, then the state must be accountable for the money and ensure that tribes benefit from the money. In the event of an emergency or a disaster, CDC should contact the state to ask what the state has done for the Indian tribes located within its borders.
- ❖ The Navajo Nation requests direct funding for Al/AN tribes, rather than going through the different states and federal regions in which the Nation is housed.
- Tribal nations need to be recognized as public health authorities, and they need assistance with infrastructure development.
- There is an opportunity to improve the responsiveness of the surveillance system and to collaborate and communicate with partner organizations. It is recommended that a formal authority and decision-making structure be created within the tribe.
- ❖ There is an opportunity to improve the effectiveness of tribal outreach, prevention, and promotion activities by linking them more closely with data from the clinical side of public health practice and with other data sources available on reservations.
- \* CDC can partner with IHS to help establish reporting protocols at the local level to ensure that tribes are part of the surveillance and notification process.
- \* CDC should consider reviving the AI/AN Public Health Law Working Committee.
- ❖ Tribal data must be protected. Because of past abuses, research is a sensitive issue for many tribes. Further, questions considering data ownership must be resolved, as there is a hesitancy to ask for epidemiologic assistance if data will be shared on a wider scale. These data issues must be resolved.
- ❖ Language in terrorism preparedness and emergency response grants should be changed so there are fewer restrictions on how the funds are spent. Tribes need to build public health infrastructure. The grant language is appropriate for counties and other groups that are concerned with data transmission. Tribes, however, need to build their infrastructure.
- ❖ Elder care and long-term care are serious concerns for tribes. CDC should understand that tribes look at these issues from a holistic perspective. The NCAI, NIHB, individual tribes, and the Centers for Medicare and Medicaid are working on position papers and making connections to provide services for long-term care needs.
- \* Federal agencies, including CDC and ATSDR, should include adequate levels of funding consistent with the coordinated five-year plan to carry out the eight objectives created in the Waxman Congressional hearing in October 2007.
- ❖ Tribal lands need clean, safe water and trained, certified operators to keep the water clean. Groundwater has been contaminated by industries.
- ❖ Obesity is a critical public health problem for Native Americans. The focus must be on prevention, and efforts must take place at the societal, community, and individual levels. Diet and physical activity patterns must be changed. Tribes need help implementing these programs.
- Tribes need increased funding to address childhood obesity. Because of the number of children in need, more funds are needed to help schools mandate physical education. TCAC needs information regarding these grants to share with their tribal constituents.
- CDC should consider the implications of their population service requirements for their cooperative agreements.
- \* Regarding public health preparedness, CDC should remember tribes that border Canada as well as Mexico often encounter are significant public health issues connected to both borders.
- Alternatives need to be made available to tribes that do not have good relationships with their states.
- ❖ Technical assistance is requested from CDC regarding increases in cancer rates in Indian country and to investigate the perceived link between cancer rate increases and environmental factors.

- ❖ A strongly coordinated approach similar to tobacco cessation initiatives needs to be developed to address obesity issues. Funds should be directed to tribes and not have tribes negotiate with states to get resources to benefit their population.
- One of the directives of the TCAC Budget Subcommittee should be to affect the CDC and HHS budget, particularly direct funding for tribes. Further, the Budget Subcommittee should examine the HHS Strategic Plan for FY 2007 – 2012. Their comments regarding emergency preparedness should align with that document.
- ❖ High rates of infant mortality and injury disparities persist in Indian Country, and numerous tribal leaders articulated significant rates of suicide and a desire to work with CDC to address public health threats to Al/AN youth.
- CDC should develop more collaboration among tribal entities and federal, state, and local agencies and entities.
- It was noted that the tribal consultation should last more than one day in order to allow all leaders to speak their issues without time constraints.

## **Summary of Recommendations to CDC during Consultation Session:**

- ❖ TCAC has only scratched the surface of creating a relationship between CDC and Indian Country. TCAC strongly urges the new administration to encourage additional development and full support of the relationship to impact the public health issues negatively affecting AI/ANs.
- CDC should increase funding and technical assistance as needed to improve local, regional, and national epidemiologic comprehensive data and knowledge regarding Al/AN tribes and people.
- CDC should work directly with TECs and their constituent tribes to gain access to multiple disease surveillance systems that potentially have data about AI/AN populations.
- CDC should systematically assist the TECs in pulling information from multiple data sources into a more reliable, valid, and succinct description of community health status that tribal leaders can use for improved public health planning.
- Tribal infrastructure to address public health needs is limited. CDC needs to increase funding to support capacity and infrastructure development in public health, including building and supporting a AI/AN public health workforce.

Summary of Al/AN Portfolio: In FY 2008, total funds allocated through competitively awarded grants and cooperative agreements to tribal partners approached \$23.0 million (\$22,839,514). In addition to grants and cooperative agreements awarded directly to tribal partners, CDC also allocated more than \$10.6 million through grants/cooperative agreements awarded to state health departments and academic institutions for programs focusing on AI/AN public health issues. The remainder of CDC's AI/AN portfolio falls into three categories: (1) intramural resources (about \$6.8 million), (2) federal intra-agency agreements (about \$2.0 million), and (3) indirect allocations (about \$65.7 million). The indirect category primarily represents resources devoted to immunizing AI/AN children through the Vaccines for Children (VFC) program. CDC estimates its total FY 2008 resource allocation for AI/AN programs to be approximately \$108 million. In FY 2008, 21 percent of these resources went directly to tribal partners, compared to 19.8 percent in FY 2007. The total figure (\$108,079,306.00) represents a 2.7 percent decrease compared to Al/AN allocations in FY 2007 - a decrease that is consistent with an overall reduction in VFC funds received by CDC in FY 2008. If VFC funds are not included, CDC estimates its total FY 2008 allocation for AI/AN programs to be approximately \$44 million, 52 percent of which goes directly to tribal partners and 76 percent overall is expended outside of HHS. The total figure (\$43,815,405.00) represents a 4.6 percent increase over non-VFC AI/AN allocations in FY 2007.