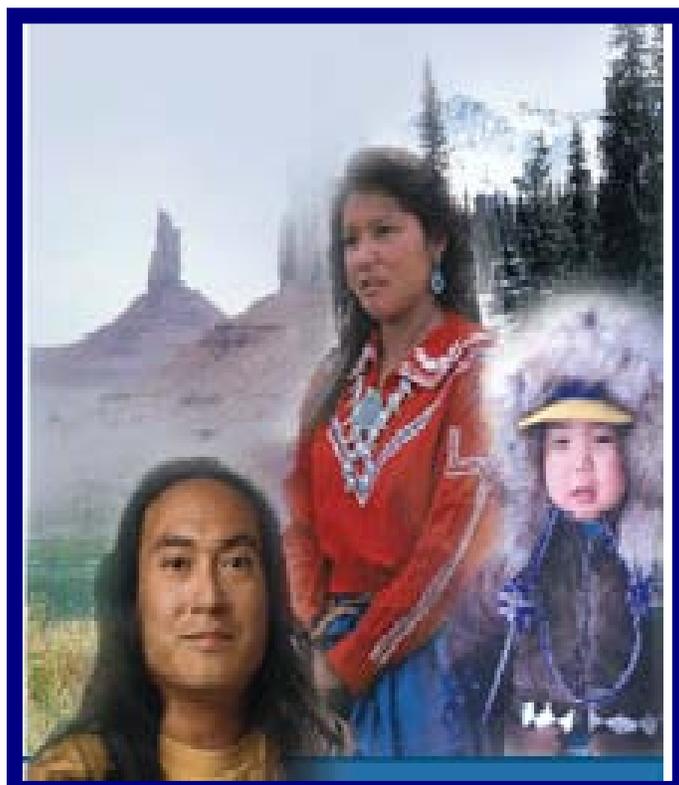




**Department of Health and Human Services
Centers for Disease Control and Prevention
Agency for Toxic Substances and Disease Registry**

**4th Biannual CDC / ATSDR
Tribal Consultation Session**



**January 28, 2010
Minutes of the Meeting**



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Acronyms

AAIHB	Albuquerque Area Indian Health Board
AATCHB	Aberdeen Area Tribal Chairman's Health Board
AI / AN	American Indian / Alaskan Native
ARRA	American Recovery and Reinvestment Act
ATS	Adult Tobacco Survey
ATSDR	Agency for Toxic Substances and Disease Registry
BIA	Bureau of Indian Affairs
CBOs	Community-Based Organizations
CBPR	Community-Based Participatory Research
CDC	Centers for Disease Control and Prevention
CLC	Central Leadership Council
CPPW	Communities Putting Prevention to Work
CRIHB	California Rural Indian Health Board
CVD	Cardiovascular Disease
DHS	Department of Homeland Security
DNPAO	Division of Nutrition, Physical Activity, and Obesity
DOJ	Department of Justice
DSLRL	Division of State and Local Readiness
DVP	Division of Violence Prevention
ELB	Executive Leadership Board
EOCs	Emergency Operation Center
FEMA	Federal Emergency Management Association
FMO	Financial Management Office
FOA	Funding Opportunity Announcements
HHS	Health and Human Services
HRAC	Health Research Advisory Council (HHS)
HRSA	Health Resources and Services Administration
ICC	Incident Command Center
IDU	Intravenous Drug Users
IHBN	Indian Health Board of Nevada
IH S	Indian Health Service
IPV	Intimate Partner Violence
LGBT	Lesbian, Gay, Bisexual, Transgender
MSM	Men who Have Sex with Men
NARCH	Native American Research Centers for Health
NCAI	National Congress of American Indians
NCCDPHP	National Center for Chronic Disease Prevention and Health Promotion
NCEH	National Center for Environmental Health
NCIPC	National Center for Injury Prevention and Control
NIHB	National Indian Health Board
NNAAPC	National Native American AIDS Prevention Center
NPAIHB	Northwest Portland Area Indian Health Board
OD	Office of the Director
OMB	Office of Management and Budget
OPDIV	Operating Division
OSH	Office on Smoking and Health
OSLS	Office of State and Local Support

PHER	Public Health Emergency Response
PIMC	Phoenix Indian Medical Center
PTSD	Post Traumatic Stress Disorder
SAMHSA	Substance Abuse Health and Services Administration
SES	Socioeconomic Status
SIDS	Sudden Infant Death Syndrome
SDPI	Special Diabetes Program for Indians
TCAC	Tribal Consultation Advisory Committee
THPS	Tribal Health Program Support
VTrckS	Vaccine Tracking System
WHO	World Health Organization
YLL	Years of Life Loss

DRAFT



**Centers for Disease Control and Prevention (CDC)
Agency for Toxic Substances and Disease Registry (ATSDR)
Tribal Consultation Session**

**Minutes of the Meeting
January 28, 2010**

Opening Blessing / Welcome

**CAPT Pelagie “Mike” Snesrud, Session Moderator
Senior Tribal Liaison for Policy and Evaluation
Centers for Disease Control and Prevention (CDC)
Agency for Toxic Substances and Disease Registry (ATSDR)**

**Ms. Donna Garland
Acting Associate Director for Communications
Centers for Disease Control and Prevention (CDC)
Agency for Toxic Substances and Disease Registry (ATSDR)**

**Mr. Lester Secatero, Chairman
Albuquerque Area Indian Health Board (AAIHB)**

CAPT Snesrud called the Tribal Consultation Session to order, indicating that she was pleased and excited to have Tribal leadership, CDC leadership, and American Indian (AI) / Alaska Native (AN) stakeholders present. She then introduced Acting Associate Director for Communications, Ms. Donna Garland.

Ms. Garland welcomed everyone, noting that she had the honor and privilege of announcing the names of the attendants of the Tribal Consultation Session. She then read the names of those present. The attendant roster may be found at the end of this document.

Mr. Lester Secatero expressed the importance of starting the day with prayer, which is very important to Native Americans. He then offered the opening blessing, focusing on being grateful, opening the hearts and minds of those present, and helping them all to dialogue wisely and productively during this session.

Ms. Donna Garland then introduced Dr. Frieden, indicating that he joined CDC in June 2009. Everyone is pleased to have Dr. Frieden bring new energy and focus to the work of protecting the health and people of the world. The public health work of CDC and the work the agency does are critically important. Dr. Frieden served as the Commissioner of the New York City Department of Health and Hygiene for about seven years, prior to which he did significant work in India to address their health concerns, particularly with respect to tuberculosis. Dr. Frieden's effect is epic and his name is known in many quarters from the federal, to the local to the street levels of New York and other places.

CDC Director's Opening Remarks

Thomas R. Frieden, MD, MPH
Director, Centers for Disease Control and Prevention (CDC)
Administrator, Agency for Toxic Substances and Disease Registry (ATSDR)

Extending his welcome and gratitude to everyone for their attendance, Dr. Frieden said that CDC was honored by their presence and was looking forward to their interactions together. He thanked them for their time, commitment, and participation on the Tribal Consultation Advisory Committee (TCAC), which CDC values greatly. TCAC participation gives CDC a sense of direction and the opportunity to approach major challenges as partners. He expressed particular gratitude to the TCAC Co-Chairs, Kathy Hughes and Chester Antone, for their leadership and guidance. CDC relies on TCAC to help maintain a productive relationship.

Dr. Frieden's philosophy of public health is to keep it very simple: Figure out the major causes of illness, death, and disability; determine which of those something can be done about; and focus on those about which something can be done, implementing programs that are likely to work, and rigorously evaluating successes. If a program is implemented and is proven to succeed, it can be defended. If a program is implemented that is not successful, there is an opportunity to fix it.

Since coming to CDC, Dr. Frieden has had five basic priorities:

1. *Improve knowledge of what is occurring in communities through better surveillance, epidemiology, and laboratory services in order to better understand the problems and share that information—convey it in ways that are understandable and impactful:* Joining them during this meeting was Dr. Thacker, Acting Deputy Director for Surveillance, Epidemiology, Laboratory Services, who is in charge of this priority. One of the core missions of CDC is to shine a light on problems. Sometimes people do not like lights being shined on problems, but that is a role for CDC—a bearing witness role as an honest broker of the real issues due to which people are getting sick and dying;
2. *Support communities through the leadership responsible for health:* That varies by whether it is state, local, tribal, or territorial. Each must be nuanced in terms of differences. For example, there are real differences between the large states and small states in terms of approaches. There are major differences in local health departments and between large cities and very small rural areas. The territories have unique problems with distance and travel. For H1N1, vaccination boats made the rounds among the territories. Dr. Frieden said he was looking forward to learning from the tribes about what some of the issues and concerns are. He reviewed the materials from the last Tribal Consultation. He expressed his regret that he was unable to join them in Alaska, but stressed that he had very much been looking forward to this meeting in Atlanta. He stressed that they must think together about what the major problems are, which they could do something about, and on which ones they could partner together to make a difference. CDC recognizes that ultimately public health is local (e.g., in a community, in an area). Public health is what organized communities do to live longer and healthier lives—to prevent avoidable illness and death;

3. *Increase impact in global health:* CDC has many activities around the world, including many activities that affect individuals who are original inhabitants of the lands where they live. In India, Dr. Frieden worked on tribal health issues and particularly challenges. He was very privileged to be on loan from CDC to the World Health Organization (WHO) for five years in India. He traveled throughout India getting to know the country and remembered vividly many of the communities he was in;
4. *Increase policy impact:* While there may be a focus on programs, it is often policies that save the most lives; and
5. *Through all of the activities of CDC to focus on the bottom line:* For CDC, the bottom line is not money—it is preventing illness, disability, and death.

With those priorities in mind, there are a few things that Dr. Frieden likes to raise with regard to the data from Indian County. Just as in global health this is done in a respectful way and a government-to-government relationship. While they may always disagree on interpretation or policies, CDC hopes to get to a relationship in which they do not disagree about the facts. They should all be willing to face the facts clearly and forthrightly.

Over 30 years ago, Dr. Frieden coordinated an event for a group of very committed American Indian leaders. After a week long, highly intensive set of interactions, they had a final meeting during which the issue of tobacco arose. A member of the Lakota Sioux said to Dr. Frieden that they knew that tobacco was dangerous, but it was stolen from them and the result was that it was being used in ways that the Lakota Sioux knew for hundreds of years it should not be used. It was known that if tobacco was used more than occasionally, one would become addicted to it. Tobacco remains the leading preventable cause of death in the world.

It is important to recognize that there is a bright dividing between ceremonial use of tobacco and commercial tobacco use. Very effective ways of reducing tobacco use are known, most of which are policy. If these are implemented, tobacco use is reduced substantially. Dr. Frieden is sometimes criticized for meddling in people's lives and is told that he should just let people do what they want to do. Of course, people have every right to do what they want to do. However, as a doctor he has known many people who have suffered terribly from the effects of harmful use of tobacco. He remembers some of his patients who gasped for every breath with emphysema or who died young and left children or spouses behind.

There is some good news. Smoking and pregnancy has decreased among American Indian women from 27% to 21%, and among Alaska Native women from 45% to 36%. The trend is in the right direction, but nearly far or fast enough. This is so important because every child should be born with the full potential to lead a healthy life and reach their full potential. There is a lot that can be done to reduce tobacco use to protect children, workers, and people who may be exposed to tobacco; to educate people about the harms of tobacco; to protect people in the workplace; and to address some of the price issues of tobacco. It is a delicate issue, but because it is the one that both kills the most people and is the most preventable, he raised it first.

Second, Dr. Frieden raised the issue of motor vehicle accidents. He pointed out that sitting next to him was Dr. Ileana Arias, who he named as Principal Deputy Director of CDC, prior to which she served as the Director of the National Center for Injury Prevention and Control (NCIPC). The example of the intervention that was implemented to increase seatbelt use in tribal communities offered an example of something that could be a real success and make a real difference in reducing the number of people injured and killed. Seatbelt use is approximately 55% in Indian Country compared to 82% overall in the US, but it varies greatly among communities, some of which have much higher use than others. Child safety seats are also at a very low use compared to the US. Alcohol is responsible for a large number of motor vehicle injuries in the US and in Indian Country. It is known that morbidity and mortality resulting from tobacco and motor vehicle accidents can be greatly reduced through interventions.

A third challenging area is alcohol. Alcohol attributable deaths account for about 1 in every 8 deaths among American Indians and Alaska Natives compared to about 1 in 33 for the US population. Motor vehicle accidents are the leading cause of alcohol-associated deaths.

Sudden infant death syndrome (SIDS) is another issue. The SIDS rate is about twice as high in Indian Country as in the US rate. There are very simple, effective ways to reduce SIDS deaths that often rely on community education. In New York City, where Dr. Frieden served as Health Commissioner for 7.5 years, there was a higher rate of SIDS deaths among African Americans. Some anthropological research was conducted to try to understand why. The fundamental direction is to place babies on their backs to sleep. The research found that mothers did not believe the health care system when health workers told them to place their babies in their backs because it is counterintuitive. Babies do not sleep as well on their backs and there was a concern that they would choke. Mothers said they would certainly believe older people, grandmothers, in their communities. This was good information that helped them reach communities to reduce SIDS deaths by working through grandmothers and other leaders in communities.

Over the last 30 years in the US, there has been an epidemic of HIV in the US; there has been autism, which is being recognized more and is possibly increasing; and there has been an epidemic of obesity. Diabetes is an enormous problem. The rate of obesity in adults is twice what it used to be, and the rate in children is three times what it used to be. With obesity comes diabetes, which can take many years off of one's life and affect them in many ways (e.g., vision, kidney function, amputation, heart attacks, strokes, et cetera).

Much needs to be done to promote physical activity, better nutrition, and better health care. Public health has important information to bring to bear in health care, which is a sense of priorities. There are many things that the health care system can do. Some of the most important is to protect people's hearts. Blood pressure control is the single most important thing the health care system can do to prevent heart attacks, strokes, and premature deaths. Yet, only 44% of people with high blood pressure in the US have it under control. Cholesterol is also pretty simple to control, but only 29% of people in the US with high cholesterol have it under control. Most people who want to quit smoking do not get proven means to help them quit. Something as simple as people who are at high risk of heart attack taking an aspirin is also not done regularly. This is what Dr. Frieden calls the ABCS: Aspirin, Cholesterol Blood Pressure, and Smoking.

Dr. Frieden stressed that he recognizes that Indian Country is politically and culturally unique, and that different tribal groups have different characteristics, strengths, challenges, and structures. However, he said he was convinced that in all communities there are ways to address leading problems that those communities decide to address. He worked on tuberculosis for more than a decade. Many of the approaches to tuberculosis control were developed in Indian Country, Alaska, and Continental North America. One of the key lessons was the importance of using community leaders and community staffing to engage in outreach, follow-up, and education.

In thinking about 2010 and forward, there are at least six areas in which there are winnable battles that need to be fought from which a big difference can be made:

- 1) Tobacco, because this is still causing the most illness and death and is the most preventable;
- 2) Nutrition and obesity, including efforts such as salt reduction and fortification of foods. Ultimately in public health, the idea is to change the default value so that it takes effort to do the unhealthy thing rather than taking effort to do the healthy thing;
- 3) Reduce avoidable infections in hospitals and health care settings. It is known that many people become ill from hospital infections, and this is very preventable.
- 4) Reduce motor vehicle injuries;
- 5) Reduce teen and unintended pregnancy, because many unintended pregnancies occur among young people who are not ready to have children—every child must come into the world with the best possible opportunity for a long, healthy, and rewarding life and for fulfilling their potential; and
- 6) Reduce HIV, given that it remains a terrible pandemic that is still taking too many lives. Tremendous progress has been made in treatment. As an infectious disease physician by training, Dr. Frieden went to India in 1996, which was just when triple therapy for HIV was established. He had two close personal friends who had AIDS, who he was certain he would never see again. However, during the month he went to India, new treatment for HIV became available and those two friends are both currently working fulltime. While there is remarkable treatment, there has also been an increase in risky behavior. Moreover, many people are not benefitting from treatment because they are not being tested.

Accountability is very important. They must all keep themselves accountable for being very specific and concrete about what they want to accomplish, and about how they will know whether they have accomplished their goals. Dr. Frieden sees these consultations as an on-going partnership to ensure that they are accountable to themselves and to each other in that way, and that they think about the types of interventions in which they can partner and be accountable for whether or not they occur. The best public health programs he is familiar with include regular feedback about the degree of progress or lack thereof individual areas, whether it is policy change or quality of treatment, such that the people in those areas can know how they are doing and also so that additional assistance can be given when needed. Sometimes people need to see that others are doing better than they are, and they can be encouraged to do better that way, or can be reinforced by knowing that they are doing excellently well. Consideration must be given to policy changes that can reduce the leading causes of illness and death and whether they are being implemented.

In closing, Dr. Frieden reiterated that he was honored to be in attendance at the 4th Biannual CDC / ATSDR Tribal Consultation Session, and that he was looking forward to listening to and learning from their insights, perspectives, and suggestions.

