

February 2008 TCAC and Tribal Leaders Recommendation to CDC

Focus Area 1: Resource Allocations and Budget Formulation

From the listing of recommendations submitted to CDC in 2006-2007

1. Assure that Dr. Gerberding and other executive leadership responds in a timely and effective manner to the recommendations made by TCAC.
 - Recommendation: CDC should communicate its delegation stream on specific issues and questions as soon as possible after receiving the request.
2. Assure adequate staff and resources are available within the Office of the Director to support Tribal Consultation Plan implementation
 - Recommendation: Consider restructuring the STL command structure to a more senior level and move it into the Office of the Director.
 - Recommendation: Articulate succession planning for senior Tribal liaisons and other positions critical to the implementation of the TCP. Share pre-decisional plans with TCAC.
3. Develop, in partnership with the National Indian Health Board (NIHB), a process to assure ongoing communication to Tribal stakeholders about important information, funding and training opportunities, major issues, and updates on CDC responses and actions to Tribal stakeholders.
 - Recommendation: Share the Final Standard Operating Procedure with TCAC.
4. Expand efforts to ensure that funds currently awarded to state health departments through CDC cooperative agreements are appropriately benefiting American Indian Alaska Native (AI/AN) people in those states.
 - Recommendation: CDC should require the remaining state block-grant programs to follow their lead.
 - Recommendation: In CDC's evaluation of the Public Health Emergency Preparedness funding implementation, pay special attention to the *completeness* and *accuracy* of the state reports documenting Tribal concurrence to state plans. In addition to requiring Tribal council concurrence, it would be best to include TCAC in a pre-decisional review of final checklists and templates to the updated guidance.
5. In follow up to the above recommendation, CDC should provide authoritative guidance within funding opportunity announcements (FOAs) on how states should work with Tribes, specifically requiring that applicants who use Tribal populations to justify proposals document Tribal involvement in both design and implementation of proposed activities.
 - Recommendation: TCAC requests a pre-decisional review of these documents.
 - Recommendation: Implement standardized language for CDC FOAs that specifies Tribal eligibility unless precluded by authorizing language, single eligibility approval, or similar contingencies.
 - Recommendation: Identify how the \$15 million expansion to the BioSense program will include Tribal EpiCenters and Tribally-serving organizations.

- Recommendation: Ensure that the National Center for Health Statistics transitions funded by the \$11.1 million increase will benefit Tribal groups and increase the accuracy and applicability of CDC’s disease burden estimates for AI/AN. Tribes are noticeably absent from the CDC justification of this increase.
 - Recommendation: Ensure “true access” to Tribes and Tribal organizations to CDC FOAs seeking “ground truth.” Putting priority on funding the largest populations does not always serve the greatest good. In funding decisions, include smaller Tribes and don’t allow data “strength” concerns to deprive small communities of the benefit of this work.
6. Develop a CDC-wide AI/AN action plan that will strategically integrate AI/AN – focused policies, resources, and programs; align these activities with CDC’s Health Protection Goals; and serve as a roadmap and portfolio management tool for CDC’s overall efforts to optimally impact the public health of AI/AN people and communities. *This recommendation has been “pending” CLC response for some time now.*
- Recommendation: Strategically integrate AI/AN-focused policies, resources and programs.
 - Recommendation: Align these activities with CDC’s health protection goals and starter objectives.
 - Recommendation: Includes these as a roadmap and portfolio management tool for CDC funding opportunities and how to obtain technical assistance during the grant application process.
7. Continue to engage TCAC and other Tribal stakeholders in the CDC goals management process.
- Recommendation: Establish a plan for ongoing TCAC and Tribal Stakeholder input.
8. Within selected CDC programs, explore the possibility of designating a certain proportion of cooperative agreement funds as intended for Tribal/Tribal organization awardees.
- Recommendation: Involve TCAC in discussions across Centers on expanding these approaches.
9. Provide culturally appropriate training for project officers assigned to States with established AI/AN communities.
- Recommendation: Include TCAC in the planning and share materials with TCAC before implementing training.
 - Recommendation: We request the career development accounts remain.
10. Continue discussions to allow Tribal stakeholders to provide annual input into the CDC budget formulation process.
- Recommendation: Monitor and track where Tribal recommendations have influenced CDC priorities and goal process, and have enhanced Tribal resources.

