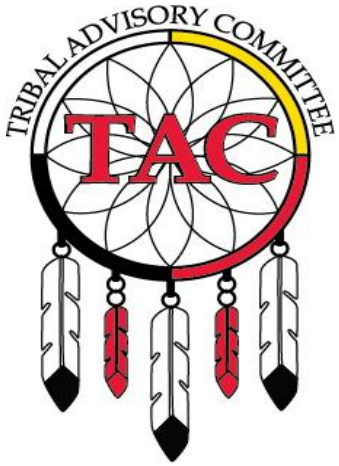

Department of Health and Human Services
Centers for Disease Control and Prevention
Agency for Toxic Substances and Disease Registry

8th Bi-annual Tribal Consultation Session

February 2, 2012
Meeting Summary

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Acronyms

ABCS	Aspirin, Blood Pressure, Cholesterol, and Smoking
ACA	Affordable Care Act
AHRQ	Agency for Healthcare Research and Quality
AI/AN	American Indian / Alaska Native
ATSDR	Agency for Toxic Substances and Disease Registry
CDC	Centers for Disease Control and Prevention
CER	Comparative Effectiveness Research
CMS	Centers for Medicare and Medicaid Services
CPPW	Communities Putting Prevention to Work
DHAP	Division of HIV/AIDS Prevention
EDLs	Essential Drug Lists
EPA	Environmental Protection Agency
FDA	Food and Drug Administration
HHS	Health and Human Services
HIT	Health Information Technology
IHS	Indian Health Service
I/T/U	IHS/Tribal/Urban
IHCIA	Indian Health Care Improvement Act
NCBDDD	National Center on Birth Defects and Developmental Disabilities
NCEH	National Center for Environmental Health
NIHB	National Indian Health Board
OSTLTS	Office of State, Tribal, Local, and Territorial Support
PSAs	Public Service Announcements
SIDS	Sudden Infant Death Syndrome
SPDI	Special Diabetes Program for Indians
STAC	Secretary's Tribal Advisory Committee
STDs	Sexually Transmitted Diseases
TAC	Tribal Advisory Committee
TB	Tuberculosis
VA	U.S. Department of Veterans Affairs

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Opening Blessing / Welcome

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

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

CDC Director

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

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

For clinical prevention, the campaign will focus on the ABCS, health information technology (HIT), and clinical innovations in care delivery.

Turning his discussion to chronic diseases, Dr. Fieden indicated that Dr. Ursula Bauer, Director, National Center for Chronic Disease and Health Promotion, CDC, directs grants to address chronic diseases, including Community Transformation grants. Specifically, he noted that nine Tribes were awarded a total of $7 million to focus on chronic diseases. Dr. Frieden also discussed the problem of prescription drug abuse in the U.S., stating that 1 in 20 people (in 2010) reported non-medical prescription drug use in the past year—with AI/ANs having the highest ration of prescription drug use of all groups.

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

Below, and throughout this document, questions, answers, and comments following each presentation are denoted by "Q," "A," and "C," respectively.

Discussion Points

C: (Connie Hilbert) Whatever support you can provide for the Special Diabetes Program [for Indians] would be appreciated. Every year we are challenged with trying to keep that funding at a constant level. There is a great need in our communities. A lot of our youth are pre-diabetic.
C: (Tom Frieden) We will do everything possible. We are figuring out ways to cover pre-diabetes through Medicaid or private insurance. It has a lot of potential. We want to find a reliable funding stream for programs over a long period of time. Things that can be done to highlight traditional practices that are effective and can save health care insurers a lot of money. Last week we launched a program to recognize providers; CDC recognizes them and insurers will pay them for the services they provide. We should think about whether Indian providers want to be registered in the program.

C: (Chester Antone) Over the past couple of days I have been suggesting that previous consultation reports be reviewed, as smoking cessation and the issue of contamination in mines have come up before. I agree, we need support for the SDPI [Special Diabetes Program for Indians]. I would like the AHRQ [Agency for Healthcare Research and Quality] to do a literature review of cancer in Natives and give that information to one of the CER [Comparative Effectiveness Research] centers; this was also discussed at the last STAC meeting. Over the years, we have been emphasizing the need to work with Tribal governments. There is an NIHB [National Indian Health Board] tracking sheet that is used to track testimonies from Tribal leaders. Please look at that and have OSTLTS work in a similar manner to track Tribal concerns. Finally, we were told we no longer have Grade

13 positions in OSTLTS; I would ask that you revisit that to see if you can adhere to the positions we discussed 3 years ago.
C: (Tom Frieden) I agree with you on the issue of tracking, so we will follow through and be frank about our limitations. In the past we did a pilot program to reduce motor vehicle injuries, so tracking is important to identify and celebrate successes and hold us accountable.

C: (Brenda Nielson) STD/HIV funding was not talked about during your presentation. We need continued funding for this area. Great work is being done in the field.

C: (Lester Secatero) My office said they wanted to see more HIV funding. Immunizations are available in September from the VA [U.S. Department of Veterans Affairs], but Tribes don't get them until January. By that time people have gotten sick.
C: (Tom Frieden) Two years ago issues were raised about interactions with State government and we mediated meetings to try to ensure better communications.

C: (Chester Antone) Our Tribe has seen an outbreak in Rocky Mountain Spotted Fever in Arizona. Regarding the budget, we asked Judy Monroe how the sequestration will work in terms of OSTLTS. We were told computers, space, travel, and other administrative expenses would be cut to avoid cuts to Indian Country. We would like to extend that protection to Indian programs, as a matter of trust responsibility. We ask that you take that same position.
C: (Tom Frieden) We have faced reductions in FY 2012 and we are protecting grants, with few exceptions for those that are Congressionally directed. No one knows how sequestration will work, so we can't guarantee what will happen.