Tribal Testimonies to Dr. Frieden and Executive Leadership / CDC Responses

Overview

Ms. Kathy Hughes, Session Moderator
Vice Chairwoman, Oneida Business Committee
Tribal Consultation Advisory Committee (TCAC) Co-Chair

Ms. Hughes thanked Dr. Frieden for his comments. She said she thought it was extremely important for his Advisory Council and for Tribal Leaders to understand his philosophies and priorities. She thought that their work was a combined effort, and that they were looking for his understanding and support to deal with issues in Indian Country. His opening comments during this session should help them to figure out ways to better work together and improve collaboration between CDC and Indian Country.

Tribal Testimonies

Mr. Chester Antone
Tohono O'odham Legislative Councilman
Tribal Consultation Advisory Committee (TCAC) Co-Chair

Mr. Antone thanked Dr. Frieden, indicating that he had listened intently to his comments. Regarding accountability, coming from the backdrop of the *Tribal Consultation Policy*, tribes want to focus on the government-to-government relationship between CDC and Indian Country. He pointed to the CDC / ATSDR Tribal consultation policy, which has numerous references to tribes, the government-to-government relationship, and how this unique relationship came about. This is what should be taken into consideration when dealing with Indian Tribes as opposed to race, which is sometimes misunderstood among federal agencies. In the first paragraph of the tribal consultation policy, Section 5, Background also references the *American Indian Policy Review Final Report*.

Three key recommendations were made in the *Fiscal Year 2004 Annual Report on Tribal Consultation* from CDC, one of which was to establish an organizational unit within the Office of the Director to guide and monitor American Indian and Alaska Native programs across the agency. At that time, this was still under consideration by the CDC Director. In the January 30-31, 2007 recommendations from TCAC to CDC, again the recommendation was made to assure that adequate staff and resources be made available within the Office of the Director to support Tribal Consultation Policy implementation. On February 28, 2008 again TCAC recommended much of the same. During the November 18-19, 2009 Consultation in Tucson, TCAC strongly recommended that the Health and Human Services (HHS) leadership, by the new administration as part of the transition process, establish an American Indian and Alaska Native Organizational Unit as a specific office within the Office of the Director at CDC. Furthermore, in order to assure institutionalization of the CDC Office of American Indian and

Alaska Native Tribal Affairs, develop a plan to staff positions at CDC and ensure a smooth transition of staffing needs to be developed in order to assure continuation of services.

The reason for reviewing previous recommendations is that there have always been voices raised toward the idea of having a place for the Native American within certain agencies. The reason for this is to have a central location from which to work, which falls in line with the priorities that Dr. Frieden mentioned, such as the tribal differences in terms of population and various diseases specific to certain areas. The idea of the central location from which to work has been expressed throughout the years. Native Americans and Alaska Natives want to become partners in advancing public health through this unique relationship of working government-to-government. Additional staffing is needed to support this relationship, to support interactions between states and tribes, and to battle these diseases. The tribes speak on this every time they can.

Accountability includes the current organizational restructuring also. Tribes want to relate to CDC / ATSDR that they are very interested in knowing where their recommendations go. Previously they went to the Executive Leadership Board (ELB) or the Central Leadership Council (CLC). Currently, the process of getting recommendations to the Office of the Director of CDC is not clear. As Dr. Frieden mentioned, feedback is key. It seems that TCAC is operating in a vacuum, but with Dr. Frieden's office involved as partners, they will know where to go.

Regarding federal / tribal / state relations, during the TCAC meeting, changing the culture at CDC was mentioned with respect to redirecting of funding directly to tribal nations. Oftentimes, state and tribal processes do not mesh, but in the end, tribes lose funding due to the reimbursement process. This makes the tribes appear not to need the funding. It is important to concentrate on policies to ensure that they are all working toward one cause. Numerous instances regarding this issue are highlighted in the TCAC recommendations and the annual reports submitted to HHS, particularly with regard to border states. There must be a review of the funds that are funneled through the states. Set-aside funds have been discussed many times, and this is where the key point should be considered in terms of the relationship between the federal government and tribes. Set-aside funds often fall into a racial category, which is not appropriate. It should be recognized that the federal-tribal relationship is established per the Constitution of the United States. Tribes also ask that Dr. Frieden advocate on their behalf for certain cross-cutting issues that perhaps cross agencies in order to better impact decision makers.

In conclusion, Mr. Antone reiterated the request that CDC and tribes become government-to-government partners, and that TCAC will be reviewing the proposed new unit within CDC and its critical components. Communication is needed from the Associate Director of Communications. Prevention through health care is also needed, under the purview of the Associate Director for Policy. Another important objective is the redesign of select program priorities, which falls under the Associate Director of Programs. Global Health is also very important. About two years ago, issues pertaining to Mexico, Texas, North Dakota, Arizona, and Alaska were brought to CDC.

Mr. Derek Valdo
National Congress of American Indians (NCAI)
Southwest Area Pueblo of Acoma

In his language, Mr. Valdo wished everyone a good morning and welcome. He thanked everyone from CDC for taking time away from their busy schedules to engage in this Tribal Consultation. He indicated that Pueblo of Acoma is considered one of the first and oldest continuously inhabited communities in the Northern Hemisphere, with some carbon dating that suggests they have been on their Mesa since about 700 AD. On behalf of the Tribal Nations of the National Congress of American Indians and the Pueblo of Acoma, he thanked CDC for hosting this Biannual Tribal Consultation Session. They welcome the opportunity to provide their views and priorities on issues that are important to Indian Country.

As tribal leaders, they are all facing many difficult challenges. There are competing priorities at home and across Indian Country. There are 565 federally recognized tribes, over 200 of which are in Alaska, and another 200 of which are in the lower 48 across 32 states. While tribes represent less than 2% of the general US population, they represent approximately 10% to 15% of the land mass of the US. In the global perspective, tribes are consistent players in terms of geographical area.

During the past couple of days, tribal leaders discussed topics with CDC staff that are imperative to the past, present, and future of health in Indian Country communities (e.g., pandemic response, chronic disease, environmental health, injury, suicide, and violence). Each of these issues is having devastating effects in Indian Country. All of these topics are cross-cutting across multiple agencies within HHS. HHS provides these services in support of the unique legal and political relationship that exists between the United States and the Indian Tribal Governments. These relationships are confirmed by the Constitution of the United States, Treaties, Statutes, Executive Orders, and Judicial Decisions. Therefore, the premise behind why these services are being provided to tribes is different.

The National Congress of American Indians (NCAI) offered the following three priorities:

1. Continued inclusive consultation, partnership, and dialogue with tribes: Historically, the interactions and partnerships between the US and tribes have gone through cycles: elimination, extermination, assimilation, et cetera. An increase in tribal consultations and inclusion have been observed in the new millennium of the 2000s. There is a saying at the Substance Abuse Health and Services Administration (SAMHSA), "By us or for us, it is a better local decision." He always reminds them that in terms of Indian Country, it has always been done "for them." They have never been asked to do it themselves until relatively recently.
2. Better interagency coordination: Those in Indian Country do not have consistent access to a health care system per se. Tribes are pushed through many doors: Indian Health Service (IHS), SAMHSA, and CDC. It is like a teleconference trying to make connections, and somewhere along the line paperwork is dropped, symptoms are dropped, critical information that is critical to the wellbeing of the individual is dropped, et cetera.
3. Decrease health disparities of the nation: Tribes are very happy to be included, but would like to see the health disparities of tribes decreased to at least the level of the general US population.

NCAI believes that with these three priorities, current available resources can be leveraged to provide for a full range of prevention, early detection, intervention, treatment, and recovery services that embodies a whole health system approach in the communities with the greatest needs and highest health disparities, especially in the context of the national outlook of freezes in funding. As an economist by training, Mr. Valdo acknowledged that spending could not continue without any penalties or consequences. Tribes are part of that pot of the US. Clearly, everyone must make hard decisions during the next 5 to 10 years to pay off some of the debt that has been incurred. Therefore, creativity is important.

Mr. Valdo indicated to Dr. Frieden that he had support with the continuation of tribal consultations, noting that his presence during this consultation was evidence of this relationship. He said he could not emphasize enough the importance of Dr. Frieden's attendance. Being able to speak to the highest level of CDC represented a great big deposit into the trust account. In addition, it would be great for the new home of tribal issues, the Office of State and Local Support (OSLS), to include "Tribes" in the name to elevate and make this visible internally and across HHS. If they could not have their own Office of Tribal Affairs, at least call this new office: The Office of State, Tribal, and Local Support.

Regarding the 50% to 300% or greater health disparities documented in Indian Country, Mr. Valdo believes in data as well. It is only through data that they will be able to measure performance and hold each other accountable. Elevating or at least including tribes in this office requires that visibility. Excluding the vaccines for children, over the last 5 years an average of approximately \$25 million has been directly funded to tribes. It is biased thinking to presume that \$25 million across 565 tribes is enough to make a difference. This is an opportunity for improvement. There are some winnable battles among high health disparities in Indian Country.

Mr. Valdo said that he looked forward to hearing from CDC on ways in which they were working with other agencies like IHS, SAMHSA, and every other agency involved in Indian Country, because he is a firm believer of the old adage that he could not lift the table by himself without straining or injuring himself, but lifting together would be quicker and easier. In closing, he thanked everyone for taking time away from their responsibilities at CDC, from their families, and their homes. For tribal members to attend, it takes time away from their homes and families. What they do together will improve the health and wellbeing of all children, grandchildren, and the generations yet to come. This is an exciting and hopeful time in Indian Country, and he looks forward to a successful and productive year.

Indian communities are very spiritual. This is one of the common themes in Indian Country. This is not religion per se, though there is a heavy influence of Catholicism, Christianity, and other religions that were forced on tribes many years ago, but there is always a deep-rooted spirituality. He expressed his appreciation for those present for taking the time to honor the tradition of offering prayer. When they pray at Acoma, they pray for the people, the land, the things that walk and grow on the land. They pray for the world first, then they pray for the United States, then they pray for the Acoma, and then they pray for their families. At the end of the prayer they always say that if there is anything left, and after everybody else has had theirs, this is what I would like. This is a totally different perspective, and Mr. Valdo thanked everyone for listening. He acknowledged that tribal leaders have a problem of not being able to be direct and concise and get things out the door right away. That is just their culture. They tell stories, are very oral, are very visual, and learn and see through their experiences. With that in mind, when the elders speak but they go beyond their time, he implored CDC to please listen to the whole story, let them finish, and do not be too quick to jump in in order to get the whole picture.

In conclusion, Mr. Valdo said that his motto would be “Trust but verify.” As the new leader of CDC, Mr. Valdo said that he had trust and faith that Dr. Frieden would help all people. He asked that they work together to make a difference. In his native language, Mr. Valdo offered concluding remarks, which translated to: “Be brave, be courageous, and may your family and yourself be protected, and may all that you wish in life be given to you.”

Mr. Reno Franklin

Chairman, National Indian Health Board (NIHB)

Chairman, California Rural Indian Health Board (CRIHB)

Mr. Franklin emphasized how glad he was to see Dr. Frieden, pointing out that if he had traveled all the way to Atlanta away from his family and Dr. Frieden had been on the television screen rather than in person, it would not have been a consultation. With that in mind, he thanked Dr. Frieden for inviting him into his house. In return, Mr. Franklin invited Dr. Frieden into his house in Northern California to see how they do traditional health in California. He said that we was honored and humbled to be delivering this testimony on behalf of the National Indian Health Board and the 565 federally recognized tribes in the United States. Mr. Franklin submitted two lengthy and well-written testimonies to Dr. Frieden to review, indicating that a number of issues had been identified in Indian Country with which the tribes believe CDC can help. Of these, Mr. Franklin presented four that were selected as pressing emerging issues on which CDC could make an immediate impact:

1. Adherence to CDC’s own Tribal Consultation Policy: Chairman Antone discussed some of this policy earlier. Mr. Franklin watched and listened the previous two days as CDC staff delivered what was basically CDC 101 training, which was awesome. He complimented Dr. Frieden on having some good troops leading his charge. The reoccurring theme that Mr. Franklin heard was the reluctance to say “tribal” or the tendency to call them “tribal organizations.” This clearly said to him that further education is required. They are tribes. They are sovereign nations within a nation, and are not necessarily tribal organizations. It seemed to Mr. Franklin that Dr. Frieden had come into this position and immediately his impact was being felt, which Mr. Franklin appreciated and commended. However, with respect to where tribal programs would be housed in the Office of State and Local Support, it was an oversight not to have consulted with tribes in this process. At the very least, the advice of the TCAC should have been sought regarding how that process would impact tribes and how they could better partner as they move forward during Dr. Frieden’s time as the Director of CDC to make the greatest impact for tribes. That was why there were all gathered for this Tribal Consultation, and Dr. Frieden’s presence clearly demonstrated to tribes that he would like to move forward with them. With that in mind, he echoed the request heard from Mr. Antone and Mr. Valdo that the word “Tribal” be included in the name of the Office of State and Local Support. Mr. Franklin expressed his preference for the name: Office of Tribal, State, and Local Support. He quipped that he would give Dr. Frieden a free pass if he put Tribal before Local.
2. Funding: As funding is funneled down through CDC, a lot of the relationships that tribes have with states are strained. Using California as an example, they have the Terminator as their Governor. Growing up in Austria, Governor Schwarzenegger probably did not receive a lot of education on American Indians. It shows because when tribes make attempts to work with the state, especially during the recent H1N1 outbreak, there is no tribal-state relationship. It simply does not exist. This occurs throughout Indian Country. Some areas work great with their state, while other areas do not work with their states at all and some are in between. What Dr. Frieden could do to assist with that is to monitor the states

closely. He should require the states to report back to him and he should hold them accountable. Everyone must be held accountable: How do tribes hold Dr. Frieden accountable? How are tribes held accountable to Dr. Frieden? How does Dr. Frieden hold the states accountable to tribes when receiving CDC funds for activities that are going to save lives. The tribes look to Dr. Frieden for his assistance and intervention with that. A broader discussion took place the previous day about how CDC can ask the states to be more responsive to tribes. American Indians are the most regulated people in the United States. If Tribes have a grant and are slightly off, the funding is pulled. Mr. Franklin cannot imagine how the states are required to, but do not, work with tribes and are able to get away with that. He expressed his hope that there would be change with regard to this issue, and that tribes could assist Dr. Frieden with this effort in terms of thinking of ways to include language in grants that hold states accountable.

3. CDC budget, priorities, and recommendations: The history of the CDC budget priorities for Fiscal Year 2009-2010 are reflective of CDC leadership and divisions being responsive to the needs of American Indian / Alaska Native communities, and the needs that have been expressed and delivered to CDC via the CDC TCAC and Tribal Consultation process. A detailed examination of where CDC locates funds directly to tribes and under what circumstances will allow the TCAC will use this information to make well-informed recommendations to CDC regarding American Indian / Alaska Native health priorities. Mr. Franklin pointed out that when looking at the full document he submitted, Dr. Frieden would see the Fiscal Year 209-2010 CDC budget priorities and recommendations. A number of these priorities and recommendations directly impact Indian Country. Increasing those will have some impact on American Indian / Alaska Native people, but where there is a disconnect and where American Indian / Alaska Native people suffer is that there are not a lot of direct funding allocations to tribes. A better way must be found for allocating direct funding. How can the \$51 million increase in HIV / AIDS be better allocated to the tribes? How are tribes able to access that and distribute it among their communities? Prevention is very important, would impact Indian Country, and funds for this is an area in which Indian Country believes Dr. Frieden can offer assistance in terms of funneling these funds to tribes in a better manner—hopefully never through counties.
4. Data: Indian Country is experiencing problems with their Epidemiology Centers in that they do not have data access agreements in some areas with their IHS contractors or office. Anything that Dr. Frieden could do to help them obtain these agreements would be a major service to Indian Country. When presenting the facts, and the facts are in the numbers, a better case can be made for how to protect and improve the health of Indian Country communities.

In closing, Mr. Franklin took the opportunity to thank all of the tribal leaders and CDC staff in attendance and again recognize all of the sacrifices they all made to be present.

At this time, Ms. Hughes extended an invitation to other tribal leaders at the table to offer their testimony.

Mr. Roger Trudell
Chairman, Santee Sioux Tribe of Nebraska
Aberdeen Area

Mr. Trudell began by congratulating Dr. Frieden on his appointment to CDC and the new Director.

He indicated that he represented the Aberdeen Area, which is composed of 4 states, 17 tribes, 1 service area. The tribes from this area approach consultation and other matters in such a way that sometimes even upsets other tribes, but the Santee Sioux are treaty tribes. There are certain things within the treaties to which the United States government is obligated that have not been fulfilled. These are services for education, health, and other matters that were paid with land and the blood of the tribes' ancestors. They do not come in the sense that they have "their hand out." Instead, they come in the sense that they are coming to collect what is obligated to them through treaties. As treaty tribes, they have a unique relationship with the United States, and they expect the United States to honor its commitments to the Indian Nations. This obligation has not been fulfilled since the signing of the treaties, so there are a lot of gaps to be filled.

In his community in the Aberdeen area, where they are one of the smaller tribes, their service user population is typically between 1,100 to 1,200 people, but can be as high as 1,800 on any given day. The issues that impact tribes in the Aberdeen area are the same as those that impact all of the tribes throughout the country. For example, 20 cases of diabetes have the same impact on the Aberdeen area tribes as Ogallala Nation with 2,000 members having diabetes out of 20,000 members. So all things are relevant and impact the community at the same level based upon the population.