- Recommendation: Re-analyze the CDC AI/AN Resource Allocation Portfolio such that resource allocations are a) stratified by categorical programs that are of high priority to Indian country; and, b) stratified geographically (e.g., by IHS Areas or HHS regions).
 - Recommendation: Share the guidance document for TCAC/Tribal leaders outlining key opportunities and processes for providing input on budget formulation.
11. Increase Tribal stakeholders' knowledge of CDC funding opportunities and how to obtain technical assistance during the grant application process.
- Recommendation: Work through TCAC to establish a technical subcommittee to evaluate how CDC FOAs and the grant application process could be modified to encourage more Tribal applicants and to help ensure that Tribal applicants have equal opportunities to compete successfully.
12. For competitive applications responsive to AI/AN-focused program announcements, seek objective review panel members who are knowledgeable about working with AI/AN communities.
- Recommendation: Share this information with TCAC to the extent that privacy laws allow.
13. Strengthen the relationship between the Division of Adolescent and School Health (DASH) and Tribal stakeholders to maximize resources and opportunities to address issues facing AI/AN youth. (DASH and NCHHSTP)
- Recommendation: Report CDC's plans to convene a working group of internal staff and external partners this fall to identify collaborative strategies and activities to impact the health of native youth. Please plan to report back to TCAC on the measures of success in this work.
14. In review of the National Center of HIV/AIDS, Viral Hepatitis, STD, and TB Prevention tribal leaders make the following:
- Recommendation: Reconsider recent decisions regarding funding for HIV and STD prevention programs in Indian country. This response was noted by CDC to be complete in October of 2008 but we have persistent concerns. Particularly because CDC is planning a Domestic HIV/AIDS initiative to increase testing in medical and community-based settings, make voluntary testing a routine part of medical care, and create new testing guidelines, models and best practices. The initiative is planned to be focused on areas and populations with the "highest burden" of disease. The overall CDC FY 2009 budget for HIV/AIDS will be increased by \$10.6 million to make an overall investment of \$93 million. Please explain how CDC will assess "highest burden" and remember that the reality of the HIV epidemic in Indian Country is not readily apparent in CDC's estimates of its scope.
15. CDC Program Models - The CDC has a list of model programs in their 'Compendium of HIV Prevention Interventions with Evidence of Effectiveness' that have

been scientifically determined to be effective. In order to receive funding from the CDC, an agency must choose from a list of intervention to implement in its community. The majority of the interventions are designed for non-native populations in large metropolitan areas who engage in very high risk behavior. As such they are culturally incongruent with Alaska Native communities. To use these interventions, a program must adapt and tailor them while still remaining faithful to the original intervention. This has proven to be problematic, time consuming and often unsuccessful.

- Recommendation: CDC commit to developing and supporting culturally-specific best practices that effectively and appropriately address HIV prevention in diverse Native communities.

16. HIV Research and Epidemiology - A literature review of American Indian/Alaska Native HIV risk is very sparse. The basic research needed to develop more effective programs has not been conducted. Epidemiology around HIV/AIDS incidence and prevalence is inconsistent in many areas. For example, many American Indian/Alaska Native people with HIV have been misclassified within other racial or ethnic categories. We are poorly equipped to address the threat of HIV/AIDS in our communities without the basic epidemiologic studies. We must expand the research to better equip our communities to address the associated issues in Alaska and within American Indian communities.

- Recommendation: CDC to commit resources and expertise to expand research on the American Indian/Alaska Native HIV risk and to improve epidemiological systems so they more accurately reflect the disease burden in our communities.

17. HIV Awareness - American Indian/Alaska Native HIV prevention are typically overlooked in the national HIV prevention field and the federal government. Even in our home communities HIV/AIDS prevention is a low priority when compared to other immediate health concerns. We must find ways to break the silence about HIV/AIDS and STIs in our communities. Several committed American Indian/Alaska Native organizations and individuals are rallying to this call. CDC has a role to play in this as well.

- Recommendation: Develop funding mechanisms to raise the awareness of HIV risk in Native communities by supporting national initiatives like the March 20th National Native AIDS Awareness Day and to provide funding for National HIV/AIDS conferences for American Indians/Alaska Natives such as the Embracing our Traditions conference held in Anchorage, Alaska in 2006.