C: (Rex Lee Jim) Treaties established government-to-government relationships, so meaningful dialogue with Tribes is needed. We also need direct funding to Tribes.

Before leaving the meeting, Dr. Frieden thanked the participants for their attendance, acknowledging the need for communication with Tribes. Delight Satter, Associate Director for Tribal Support, Tribal Support Office, OSTLTS, CDC, explained the difference between an Advisory Committee meeting and the day's consultation session, noting that the floor would only be opened for questions from the general audience if time permitted at the end of the day.

Discussion with Center Directors

Dr. Ursula Bauer, Director, National Center for Chronic Disease and Health Promotion, CDC, said 2011 was a remarkable year in terms of her learning about work occurring in Indian Country. Having joined CDC 2 years prior, she's since been able to meet with Tribes on the west coast and witness various programs in action, she said. Noting that she was particularly proud of the Chronic Disease Center's ability to maintain its funding (with some increases in Indian Country), Dr. Bauer discussed the need for Tribal input on Community Transformation grants and she talked about an experimental mentoring program that funded the Cherokee Nation to mentor other Tribal grantees. Dr. Bauer also expressed optimism regarding a new program in 2013, called the Coordinated Chronic Disease Prevention Program. Before ending her presentation, Dr. Bauer informed that group that she welcomed its feedback on how to best invest Tribal dollars, i.e., how to get funds to

the widest possible array of Tribal Nations to make a difference and still have a manageable workload in terms of grants. Having heard suggestions to work through Epi Centers, Health Boards, and directly with Tribes, she encouraged the group to weigh in with their opinions.

C: (Lester Secatero) It is disappointing to have only one Director here. When we talk about meaningful Tribal consultation, this is unacceptable.

Q: (Connie Hilbert) You spoke about seven Tribal grantees and I want to know the size of Tribes that get those grants. Some Tribes are less than 1000 members. My experience in applying for grants (we are over 1900) is that we are left out because we are small. What advice do you have for small Tribes without the necessary numbers and data to get funding?
A: (Ursula Bauer) The need may be great, but if numbers are small it's difficult to influence national trends. In the Community Transformation grants we have a 500,000 population criteria, but it was waived for Tribes. We do have among the seven Tribal grantees several that represent very small populations, like in the hundreds. We know there is huge need and we try to balance community needs with program needs. For those that had fewer than 500,000, we didn't fund at the per capita amount. This is still a huge challenge for us. We are not funded at a resource level where we can invest adequately in all programs across the country. Again, this is a challenge. I'm interested in hearing from you on whether it makes sense to look at Epi Centers or Health Boards to get training and technical assistance and seed money into Indian Country without having to do a per capita funding that doesn't really help small Tribes.

Q: (J.T. Petherick) The Epi Centers and Health Boards play a valuable role. Are there funds at CDC to do outreach for the Coordinated Chronic Care Program?
A: (Ursula Bauer) We don't have dollars in 2012, but we anticipate dollars in 2013.
C: (J.T. Petherick) We can give our opinions, but we may need a broader consultation. Using our Health Boards and Epi Centers would be an excellent resource, but some Tribes have capacity beyond the Epi Center. In the past, organizations have gotten funds, but Tribes have better capacity; so collaboration can be difficult. A broader discussion is warranted on this.

Q: (Ursula Bauer) Is a mentorship approach another way to do this? Is there a way to have a series of mentorships or technical assistance competitive grants that have capacity, but require them to cite who they are reaching out to?
A: (J.T. Petherick) I think that would be valuable, not just to have a mentorship relationship but to share information. We need to get away from the "haves" helping "have-nots." We need more sharing of information.

Q: (Ursula Bauer) How do we conceptualize that? The money has to go to a particular agency. We have an opportunity to think outside the box and build a structure that makes sense. Maybe Delight can help us set up a conference call to brainstorm this.
A: (Delight Satter) I would be happy to.

Community Transformation Grants and Communities Putting Prevention to Work: Update on Tribal Activities

Dr. Bauer provided information on Community Transformation grants. For the Communities Putting Prevention to Work (CPPW) grant, she said the $650 million program was time-limited. She further noted that the closing period for the $373 million currently allotted ended March 2012. With a number of grantees having unspent dollars, she indicated that many were requesting no-cost extensions to continue their work. Three of the 50 awardees were Tribes/Tribal organizations: Cherokee Nation Health Service Group; Great Lakes Inter-Tribal Council; and Pueblo of Jemez. Among the accomplishments realized in the programs include tobacco-free policies in casinos, on worksites, and on campuses; and the availability of nutritious foods markets and from vendors. Additionally, following lessons learned from the Traditional Foods Program, she said the Communities Putting Prevention to Work programs also addressed the use of traditional foods and physical activities. Dr. Bauer expressed hope in terms of the programs continuing their activities beyond the grant and influencing positive changes in health behaviors and health statuses.

Dr. Bauer explained that the Prevention in Public Health Fund was created under the Affordable Care Act (ACA) as part of the Community Transformation grants. With $145 million in 2011 [for the Capacity Building and Implementation awards], the program was designed to move beyond the activities of the Communities Putting Prevention to Work grant to align efforts with national prevention strategies. Of the 61 grantees, 7 are Tribal Nations (5 capacity grantees and 2 implementation grantees). Dr. Bauer cautioned that funds for 2012 were at risk as Congress tries to get the budget under control. In the future, she said there would be an opportunity to see where to go with the Community Transformation grants, assuming there will be funds to grow the program; and how to ensure other grant programs were reaching Tribal Nations.