Data are very important to measure need and accomplishments. However, as tribal people, there are some things that cannot be counted. For example, there is no way to count the emotional loss in the hearts and minds of people when they lose a relative to diabetes, cancer, youth suicide, or any of the other health issues that are ravaging tribal people. Youth suicide impacts his community greater than it does the City of Atlanta because his is a much smaller community. It will stop nearly everything in his community for a period of days to assist the families. There are no data to measure the after effects of the loss of life expectedly or unexpectedly. Hopefully, tribes have not come to accept that this is how life is meant to be for them—that they should be a sick people.

The spirituality of the people is much more involved than just saying that they pray to God. It is a way of life. They have the Continuous Circle of Life that involves the emotional, spiritual, physical, and mental well-being of the people and they stay connected with their ancestors as well as the seven generations who are yet to come. They not only talk about *today*, but also they talk about how what happens today affects the seventh generation from today. Over a period of years, tribes have lost this and have become more *now* oriented. To be successful and to rid tribal communities of a lot of these illnesses and social ills, they must once again start planning for that seventh generation.

The mental well-being of tribal communities is a number one medical need on most of the Great Plains reservations. The lack of qualified practitioners to assist those with emotional problems has not been emphasized as a priority in any of the organizations with which tribes deal. Yet, to overcome many of the other illnesses, a person must be mentally well (e.g., learning to cope at a very young age with a very difficult situation). The social structure that grandfathers and grandmothers used to have no longer exists as it once did and must be rebuilt. Within that structure there was once respect for elders, respect for youth, and respect for everyone in between. As part of that came the emotional, spiritual, physical and mental wellness of being in balance as a person. Although not a wealthy tribe by any means, the Santee Sioux Nation has sacrificed a lot to try to address youth suicide, given its devastating impact on their people. They are in the process of developing a cadre of 10 underground counselors who can be available around the clock. Because they really do not have the \$200,000 they have invested in this intervention, other issues that need to be addressed will not be taken care of.

There has been a great deal of discussion about priorities. Mr. Trudell stressed that in the Great Plains, everything is a priority. It is like having 8 or 9 children and having to choose which 5 children will go to be hungry, which 5 will go to school without shoes, or which 5 will be hidden in the back room because there is no food or clothing for them. There are so many priorities to be addressed, that if they do not receive attention, they will develop into even more priorities. While he said he understood Dr. Frieden's philosophy regarding issues that could be managed, because tribes have to work with such a diverse number of priorities, the thought process must be expanded. Perhaps this may not result in as much success as Dr. Frieden would prefer, but it may result in gaining control over 7 or 8 priorities rather than just achieving reductions in 4 or 5 priorities.

In conclusion, Mr. Trudell expressed his gratitude for the time Dr. Frieden and his staff were taking to join them during this Tribal Consultation.

Ms. Cynthia Manuel
Council Woman, Tohono O'odham Nation
National Indian Health Board (NIHB) Board Member

Ms. Manuel indicated that her reservation is in Southern Arizona, has 13 nations on the Mexican side of the border, and borders 75 miles of Mexico. While they did not ask to be divided, the Gadsden Purchase divided them. She agreed that the tribes should have direct funding, with the state and local agencies cut out, because of things that have occurred with state and local agencies. Sometimes the tribes do not know until much later what is coming down the pike—good or bad. For example, with H1N1, it took the state two days to contact the tribes to notify them about H1N1. The tribal communities in Mexico already knew and were questioning what was going on before the state offered any information. Direct funding would have permitted the tribes to know firsthand what was occurring, and they know their own people their needs. Ms. Manuel shared a map to show where they are located, and which reflected their original land that fell almost to Hermosillo and past Guaymas. Since then, they have only the 13 villages all the way to Hermosillo, so they have to work with a tri-national situation with the state, tribe, and Mexico. They could do more, better, faster with direct funding. This would really benefit the other tribes along the border. When she visits her grandfather she cannot ask him how long it will take, because sometimes he will talk a whole day because he wants to share something important. Yet, it may be years later before she understands the message he was trying to convey. With that in mind, she thanked Dr. Frieden and his staff, stressing the importance of the Tribal Consultation including CDC's Director and his staff in person, because that is the meaning of a consultation.

Buford L. Rolin
Tribal Chairman, Poarch Band of Creek Indians
Vice-Chairman, National Indian Health Board (NIHB)

Mr. Rolin expressed his personal gratitude to Dr. Frieden for his presence at this Tribal Consultation. He reflected on the first meeting convened at CDC, after having made such a request to the IHS for a long time. He commended CDC for its continued involvement with tribes, and for hosting their meetings. Things have changed. This is a new nation now, especially since they have the opportunity to talk to CDC. He thinks that CDC now has a better understanding of who tribes are, what their needs are, and how the agency can better assist tribes. As mentioned, the one area in which all tribes seems to have experienced varying degrees of problems has been in communicating with their states. Hopefully, that barrier will gradually be moved. On a daily basis, all tribes certainly deal with the six areas Dr. Frieden's mentioned. One area of major concern is motor vehicle injuries. He is always concerned with tribal youth and teenagers, and how their quality of life can be improved.

This all gets back to accountability. Tribal leaders know this, given that they must be accountable to their communities. They must obtain input from their communities, and must then respond to and work with these communities to achieve their goals and objectives. Like the United States, tribes must deal with nutrition and obesity issues. Although there are 565 federally recognized tribes, and these tribes share many commonalities, they range from 100 to thousands of people. Therefore, it is important to remember that every tribe is uniquely different. His area is part of the organization United South and Eastern Tribes, which represents 14 states along the East Coast. Just being able to communicate within those 14 tribes and share their issues and what they need to do is complicated. They convene regular quarterly meetings to try to make sure that they communicate with one another, and they are also involved at the national level of participating in other national meetings to address these very issues.

Mr. Rolin stressed how wonderful he thought it was that they now have this partnership with CDC, pointed out that they are ready to expand on it, and expressed gratitude for being a part of the Tribal Consultation process. He is a firm believer in consultation. If they continue to consult with each other, they will know and understand each other's issues. There remains much work to be done with regard to tribal-state-local relationships. The meeting two years ago very historic, and Mr. Rolin was pleased to see the continuation of the Tribal Consultation Sessions. Tribal leaders have limitations and cannot always participate, but he emphasized that he and the NIHB were willing and ready to reach out to CDC and to help in any way they could.

**Lester Secatero, Chairman
Albuquerque Area Indian Health Board (AAIHB)**

Mr. Secatero thanked all of the tribal leaders for their attendance and support. He indicated that he is from the Canoncito Navajo, which is a satellite of Big Navajo, so they sometimes get left out. His reservation is about 35 miles outside of Albuquerque. He has 7 non-Pueblos (Apaches, Utes, and Navajos) and 20 Pueblos up and down the Rio Grande from Southern Colorado to El Paso. They touch approximately 100,000 Native Americans in New Mexico. He spent the two previous days with his brothers and sisters of other tribes, and the accommodations were great. Growing up sleeping on sheepskin, anything is nice for him. He is an elder of the Navajo Tribe and it does not take very much to please him. He has been a minister for 27 years. What really hurts is when he conducts funerals for those who have died from diabetes, car accidents, suicide, et cetera. He just buried his mother the week before, and it was hard. Burying young Indians who had long lives ahead of them, but whose lives were cut short is very hard. In the hospitals he visits patients whose legs have been amputated from diabetes. They are doing well with the special diabetes funding. They have CHRs constantly monitoring the people, and they are doing a super job. He requested that Dr. Frieden hold states accountable for funding, thanked him for dialoguing with them during this Tribal Consultation session, and expressed his hope that CDC would continue to dialogue and build their relationship with the tribes across the nation.

**Cathy Abramson, Board Member
Sault Tribe of Chippewa Indians
National Indian Health Board (NIHB)**

Ms. Abramson introduced herself and greeted those present in her native language. She indicated that she is from the Sault Tribe of Chippewa Indians and is a new member of the National Indian Health Board. She represents the Bemidji Area and is from the Upper Peninsula of Michigan— Sault Ste. Marie. They are woodland people and have beautiful country there. Like California, they have wine. Their people also experience problems with alcohol, suicides, et cetera. While tribes share many of the same problems she stressed the importance of understanding that Native Americans are not all the same people. They are from different areas and different tribes. Many of the problems stem from when Native Americans were interrupted. They had a beautiful way of life, but because of the interruption, their way of life changed. She was told by her elders that she needed to go out and educate, educate, educate. As a Wolf Clan member, her job is to help protect her people.

She noted that while some introduce themselves in their native language, it was the federal government's plan to assimilate the native people by placing them in boarding schools where they were not permitted to speak their own language. Because of that, many people did not learn their language. There is a renaissance of people bringing back the native language. Language is important because it was part of their way of life. When pieces of a person are taken away, it affects their whole being, including their health. Not only was their language taken away, but also their land and the ways that they lived were taken away. The ways they lived kept them healthy, but now they are having to adjust. It is not just about losing weight, quitting drinking, et cetera. Her great grandmother only spoke the native language, and her grandmother could speak Ojibwe and English. However, they were taught not to teach it to their children because that was a bad thing. She saw their elders who were pushed down and treated like second class citizens so much that they felt like they had nothing to offer. Because they are coming back, learning, and being stronger, they find that they have this beautiful gift of the native language and the beautiful ways that they lived. They are teaching this to their youth.

In the Upper Peninsula, a person visited one of their tribes and was pointing out to her father-in-law, a Finlander, how many bars there are in the Upper Peninsula and that they have a lot of problems with alcohol. He agreed, but pointed out that everyone else has a lot of problems with alcohol as well—they just admit it.

While they admit that they have many problems. Ms. Abramson stressed that many of their problems are because of the history and how tribes have been treated. But they want to do something about it—they want to fight back. To do this, they need CDC's help. She thanked Dr. Frieden for listening to them, and presented the following formal testimony for the record:

In 2004, CDC funded service providers with expertise from Asian Pacific Islander, African American, Hispanic / Latino and Native communities to provide Technical Assistance and training to strengthen agency capacity to implement sustainable HIV programming. Three agencies, including the National Native American AIDS Prevention Center, were funded to provide services specifically to tribes, tribal entities, community-based organizations (CBOs), and health departments to strengthen their internal and programmatic capacity. The need in native communities and of native-serving agencies continues to rise as the incidence continues to rise. Currently, CDC funds only in one regional tribal organization to do capacity-building work for prevention services. It is imperative that specific funding be committed to fighting AIDS in native communities as Native Hawaiian and Native American / Alaska Native populations comprise the third and fourth highest rates of new HIV infections. Of persons who are diagnosed with AIDS, American Indian / Alaska Natives have the shortest overall survival rate. There are tremendous barriers to prevention and testing for American Indian / Alaska Native people, including confidentiality, disease taboo, migration, and realities of access to care. All of Indian Country needs a coordinated national effort that is culturally specific, including:

- Providing services such as assistance to developing native-specific social marketing campaigns;
- Adapting and diffusing evidence-based interventions that are appropriate for native communities;
- Providing training on leadership capacity, community assessment, and mobilization;
- Addressing the needs of native intravenous drug users (IDU) and men who have sex with men (MSM); and
- Disseminating prevention information, statistics, and facts on HIV, STIs, and risk co-factors that are relevant to the prevention and intervention needs of native communities.

Tribal leaders in the National Native American AIDS Prevention Center (NNAAPC) ask CDC to create specific funding for a National Native HIV / AIDS Resource Center to provide services to address prevention, education, data collection, training, and technical assistance activities in native communities. In November 2009 on a conference call between representatives of CDC and NNAAPC to discuss the request for a National Native HIV / AIDS Resource Center, a CDC representative stated that recent funding decisions have left a gap in services. It is important to know specifically how CDC is planning to address this gap in service that will further widen the health disparity. CDC and state health departments are creating initiatives and funding opportunity announcements (FOAs) that promote the use of evidence-based interventions and interventions that are tailored to meet the prevention needs of the local culture. However, native-specific capacity-building services are not available to assist native agencies and tribes in

the development of implementation of such interventions. Advances in HIV prevention in native communities cannot be expected if the resources are not available to support prevention programming and innovative program development. CDC has stated that they fund two agencies to provide capacity-building services to native communities: Aberdeen Area Tribal Chairman's Health Board (AATCHB) and Colorado State University. However, Colorado State University has been funded to serve as a CBA provider to all communities of color rather than native-specific. AATCHB, while funded as a native-specific organization, is only funded as a regional organization and cannot provide services to states with large native populations such as California, Washington, Alaska, Arizona, New Mexico, Oklahoma, or any state in the South.

In October 2009, a bi-partisan coalition of US Senators sent a letter to Dr. Frieden decrying funding decisions that de-prioritize native prevention services, and calling for the CDC center to partner with NNAAPC to create a National Native HIV Resource Center. Dr. Frieden, I ask you to listen to us as tribal leaders, and I am so glad you are here listening. In our communities, make a significant investment in HIV / AIDS preventions in Indian Country through a National Native HIV / AIDS Resource Center at NNAAPC. Miigwech to you for being here and listening to us.

**Ms. Kathy Hughes, Session Moderator
Vice Chairwoman, Oneida Business Committee
Tribal Consultation Advisory Committee (TCAC) Co-Chair**

Ms. Hughes noted that it appeared to be unanimous that everyone was grateful for Dr. Frieden's presence at this Tribal Consultation to listen to them. She reported that prior to the beginning of this session, Dr. Frieden shared with her that this was the first two-hour block meeting he had scheduled in his seven months in office, so she really felt privileged. Those present applauded Dr. Frieden. Ms. Hughes pointed out that a number of key points were made by tribal leaders, including two very important points:

- Renaming of the Office of State and Local Support: While the naming of this office may seem to be a minor issue to others, to tribal leaders it is a significant issue. Tribal leaders believe that the name should include Tribal along with State and before Local.
- Data: Tribal leaders' philosophies appear to be aligned with Dr. Frieden's in terms of access, accountability, et cetera.

She then requested that Dr. Frieden and CDC staff offer their responses.

Director's Response

Thomas R. Frieden, MD, MPH

Director, Centers for Disease Control and Prevention (CDC)

Administrator, Agency for Toxic Substances and Disease Registry (ATSDR)

Dr. Frieden thanked each of those present for taking time from their families, communities, and schedules to attend the Tribal Consultation and to share with CDC in order to reach a situation of better partnership. He said he thought he learned something different from each person who spoke, and he appreciated that. He was recently attending a Congressional retreat where, during a wrapping up session, a Congressman said, "Well, everything I wanted to say has been said by someone already, but it hasn't been said by me" and then he proceeded to give his remarks. He thought each of the tribal leaders brought a different perspective to this session. He stressed that he was still quite new to CDC. While he worked for CDC for 12 years before, he was never based in Atlanta. He was more about getting the work done in the field, so he was in New York City or India. In addition, he has been somewhat preoccupied with H1N1 since coming to CDC as the Director, and is now occupied with the Haiti disaster where CDC has quite a few staff, one of whom is tragically unaccounted for who was in a collapsed building. He offered the following feedback, in no particular order:

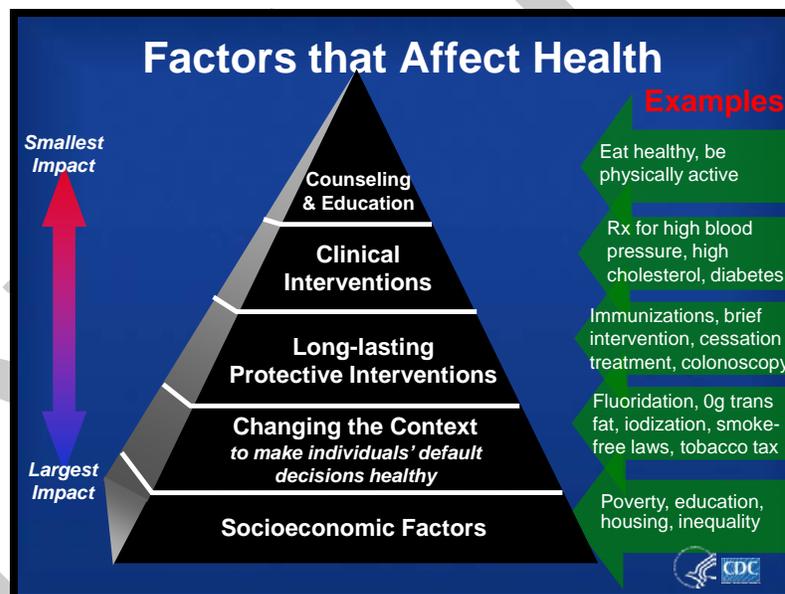
- ❑ Regarding the name of the office, perhaps CDC made a mistake. If they make a mistake, they admit, fix it, and move on. Certainly, no offense was intended, and Dr. Frieden said that he had always felt that if offense was taken, it was usually not the problem of the person who took offense. This suggestion will be considered very seriously. One of the things that CDC has tried to do by creating this office focused on community health, whatever it ends up being named, is accountability. By that Dr. Frieden means not just that they need to do a better job of providing technical advice, data, more guidance and technical support, and more staff, but also accountability in the sense of tough love—that they are very frank with the groups with which CDC works in that they expect the funding to flow down to where the work actually needs to get done. As a City Health Officer for 7.5 years, he assured them that this was a standpoint that was very strongly in his perspective on programs.
- ❑ The Tribal Epidemiology Centers was not something with which Dr. Frieden was familiar until reading the background materials for this Tribal Consultation. He said he would be very interested in expanding CDC's cooperation with those centers. This is an area where CDC can definitely do more. He would like to learn more about the data access agreements in terms of what is not working and whether CDC can help in some way.
- ❑ Regarding direct funding, with the stimulus package, Communities Putting Prevention to Work (CPPW) there is a separate tribal track, so there will be direct funding. Unfortunately, this will not go to nearly as many tribes as CDC would like. However, CDC hopes that with that program, which focuses on nutrition and tobacco, is that they will fund some tribal communities, some large cities, some urban cities, and some rural cities enough so that they can really make an impact, demonstrate that impact, and serve as a model for other places. CDC was not able to fund tribes directly for H1N1. In fact, the agency was not able to fund in many ways because of the timeframe required. They had to try to make the government system move quickly, which is very difficult. However, tribes were quite prominent in CDC's planning in terms of the need to ensure that each state worked effectively with their tribal populations, which are believed to be, for whatever reason, at higher risk of serious illness from H1N1. This is something that Dr. Frieden was regularly both asking about and being briefed about, so he was able to confirm that it was taken very seriously. When there were

any miscommunications, perceptions, or issues these were immediately raised and addressed. Thought must be given to organizations that aggregate groups, because 565 tribes is a large number.

