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**2010 Budget and Policy Tribal Consultation CDC Testimony**

**1. Introduction**

I am encouraged by the Department's evolving efforts to improve the process and outcome of Tribal consultation, specifically the work of the Tribal Consultation Advisory Committee (TCAC). Making sure these relationships continue to grow in a positive fashion will require a strong and clear consultation process with Indian Tribes as well as adequate resources nationally, regionally and locally to do the policy analysis, education and system capacity building needed to participate as partners with HHS.

The TCAC has recommended that a process be developed to analyze and develop tribal recommendations for CDC's annual budget. It is expected that the recommendations could be used by tribes and tribal organizations to advocate with the HHS, CDC, and Congress to provide additional funding within CDC's budget to address public health needs of tribes and to address the significant health disparities that American Indian and Alaska Native (AI/AN) people face.

**II. Top Health and Human Services Priorities**

1. Support for sustainable infrastructure for Tribal Epicenters
2. Support funding for HIV/STD prevention activities.
3. Support funding for Injury Prevention activities.
4. Support funding for Emergency Preparedness and Panflu activities.
5. Support and improve Data Access.

**III. Describe Top Health and Human Services Priorities**

1. Support for sustainable infrastructure for Tribal Epicenters.

Support for sustainable infrastructure for Tribal Epicenters. The work of the Tribal Epidemiology Centers (TECs) is to assist Tribes and Urban Indians to improve their health status and quality of life. This is accomplished through accurate data collection and analysis, which leads to development of health promotion and disease prevention activities and advocacy for appropriate policy. The EpiCenters are charged with collecting data relating to and monitoring progress toward meeting health status objectives; evaluating delivery systems and data systems; and assisting Tribes to identify high priority needs for health care delivery, health care promotion and health education. In each of the past 4 fiscal years, the Tribal Epidemiology Centers have taken a financial decrease. This cut in funding has equaled approximately 4 percent per year, for a total of approximately 16% decrease in funds. This forces the TECs to cut staffing and projects that are able to be effectively completed, in the absence of adequate funding. There is a need for accurate data in Indian Country and funding the TECs on a consistent basis would assist in making great strides in data accuracy, and thus assist in tracking initiatives and the elimination health disparities in Indian Country.

2. Support and funding for HIV/STD prevention activities.

**STD/HIV Statistics:** American Indians and Alaska Natives are disproportionately impacted by high rates of sexually transmitted infections. In 2007, chlamydia rates for AI/ANs were 4.5 times higher than rates reported among Whites, gonorrhea rates were three times higher, and syphilis rates were nearly twice as high. For all ethnicities, STD rates are highest among young people 15-24 years-old. While many STDs can be easily treated or cured with medication, the consequences of untreated STDs can be severe, including: infertility, pregnancy complications, cervical cancer, and pelvic inflammatory disease. STDs also increase vulnerability to HIV. People infected with an STD are 2-5 times more likely to become infected with HIV when exposed. Altogether, more than 3,200 AI/ANs have been diagnosed with AIDS since the beginning of the epidemic, and currently have one of the highest rates of new HIV infections (14.6 per 100,000 persons). In 2007, young people under the age of 25 made up 19% of all AI/AN HIV/AIDS diagnoses. Due to late testing and suboptimal treatment, AI/ANs currently have one of the lowest survival rates of any ethnic group, with just 1 in 4 individuals living more than 3 years after their diagnosis. Washington is among the five states with the highest numbers of reported AI/AN AIDS cases, which together account for more than half (53%) of the AIDS diagnoses in Indian Country.

- Funding for STD/HIV prevention and capacity building in Indian Country has decreased considerably over the past five years. The National Native American AIDS Prevention Center (NNAAPC) has worked nationally to strengthen and enhance tribal HIV prevention programming for over 22 years. Similarly, Project Red Talon has worked for the 43 Northwest tribes for over 20 years to prevent sexually transmitted infections (STDs and HIV/AIDS), as the longest funded health promotion project at the Northwest Portland Area Indian Health Board. Tragically, HHS funding for both projects was severely cut in 2009.
- With few other appropriate funding sources to turn to, the CDC has been the backbone of these programs since their inception. For the first time in 2009, the CDC did not fund a Native-specific organization to provide nationwide capacity building assistance on the delivery and evaluation of effective HIV prevention interventions and organizational development. As a result, NNAAPC saw over a million dollar decrease in its operating budget.
- HIV STD prevention programs across Indian Country have been forced to reduce their levels of service, re-allocate funding, and reduce staffing. Native communities will not be able to receive the culturally-specific training, policy advocacy, outreach and education, and materials that were previously available through NNAAPC and Project Red Talon, and in the future, Tribes will have to rely upon non-Native organizations to obtain many of these services.
- While strong progress has been made, a great deal remains to be done to eliminate STD disparities among American Indians and Alaska Natives. Inequalities in STD morbidity and HIV mortality will continue to persist among our Native populations until adequate health services are made available and healthy social norms are established. This manner of change will not occur quickly or without sustained effort. Comprehensive, culturally-relevant programs STD/HIV prevention programs like NNAPC and Project Red Talon must continue to facilitate this process to protect the health and wellbeing of future generations.