Discussion Points

Q: (J.T. Petherick) In terms of the Community Transformation grants for this year, the funding is up in the air, right?
A: (Ursula Bauer) We think we will see funding from 2011 continue into 2012, so current grantees can continue their work; but we don't know if there will be additional funds invested for new programs. There is the potential of a new funding opportunity announcement focused on communities with a population of 500,000 or less. The Senate language lists transportation authorities, school districts, and Tribes [as eligible entities].

Q: (Connie Hilbert) Were any Tribes on the approved but unfunded list?
A: (Ursula Bauer) We received 30 to 35 applications from Tribes, so I'm sure some were on the list.

Q: (Lester Secatero) We always need training and technical assistance at the grassroots level. Is training and technical assistance a part of your programs?
A: (Ursula Bauer) We had training and technical assistance contracts that supported the Community Transformation grant in 2011. When we convened grantees in October, the seven Tribal Nations requested a special session to share among themselves. I had an opportunity to meet with them and the discussion amongst them was stimulating in terms of their expertise and sharing of information. They identified an overarching need for technical assistance. We are looking at how we can address

the needs of those seven within the program. Last year you recommended that we put together a best practice compendium to harvest the successful programs implemented in Indian Country and write them up as case studies. We are working on that and we have 2 prototypes on tobacco that Tribes have done. We have also applied for resources for a staff person to pull that information together. The purpose of the core dollars of the coordinated grant proposal is to build capacity and expertise so it may fulfill some of the needs that Tribes are identifying.

Q: (Stacy Bohlen) Do you employ a cadre of Native Americans/Alaska Natives as reviewers for your grant review process?
A: (Ursula Bauer) We have an objective review process for the agency. Often reviewers have less knowledge of a particular program. We have some experience where announcements may be limited to a particular group, so for limited eligibility programs our reviewers are knowledgeable of those programs.
C: (Stacy Bohlen) The NIHB is hosting a Tribal health summit in May 2012, in Oklahoma, and a part of that is to showcase best practices. We are including grantsmanship training opportunities. Tribes consistently say this is a need. We invite CDC to have sessions at the summit on topics like how to be a grant reviewer, the grants process, and/or grant writing technical assistance. We can't keep building capacity without also bringing along those that need help starting.
C: (Ursula Bauer) I need to make a correction to what I said earlier, we are creating a web-based program for Tribes to go through the grant application process. This is the partnership we have with OSTLTS.
C: (Stacy Bohlen) The web-based training is valuable and CDC should be recognized for that, but a web-based platform alone will not be sufficient for Tribes.
C: (Ursula Bauer) We'd be happy to help with getting staff to your summit.

Q: (Connie Hilbert) Are you putting the compendium together?
A: (Ursula Bauer) We are.
Q: (Connie Hilbert) Do you have a timeline?
A: (Ursula Bauer) We have made progress; hopefully by this time next year we will have something.
C: (Chester Antone) Hopefully at that time we will also have an approved Tribal Consultation Policy and Charter.

C: (Chester Antone) I know technology is heading towards being paperless, but in Indian Country we need paper. Most of us with laptops get them on our own or they are given by the Tribal Council to conduct business. The majority don't have them.
Q: (Ursula Bauer) So do we need a paper companion to web-based information?
A: (Chester Antone) Yes! Some Tribal Nations don't have that capability for web-based information.

National HIV/AIDS Strategy for the United States

Dr. Jonathan Mermin, Director, Division of HIV/AIDS Prevention, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, CDC, said he was grateful to see such interest in HIV/AIDS, noting that 1 in 200 people in the U.S. that live with HIV is AI/AN. He said the Division of HIV/AIDS Prevention began a new strategic direction that is focused on reducing incidence and health equity. He said they try to distribute resources in alignment with the epidemic,

but realize some communities need extra resources and therefore more is given to Native Americans because it's a significant public health issue. To that end, he referenced increased collaborations with IHS under the new National Strategy—with $1 million going to IHS for the expansion of some of its HIV programs.

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

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

Discussion Points

Q: (Donna McCree) ***How should the public health community frame the discussion about HIV/AIDS in the Native community? What are the obstacles to continuity of care, i.e., testing, linkage to and maintenance in care, in Native Communities?***

Q: (Jay Butler) What do you mean by public health community?
A: (Donna McCree) We were talking in general. At the recent U.S. Conference on AIDS there was a mini protest around how we talk about the epidemic. Some said we were framing it as a "brown and black epidemic." So, what is appropriate in terms of the words we use?
A: (Chester Antone) We've know about HIV/AIDS for years, before it hit the U.S. Once it got to the U.S., that's when it got attention. Therein is the disparity. The focus comes only after others have had to deal with it. When it affects higher-level income folks, then it gets attention. Then it seems like resources go towards combating it in those higher groups. That is one of the things that stands out to me. We have negative tones around HIV/AIDS in the Native community. We don't have an understanding of disease and there are a lot of stereotypes. I don't know how many people in my Tribe have it. It has taken a while for people to talk about it in an open forum. In my district we have 11 representatives, so when the discussion happens it is among a few, not community-wide. Education about HIV/AIDS and where it comes from really needs to happen. Some facts about transmission to help us explain this to our community would help. Since it's a disease of the world,

I think about a quote that says for every illness there is a cure. Maybe some of our traditionalists don't have the knowledge to deal with this disease right now. In our culture some things remain in the closet for many years, but this is a public health issue.

C: (Donna McCree) The issue around stigma, knowing results, getting results, is seen in many communities, so thank you for bringing that up.