18. Tribes would like to know the extent the 50 States, the DC, and US Territories who receive financial support and technical assistance from Division of Diabetes Translation are working with Tribal or indigenous populations within their borders to ensure that Native People are benefiting from these programs. CDC funds states with the assumption that the Tribes or Villages within the State's borders also will be served by these programs. That is not so. In many cases, the shocking health disparities of American Indians and Alaska Natives are used by States when applying for funding, yet the Tribes do not often enjoy the benefits of the programs once funding is secured.

- Recommendation: Tribes request that CDC place accountability standards in place through which the States provide a detailed report on their work with Tribes.
- Recommendation: That a separate line item be identified for disease prevention and health promotion activities specifically for American Indians and Alaska Natives.
- Recommendation: Continuity is critical in programs such as the HIS Special Diabetes Program Initiative – and more partners can only strengthen the program and its outcomes. Tribes invite CDC to be a partner in this critical effort.

19. Recommendation: For Disease Prevention and Health Promotion, tribal leaders ask that CDC include \$200 million for a Well Indian Nations Initiative (WIN!) – crafted to these activities in Indian Country.

20. Indian Country has become more aware of States’ grant proposals to CDC that cite Tribal disparities to demonstrate high level of need. Tribes have not usually been involved in the writing of the proposal and once state receives the grant, no services or resources have been provided to address AI/ANs needs.

- Recommendation: CDC needs to continue to develop mechanisms to hold states accountable to assure that tribes and AI/AN people do benefit from these resources that were provided to the states because of the inclusion of AI/AN disparities.

21. CDC’s *Justification of Estimates for Appropriations Committees* report for 2009 lists many successful AI/AN programs in prevention and disease reduction from Viral Hepatitis to Diabetes within the Racial and Ethnic Approaches to Community Health United States (REACH US) program. Some of the broader programs that host these best practices appear in the list of areas targeted for funding decreases in the coming budget. The investments the Agency has made to Tribes in these programs are very low in relation to CDC’s overall budget.

- Recommendation: We believe that maintaining these investments should not prevent CDC from making its overall budget cuts for the year. With the budget documents we have been provided, it is not possible to view specific impacts on Tribal programs of your planned reductions to make an accurate analysis. Please provide us with greater transparency to review such plans and demonstrate to us how CDC plans to protect these funding streams benefiting AI/AN people.

Focus Area 2: Environmental Health in Indian Country

22. We understand the ATSDR is in the final stages of hiring a new person for its Tribal coordinator/liason role.

- Recommendation: We request to be updated and introduced to this scientist as soon as possible to engage them in our issues.

Focus Area 3: Public Health Preparedness and Emergency Response

23. Specifically, TCAC will be doing a State-by-State review of Tribal inclusion in PHEP activities. Concurrence is not enough, we need real inclusion of Tribes in preparedness planning.

- Recommendation: Work together with tribes and tribal organizations to ensure American Indians and Alaska Natives are included in the planning of these activities and events to assure a coordinated and effective public health response.
- TCAC plans to:
 - ❖ Review and provide comments on the Preparedness Goal Action Plan 2007
 - ❖ Follow up with CDC on the addition of a Tribal desk to the Director's Emergency Operations Center (DEOC)
 - ❖ Review Mutual Aid agreement case studies where Tribes have worked well (or not well) with other jurisdictions to provide for their citizens
 - ❖ Discuss Federal Quarantine Regulations Public Awareness and Marketing Plans
 - ❖ Share research and new information on Tribal Capacity and Tribal Preparedness Plans
 - ❖ Follow up on Public Health Emergency Planning (PHEP) Funding and Implementation Issues.
- Recommendation: Obtain answers from CDC on these questions:
 - ❖ Do the existing quarantine stations cast a wide enough net to address the needs of Tribal communities?
 - ❖ Will the expansion of the quarantine stations include outreach and technical assistance to Tribal governments on creating and maintaining their own quarantine communication infrastructure?
 - ❖ What is the Tribal role in the Strategic National Stockpile? TCAC wants information on how Tribes fit, if at all, into the plans.
 - ❖ Will the almost \$20 million increase in SNS funding adequately address AI/AN populations? How does the SNS include Tribal Health departments? Is there a plan to allow Tribes to access SNS-level costs for drugs to address their own stockpiling needs?