- ❑ As several tribal leaders mentioned, money is scarce and will be for some time. They are dealing with the aftermath of a very unfortunate period of time when a lot of people made a lot of money, but people who needed money did not make much money. Now the consequences must be paid for very irresponsible financial approaches. It is not fair, and it means that they must do whatever they can in this time to better address inequalities and to be clear about making the best possible uses of the scarce resources there are. There is a real value to programs that are demonstration projects from which others can learn.
- ❑ In terms of the functions at CDC, Dr. Frieden would like to understand more, as they continue these Tribal Consultations in the future, what things are not being done from a content perspective that tribes believe should be done so that they can be addressed specifically.
- ❑ With respect to inter-agency coordination, there is a wonderful, really positive set of interactions between various agencies. For whatever reason, there is a very strong commitment to working together. He met the previous day with Pamela Hyde, the new SAMHSA Administrator, and they talked about areas in which they can work together. He and Mary Wakefield, the Health Resources and Services Administration (HRSA), Administrator were to speak later in the afternoon.
- ❑ He thanked the tribal leaders for the testimony they submitted, stressing that he does read what he is given, and that he would read and learn from their submissions.
- ❑ In regard to information and training for CDC's own staff, Dr. Frieden is a big fan of e-learning. With the shortage of dollars, they must do things that are more efficient. He did this in New York City, which allowed them to train more people for less money better. He would like to do this with the CDC and to make electronic resources available to whomever is interested. The first thing that he did as the new Director of CDC was to establish a Public Health Grand Rounds, which is typically on the third Thursday of each month. Unfortunately, it is at 9:00 AM, which has been complained about from CDC's colleagues on the West Coast. However, it is archived and available. Each session is approximately an hour and 15 minutes on a cutting edge topic in public health. A host of electronic resources is important.
- ❑ One of the reasons for the organizational change was to emphasize data and policy change. In New York City, Dr. Frieden created a policy called Take Care New York, which identified the key things about which they could do something, and then set measurable goals for trying to deal with that. He stressed that he really appreciated the point that was made about priorities. In fact, within CDC there has been a lot of discussion about this. Instead of talking about priorities, because each program and community will have its own priorities, they talk about winnable battles: What are the things that we know we can do something about, and let's challenge ourselves to accomplish that. He also appreciated the education about community values. One of the things he thought about in preparing for this meeting regarded how burden is prioritized and measured. One of the means in public health has traditionally been a measure known as Years of Life Loss (YLL), which is a simple measure which says that if someone dies at the age of 75, then YLL before age 80 would be 5. If someone dies at the age of 5, that would be 75 YLL. Everyone would probably say that in

some ways, a younger person dying is more tragic than an older person dying, yet in communities which revere their elders, perhaps that is not an appropriate way to prioritize.

- Pertaining to responsibility and blame, which was a theme he heard, Dr. Frieden shared his philosophy. He typically shows the following slide, which has five levels. At the bottom of the pyramid is the social structure (e.g., education, poverty, housing, jobs, inequality). These are the things that have the biggest impact on health. One level above that are the classic public health programs (e.g., clean water, fluoridated water, et cetera). These are things that change the context so that people would have to really work to not do the healthy thing. One level above that are light touch clinical interventions (e.g., immunizations, colon cancer screening, et cetera), which only have to be done once a year or once every five, but which will have long-term protective effects, so they are easier to do. One level above that is long-term clinical care (e.g., treatment for high blood pressure, high cholesterol, diabetes, et cetera). These are issues that require on-going, effective clinical care. One level above that are counseling and education—telling people what to do (e.g., eat healthy, be physically active, et cetera). These levels are in a pyramid form because they are roughly in a level of effectiveness of interventions. People can be told to eat less and exercise more incessantly and it will not make any difference. The structures must be addressed to make it easier for people to do the healthy thing:



In closing, Dr. Frieden expressed his gratitude for the invitations to visit various tribes and said that he would try to take them up on their offers. He has been in the Upper Peninsula. He used to ride his bicycle around the US and went through many reservations while doing that. He had a wonderful experience getting to know the country. The Upper Peninsula is not a very easy place to ride a bicycle around. In fact, the map he had of Michigan had a symbol every 50 or 100 miles on it that he had never seen before. When he finally had the opportunity to read the key, he discovered that they were telephones on the map. He stressed that as they continued their consultations in the months and years to come, they should ensure that they have good communication. They have internet, they do not have to put telephones on the map, and they can communicate with each other. He again offered his appreciation for the tribal leaders

having taking time to attend this Tribal Consultation, indicated that a number of the CDC leaders who could address many of the tribal issues would remain after his departure, and said that he had very much enjoyed this interaction and looked forward to productive future interactions toward the shared goal of healthier people and healthier communities.

Staff Responses

Henry Falk, MD, MPH

Assistant Surgeon General (Retired), USPHS

**Acting Director, National Center for Environmental Health (NCEH) /
Agency for Toxic Substances and Disease Registry (ATSDR)**

Dr. Falk added his welcome to those present. He indicated that Dr. Frieden had asked him to take the position of Acting Director of NCEH / ATSDR a little over a week prior to this meeting. During that first eight days, he worked with Annabelle Allison, the Tribal Coordinator at NCEH / ATSDR. He was instrumental in his previous life in helping to establish the Tribal Coordinator position at ATSDR, although they did not always have staff with the strong tribal background and skills that Annabelle Allison has, so they are very pleased to have her. In the environmental area, there are many problems, including issues that are addressed by NCEH / ATSDR, such as a long history of mining and exposures to lead, arsenic, uranium, and other substances. Dr. Falk assured the tribal leaders that NCEH / ATSDR would work very hard with tribes on these issues, and that he would work very hard with Annabelle Allison and the tribes to support those programs.

Kevin Fenton, MD, PhD, Director

**National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP)
Centers for Disease Control and Prevention (CDC)**

Dr. Fenton extended his welcome, noting that it was good to see friends and colleagues who he had met either in Indian Country or at CDC. Specifically speaking to the HIV issues that were raised, he thanked the tribal leaders very much for their testimony. He said he clearly understood and heard the difficulties that have resulted due to funding structures for the capacity-building grant. He reiterated his commitment and NCHHSTP's commitment to work with the tribal community to determine ways to rebuild capacity for native peoples, to identify new funding opportunities that would help to extend the work being done with communities, and to continue his advocacy for this work with HHS and the White House as they prepare the national AIDS strategy to ensure that the voices and perspectives of native peoples are included in those strategies in order to increase the resource base for HIV prevention. NCHHSTP recognizes that this is a major and emerging issue for many tribes across the country, and is committed to working with states and local health departments to ensure that the funding gets to those tribes and communities which are hard hit and affected. NCHHSTP is also committed to continuing to listen to the tribes to hear how they can do their jobs better. Dr. Fenton indicated that he would be there for the remainder of the morning, and that he looked forward to any further comments on HIV, sexual health, and tuberculosis prevention in the tribal community. Hopefully, as a result of this meeting and other on-going engagements they would find a new way forward.

**Ursula E. Bauer, PhD, MPH, Director
National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP)
Centers for Disease Control and Prevention (CDC)**

Dr. Bauer indicated that, like some of her colleagues, she was very new on the job (this was her fourth week). She recently moved from a state that did not have good relationships with the tribes there, so she was listening carefully for the tribal leaders' calls for more direct relationships—especially direct funding relationships. She said she looked forward to working with Dr. Frieden to determine how they could strengthen those ties and be more efficient and effective with the agency's chronic disease prevention and health promotion work. She thanked the tribal leaders for attending and for allowing her to listen to their comments, and said that she looked forward to working with them in the future.

**Marian McDonald, PhD, Associate Director
Office of Minority and Women's Health (OMWH)
National Center for Preparedness, Detection, and
Control of Infectious Diseases (NCPDCID)**

Dr. McDonald thanked the tribal leaders for their attendance. She found what they shared to be extremely informative, helpful, and highly moving.

Open Tribal Testimony / Discussion

Overview

**Ms. Kathy Hughes, Session Moderator
CAPT Pelagie "Mike" Snesrud, Session Moderator**

During this session, Tribal leaders were invited to provide testimony, make commentary, and / or ask questions regarding public health priorities in their communities.

Open Tribal Testimony

**Berda Willson, Board Secretary
Norton Sound Health Corporation**

Ms. Willson indicated that she was representing Norton Sound Health Corporation, which is headquartered in Nome, Alaska. She is on the Board of Directors. Norton Sound Health Corporation is a tribally owned and operated health facility, celebrating its 40th anniversary this year, which they are very proud of. She pointed out that while many of them had visited Anchorage and were impressed with the beautiful Alaska Native Medical Center facility there and probably thought that people in Alaska had it very good, it is a large city that is not representative of all of Alaska. While tribal members are very proud of this facility, and they do travel there if they need surgery, cancer treatment, et cetera, from some of the villages travel may be limited. For example, the Diomed Village is located out in the Bering Sea next to Big Diomed, which is Russia. Little Diomed was recently without passenger travel for four months. It has no airport, though a helicopter came in once a week, weather permitting, to bring

mail and other things. They also brought H1N1 into the Village of Diomedé, which brought a lot of attention to Diomedé since the National Guard stepped up to take health care providers out there. The health care providers worked around the clock to treat those who had the flu and to immunize the rest of the village. They also took four patients to the hospital in Nome. There is an ice runway, but the ice is not good enough for their ice runway. She shared a photo of the ice runway.

Regarding the priorities and issues in this area, the Alaska Native Health Status Report by the Epidemiology Center in Anchorage reports that Ms. Willson's region has some of the highest rates of most health issues, with the exception of smokeless tobacco. Suicide is a particular problem, and they would like to have more suicide prevention and injury prevention capacity. They have one employee for injury prevention for 9,000 people who must travel to 15 villages. While this individual is doing a good job and is providing ASSIST training, more is needed. They also have one Suicide Prevention Coordinator who travels to the villages who is funded by a grant. They also have a tobacco cessation program, but she understands that this funding is becoming more difficult to obtain. There is a major drug and alcohol problem in this region, but there is no in-house treatment. If someone presents at the hospital and indicates that they would like to go to treatment, it could be a six-month or longer wait for them to be placed in in-patient treatment. They also have a greater than 200% increase in diabetes in this region, as well as a high rate of STDs.

Ms. Willson advocated for more prevention and more education. Many of the villages do not have water and sewer, and there is a high use of soda because it is much more palatable than the water that may not taste good or may be suspect for some types of disease. Born in 1940 pre-statehood, it has been only in her lifetime that there has been a lot of use of soda. Lifestyles changed in this region after statehood. Airports were built, with the exception of Diomedé, so that there would be more travel and most import of goods that customarily were not consumed in the villages. Then the State of Alaska decided that everyone should have television, so there was another influx of commercialism for the latest treats. It will take time to work backward. Diabetes has increased dramatically due to change in diet and lack of activity. When she was growing up, if someone wanted to go somewhere, they had two legs that would take them there. There were no four-wheelers or snow machines. People had to walk, had a dog team, or had a boat. Most people did not have motors and had to row their boats. These are some of the friendliest most caring people in the world. It is just that there has been an influx of non-traditional habits in the region.

Also a problem is that sometimes funding cycles are only three years long, but there will be an expectation that magic can be done during that time. Whatever is popular will also move to the top for funding, while other issues that are not resolved have their funding reduced. Ms. Willson also advocated for continuing funding streams for prevention so that some of the health problems have time to be successfully reduced or eradicated. This will save lives, save funds, and improve the mental health of communities. When a community loses someone to suicide, it is a blow to the region and the communities since they are all interrelated—it affects everyone.

In closing, Ms. Willson expressed her appreciation for the opportunity to hear and give testimony. She indicated that this was the first time that she and Ruth Ojanen had been to Atlanta. Their Board of Directors Chairperson thought it was important for them to attend. It took them 17 hours to get to Atlanta from Nome, Alaska. They were very pleased to be in Atlanta and they found the Atlanta people to be very friendly. She expressed disappointment that Dr. Frieden had already left, because she wanted to invite him to visit Nome and take a trip out to one of the villages to better understand what it is really like versus what Anchorage is like.

There is an area from the Northwest coming down through the Norton Sound down to Bethel that is often overlooked, but which has the same high rates of suicide, diabetes, obesity, and other issues that are detrimental to the health of their people. She requested that someone relay the invitation to Dr. Frieden to visit the region and see with his own eyes. They would be happy to host him. She stressed that they were not just up their wringing their hands hoping that someone would come. They have done a lot for themselves. They are in partnership with the non-profit corporation that has a suicide prevention grant. They have a volunteer regional wellness forum that is working to bring wellness and education to the villages. The Norton Sound Health Corporation has installed a mammogram and is also going to install a digital mammogram that will make it much easier for women to be screened. Breast and colorectal cancers are the number one and two cancers respectively in the region. They also installed a CAT scan, with the funding coming from various sources (e.g., private donations, foundations, the Board of Directors, et cetera). There is a lot of hope in the region that things will turn around and they will make a difference, but it would be beneficial to have continued funding beyond three years in order to make long-term progress.

**Alicia Reft, Alaska
Karluk Ira Tribal Council**

Ms. Reft indicated that she, too, would like to have presented her testimony while Dr. Frieden was present. She is from a small community in Alaska where the health care is dependent on the Administration, President, and CEO who are current at the time in their regional non-profit health organization. It is really sad that the only place their people have to go for health care is all about money and power. The people are losing out. There are people from her home town who do not trust the doctors in this area, so they will not be seen and nothing will change their minds about this. They are from Kodiak Island, which is 278 air miles south of Anchorage. There are 15,000 people total on the island. Everybody knows what other people are talking about. People are heard to say that they have gone to doctors for a year and have never received a diagnosis, only to go to another doctor and pay for it out of pocket to find out they have cancer. People say, "Don't go to IHS facilities because you get what you pay for, which is nothing, so you get nothing." That is really hard to hear. She was recently booted out of the non-profit health organization after serving there over 20 years because she did not agree with what the current administration was doing with the health care dollars. They gave a \$5 million loan to a regional for-profit corporation. When Ms. Reft spoke up against this, they found a way to remove her from the board.

As Ms. Willson pointed out, while the Anchorage facility is nice, there are problems. Ms. Reft has been waiting three months to see a cardiologist. During that time she has continued to try to attend meetings, which was why she traveled to Atlanta. She has been in the emergency room three different times. Because she was able to go to Piedmont Hospital while in Atlanta and they called the Anchorage facility, the Anchorage facility finally agreed to see her on the Monday following the Tribal Consultation. It is pretty awful that this is what it took to finally be seen.

The regional corporations have the money and the power in Alaska and they try to keep the smaller areas shut up by telling them that they will not get funding if they fight with or do not agree with the administration. No one speaks up because they are told not to. Because the health care in her area is about money and power, they are losing a lot of their people. People young and old give up on the system, and they will not go to be checked. There is also a confidentiality problem. They do not want to go because the people there will all talk about it, and it does not take long for word to spread. It is just not fair. Ms. Reft remembers days when

people cared, but good doctors will not stay there because it is too political. They cannot simply give health care and they do not receive the support that they need. They are told to do their job. She said she was tired of hearing that it was “The white man this, and the white man that.” The people who have hurt them the most are their own people. Funding goes to the board and regional non-profit, and they are supposed to provide education in the villages about HIV, diabetes, heart disease, and other issues. However, because it is not a priority to the board and regional non-profit, they do not provide these services as they are supposed.