C: (Brenda Nielson) Culturally and traditionally, sex was not spoken about in the home. I think the stigma of HIV is prominent in Indian Country. Education is very important. On my reservation we have a couple of cases and people don't want to breathe the air they breathe. I would like to see funding to Health Boards to educate the communities.

C: (J.T. Petherick) We do have stigma issues. Even in large Tribes, you can identify someone with HIV when you look at data points. A focus on specific populations needs to happen, but there needs to also be a focus on safe sex.

C: (Sherrilla McKinley) You need to look at who has the influence in Native communities. In some communities the church has the most influence. I had an advocate on the Tribal Council who spoke up for me and I had to get the churches to support what I was doing and not believe that we were advocating for early sexual behavior by promoting condom use. You need to get the support from the influencers in the community. Eventually we were able to get STD/HIV education in the schools (elementary and high schools).

Q: (Jonathan Mermin) There has been a normalization in society over time. On the other hand, if it's being compared to diabetes, it's like it's just another illness. Access to testing may influence why AI/ANs die sooner. If stigma is too great, a person may not seek service. A study came out a few months ago saying that by taking a drug you reduce the chance of spreading HIV by 96 percent. So, it helps the whole community if infected persons take care of themselves. Are there other obstacles for people getting care? And are there specific ones to Natives?
A: (Sherilla McKinley) There are still confidentiality issues. Some clinics don't have policies and some don't follow them, so people don't go in for testing. This is especially true for smaller Native health clinics.

C: (Stacey Bohlen) I have some responses from other Tribes in response to Kim's questions that I want to share. They said, "Community health departments do outreach and talk about HIV/AIDS in the clinic, but education must be age appropriate. Care in the clinic specific to infectious diseases is provided, but for HIV positive people they often choose to seek treatment outside the clinic."

C: (Stacy Bohlen) An idea that came out at a national forum with Tribal College students was that an innovative approach for testing is the use of global incentives (like a gas card) so that everyone will get tested and be "protected" by the incentive. There is a need to address transmission of the disease through drug use for Alaska Natives/American Indians. The Red Talon Program is doing good work and we want to go on record about the need to continue their work.

C: (Jay Butler) The discussion needs to be framed locally. In Alaska, from one village to another, people have different comfort levels in terms of discussing this. I agree it should be done as part of

an overall wellness conversation. I encourage you to think about that in terms of program support and funding. We need to take a holistic approach to wellness in our communities.

C: (Rex Lee Jim) We need to sit down with communities, in this case Navajo, and involve the medicine people and talk about how to talk about it in terms of curing disease. It would be easier then to work with the communities and talk about it. We need to validate Native views and approaches to disease. We need to put it in a framework where we talk about other diseases and not isolate it. We need to say it is a disease and not emphasize it is prevalent among poor people and those living in horrible conditions, because people won't want to be seen like that. The stigma will stop them from going in for services. We need to approach this by not emphasizing the sexual activity, because it can be taboo in Native communities. We can talk about other means of contraction and then include sex.

C: (Lester Secatero) When I give a presentation I say "AIDS" and people know what I'm talking about; they know it's a bad disease. I have an AIDS program and we do a conference every other year. We have fry bread sales to raise money. It seems like it's not a top priority. When I first heard about it, it didn't sink in. After I attended my first conference and spoke to a couple of well-dressed men and I learned they all had AIDS, it started to sink in. Bring in those that are infected and let them give their testimonies. It is very moving. I've seen Navajo do skits that will bring tears to your eyes. My passion is to do a conference every year. Every April in Albuquerque we'll have a conference. Confidentiality is a problem in local clinics. The drugs are also very expensive. I was invited to a Hispanic Chamber of Commerce meeting. Representatives from the White House came out. I have a lady working in the field that wants to retire and for 7 years she has stayed in her job because no one wanted to take over. Now we have a new girl.

C: (Donna McCree) It seems like the first two questions have been covered. I've heard you talk about stigma, confidentiality, being culturally and linguistically appropriate, identifying key stakeholders, use of faith-based communities, an approach around whole health of the person, and a need to communicate that HIV is preventable.

C: (Sherilla McKinley) We talked about Native history when we talked about HIV/AIDS. We talked about sexuality and made it Native-specific to include history and then went into STDs and HIV. So, we started with history, then sexuality, then HIV. It seemed to work. That is the approach we used for addressing HIV in schools.

Q: (Chester Antone) Is there an emphasis on HIV in the current Health Care Reform?
A: (Jonathan Mermin) There are some opportunities for HIV. The National Strategy guides what we are doing, and that is to make sure what you do has the greatest impact possible. The ACA says any intervention at certain levels will be covered with no co-pay by most insurers and that [unintelligible]. So, if we can link some of those services into other care it could be covered within the health system. That would be beneficial because it would improve access. There is also funding through Ryan White.

C: (Delight Satter) In IHCIA there is language to develop an HIV office in IHS.

C: (Lisa Neel) There were two specific activities:

1. Section 199B requires the IHS to give a report to Congress every two years (March 23, 2012 is the due date and the report is currently in clearance) and
2. Creation of the position of the Director of HIV Prevention and Care (and that description is underway). They are pre-decisional actions that are not released to the public.

C: (Chester Antone) On my reservation we have a person with HIV and we have made progress in eliminating stigma. There is a high impact on prevention when Tribal members hear from people who have HIV, especially if they are family members.

Q: (Donna McCree) ***How should the High Impact Prevention approach to HIV prevention work in Native Communities?***

Q: (Jonathan Mermin) We were asked to do the best we can to prevent infections and reduce disparities and maybe some things we shouldn't keep doing because of limited funds. If you routinely offer HIV tests, then people wouldn't have to ask for it. So the question is, "Are there strategies in Native communities that we haven't done right or that you want to expand?"