24. There is a need to determine and quantify a Tribe's capacity for emergency preparedness. Once a Tribal is identified as possessing less capacity than adjoining counties and the state, CDC should ensure that funding streams and other mechanisms to increase capacity are used to assist the Tribe to reach the same level of readiness.

- Recommendation: As a first step, CDC should play a greater role to assist States and Tribes to evaluate Tribal emergency preparedness capacity and to identify the level of funding and other support that would be necessary to achieve parity in preparedness readiness so that all people within States can be protected. This effort should seek the "ground truth" of Tribal – Local – State cooperation and partnerships. Funding is meaningless if it is not a support for joint planning.

Focus Area 4: Partnering to Build Public Health Capacity in Indian Country:

25. Pan Flu/ Communication Focus

HHS has a total funding level for 2009 of \$509 million. The CDC plans to increase its Pandemic Influenza funding by more than \$3 million in FY 2009. This funding is noted to include priorities such as risk communications. We have some specific recommendations regarding this increase:

- Recommendation: The National Center of Health Marketing (NCHM) should demonstrate its commitment to invite the TCAC, NIHB, Direct Service Tribes, Tribal Self-Governance Advisory Committee, National Tribal Environmental Council, and the National Council on Urban Indian Health to the Annual CDC Leaders to Leaders Conference by providing funding for travel needs. Many of your typical attendees are grantees and receive funding from CDC to attend: Tribal leaders do not. This is a barrier to real inclusion.
- Recommendation: The Office of Enterprise Communications (OEC) should follow up on the formal orientation to CDC for TCAC members and other Tribal leaders by:
 - ❖ Developing and fielding trainings for Tribal participants designed to explain CDC activities and goals to the Tribal communities.
 - ❖ Developing and distributing a directory of CDC and ATSDR services and resources to the TCAC.
 - ❖ Produce an educational film clip that would include an overview of CDC's history, its domestic/international activities, and highlights of programs for Tribal communities, and CDC's vision for improving public health in Indian country. This could be facilitated by involving TCAC members and other Tribal leaders to provide voice-over or language specific concepts, i.e., a description in Yup'ik or Navajo, for American Indians and Alaska Natives.

26. Many Tribes are ready, willing and able to build their public health capacity. The time has come for this work. We are willing to continue to assist in helping CDC become a known partner and an important resource to many Tribes. NIHB, NCAI and TCAC members serve an important catalyst function to establish relationships, bridge resources, and to promote public health infrastructure development in all interested Tribal communities.

Collectively, we desire to seize the opportunity to build on the foundation of CDC's Tribal Consultation Policy. This is an opportunity to demonstrate through measured action, how prevention and building the health protection and promotion capacity of Indian Tribes and Alaska Native villages, promoting and strengthening the integration of inter-agency agreements, organizational systems, policies, and laws to ensure our health and safety.

It has been said in many different ways that the United States can only be as healthy as our least healthy communities. The Tribal testimonies presented on 2-28-2008 should help you to understand how much farther we must all reach.

- Recommendation: An invitation extended to CDC leadership to visit Indian Country to see the people and hear from those at greatest risk in an outbreak and in a public health emergency and who suffer from great health disparities.

Public health, you should know, is the underpinning for wellness in Tribal communities. Public health includes having safe drinking water and sanitation services. Public health includes having disease prevention through education, immunization, and screening programs for early detection and intervention.

We want Tribes to be among the local, state, national, and international communities CDC can say it has helped improve its public health capacity through its strategic planning, resources, and partnerships. As leaders of sovereign entities, we see opportunities to partner to help CDC leadership advocate for specific budgetary line items. To paraphrase Mr. Jerry Freddie of the Navajo Nation, our colleague and fellow TCAC member representing the National Indian Health Board, “We invite you to be part of a championship team!” Together, Tribal leaders and the CDC can help protect American Indian and Alaska Native people and help to protect the health of all citizens in the United States.

27. Tribes typically are categorized as political subdivisions or within a “local unit” of government. When categorized this way, Tribes can only receive funding through a State or a County funding mechanism. Funding formulas are typically based on population. While this is meant to be fair, it is not enough to properly address the health disparities within Indian Country.

- Recommendation: CDC assist States in developing additional criteria for disbursement of CDC emergency preparedness funding to address populations or communities with the greatest health disparities. This should include a mechanism to reduce the disparity between populations to ensure all people are protected adequately