### 3. Support funding for Injury Prevention activities.

According to the most recent publication of Trends in Indian Health, Accidents are the third leading cause of death for AI/AN, with motor vehicle accidents being the largest sub-category. The 2009 CDC budget for Injury Prevention in Indian Country was \$1.4M. In order to make effective strides and

began to penetrate further into Indian Country, I would recommend that the CDC at least double its efforts and budget in this category.

4. Full support and funding for Emergency Preparedness and Panflu activities.

In November 2009, twelve State Epidemiology offices in partnership with their respective Tribal Epidemiology Centers analyzed case activity for H1N1 for the time frame between April 15 and November 13, 2009. The results indicated that participating states had a H1N1 mortality rate four times higher than persons in all other racial/ethnic populations combined. This is unacceptable. Reasons for this disparity in death rates are unknown and need further investigation; however, they might include a high prevalence of chronic health conditions (e.g., diabetes and asthma) among AI/ANs that predisposes them to influenza complications, poverty (e.g., poor living conditions), and delayed access to care.

Funding for increased efforts must be made to promote awareness among AI/ANs and their health-care providers about the signs and symptoms of influenza and recommendations for vaccination and the use of influenza antiviral medications early in the course of suspected influenza illness for those at increased risk for complications.

5. Data Access

Tribes and Tribal Organizations must have adequate access to data and control of data relating to the health status of members of their Tribe. To this end the NPAIHB Delegation passed a resolution with regard to data ownership and sharing which indicates that the Tribes retain control of tribal data. To be effective in their work, the TECs have negotiated data sharing agreements and data use agreements with the Tribes and government entities. There has been reluctance by some Federal Agencies to sign data sharing agreements with TECs and/or Tribes. The mentality has sometimes been stated as, "we (the Federal Agency) paid for it, we own it". This is simply not true. Tribal leaders are asking for a say in how data about Tribal members are used. This seems fair, especially in light of egregious scientific practices which occurred in the past, such as Tuskegee and numerous other projects where human subjects considerations were not taken seriously. There also needs to be a willingness by Federal agencies to share data with Tribes and Tribal organizations. Often, there are procedural barriers which make it difficult for TECs in some areas to get data from Indian Health Services and other Federal Agencies. It would be beneficial to have national guidance and policy, that filters down to local areas on how data should be shared, what protections should be in place and how that data can be fairly accessed by those tasked with data analysis and monitoring.

- Support record linkages such as with the Comprehensive Hospital Abstract Reporting System of Washington to correct racial misclassification of AI/AN so that it can more accurately report on hospitalization trends among AI/AN in the Northwest.
- Support the work of the NPAIHB NW Tribal Registry Project's work to correct identification of AI/AN in vital statistics records. Accurate data is essential for understanding the distribution of health events and planning prevention and intervention efforts allows for more accurately report on mortality trends for AI/AN in the Northwest.
- Finalize and release a standardized Data Sharing Agreement that provides for routine and special access to HIPAA defined protected health information to each IHS funded Tribal Epidemiology Center and the subsequent transfer of the agreed data sets.

- Any tribe that participates in health-related research must be given possession of the primary data, with the necessary protections taken to protect the rights and privacy and confidentiality of individuals. We further recommend that any health-related search undergo review and approval by an IRB and that the tribe have the opportunity to review and give input on publications and presentations, while in the draft form.

#### **IV. Identify Top Budget Specific Issues**

CDC's budget should continue to support tribal communities in their prevention efforts.

1. Enhance existing funding to AI/AN programs.
2. State accountability for HHS funding received for services for tribes and include tribes in the distribution of funds.
3. Restore AI/AN HIV STD funding.
4. Fund Injury Prevention activities in Indian Country.
5. Provide funds directly to tribes and tribal organizations to carry out Emergency Preparedness and Panflu activities.
6. While the funding provided among the five categories that CDC tracks is important to addressing AI/AN public health concerns and disparities, it would be more effective to provide funding directly to Tribes and Tribal Organizations that conduct work immediately in reservation and Alaska Native communities.

#### **V. Identify Top Policy and Legislative Specific Issues**

1. Continue to fund and support the Tribal TCAC.
2. Encourage CDC to support the development of and fund a "CDC/TCAC American Indian & Alaska Native Five Year Strategic Plan" similar to the CMS TTAG report.
3. Facilitate Data Sharing agreements between Tribal EpiCenters and other governmental entities with vital statistics, including dissemination of model agreements already in effect.
4. Develop an alternative mechanism for getting vital resources directly to Tribes without going through the State and Locals.

#### **VI. Summary of Tribal Testimony Submission**

The Department is at a critical juncture in developing its relationship with Indian Country and it's important that it begin by proactively engaging with Tribal leaders around key policy issues. This dialogue is imperative and should be centered on President Obama's statements and positions supporting Tribal nation building and enforcing the federal government's obligations to Indian people. These are principles that the President instilled during his campaign, his inaugural address, and Executive Order 13175. We expect that the Administration's cabinet and subcabinet will honor the President's commitments made to Indian Country and work with us as Tribal leaders to begin to close the gap in health disparities that currently afflict too many Tribal communities.

Thank you.