A: (Chester Antone) Regarding the STD epidemic we had, it's now over, but we used a more secure area for confidentiality reasons. Our policy has changed and that has been effective.

A: (Stacy Bohlen) An effective approach is to ask us. When you look at the success of diabetes, it is because it is community driven. That model works across the board. There are sensitivities that Tribes address in their own way. Peer-to-peer education, counseling, and interventions are also effective. When we engaged college students to do PSAs, we had four scenarios and at a focus group when we showed the PSAs we got shocking information. The Native American men said, "I'm never getting with an AI/AN woman again." Global messaging doesn't always work. So we then did peer-to-peer groups instead; then the information was well received.

C: (Rex Lee Jim) It's time for full scale collaboration with CDC and Tribes. When we talk about technical assistance, this is the time. We have to build capacity. As sovereign Nations we want to be on our own and build capacity within our nations.

C: (Donna McCree) Yesterday Rex Lee asked about what evidenced based means. Jonathan, maybe you can talk about that in terms of the high impact approach.
C: (Jonathan Mermin) We tend to say, "Is there enough information to say we will get the best return on our investment?" For other aspects of care it is much harder. Half of the people that have HIV and see a clinician fall out of care. So, when we look at evidence we are looking for interventions that work and how they compare to other interventions that work. Some of it can be research based to continually improve on what we are doing. We fund some research in a variety of settings, so when we give technical assistance it is accurate.

Ms. Satter thanked Dr. Mermin, Dr. McCree, and Ms. Neel for their presentations. She mentioned that she had worked in HIV in the past and had done studies with Tribal communities. She said she looked forward to providing support in this area. Dr. Mermin encouraged the consultation participants to contact him or Dr. McCree with additional comments or to connect them with others

in their community. Dr. McCree echoed Dr. Mermin's remarks, adding that she would share the comments and recommendations expressed with colleagues in the Office of the Secretary.

Before breaking for lunch, Dr. Monroe informed the group that it had been brought to her attention that the Center Directors did not get information regarding the Tribal consultation. She apologized for the mishap, stating that many of them would stop by the meeting throughout the remainder of the day.

Discussion with Center Directors (con't)

Dr. Coleen Boyle, National Center on Birth Defects and Developmental Disabilities (NCBDDD), provided an update from the NCBDDD, noting it is the newest center at CDC and that it is congressionally mandated. She said the center has grown to include other issues, and has a current focus on individuals with disabilities, assuring healthy pregnancies, and preventing developmental disabilities. She said the Center is working with State Health Departments and would like to reach out to Tribal Nations. Specifically, she said the Center is working with State Health Departments to monitor and track malformations and to help with prevention programs. As part of her remarks, Dr. Boyle also discussed the Center's Pulmonary Embolism Initiative; work with non-malignant blood disorders; efforts to target Hispanics' corn based diets; as well as efforts in autism and other neurologic disorders. Regarding work with Tribes, she said the Center had previously focused on healthy pregnancies regarding alcohol use and is trying to implement screenings and brief interventions for women that exceed the daily recommendations for alcohol consumption.

Discussion Points

Q: (J.T. Petherick) Do you have data specific on AI/ANs?
A: (Coleen Boyle) We have information on structural malformations; we can share that with you. We have information on autism also. We do have information on other developmental disabilities, but it is limited. We also have some national survey data that we can pass on.

Q: (Brenda Nielson) What information do you have on SIDS [Sudden Infant Death Syndrome]?
A: (Coleen Boyle) That falls under Ursula's program.
A: (Ursula Bauer) We do surveillance on SIDS. We have some areas where we are tracking case follow-up, making sure proper investigation is done.

Q: (Jay Butler) Are metabolic diseases in your shop?
A: (Coleen Boyle) Yes.
C: (Jay Butler) We still struggle with post-neonatal mortality. We have an interest in developing programs about risks associated with fasting during pregnancy. I'm pleased to hear you are aware of this.

Environmental Public Health

Dr. Christopher Portier, Director, National Center for Environmental Health and the Agency for Toxic Substances and Disease Registry (NCEH/ATSDR), said the ATSDR was created by the

Superfund law circa 1985. Charged with going to Superfund sites to see if people are being affected, he said a community can ask for an assessment of toxins in the community. Dr. Portier told the participants that the National Center of Environmental Health has national programs that look at evidence linking environmental exposures to health and then creates programs to address them. He also indicated that there is an environmental health lab at NCEH. Next, Dr. Portier shared organizational changes he made in ATSDR, saying he saw a need to focus efforts on a community level. Notably, he said he's considering developing a 5-year strategic plan; he is elevating the Office of Tribal Affairs; and he will increase focus on education and outreach. Dr. Portier also indicated that regional offices for ATSDR will increase staff, including health educators and community involvement specialists. Regarding the budget, he said it has been a tough year with a $27.2 million decrease for NCH. He said ATSDR saw a minor drop in its budget ($.5 million). With the Lead Poisoning and Prevention program virtually eliminated, he said other lines remain the same. As part of his presentation, Dr. Portier discussed the Navajo Nation Birth Cohort Study involving mining and milling on Navajo and abandoned uranium mines and the subsequent contract award in 2010. He said a study team is being trained with plans to recruit participants in 2012. Dr. Portier also discussed the Asthma Control Program—which aims to prevent attacks, hospitalizations, and death. He said environments trigger asthma; and it can be controlled through education, medication, looking at the environment, and having a healthy lifestyle. The Asthma Control Program provides funds, conducts surveillance, and implements Asthma Control Programs with State partners (with 2 Tribes working with States for programs.) Dr. Portier also provided information on a national bio-monitoring program (which will produce a national report on 350 to 400 chemicals); discussed the importance of environmental justice; and shared information about Health Understanding grants.