**Ruth Ojanen, Board Member
Norton Sound Health Corporation**

Ms. Ojanen expressed gratitude for the opportunity to speak. She said that she was very proud to say that, as Norton Sound Board Members, they are proactive. They have a native member who serves as the CEO who is doing a wonderful job. Ms. Ojanen’s parents were born and raised on King Island, which she likes to say is a “little rock” out in the Bering Sea because it is only three miles wide by six miles long. Her father has always said that it is paradise, and it is. She went back there in 1981 with her parents and did not want to leave. It is now abandoned. The people were relocated by the Bureau of Indian Affairs School System. They closed the school down, saying that it was dangerous to live there because they basically lived on a cliff. She is a very proud member of the Uguivangmuit Tribe. Ms. Ojanen believes that her people experienced trauma due to being relocated from King Island. They have many health issues. Diabetes, alcoholism, and drug abuse are on the rise. She services on the King Island Native Council, which is in the process of discussing becoming proactive in wellness issues. She advocated for CDC to give them tools to help their people because they, as a tribe, must be proactive in helping their people. Help must come from their own people. They understand where they are, where they come from, and know that they have to learn to help themselves. It would be great to have funding for their own toolkit to help with this process.

**Andy Joseph, Jr., Colville Tribes
Northwest Portland Area Indian Health Board
Chair, HHS Chair Tribe Council, NIHB**

Mr. Joseph (Badger) greeted everyone in his native language. Earlier in the morning he heard discussion about various resources that might be available for tribes. Some of the tribes living in rural areas cannot afford really good grant writers to apply for some of the funding available. Some of these tribes are some of the poorest tribes. They do not have the resources to seek funding. He always thought that it would be better for the HHS government agencies to utilize IH S’s user count population for distribution of funding so that every tribe in the nation would have access to some of this funding to help with the diseases that are being brought to their people. He indicated that later in the afternoon he would speak toward the H1N1 issue. He said that he was really glad this Tribal Consultation Session was taking place, and that he looked forward to more meetings like this.

**Maria Garcia
Program Manager Alternative Medicine
Pascua Yaqui Tribe**

Ms. Garcia expressed her gratitude for the opportunity to offer testimony, and to all of the CDC staff who were in attendance to listen. She indicated that she came wearing two different hats for this meeting. Originally it was not clear to her why she was asked to participate in this meeting, which is what sometimes happens on the tribal level. It is always a very humbling and

eye-opening experience, which she appreciated. On behalf of the health department, she knew that some of the goals Dr. Frieden listed were not the same as those the health department had for 2010. However, she thought she could at least ensure that Dr. Frieden's goal regarding data sharing and surveillance could be addressed. She will take that back to the Executive Director. She agreed with the issues regarding the funding mechanism and the issues regarding that. For those not familiar with her tribe, they are very complex. They are a small tribe, not too tiny but not too large. Their primary care system is an especially complex issue because they do not have an IHS facility. The primary care system is run by a Community Health Center, which is in the Tucson area. Also complex is that they are made up of multiple communities within different counties. Thus, some of their community members receive services at the Phoenix Indian Medical Center (PIMC) and some receive services through the Community Health Center.

Because CDC staff members were in attendance, Ms. Garcia said that she also wanted to teach and educate them. She thought it was very important for them to understand, as was mentioned earlier, that not all tribes are the same in that not all have IHS facilities, not all have some of the same opportunities as other communities, some are very isolated, some have many community members in urban areas, et cetera. The situation is very dynamic for each and every one of their communities. Regarding funding, Ms. Garcia was able to participate in an initiative a few years ago, the Native American Research Centers for Health (NARCH) grants. That funding mechanism was through the IHS and funds were funneled down through some of the tribes. They were fortunate at the end that NIH and IHS were willing to help them evolve through process to be able to do direct funding to some of the tribes instead of going through the universities or other organizations. She was not sure of the status of this initiative, but thought that it may be an opportunity that would work with CDC funding and the communities, although it is still very complex.

Ms. Garcia said that the second hat she wore was more from a personal perspective. She is also a Program Manager for one of their health department programs. For this issue, she directed a request for help to the CDC staff. She had heard discussion regarding evidence-based projects and the implementation of programs that work. However, she had not heard any information about the programs that exist in many of the tribal communities that perhaps do not meet the standard criteria for being evidence-based, but which are certainly working in these communities. She wondered how they could fit these programs that were not evidence-based per se into CDC's model to be able to receive some funding. Her program is the Alternative Medicine Traditional Healing Program, which is a rather unique program within the health department that provides direct services to community members for a variety of conditions and prevention efforts. She said that she needed help in the sense of how to modify CDC's information to make it more practicable and applicable to the "busy bees" on her level. She could see the multiple levels of translation from the leaders down to those who work on the front lines dealing with direct patient care or with community members. She understood the responsibility of the leaders to funnel money down, but at the same time, information gets trickled down in a way that does not make sense to frontline workers and the community. CDC has many great and useful programs to offer, but it was not clear to her how to tap into CDC as a resource. Her program is run by a lot of the tribal funds. They do not seek grants per se from CDC, IHS, or others. There is a major demand for their program, but additional resources are needed in order to continue to provide services for the tribal community.

Ms. Dee Sabattus
Interim Tribal Health Program Support (THPS) Director
United South and Eastern Tribes, Inc.; Nashville Area

Regarding accessing opportunities, Ms. Sabattus pointed out that they all take home knowledge to their tribes to tell them that there is money available for them to access. However, without Indian Country set-asides, they are competing against large universities and states in areas where tribes have populations ranging only from 120 to 15,000 members. Even combing all of the tribes as one applicant, it is still difficult to compete against the potentially millions that universities can reach. Therefore, it is extremely hard to access funds. Many of the grant reviewers for the larger opportunities do not have any knowledge of tribal communities or what a tribal program can do. There should be Indian Country set-aside funding. Even if they compete against each other, at least they would know that some of the funding was going to Indian Country. They could then work together to compile best practices.

Mr. Reno Franklin
Chairman, National Indian Health Board (NIHB)
Chairman, California Rural Indian Health Board (CRIHB)

Mr. Franklin pointed out that Pete Penny described what they envisioned as an Office of Tribal Programs within CDC that would be fully staffed. TCAC members discussed this possibility the previous day in terms of having grants, contracts, and programs people within that office. This is a really nice fit. He thought that most of the TCAC members agreed that there was a need for that type of program. He recognized that there was probably a lot of panic when thinking about have a contract with each of 565 tribes; however, he did not think this was necessarily the answer. Not every tribe could do this. Some tribes are huge and have large programs, and some do not. He heard an EPA representative talk about treatment as a state in the TASK Program. Mr. Franklin sent an email to his Environmental Director to ask him about that program. Individual tribes have to apply to that program to get that status and have to demonstrate certain things. This may be one way for CDC to approach this. Or, as another example, CRIHB is comprised of 36 tribes, so perhaps a tribal organization with a resolution supporting tribes could apply for that type of status.

J.T. Petherick
Health Legislative Officer
Cherokee Nation

Mr. Petherick indicated that he was representing the Oklahoma City area tribes, which include tribes in Oklahoma, Texas, and Kansas. He was serving as an alternative on behalf of Lt. Governor Jefferson Keel for the Chickasaw Nation who was unable to attend, and on behalf of the Cherokee Nation's Principal Chief Chadwick "Corntassel" Smith.

Regarding set-aside funding and travel funds, Mr. Petherick said that coming from the Cherokee Nation it was somewhat awkward for him to say this because under the current system the fare very well in terms of funding. Certainly, it is well-deserved, but he agreed that there needed to be changes made to the way that the CDC funds tribal activities because it is not equitable. Every grant that the Cherokee Nation receives is deserved and the programs are needed, but so do all of the other tribes. He thought they all needed to come together to think of a different way to do business in Indian Country.

Throughout the day there were also discussion about tribes trying to work with their respective states to receive some of the funds for certain programs and to have a say in how they are utilized, for example, H1N1 and how vaccines are utilized. Mr. Petherick drew on one example of why that does not work and why other opportunities should be considered. Mr. Joseph mentioned utilizing some of the systems within the IH S, and this is a potential way to get funds to Indian Country. Indian Self-Determination and Education Assistance Act compacts and funding agreements is another means by which dollars can be distributed pretty much instantly into Indian Country. The major problem is that once dollars go into the state coffers, the likelihood of them getting to the tribes diminishes significantly. On top of that, once those dollars get into a state, even if a state is interested in working with tribes, states are subject to state law, which brings a whole host of other problems in getting contract or agreements implemented. There may not adequate mechanisms in place such that those dollars could be distributed to tribes.

Mr. Petherick thought these were issues with which CDC could assist them. He left them with a concrete example from Oklahoma that is starting to be a trend with the Tobacco Settlement Endowment Trust Funds. There are many grant programs that want to work with tribes, but if a tribe enters into a grant through this program, even though the grants are not very big at this time, the Office of the Attorney General is requiring that the tribes agree to a waiver of sovereign immunity. Quite frankly, no one is going to do this for a \$60,000 annual grant. On top of that, how dare they even ask such a thing.

Ms. Kathy Hughes
Vice Chairwoman, Oneida Business Committee
Tribal Consultation Advisory Committee (TCAC) Co-Chair

Ms. Hughes said that CDC, from what she understood, was present to help prevent such things from occurring, and to deal with catastrophe when it does occur. In Indian Country it is really difficult to speak from a prevention perspective because they are still trying to deal with the catastrophe. Funding is the one thing they always ask for, but they know that there is no funding available. Working together, they should be able to start addressing some of the issues. The resources at CDC are large, and tribes really have not tapped that CDC resource yet. She expressed her hope that with these Tribal Consultation Sessions, the training sessions, and the meetings that are convened in Indian Country, that the tribes will become more knowledgeable about the CDC and better able to access the information that is available through the CDC: data, technical assistance, and other ways of helping to deal with the problems in Indian Country. This is the only way they will really be able to start attacking those problems, with the hope of someday getting into the preventive mode. Progress has been made in some areas, but clearly there are where progress is not being made. There is still a lot of work to do. She suggested that if there were any process or policy changes, before any final decisions were made, perhaps the TCAC could be of assistance in terms of input. In terms of funding mechanisms, it is time to be more creative and "think outside the box" regarding how CDC distribute its funding. Tribal leaders believe there are alternative measures that simply have not been considered on CDC's or the tribes' part. It is time to work together to improve the funding flow. From the tribal perspective, automatically funding through the states is not working. Thus, the tribes would like to discuss alternatives to make it work for the tribes.

CDC Staff Responses

**Marian McDonald, PhD, Associate Director
Office of Minority and Women's Health (OMWH)
National Center for Preparedness, Detection, and
Control of Infectious Diseases (NCPDCID)**

Dr. McDonald thanked Ms. Willson for her testimony and indicated that she would like to see the report Ms. Willson referred to regarding the status of Alaska Native people. She expressed her hope that Ms. Willson knew about CDC's people in the Arctic Investigation Program who have done a lot of work with the Alaska Native Tribal Health Consortium. Ms. Willson submitted the report to Dr. McDonald.

**Pete Penny, Procurement Analyst
Procurement and Grants Office (PGO)
Centers for Disease Control and Prevention (CDC)
Agency for Toxic Substances and Disease Registry (ATSDR)**

Mr. Penny said that all of the talk about Alaska took him back to 1980 when he was stationed at Shemya for a year. A lot of people in Alaska do not like to claim that particular island. When he was in the Air Force, he spent a lot of time roaming around between Fairbanks and Clear, Alaska at a variety of different radar sites they had there. He saw a lot of the issues 30 years ago that the tribal leaders were reporting about during this Tribal Consultation Session. While he saw it through different eyes totally, he could certainly relate to what they were talking about as far as the remoteness, lack of medical care, and all of the other issues. He stressed that they had a supporter in him, and that he would see what he could do as far as the grants side to help them out.

Responding to Ms. Sebattus's comments pertaining to funding, Mr. Penny said that while he worked in the contracting rather than the grants side of PGO, he has enough exposure that he is aware of the issues that are occurring. On the contract side, HHS headquarters has an 8A representative housed at CDC. He said that he could take this information forward to inquire as to why they have two individuals to support small and disadvantaged businesses, but do not have someone on the other side who can work as a representative to the Tribal Councils. The small business representatives offer counseling on how to acquire contracts. He pledged to take this information forward to his Director, Alan Kotch, to let him know that this is something they could pursue and at least put a grassroots effort within CDC to determine how they might be able to influence that type of decision in the HHS area.

**Christine Kosmos, Director
Division of State and Local Readiness Director (DSLRL)
Centers for Disease Control and Prevention (CDC)
Agency for Toxic Substances and Disease Registry (ATSDR)**

In response to Ms. Garcia's request for assistance in better understanding how to leverage resources and tools from CDC, Ms. Kosmos indicated that this is a major part of what CDC is trying to do better by creating the new Office of State and Local Support in order to reach down in a better way directly into communities. In their work with the states, as CDC has grown bigger, more complex, and has increasingly more services, they have become almost less accessible to the outside world. She said that she sometimes has better luck Googling information than trying to locate it in the CDC intranet, which is a sign of accessibility not being

very good. A major issue regarding accessibility is being able to find a name, a person, to call rather than a 1-800 number that requires one to go through many layers that never gets them to the person they really need to speak to. Phone calls are often not returned because staff have a million other things on their plates. She encouraged everyone to contact Dr. Bryan and CAPT Snesrud as their initial means to tap into the keys to unlocking community-specific resources and to get the attention of the appropriate individuals in the programs at CDC.

In response to Ms. Sebattus's comments, Ms. Kosmos indicated that they have been working with Dr. Bryan and CAPT Snesrud to do some work with connectivity with what is now being called State Health Officer Training, which is similar to the training that took place the previous day. It is basically a CDC 101 for public health leaders in communities. They do a lot of work with Alan Kotch and the staff at PGO. They are trying to educate public health leaders about the money allocation process. It is very complex, even for states who do this all the time. Somehow CDC has managed to make this as complex as possible. She quipped that she sometimes hears her colleagues say things such as, "Wait, there is a harder way" or "I'm sure we can think of something harder." One of the jobs of her office is to simplify the grants management process and to make it more transparent to the user. She stressed that she heard them and that they certainly were not alone in saying this.

CDC Budget and AI / AN Resource Allocations

**Mr. Robert Curlee, Deputy Director
Financial Management Office (FMO)
Centers for Disease Control and Prevention (CDC)**

Mr. Robert Curlee indicated that he had been able to listen in part during the morning, but had to depart for a while to attend the VFC Executive Committee meeting. The VFC program has a tremendous impact with the tribes, and the VFC Executive Committee is considering some streamline effects to work with getting vaccine orders and distributions out much more effectively with a new system, and working with contractors in that process. This has been a long-term activity in which CDC has been engaged in an effort to improve the Vaccine Tracking System (VTrckS). He was able to be part of the session with Dr. Frieden earlier in the morning, so it was encouraging to Mr. Curlee to hear him address the tribal leaders, and to hear some of the testimonies delivered at that time. FMO is also trying to work with the TCAC and tribes to explore alternatives and options for funding sources. This is a challenge on everyone's part. He took note of the comments pertaining to direct funding, and will take that message back to FMO and will raise the issue in future discussions with Dr. Frieden.

Mr. Curlee then showed several tables representing CDC / ATSDR resources committed to programs that benefit American Indian / Alaska Native (AI/AN) populations and communities from 2009 compared to 2008. Fiscal information was summarized in the data presented according to organizational and disease-specific programs, and by defined funding allocation categories. Recovery act funding was not included in this information, nor had 2010 information been prepared at this time, although Mr. Curlee noted that there are some efforts underway.