Discussion Points

Q: (Connie Hilbert) What do budget cuts mean to respective States and prevention programs? Lead poisoning is a significant issue for us in Michigan. We rely on monitoring of EDLs [Essential Drug Lists].
A: (Christopher Portier) I can't give you a definitive answer right now. It went from 30 to 2 million dollars a year. That means there is no funding to States. The language requests that the Health Resources and Services Administration (HRSA) take over some parts and fund States. HRSA has conflicting laws and doesn't know if it can. Lead poisoning cooperative agreements will fund States through August 2012, so we have some time to work out funding solutions.

Q: (Rex Lee Jim) What happens at the end of the Navajo study in terms of sustainability and what to do with the findings?
A: (Christopher Portier) The Navajo study is a study. In a perfect world if we saw something of concern it would lead to additional cleanup. If we found nothing, then we'd say the current cleanup is adequate.
Q: (Stacy Bohlen) Is any program looking at the impact of fracking on Tribes, even when it's not done on their land?
A: (Christopher Portier) This is a hot debate. There is a program looking at fracking. We are partnering with EPA to look at fracking and getting national standards. EPA is already looking at standards for hydrofracking. It is not regulated nationally. In some places it is regulated locally. We are working with EPA to figure out how to do this safely.

Q: (Stacy Bohlen) My question is specific to Tribes' rights regarding Tribal land and the impact on Tribal lands. Is that being looked at?
A: (Christopher Portier) I am unaware if that is being looked at. It is a legal issue that I would not be involved with.

Discussion with Center Directors (con't)

Dr. Beth Bell, National Center for Emerging and Zoonotic Infectious Diseases, provided an update from that Center, saying that it deals with issues ranging from vector born infections, to food borne illnesses, to quarantine systems. As part of her remarks, she highlighted a pilot study involving spay and neutering as a vehicle to manage Rocky Mountain Spotted Fever.

Discussion Points

Q: (Chester Antone) Can you talk more about the pilot project on spaying and neutering?
A: (Beth Bell) It's called the Neighborhood Pilot Project and it will start this summer. They have interesting ways to use anti-tick collars and other methods to control ticks. I can ask Dr. Jennifer McQuistin to send you more information.

Q: (Connie Hilbert) I have a question about the Food Safety Program. Casino resorts do a lot of food services. We had an occasion where the FDA came and got into our warehouse to look at salmon products we had. It was challenging to work with them for a lot of reasons. They said we were not commissioned, so they could not share their reason for showing up on our site. In a case like that, is there an opportunity to reach out to you to get that type of information?
A: (Beth Bell) I don't know about the specific situation, but yes, it is possible. Wisteria is a special case and there is a monitoring program. The FDA has to issue recalls without disease in people. It is possible that the outbreak may have identified wisteria in food without causing harm to people. In that situation, we deal with the people. We find it challenging to deal with them also sometimes. If we have involvement, we work closely with the FDA.
Q: (Connie Hilbert) Can we work directly with you?
A: (Beth Bell) If it involves people, you would be working with us.

C: (J.T. Petherick) A lot of the areas you oversee interact with the State. It seems like you can help collaborate with States and local health departments. It would be nice to formalize agreements to ensure everyone is operating legally.
C: (Beth Bell) We don't have a lot of legal authority, but the model we try to follow is to work with groups that represent State and local health departments. Your point is well taken. We could do something similar with organizations that represent Tribes and help to broker relationships.

C: (Jay Butler) In Alaska we don't have local public health, so consortiums know the public health nurses. The legal authority lies with the State, but Tribal organizations are fairly organized. It can be difficult if you have multiple counties.
C: (Jay Butler) Your staff runs the Anchorage quarantine system and they have been very useful. Rabies is prevalent and your staff has been helpful. Regarding Hepatitis A, we have gone from worst to the first.

Native Diabetes Wellness Program

Larry Alonso, Traditional Foods Project Lead, Native Diabetes Wellness Program, Division of Diabetes Translation, National Center for Chronic Disease Prevention and Public Health Promotion, provided background information on the Traditional Foods Project, slated for 2008-2013. Given the anticipated conclusion of the Traditional Foods Project, Mr. Alonso asked the group its thoughts about the possibility of a new project. Originally funded for 11 partners, he said money from IHS increased the number of partners to 17, including Alaska. Grantees focus on things such as harvesting, planting, and traditional fitness activities. Mr. Alonso said the program has brought about community transformation in the way of more healthy decisions and has afforded the sharing of data on traditional foods, social supports, and traditional forms of exercise. Additionally, he said the project has shown that small communities, when funded, can demonstrate quick, significant impact. With consideration being given to another iteration of the project, and Traditional Foods programs being woven into Community Transformation grants, Mr. Alonso asked for ideas regarding future iterations of the project.

Discussion Points

C: (Jay Butler) I wanted to follow-up on the issue of evidence based practice that was raised yesterday. There is value in traditional ways of knowing. How do you go forward with developing a sustainable program? We think there is practice based evidence to show benefits of traditional foods. I know we get push back if there is no science. The way CDC has begun to think more broadly about "knowing" should be applauded and we want to work with you on that.

C: (Chester Antone) We need to figure out different ways of putting funds together to let communities suggest what they want to do, like you did with the original program. We should look at traditional methods for mass production of food, before we start pumping water. There are things that are edible that can grow in desert type climates. Some of the traditional foods also bring with them traditional medicine.