Total CDC / ATSDR funding with VFC (73%) is \$168,275,464. Total funding without the VFC is \$46,009,312 (27%). Excluding ATSDR, total funding with VFC is \$167,637,959 and without is \$45,371,807. Funding resources aligned with coordinating centers is reflected in the following table:

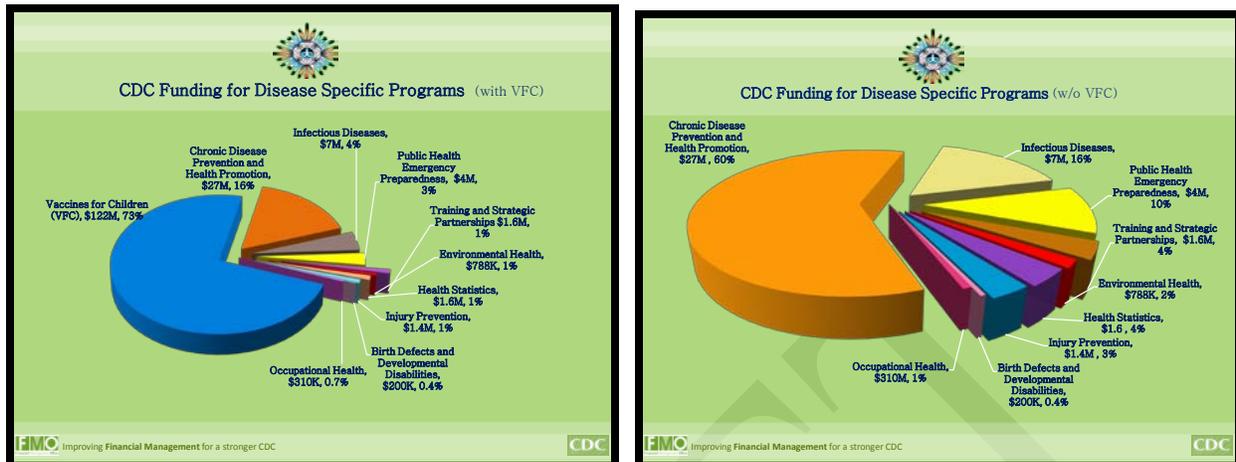


Funding Resources Aligned with Coordinating Center Center/Institute/Office (CC/CIO)	Total Funding FY2009 w/ VFC	Total Funding FY2009 w/o VFC
Coordinating Center for Infectious Diseases	\$129,574,394	\$7,308,242
NCYZED	\$106,000	\$106,000
NCHHSTP	\$3,542,458	\$3,542,458
NCIRD	\$122,605,845	\$339,693
NCPDCID	\$3,320,091	\$3,320,091
Coordinating Center for Health Promotion	\$27,568,187	\$27,568,187
NCBDDD	\$200,000	\$200,000
NCCDPHP	\$27,368,187	\$27,368,187
Coordinating Center for Health Information and Service	\$1,665,361	\$1,665,361
NCHS	\$1,665,361	\$1,665,361
Coordinating Center for Environmental Health and Injury Prevention	\$2,240,561	\$2,240,561
NCEH	\$788,371	\$788,371
NCIPC	\$1,452,190	\$1,452,190
National Institute for Occupational Safety and Health	\$322,140	\$322,140
Coordinating Office for Terrorism Preparedness & Emergency Response	\$4,651,716	\$4,651,716
Office of the Director	\$1,615,600	\$1,615,600
OWCD	\$496,079	\$496,079
OMHD/OD	\$1,119,521	\$1,119,521
CDC-CC/CIO Grand Total	\$167,637,959	\$45,371,807
ATSDR Total	\$637,505	\$637,505
CDC/ATSDR Grand Total	\$168,275,464	\$46,009,312

Funding resources aligned with disease specific programs (with ATSDR) are shown in the following table:

CDC Funding Resources Aligned with Disease Specific Programs (with ATSDR): A Comparison	FUNDING LEVEL FY 2008	FUNDING LEVEL FY 2009	Percent of Change
Chronic Disease Prevention and Health Promotion	\$ 25,884,960	\$ 27,286,210	5%
Cancer	\$11,502,097	\$14,077,332	22%
Cross-cutting Programs	\$7,178,202	\$5,613,762	-22%
Diabetes	\$3,349,585	\$4,039,402	21%
Tobacco	\$2,162,395	\$2,064,618	-5%
Heart Disease and Stroke Prevention	\$1,010,000	\$975,000	-3%
Maternal Child Health	\$292,584	\$147,749	-50%
Adolescent and School Health	\$390,097	\$368,347	-6%
Infectious Diseases	\$ 7,715,374	\$ 7,390,219	-4%
Infectious Disease Prevention (new category for FY 09)	N/A	\$46,000	N/A
Infectious Diseases in Alaska Natives	\$2,631,565	\$3,380,091	28%
HIV/AIDS	\$3,194,327	\$2,493,544	-22%
STDs	\$1,117,005	\$898,891	-20%
Vaccine-preventable diseases (non-VFC funds)	\$321,477	\$339,693	6%
Viral Hepatitis (not reported for 09)	\$217,000	\$232,000	7%
Other	\$234,000	\$0	-100%
Public Health Emergency Preparedness	\$ 5,192,034	\$ 4,651,716	-10%
Public Health Capacity, Strategic Partnerships and Training (OD)	\$ 1,612,545	\$ 1,627,600	1%
Environmental Health	\$ 614,686	\$ 788,371	28%
Environmental Public Health Services/Research	\$614,686	\$788,371	28%
Health Statistics	\$ 1,424,746	\$ 1,665,361	17%
Injury Prevention	\$ 581,920	\$ 1,452,190	150%
Unintentional Injuries	\$435,920	\$150,000	-66%
Violence Prevention	\$146,000	\$1,302,190	792%
Birth Defects/Developmental Disabilities	\$ 250,000	\$ 200,000	-20%
Occupational Health	\$ 310,140	\$ 310,140	0%
Health Marketing	\$ 229,000	\$ -	-100%
CDC Total w/o VFC	\$ 43,815,405	\$ 45,371,807	4%
Vaccines for Children	\$ 64,263,901	\$ 122,266,152	90%
CDC Total with VFC	\$108,079,306	\$167,637,959	55%
ATSDR	\$ 682,470	\$ 637,505	-7%

Funding for disease-specific programs with VFC and without VFC is illustrated in the following pie charts:



Funding allocation categories include the following:

AI / AN Awardees (Direct)

Competitively awarded programs (i.e., grants, cooperative agreements) where the awardee is a tribe / tribal government, tribal organization, tribal epidemiology, Alaska Native organization, tribal college, tribal university, or urban Indian Health program.

Intramural AI / AN

Intramural programs, the purpose of which is to primarily or substantially benefit AI / AN.*

*This category would include costs (e.g., salary, fringe, travel, et cetera) associated with CDC staff or contractors whose time / effort primarily or substantially (50% or better) benefit AI / AN.

Extramural AI / AN Benefit

Competitively awarded programs for which the purpose of the award is to primarily or substantially benefit AI / AN.

Federal AI / AN Benefit

Federal Intra-Agency Agreements wherein the purpose of the agreement is to primarily or substantially benefit AI / AN.

Indirect AI / AN

Service programs for which funding for AIs / ANs can reasonably be estimated from available data on the number of AIs / ANs served**

**This category applies only to the Vaccines for Children program and to NCHS.

In comparison to 2008, 2009 indirect AI / AN awards (with VFC) increased from \$65 million to \$123 million. Funding allocation categories aligned with disease-specific programs (with VFC) and a comparison of allocation categories for fiscal years 2008 and 2009 are reflected in the following tables:

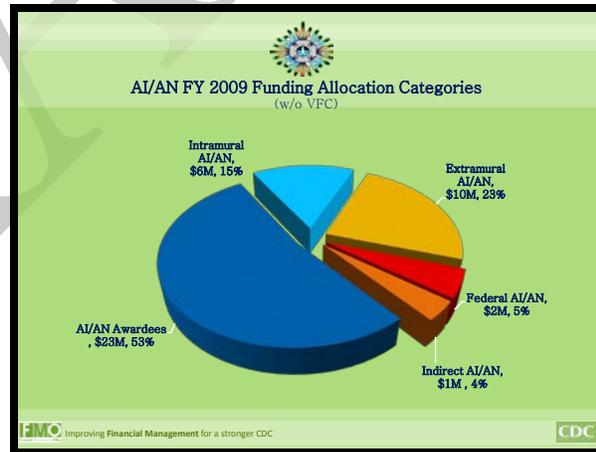
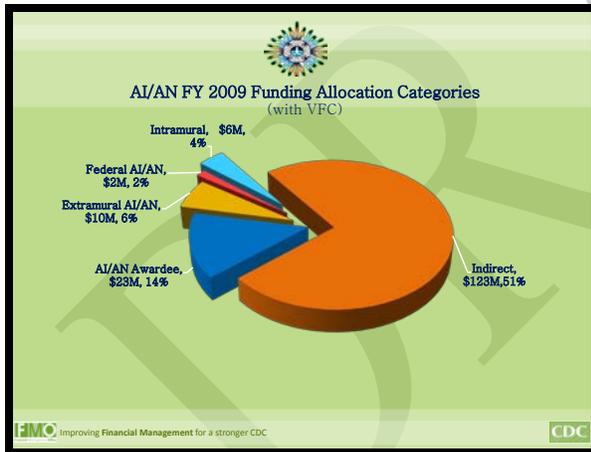
CDC Funding Allocation Categories Aligned with Disease Specific Programs (with VFC)

Disease Specific Programs	AI/AN Awardees	Intramural AI/AN	Extramural AI/AN	Federal AI/AN	Indirect AI/AN
Vaccines for Children (VFC)					\$122,266,152
Chronic Disease Prevention and Health Promotion	\$20,590,186	\$1,166,791	\$3,931,499	\$1,679,711	
Infectious Diseases	\$2,295,195	\$3,993,353	\$485,000	\$534,694	
Public Health Emergency Preparedness			\$4,651,716		
Training and Strategic Partnerships (OD)	\$596,905	\$878,585	\$124,140	\$27,970	
Environmental Health Health Statistics	\$230,209	\$552,270		\$5,892	\$1,665,361
Injury Prevention	\$141,717		\$1,160,473	\$150,000	
Birth Defects and Developmental Disabilities		\$200,000			
Occupational Health			\$310,140		
CDC Funding Allocation Categories - Grand Totals	\$23,854,212	\$6,790,999	\$10,662,968	\$2,398,267	\$123,931,513

CDC Funding Allocation Categories for FY 2008 and FY 2009

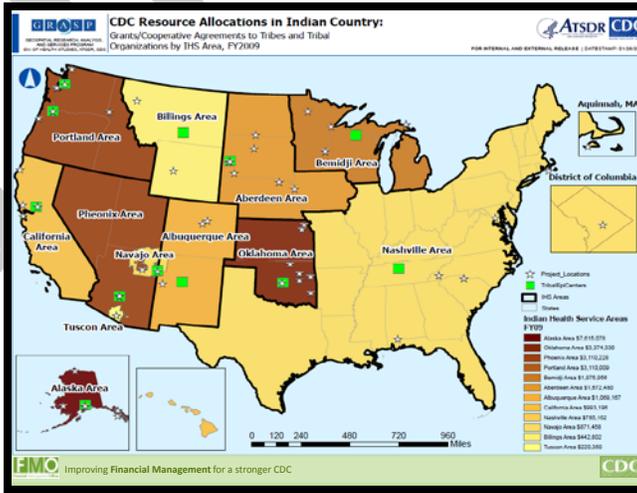
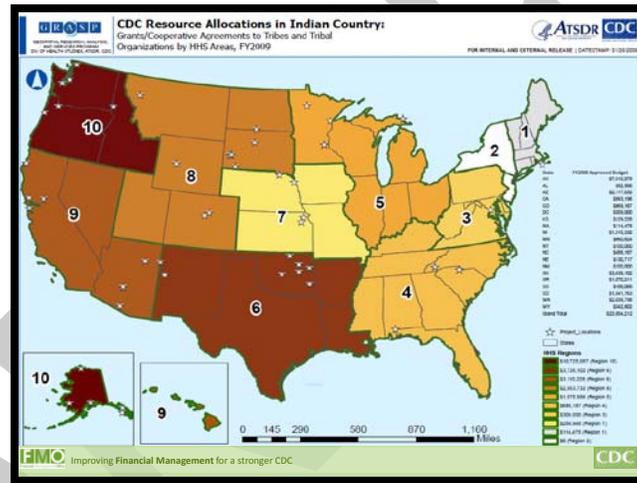
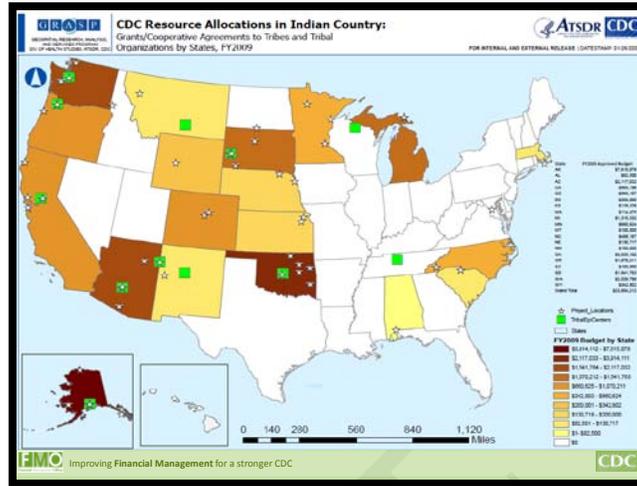
Funding Allocation Category	With VFC		Percent Change	Without VFC		Percent Change
	FY 2008	FY 2009		FY 2008	FY 2009	
AI/AN Awardees	\$22,839,514	\$23,854,212	4%	\$22,839,514	\$23,854,212	4%
Intramural AI/AN	\$6,856,724	\$6,790,999	-1%	\$6,856,724	\$6,790,999	-1%
Extramural AI/AN	\$10,687,986	\$10,662,968	-0.20%	\$10,687,986	\$10,662,968	-0.20%
Federal AI/AN	\$2,006,435	\$2,398,267	20%	\$2,006,435	\$2,398,267	20%
Indirect AI/AN	\$65,688,647	\$123,931,513	89%	\$1,424,746	\$1,665,361	17%
CDC Grand Total	\$108,079,306	\$167,637,959	55%	\$43,815,405	\$45,371,807	4%

The following pie charts reflect the AI / AN 2009 funding allocation categories with the VFC and without the VFC:



AI / AN Fiscal Year 2009 funding (with VFC) in the amount of \$168 million represents 2% of the total CDC / ATSDR budget, while the \$45 million in AI / AN funding represents 1% of the total CDC / ATSDR budget.

Grants to tribes broken down by state, by HHS area, and by IHS area are reflected in the following three maps respectively:



In the above maps, green boxes represent the Tribal Epidemiology Centers and the stars are the actual project locations of the awarded tribal programs. These maps depict only those funds that are directly awarded to tribal government, tribal organizations, Alaska Native health corporations, urban Indian organizations, and tribal colleges.

TCAC CDC / ATSDR strategic funding direction is to engage in sub-budget committee collaboration; expand division-based involvement for health impact across CDC / ATSDR; engage in program project initiatives with CDC / ATSDR Financial Strategies Committee; increase visibility in budget submission health initiatives; align with CDC / ATSDR health goals and objectives for performance- and results-based management; and collaborate further with HHS and operating division (OPDIV) shared resource initiatives.

While unable to gain any information on the American Recovery and Reinvestment Act (ARRA) funding before this session, Mr. Curlee said he would hopefully be able to provide further information on this later. Though Mr. Curlee said he was also not certain what would be taking place regarding 2010, Dr. Frieden did allude to a separate track regarding tribal activities, and that further information would be provided regarding that issue once some firm decisions were made regarding awards. Funding has been worked out the HHS on some of the ARRA funding activities that NCCDPHP will be managing.

Based on the comments throughout the day, it was clear that consideration must be given to how to make awareness of the tribal health activities funded by CDC more recognized. As evident in the funding provided previously, there is a cross-cutting network of activities with the CDC centers. While NCCDPHP is certainly a major contributor in that process, other centers are also engaged and involved. Early planning is very important. Dr. Frieden certainly gained more knowledge in preparing for this Tribal Consultation Session, and from meeting with tribal leaders to hear about tribal activities and health awareness. Moving forward, FMO certainly wants to keep him aware of these activities, and he will to the Center Directors and other leadership at CDC to work on these strategies.

Mr. Curlee noted that he had reported to TCAC the previous day that in a few days, the Fiscal Year 2011 budget would be rolled out by President Obama, which would include the HHS and CDC budgets in the huge package that would be provided for the public to see. Unfortunately, they were passed the point for adding anything to the 2011 budget. However, FMO will soon be working on the 2012 budget initiatives, and CDC's 2012 budget will be provided to HHS by the end of May 2010. FMO will soon begin to work with CDC's program offices and centers to develop strategies. This represents another opportunity to approach health awareness for tribal nations and try to provide AI / AN activities in the process. The challenge is trying to put that together into a template and narrative that can be understood and can make a difference in health activities, so that CDC can review and consider that as they move forward in the budget process. This will begin with HHS initiatives that will be provided in the early submission. Hearings will also take place. During the summer, the Secretary's Budget Council will take place, which Dr. Frieden will be a part of. Later in September, CDC's submission request will be provided to the Office of Management and Budget (OMB). OMB will respond to CDC after working with HHS. About this time next year, the 2010 budget will be submitted for rollout as well. The budget cycle is a major process with a number of timing aspects. He emphasized that tribal leaders give thought to potential initiative project-type areas that CDC could work with and work with tribes in considering moving forward.