Q: (J.T. Petherick) Once the current funding is over, is the assumption that SDPI funding will continue or will there be a process to request more money?
A: (Annabelle Allison) We don't know the future for IHS so we are only counting on our division. The amount would be $1.2 million, so we could fund 12 Tribes.
C: (Larry Alonso) If we get what we get now from SDPI, they we would have $2.2 million. Moving forward we are looking for input about traditional foods in general.

Q: (Rex Lee Jim) In Navajo we are working on a food policy to limit junk food in markets and to promote healthier foods. Can you offer technical assistance in writing those policies? Right now we are not licensed to sell locally grown foods; it's only used in traditional ceremonies and for feeding our families.
A: (Larry Alonso) Yes, we have the ability to provide technical assistance. Some of that I would like to see coming from our partners who are already doing that, so information can be transferred.

Q: (Lester Secatero) Johns Hopkins is doing a healthy foods survey. Did they apply for money and if so, when?
A: (Larry Alonso) Seventy-six letters of intent came in, with 60 applications submitted. An objective review panel chose 11 grantees. Some programs were approved and not funded.

C: (Lester Secatero) Our Behavioral Health program used its own funds for a community garden, but we don't have any water. The price of food is going up. Hopefully we can get in on the action the next time.
C: (Larry Alonso) Box gardens and other ideas have been used to address the issue of lack of water. We are looking to gather the things done by our partners and share that information.

Q: (Sherrilla McKinley) So, in 2013 those 17 programs will have their funding end and not be refunded? Will they be able to sustain their programs?
A: (Larry Alonso) Along the way we have been talking about sustainability. We have varied ability among the partners to sustain their efforts. Most are looking to take lessons learned and use them. Funding is scheduled to terminate in 2013. Our division is committed to a $1.2 million investment in the program. That may or may not happen.

Q: (Sherrilla McKinley) Are you asking for our support in funding the partners?
A: (Larry Alonso) Your support would be valuable. We would be interested in hearing your support.
C: (Sherrilla McKinley) You have demonstrated support in that there were 70 applicants and only 11 got funding initially. The data show their production. Change takes 5 to 10 years. I'd like to see, after 5 years, more funding for them to continue. I'd like to see what else they can accomplish in the community. In my community we used to garden and then it stopped. No one gardens anymore. To see this revived is very positive.

Q: (Stacy Bohlen) The 2013 end date is based on what, the end of SDPI funds?
A: (Larry Alonso) The project was funded for 5 years. We would have to offer another opportunity for the program. It is linked to SDPI funds.
C: (Stacy Bohlen) We need to make the connection that this is part of the reauthorization of SDPI.

Q: (Sherrilla McKinley) Can Tribes write letters of support? Would that help? What do you want us to do?
A: (Stacy Bohlen) From NIHB, I would say yes. We can create that messaging on behalf of the Tribes.

Q: (Lemyra DeBruyn [from Native Diabetes Program]) Would it help if we gave you aggregate data? Would it be valuable to NIHB?
A: (Stacy Bohlen) Yes, it would be valuable and appreciated.

Tribal Testimonies

The remainder of the day's agenda was dedicated to hearing testimony, recommendations, and concerns from Tribal leaders. Highlights of those remarks are provided below.

Navajo Nation (as presented by Rex Lee Jim).
[Vice President Jim indicated that the Navajo Nation would provide its full testimony and recommendations to CDC/ATSDR in writing.]

Concerns:

- Tribal Direct Funding. Navajo has a treaty with the U.S. government for government-to-government relations. The Navajo Nation asks that CDC and HHS fund programs directly to Tribes and not through States. Timeliness of funds and State requirements are problematic when funds go through States. For some projects, funds come from CDC directly to Tribes. Request for technical assistance for a process to get funds directly.
- Communicable and Infectious Diseases. TB [Tuberculosis] rates have risen. The Navajo has a 27 percent TB mortality rate. The $79,000 TB Control project needs adequate funding. In October 2011, the Nation's Council approved an HIV/AIDS Act, showing its commitment to the U.S. National HIV/AIDS Strategy.
- Chronic Disease. Cancer screening activities must be increased in Indian Country. The Special Diabetes Program for Indians will expire in 2013. No educational materials have been received from CDC. The Tribe is developing its own materials. Request that Tribes develop and distribute materials with the $1 million left.
- Health. Additional funding is needed for positions, such as a statistician, at the Navajo Epi Center. The Division of Health will request technical assistance with data health center infrastructure. The Tribe needs direct access to State and IHS data. This is key to effective programming. There is a need for health surveillance disease systems. Tribes must be granted access to data sets. Additional funds are needed to address health disparities. CMS Innovations Challenge grant has been submitted. Medicaid Feasibility Study funding is needed for study design, timeline, and cost analysis.

Recommendations:

- CDC/ATSDR direct funding to Tribes.
- Epi Centers' direct access to data from Federal agencies.
- CDC needs to consolidate infectious communicable disease funding, such as HIV, TB, and STDs.
- Expand support for chronic diseases.
- Request for a written response to the Navajo Nation's testimony, as well as having Dr. Frieden have CDC directors attend consultations and listen to Tribal concerns.

Lester Secatero

- The funding process for Tribal organizations should be streamlined and not go through IHS.
- HIV/AIDS needs to be a funding priority in Tribal communities.
- CDC Tribal liaisons should visit Tribal organizations to build relationships and learn about programs.
- Training is needed on writing grants, implementing new programs, and networking.
- Funds and technical assistance is needed at the grassroots level.