Discussion Points

- Mr. Finkbonner wondered whether the large increase in amount for the VFC program from 2008 to 2009 was all due to H1N1.
- Mr. Curlee responded that major changes took place in the VFC program, such as with Prevnar®, which was part of the reason for the substantial increase. He indicated that FMO would acquire this information and submit it to the tribal leaders.
- Michael Franklin, Senior Public Health Analyst with FMO, added that part of the increase had to do with the population increases states reported that they serve. That also changed the scope and the landscape of the dollars to be allocated. One of the take away actions is that FMO will be working to establish a template and some guidance in trying to gather information to be used for AI / AN activities looking toward 2012. There may be some slim opportunity for 2011, but it will be challenge considering where things are going in the budget process. However, there could be an opportunity through the hearings and House and Senate mark-ups to consider something in that process. Dr. Frieden may also have some opportunity with 2011 budget to look at some initiatives as well—certainly based on his meeting with tribal leaders today. FMO will work with him on that.
- CAPT Snesrud thanked Mr. Franklin and Mr. Curlee for this presentation. She especially commended Mr. Franklin because so much of this budget information was just becoming available. They tried to prepare and have more of the budget portfolio available for the tribal leaders, but the information came in at the last minute. That being said, in relation to a lot of the conversation during this session and over the past day and a half, they really want to be able to extrapolate the data and do some comparisons in looking at the priorities and categories identified by TCAC and other tribal leaders and compare and contrast those to CDC's overall budget for the last three or four years. The TCAC is in the process of the reactivation of the Budget Committee because, and as tribal leaders know, it has taken a long time to have input and inroads into a federal budget. It took time and familiarity to influence the IHS budget and it will take time to gain a commiserate familiarity for Tribes to enable them to influence CDC's budget. CDC and tribal leaders need to have consistent dialogue with respect to CDC's budget formulation and allocations. FMO has clearly given TCAC some tools, some different ways they can collectively use to do this. However, given that this dialogue had been underway for a couple of years, it is time for Tribes to map out a timeline to assist them in doing what they can do now in January 2010, the next 6 months, the next year, and the next 18 months to influence CDC's work with tribes. Intent is to ensure that a year from now when Tribes are sitting there with CDC, that the same thing isn't being said—that we all have some specific, measurable Tribal priorities upon which CDC and the TCAC can report progress.
- Mr. Valdo thanked Mr. Franklin and Mr. Curlee for their presentation. While the \$168 million sounded really nice and awesome, most of it going through the VFC program, which is sent to the states. It sounded as though that number was based on reporting from the states indicating that they have served a lot more Indian people. Reflecting on his personal experience, his own son did not receive vaccines this year at all for anything in New Mexico. When thinking about long-term health, getting these shots is preventive up front. He re-emphasized that even though these reports showed that a lot of resources are going to Indian Country, it is not clear whether they are getting to where they need to be administered. If \$100 million goes to IHS, at least they know that their people go there for

services. As many complaints as there are about IHS, it is Indian Country's only health service. It is not like Atlanta where someone can go four blocks down the street to get to a doctor's office—it is miles away, and they may see a Journeyman Medical Officer who just got out of college and is working off his scholarship, and then will be gone in two years. The system has problems, but it is their only system. IHS is one source through which they could push cooperative agreements to better control that money than can be done with states. Mr. Valdo comes from a great state in which they have great relations with their Governor, Governor Richardson. They have law that requires states to consult with tribes, but even that law does not "bend enough arms." It is a great expression, but it is not a great action yet. It is nice to say and hear these things, but let's put our talk to the walk. From the FMO perspective, and getting back to accountability, efficiency, and effectiveness, Mr. Valdo said he would like to see any angle they could use to improve any one of those three things in Indian country (e.g., accountability, efficiency, or effectiveness). While it is nice to see these graphs and the like, they heard from most of the Indian Country areas, and there was a common underlying theme that maybe states are reporting more than they are actually serving.

- Dr. Bryan agreed that the indirect funding category, in which the VFC was a vast majority, is a population-based estimate; whereas, the other dollars shown across those categories are real dollars that they are able to track and spend. The immunization size of things is one of those things where they are able to track the dollars in an estimate mode, so it looks like a lot. This is why they split this up on purposes—so that they could look at that other \$40 million piece of the pie and focus in on that as real dollars. Immunization is a place where they can actually look more accurately at the accountability side of things and number of Indian children being vaccinated. They track whether Indian children are being vaccinated through the IHS Immunization Quarterly Reports and through the National Immunization Survey (NIS). The vaccination levels are actually pretty high, although he was not sure why Mr. Valdo's children were missed this year. Dr. Bryan pointed out that he said this not to make excuses for the dollars, because this is one area where the issue accountability falls into Dr. Frieden's other priority of improving surveillance. Surveillance is one of the tools that helps CDC track immunization coverage—vaccine uptake. In this particular example, it is where the science and the dollars have come together a little bit where someone can say, "Yeah, I see there are a lot of dollars out there, but so what?" CDC can say, "Well look. These are the immunization coverage rates, and these are data from both CDC and IHS that look pretty good." They can also identify where there are gaps. Coverage is not so good for adults for influenza or pneumococcal vaccine. They can point to areas almost geographically where that is the case. He thought they should take Mr. Valdo's suggestion one more step and apply the science as well as the dollars.

2009 H1N1 Influenza: Lessons from Indian Country

Moderators

Mr. Chester Antone, Session Moderator

Dr. Ralph Bryan, Session Moderator

Dr. Bryan began this session by showing the main CDC webpage for the week, which includes a rolling features box for which the H1N1 and seasonal piece stars Wes Studi. He then showed the public service announcement, the script for which reads as follows:

[Speaking Cherokee]

Each year, more than 200,000 people are hospitalized with flu, and about 36,000 people die. Like all Americans, native peoples and tribal communities need to protect themselves. Flu spreads mainly from person-to-person through coughing or sneezing. People can also get infected by touching something with flu viruses on it and then touching their mouth or nose.

Most people with the flu have mild symptoms, but pregnant women, young children, the elderly, and people with illnesses like asthma, diabetes, or heart disease are more likely to suffer from serious complications.

Protect yourself, your family, and your community from the flu. Get vaccinated every year. Cover your coughs and sneezes, wash your hands often, and if you're sick, stay home. Protect the circle of life. Know the facts about the flu.

[Speaking Cherokee]

There are several other services announcements in production, and there is already evidence that these are being picked up by local television stations. Dr. Bryan introduced and acknowledged Mr. Jim Crossgrove who produced this public services announcement. He and his crew have done a fantastic job, for which Dr. Bryan requested a round of applause.

Mr. Antone noted that when they receive PSAs from CDC, they forward them to their IHS facility and their Office of Emergency Management, and they in turn forward it to all of the schools. This is really helping out a lot. He then invited tribal leaders to provide testimony, make commentary, and / or ask questions regarding H1N1 issues and lessons learned in their communities.

Tribal Speakers

Ms. Cynthia Manuel

Council Woman, Tohono O'odham Nation

National Indian Health Board (NIHB) Board Member

Ms. Manuel indicated that she comes from the Tohono O'odham Nation in Southern Arizona, which is comprised of 28,000 plus members. Of those, 1500 live on the other side of the boundary of the Mexico border. There are 13 known Tohono O'odham communities, with reservations stretched out from the boundary all the way to Hermosillo. In January 2008, a member of their tribe came to meet with CDC, and they talked about the fence being built on the international boundary. Their reservation is 75 miles on that boundary. They can keep vehicles from coming through, but not animals. Something could still get through from Mexico with some type of disease that could affect them. Sure enough, H1N1 came through. She was really glad that their tribal health departments were ready. They had done exercises just in case anything like that happened. They were not notified first by the states. They received word from their

own tribal members who live on the Mexico side, who asked whether they knew anything about it. It was not until two days later that the state notified them. This is why direct funding is so important, because they had to wait for the state to put something in place and notify them. It was a while before funding came in. At the local level, their IHS and tribal health programs got together, began looking into what was going on, and set up Emergency Operation Centers (EOCs) and an Incident Command Center (ICC), and put together a team.

When this first occurred, they had 22 tribal members who were positive and 1 death. During the second wave, they had 16 positive members and 1 death. It was really good to see the collaboration of the tribal programs and IHS to move fast. It could have been much worse because they are right along the border. As noted, a tribal member traveled to meet with CDC in 2008 to tell them that they had to be ready in case something happened. They were working with Homeland Security to try to keep all of the people from bringing all the drugs to their nation, because needles and other things were found in the backpacks that they carried. But they knew that diseases could also come across. It was a learning experience for the Tohono O'odham Nation. Ms. Manuel stressed that the route of having to go through the states, to the county, and to the Tohono O'odham Nation wastes time. Even the Tohono O'odham Nation's process takes times. Luckily, they were ready when H1N1 occurred. However, the tribal members who live on the other side of the border in Mexico worry more. They want to put a tri-national plan in place with the Tohono O'odham Nation, county, state, and Mexico so that they can better communicate with each other about such issues. Direct funding is very important because they know their own people, and they know how to spend the funding. Other people should not be telling them how to spend that money. Tohono O'odham Nation knows how to spend that money according to their needs. There has been a lot of education since the outbreak, and she thanked CDC for adding her name to the listserv because she does receive the information.

Mr. Joe Finkbonner
Executive Director
Northwest Portland Area Indian Health

Mr. Finkbonner thanked CDC staff for being there and for listening to them. No one would have thought less than a year ago in April 2009 that they would be sitting here talking about lessons learned from H1N1, most of which seemed constructive. Fortunately, H1N1 did not have the severity that was planned for. State and local agencies and tribes "rolled up their sleeves" to prepare for pandemic influenza before it actually hit within the US borders.

He works with three states in the Northwest: Idaho, Oregon, and Washington. Each of these states had a different model and varying levels of acceptance in terms of how tribal populations perceived that they were treated. This, of course, is a large factor in the engagement of the system as well. They have historically had the longest period of time of a good relationship with Washington State, which chose to implement their H1N1 distribution by distributing the vaccine to the locals, and having the locals then distribute it to the tribal clinics based on the identified population and the criteria developed by CDC / ACIP for the at-risk population. The State of Oregon worked directly with the tribes rather than through the locals to distribute the vaccine. Idaho worked with the IHS to get the vaccine to tribal clinics for the healthcare providers and the tribal populations was included as a part of the general population and were notified about immunization clinics for H1N1 in which they could participate.

Mr. Finkbonner had a great amount of heartburn communicated to him from Idaho. There the tribes felt that they were just linked into the general population, and that their safety and protection was not taken as seriously as what had been conveyed to tribal and state officials of what they believed tribes' risk would be. Everyone in Oregon was happy. They thought that the state treated them respectfully and they felt like partners. Their tribes engaged in immunization clinics and worked with the state to enhance vaccination messages and get that information to the tribes. Washington had mixed results. Even in counties that have good relationships with tribes, the local flexibility in vaccinating and the clinical judgment that CDC impressed upon the states and locals was not afforded to tribes. If tribes wanted to use their discretion to vaccinate an individual tribal member who they thought would be a good candidate for the vaccine, local health jurisdiction told them if they did it, the health department would not give them anymore vaccine. Some tribes needed more vaccine but could not get it because of the allocations. Other tribes had excess vaccine who wanted the discretion to share with others, but were not permitted to do so because they were treated as clinical sites rather than separate public health jurisdictions or separate governmental jurisdictions. They were completely at the whim of the locals, and there were incredible frustrations. The tribal leaders convened on multiple occasions with the Washington State Department of Health to try to resolve the situation with the powers that be within the state. The locals essentially refused to do otherwise because they said they had their "marching orders" from the guidelines for immunizing and allocated only certain amounts based on that. They refused to vary from that much.

While hoping to present uptake rates to illustrate with data that one model worked better than the others, Mr. Finkbonner was unable to acquire this information prior to the Tribal Consultation, but indicated that he would forward the rates as soon as he received them. In terms of respect for tribal governance, the State of Oregon seemed to have best model. They talked with all 9 tribes in Oregon, all of whom reported that they felt engaged and respected, and they encouraged their tribal membership to participate. That was not to say that the other states did not encourage their tribal members to participate, but in dealing with locals, when there are large land-based tribes like Mr. Joseph's, they often cross multiple counties. Different counties chose to deal with H1N1 vaccination differently, which sent mixed messages to the tribal population about who receives vaccine and who does not. Even school immunization programs were different in that some schools with tribal populations immunized and others did not. This sends a clear message to tribes that some of them are valued more than others.

This led to Mr. Finkbonner's recommendation that the methodology of sending resources to the state, and that correspondingly going down to the locals, must be reviewed as a means to assure public health for tribal populations. The message they hear is, "We don't have the mechanism to do that currently." He was sure that sometime in the 1940s, some federal bureaucrat said, "Boy, I would really like to land on moon." What it really took was someone to commit that they were going to dedicate resources and brain power, and it happened. With that in mind, he asked CDC to dedicate some resources and brain power to think about how public health can be delivered from the federal level to the tribal level through a different mechanism than the current one because it is not a "one size fits" all situation. Perhaps a new mechanism would be using National Indian Health Boards, IHS, and / or Area Health Boards. He stressed that there were enough brilliant minds in this room, throughout Indian Country, and throughout CDC to find a mechanism that works.

Mr. Reno Franklin
Chairman, National Indian Health Board (NIHB)
Chairman, California Rural Indian Health Board (CRIHB)

Mr. Franklin began by saying that he was just reading through the barrage of emails he had received since speaking at TCAC, which was a compliment to CDC with respect to how fast they respond. He clarified that he was speaking from the CRIHB point of view only with regard to H1N1, and that there are serious issues in the way CRIHB consults with the State of California.

In terms of the response to H1N1 in California, the state is on furlough every Friday and tries to get as much work into four days as possible by people who do not want to be doing that work in four days. It is impossible to get things done. CRIHB submitted a grant for the Public Health Emergency Response (PHER) Grants that were to go to tribal organizations and have still not gotten a response. He thought the response was due in October 2008. He wondered whether he needed to drop blood on the letter and asked what they had to do in the State of California to receive a response on a grant. This was a very well-written grant, the intent of which was to provide mini-grants to tribe in the State of California to conduct H1N1 education for prevention. A major component of it pertained to cultural competency, with tribal members developing and delivering the information to tribes. The other function of that grant was to conduct monitoring statewide to determine which areas need help, and how CRIHB as an organization could provide technical support to tribes being exposed to ensure that they were receiving their share of the vaccine. These are just some components of this very well-written grant about which they have yet to hear anything. In the meantime, California Indian people are dying from H1N1.

There 52 counties in California, each of which reacted differently and each of which is at a different stage of Indian hating or Indian loving. Many counties really do not like Indians and flat out refuse to deal with them. A Tribal Council Facility came to a CRIHB meeting and discussion and reported that when they asked their county for an allotment of vaccinations and some outreach, the county flat out told them "no." That cannot be in compliance with anything: common sense, federal law, the grant, et cetera.

Thus, Mr. Franklin requested that CDC provided guidance and directives to states to address how they are out of compliance. While he received an immediate response from CDC about this, still nothing was received from the state even though this was bumped up the food chain. It is a slap in the face to the tribes that the state does not want to cooperate, or that when they do, it is on the back end of other things. Then they insult the tribes further by not answering them. In the meantime, the pressure mounts and people die. He expressed his hope that another round of funding would be disseminated with more restrictions and a requirement for states to have to outline their plans for tribes. While it is good to show that, he implored CDC to take it a step further and require that the states follow through and do what they say they are going to do. Enforce it. Get home telephone numbers. Make the states respond. The tribes would greatly appreciate CDC's support.

Ms. Roselyn Begay
Program Evaluation Manager
Division of Health, Navajo Nation

Ms. Begay said that on behalf of the Navajo Nation and Ms. Evelyn Acothley, Navajo Tribal Leader and Navajo Nation Representative to the TCAC at the TCAC Tribal Consultation Session, it was her honor to speak on behalf of the Navajo people.

Navajo Nation is the largest land-based federally-recognized tribe with a population of nearly 200,000 living on the reservation, covering a land-base of over 26,000 square miles and extending into 3 States (e.g., Arizona, New Mexico, and Utah) and 13 counties. Similar to Northwest Portland Area Health Board's situation, Navajo Nation has to work closely with two of the three states and experiences varying degrees of levels of communication and coordination, including with CDC and IHS. Unlike other tribes, they are very fortunate to have one IHS Area Office that is the Navajo Area and is housed near the Navajo Nation Capital. They are close enough to work together and coordinate to carry out their health care services for over 200,000 Navajo people who reside on the Navajo Nation Reservation.

Navajo Nation began its response to 2009 H1N1 influenza in April 2009 by providing daily surveillance activities regarding the outbreak by:

- Serving on the Navajo Command Center's Medical Advisory Team;
- Leading the Navajo Epidemiology Response Team to the NAIHS ;
- Serving on the Epidemiology Advisory Team to Arizona and New Mexico;
- Participating in national and state conference calls;
- Updating the Navajo Command Center regarding the spread of H1N1, community response and mitigation efforts to contain the virus;
- Sponsoring an educational presentation on H1N1 influenza by two experts on influenza and epidemiology; and
- Providing a massive education and information campaign about the virus to healthcare workers, children, elders, tribal workforce and general public in the English language and our native language through a variety of media and venue—this was effective and successful.

They learned during the past year with regard to H1N1 was that their Navajo Epidemiology Center played a major instrumental role. Tribes are essential partners in the response to H1N1 influenza pandemic. As such, the Navajo Epidemiology Center serves a critical link to the three state health departments, HIS, and CDC with respect to public health and emergency preparedness and response. She said she was very proud to say that this office was the hub and acted as the glue to help develop community mitigation plans and provide technical and professional expertise with the people on the ground, in the facilities, and in leadership positions in getting them prepared.