J.T. Petherick

- The dialogue today and on the previous day has been helpful.
- CDC staff attendees have been engaged in the conversations and that is appreciated.

Chester Antone

- Support reauthorization of SDPI using the success stories from the Traditional Foods grants.
- Reconsider the two positions previously slated at grade level 13 in OSTLT and consider additional positions in the ASTDR.
- Review previous consultation minutes because many issues raised today are embedded in those testimonies, e.g., water contamination and comingling of funds.
- Cancer is right up there with diabetes in terms of importance.
- CDC should do a literature review and produce results on the extent of cancer in the Native American community.
- Tribes would benefit from additional research and programming.
- The mapping of cancer patients was useful.
- There is a need for more innovation opportunities with Tribes and to share with AHRQ and NIH. Focus on more traditional foods, e.g., prickly pear juice, wild potatoes, celery, pumpkin seeds, and different ways to prepare corn.
- Address mining and its effects on ground water.
- Hold grants that benefit Indians harmless from budget cuts.
- Across all grant agencies, examine if the Grants Office will accept evaluators from Indian programs who know the community. Will they be deemed credible?
- Re-consider what you consider "credible" data. Tribes might have successes that are measured differently.

NIHB (as presented by Rex Lee Jim)

- Additional staffing is needed in the Tribal Support Office at Grade 13, but we are now being told nothing is assured and they may be put elsewhere. We object to this change and request a Grade 13 position be established in the Tribal Support Office.
- CDC should commit funding for Tribal health and infrastructure and direct funding to AI/ANs.
- Treaties guarantee Tribes various services, including health care. That does not begin and end with IHS. This includes CDC.

Funding:

- Federal budget sequestration is pending and will have influence on CDC to uphold its treaty obligations. All Indian programs must be spared from cuts of any kind.
- Funding to States does not guarantee funds will reach Tribes. States often don't understand government-to-government relationships. CDC needs to hold States accountable for CDC resources.
- NIHB suggests CDC provides States with guidance for working with Tribes.

- CDC needs to ensure that its funding is included in Tribal communities.
- Appreciation is given to CDC for supporting Tribal-State dialogue. These are responsive actions to Tribes' concerns.

Tribal Consultation:

- Tribal consultation is an essential foundational element of relationship with Tribes. In a previous meeting, we requested CDC leadership at Tribal consultations. NIHB is pleased with the efforts of Ms. Satter, Mr. Holzman, and Dr. Monroe.
- Request that CDC track action items from meetings, and include a synopsis of the actions.
- NIHB requests documents/presentations for all agenda items for all future meetings, with ample time for Tribes to discuss the information and plan next steps.
- Request that information/action items be posted on the CDC website, updated monthly, and shared with NIHB.
- Continue to increase capacity of non-Tribal organizations.
- Invest more in Tribal public health systems.
- Request that CDC supports Tribes at the same level as local and State governments.
- Identify direct funding mechanisms to address States' lack of coordination with Tribes.
- Strong relationships between Tribes and the CDC are needed because of Tribal health disparities.

Following the Tribal leaders' testimonies, Ms. Satter asked for comments from Tribal representatives in the galley. There was none.

Wrap-Up

On behalf of Dr. Frieden, CDC, and staff in the galley, Dr. Monroe thanked the Tribal leaders for their testimonies. Noting that the day's meeting and the previous two days of meeting sessions had been good, she commented that there is still a lot of work to do.

Ms. Satter thanked the consultation attendees for their participation, she and Dr. Gregory Holzman, Associate Deputy Director, OSTLTS, agreed to follow-up on the request for CDC to have a form to track Tribal concerns.

The meeting adjourned with Councilman Antone providing a closing prayer.

Action Items

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

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

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

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

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

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

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

Attendant Roster

Tribal Consultation Advisory Committee (TCAC) Members

Chester Antone, Tohono O'odham Nation
Stacy A. Bohlen, Sault Ste. Marie Chippewa; National Indian Health Board
Jay Butler, MD, Alaska Native Tribal Health Consortium
Connie Hilbert, MS, RS, Mohegan Tribe
Gayline Hunter, California Rural Indian Health Board
Rex Lee Jim, Navajo Nation
Sherrilla McKinley, Inter Tribal Council of Arizona, Inc.
Brenda Nielson, NPAIHB, Quileute Tribe
J.T. Petherick, JD, MPH, Cherokee Nation
Lester Secataro, Albuquerque Area Indian Health Board

Centers for Disease Control and Prevention

Annabelle M. Allison, National Center for Environmental Health and the Agency for Toxic Substances and Disease Registry
Larry Alonso, FNP, Division of Diabetes Translation
Ursula Bauer, PhD, MPH, National Center for Chronic Disease Prevention and Health Promotion
Kimberly Cantrell, Office for State, Tribal, Local, and Territorial Support
Thomas Frieden, MD, MPH, Centers for Disease Control and Prevention and Agency for Toxic Substances and Disease Registries
Gregory S. Holzman, MD, MPH, Office for State, Tribal, Local, and Territorial Support
Donna McCree, PhD, MPH, RPh, Division of HIV/AIDS Prevention
Jonathan Mermin, MD, MPH, Division of HIV/AIDS Prevention
Judith Monroe, MD, FAAFP, Centers for Disease Control and Prevention and Office for State, Tribal, Local, and Territorial Support
Lisa Neel, MPH, Indian Health Service
Christopher Portier, PhD, National Center for Environmental Health and the Agency for Toxic Substances and Disease Registry
Delight Satter, MPH, Office of State, Tribal, Local and Territorial Support
Dawn Satterfield, RN, PhD, Division of Diabetes Translation