Ms. Begay acknowledged their Epidemiology Center Director, Dr. Deborah Klaus for her professional and technical support to the Navajo Nation. She served in a key role in the Navajo Command Center as part of the Medical Advisory Team. She was the liaison from the Navajo Epidemiology Response Team to the Navajo Area IHS. She was the liaison to IHS, CDC, and other tribal programs. The Navajo Division of Health is just one division within the tribal government. She also served as the link to other tribal programs and other divisions like EPA, Emergency Medical Services, and Public Safety. She was also the communications link. She participated on numerous national and statewide conference calls regarding the virus. She

updated everyone at the Navajo Command center regarding what was going on outside the Navajo Nation, outside the 3 states, nationally and globally. She brought renowned experts on influenza and the H1N1 virus into the Navajo Nation to provide education and information. Just like in other Indian Country, public education and information are very critical and it is important that they be delivered by Navajo people in their own language. Dr. Klaus worked with the Navajo Bioterrorism Program to develop unique, Navajo-specific education programs that they were very proud of and which had proven some success.

As all tribes have said, Tribes are key, essentially players in public health and emergency preparedness activities in Indian communities. The Epidemiology Center is a critical link, and Ms. Begay expressed hoped that CDC would consider expanding, enhancing, and support those centers. As they had heard, across the 12 areas that have Epidemiology Centers that data sharing and communication are critical. Lack of these is the greatest weakest that they have on the Navajo Nation.

This is what the Navajo Nation learned with the 2009 H1N1 Influenza:

- ❑ Unlike other IHS Areas, the Navajo Nation is the larger of the two tribes served by the Navajo Area Indian Health Service; thereby, they are fortunate to the extent that resources and services are allocated largely to the Navajo Nation in their area.
- ❑ When the CDC distributed the H1N1 vaccine to States; in Arizona, the state dispersed the vaccine to the Navajo Area Indian Health Service (NAIHS), although the Navajo Nation requested to receive the vaccine.
- ❑ The Navajo Nation spent a considerable amount of time, energy, and effort planning for and preparing to receive and distribute the vaccine to numerous Points of Distribution. Instead, the state decided that IHS was the best way to go.
- ❑ When the NAIHS received the H1N1 vaccine, it failed to communicate with the Navajo Nation on when and where vaccination clinics would take place. To date, the NAIHS has not provided data on who received the vaccination. Therefore, the Navajo Nation is unclear as to whether the priority groups have been vaccinated.
- ❑ The NAIHS will not share information on the flu cases, such as the number of hospitalizations and numbers of deaths, if any, by age and priority groups. Therefore, the Navajo Nation is unable to determine the level and degree of health burden in the Navajo Area.
- ❑ Although Navajo Nation healthcare workers (e.g., CHRs, people living in elderly and senior citizen centers, Head Start workers, those working with the Special Diabetes Program, et cetera) were included in the NAIHS' healthcare personnel count for the H1N1 vaccine in August, staff reported the NAIHS clinics refused to administer the vaccine to them. It remains unclear whether they have now been vaccinated. An H1N1 vaccination clinic was held in early January in the Navajo Division of Health conference room, where Ms. Begay received her vaccination. Navajo Division of Health employs about 300 healthcare personnel on the ground, on the front line who should have been vaccinated first along with NAIHS healthcare personnel consistent with the CDC guidelines.

Navajo Nation is very appreciative of CDC providing funding sources for H1N1 protection. Through the State of Arizona, the Ms. Begay acknowledged and expressed appreciation to two of the three states in which they reside—Arizona and New Mexico. Navajo Nation received over \$500,000 from Arizona and about \$64,000 from New Mexico to support the Phases I, II, and III planning and community mitigation activities. The Navajo Nation Epidemiology Bioterrorism Team and the Navajo Epidemiology Response Team developed a plan regarding how to utilize these funds. When the Navajo Nation offered to assist, Navajo Area Indian Health Service refused or did not respond to this offer.

CDC has an obligation and responsibility to protect, educate, and train healthcare workers and the public. The following recommendations are made to CDC to resolve these challenges. While Navajo Nation strongly advocates for tribal participation in local decision making, they urge CDC to:

- Mandate that the states provide adequate access and coverage for the remote and isolated areas;
- Provide direct funding to tribes;
- Provide public health emergency and preparedness assets and resources directly to tribes that have the capacity and capability to receive and distribute the antiviral vaccine;
- Require states and IHS share clinical and surveillance data;
- Require states and IHS provide vaccine protection for tribal healthcare personnel; and
- Improve collaboration, coordination, and partnership between states, CDC, and IHS for effective, efficient, and quality public health system and service.

**Andy Joseph, Jr., Colville Tribes
Northwest Portland Area Indian Health Board
Chair, HHS Chair Tribe Council, NIHB**

Mr. Joseph (Badger) reported that his tribe had a terrible experience with the way that H1N1 was distributed. Their reservation spans 1.4 million acres and two counties and is surrounded by several other counties. When H1N1 vaccinations were first available, it was very upsetting because all of the counties surrounding them were vaccination people. Their counties were giving them to their own people, but were not sharing them with the tribe and tribal providers. His daughter, who was carrying at the time, had to go across the river to acquire her vaccination. They would hear on the news about all of the other locations that were giving vaccinations. Sadly, they lost a young man who had children. The tribe will have to look after those children probably for the rest of their lives and they will not have their father around.

As a tribal leader, Mr. Joseph swore an oath to protect his people. It is very hard when they lose someone and everyone wants to know why something like this happened. He did not know whether the counties were so scared about the big pandemic that they thought they needed to give all of their own people vaccines to protect them. As Mr. Franklin pointed out earlier, some counties love them and some counties do not. He did not know whether it was the color of their skin or what. It is terrible that they have to deal with the hard feelings between tribal and non-tribal people, especially when his tribe is one of the biggest employers in both counties in North

Central Washington. They pay their taxes and funding from the government comes from taxes. Every one of the tribe's employees pays taxes. To be treated this way is very upsetting.

The high school and elementary schools in his district each have populations of 50% Native Americans, so they received their vaccinations at school across the river in Grant County. However, his son goes to a school with a 98% Native American population where no vaccinations were ever administered. Ferry and Okanogan Counties have never vaccinated in the schools at all.

Mr. Joseph was very active in his emails and in asking strong questions to the state about why they were not providing vaccines to tribes. He was fortunate to receive a call from the Secretary of the Department of Health on a Sunday. He was very glad that the Secretary put out a letter to get everybody vaccinated, but probably less than half of his people on the reservation received vaccinations. His worry is not just for his tribal members. Non-tribal people live on the reservation also. There has to be a better way. IHS works by user count population numbers and distribute seasonal influenza and other vaccinations and these get out when it needs to and to who it needs to. He said he realized that there was a shortage of vaccine to begin with, and that there were measures to ensure that everyone received vaccine. Tribal governments and CDC should work together to make sure this happens. He represents 43 tribes and was worried for the rest of them who had to deal with their counties also.

Luke Johnson
FMIT Emergency Response Director
H1N1 Lessons Learned from:
The Fort Mojave Indian Tribe (FMIT)

Though not presented aloud, the following testimony was submitted for the record:



4th Biannual CDC/ATSDR Tribal Consultation Session
2009 H1N1 Influenza - Lessons from Indian Country
Atlanta, GA January 28, 2010 H1N1



Lessons Learned from the Fort Mojave Indian Tribe



Tribal Profile. The Fort Mojave Indian Tribal lands are located in the Tri-state area of Arizona, Nevada and California with 1,205 members with 32,000 acres nestled on the Colorado River basin. (There is a pictorial map on the last page).

Presenter Profile. My name is Luke Johnson, FMIT Emergency Response Director for tribal emergency response to public health education, environmental health and FEMA emergency management planning. I work for Indian Health Services for 20 years as a hospital Facilities Manager in charge of plant engineering, Safety Officer and Environment of Care specialist.

Tribal Pandemic Concerns. The Tribe in the 1850s numbered some 3,000+ natives living in their ancestral lands in the Mohave Valley and by the 1950s we were reduced to less than 400 members due to diseases and disease outbreak. The Colorado River is also an avian north south international bird corridor with birds from both continents nesting in our area all year long. Based on a history of

limited natural body defenses against diseases and our avian we have a great concern with the H1N1 outbreak and the Tribal Council has mandated my office to assure all measures are in place, all resources sought, and there is a tribal plan in place.

PHEP Partnership Planned. To venture into the unknown by one's self is unwise and the wise policy is to make the venture with able body partners that have been there before and this is the course Fort Mojave has taken. We have ventured into the pandemic influenza world with the CDC and Arizona Department of Health Services as our partners.

Tribal Public Health Emergency Preparedness and Response Plan

Plan Foundation. Every sound building structure must have a solid foundation and this includes public health planning, there must be a foundation plan and for Fort Mojave planning purposes this is the:

Tribal Public Health Emergency Preparedness and Response Plan 2005. This plan originally was called the Tribal Bioterrorism Response Plan when we had the BT program and was an early deliverable for all participants. In August 2005 we received onsite training on how to develop this plan and three templates were provided; ADHS, IHS and ITCA. We took parts from all three templates and submitted this plan in December 2005. This became our foundation plan "a living document" to which we would add building blocks or additional plans in this structured plan.

School Closing Plan 2006. In the 2006/2007 budget year we received the Pandemic Influenza Phase I "school closing plan" requirement. Fort Mojave owns and operates a Charter High School and we developed our plan to those needs. We conducted a tabletop exercise for all Mohave Valley school institutions on school closing planning and conducted an exercise drill with our Charter High School.

Mass Fatality Plan 2007. Planning "outside the box" our tribal assessments determined we were in need of addressing tribal cultural issues of "family closure" should there be a mass fatality to occur based on pandemic influenza and we developed this plan to address cultural funeral social distancing practices. In addition we have a plan for refrigerated storage of deceased persons, met and work with the local funeral parlor who also attended a mass fatality industry workshop and gave a tribal mass fatality presentation at the Arizona Summer July 2007 Conference.

Pandemic Influenza Plan 2008. The 2008 budget year required the development of a tribal pandemic influenza plan and this was developed for our tribal ambulatory health clinic setting and submitted in June 2008. This was developed from templates provided.

HSEEP Compliance 2008. My staff and I participated in HSEEP training and received our certificates of completion in the spring of 2008.

Special Needs Sheltering Plan 2008. Again planning "outside the box" we developed our tribal special needs sheltering plan to the HSEEP guidance as a test model.

Tri-County/FMIT Joint POD Drill 2009. In November of 2006 Fort Mojave Tribe was approached by Mohave County if we could instrumental in the development of an MOA for the use of the tribal owned Regional Event Center as a regional POD site for all of Mohave Valley and we successfully arranged this. By 2009 a Tri-County / Fort Mojave tribal RAC grant POD conducted a full-scale drill at

the Event Center, Fort Mojave was assigned as the Facility Coordinator in charge of facility coordination, traffic control and security.

RAND Throughput Plan 2009. The Regional Event Center was assessed to handle 79,000 people and based on this plan Fort Mojave applied for funding and with Arizona State University Decision Theatre designed a RAND computerized throughput model program to manage the maximum 79,000 throughput plan. This is a throughput plan to manage crowd flows with maximized staffing patterns.

COMMENTARY

All of these plans were added to the Tribal Public Health Emergency Preparedness and Response Plan foundation base plan as building blocks in preparation for what was ultimately expected, a pandemic influenza disease outbreak threat, so, by summer of 2009 the Fort Mojave Indian Tribe has a solid foundation with a protection wall built to address a pandemic threat.

H1N1 Phase I & II Planning 2009. We received a grant for the H1N1 Phase 1 & II Planning phase and with this fund have accomplished the following:

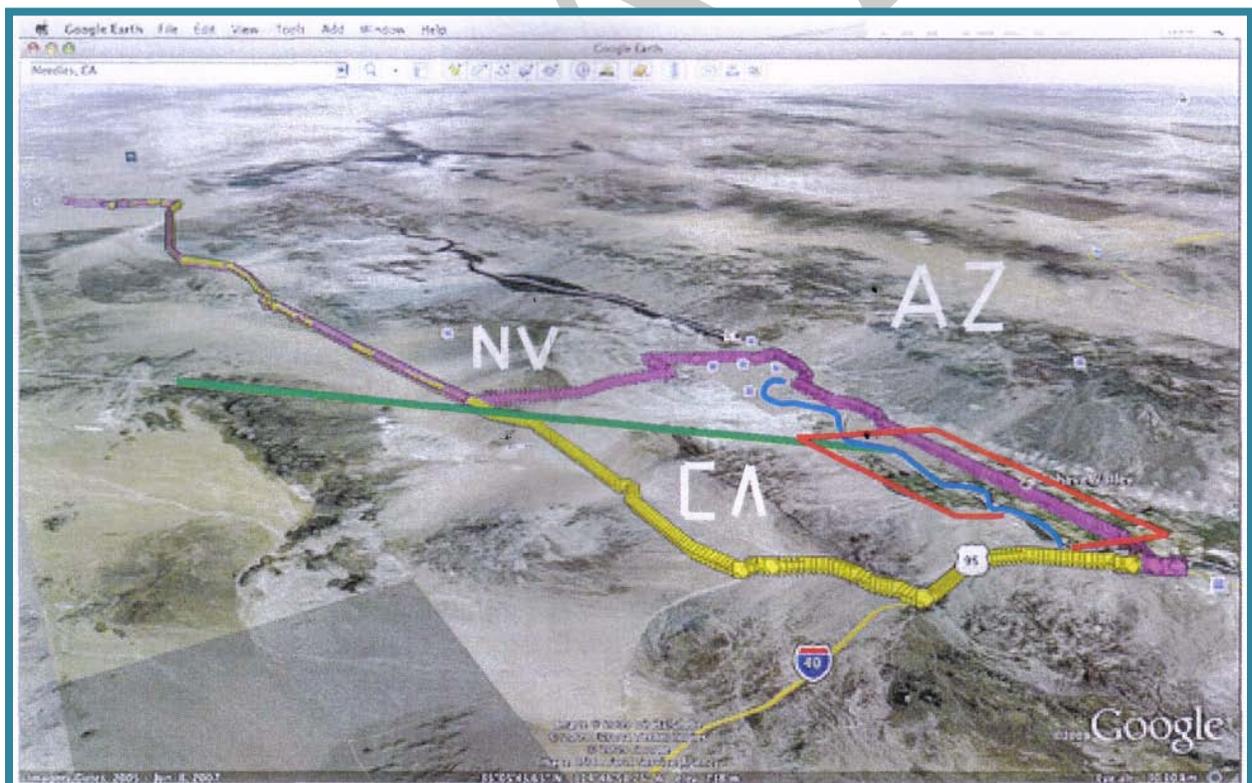
- 1- Mass Vaccination Plan. We have developed and implemented our written mass vaccination and exercise plan. We hired a professional public health educator who visited our reservation, assessed all tribal resources and developed a written mass vaccination plan specific to our real tribal conditions and capabilities.
- 2- Vaccinator Training. Our ambulatory staff is capable of vaccinating all our user populations and would be stressed beyond this in participating in a regional mass vaccination plan. This identified in our GAP assessment used our funding to train our EMS personnel in the vaccination process, this was part of the professional services provided in the mass vaccination plan.
- 3- Mass Vaccination Site Planning. We implemented a (3) stage vaccination plan, (a) clinical vaccination; (b) Arizona Gym vaccination plan for Southern Mohave Valley and (c) Event Center for our regional mass vaccination plan.
- 4- Billboard Campaign. We also participate in the Arizona H1N1 billboard campaign.
- 5- Childcare Facility Plan. We have developed and implemented the Tribal H1N1 Childcare Facility Plan which addresses tribal owned childcare facilities. This plan includes a child screening program, in-school sick children, janitorial cleaning plan, and facility closing plan with a reopen plan.
- 6- Community Outreach Program. We have developed and conducted a mass tribal H1N1 education blitz to departments and tribal communities with a power point educational presentation with encouragement to get vaccinated. We provided this to non-tribal groups when asked.

We have fully expended all H1N1 Phase I and II funding.

H1N1 Phase III Implementation. We completed our work plan with the intent of utilizing professional services to meet staff load capacity our ambulatory staff could not meet and have the following in place.

- 1- Vaccination Supplies. We obtained sufficient vaccination supplies from ADHS suppliers, Mohave County and Indian Health Services, we have ample supplies.
- 2- Vaccination Administration. We have vaccinated all our user population that wishes to be vaccinated.
- 3- Mass Vaccination Staffing. We have identified and have MOAs in place for professional services from Bullhead City Nursing Services for additional staffing should we encounter staff issues to meet mass pandemic influenza concerns.

Additional Contracted Work. ADHS at one time had a full-time *Tribal Preparedness Coordinator* and based on State reduction in staffing patterns lost this position. As sometimes is the case, you cannot hire FTEs but you can contract the work. Fort Mojave submitted a proposal to contract this service to all the tribes and has been awarded a one year contract. We provide tribes with technical assistance in the PHEP/PHER/H1N1 programs.



CDC Responders

Dr. Jay Butler 2009 H1N1 Influenza Vaccine Task Force Centers for Disease Control and Prevention (CDC)

Dr. Butler indicated that Admiral Steve Redd sent his apologies for not attending as he was called away. Dr. Butler thanked those who spoke for their testimony and for all of their work over the past 9 months. He said he thought they could all agree that it had been quite a ride, beginning with the recognition of this pandemic right in many of the tribes backyards very quickly, and in all backyards throughout the country. The issues were tricky in terms of identifying cases, understanding how much of a threat the pandemic would be, and communicating this to communities in order to strike the right balance of people having the appropriate level of concern but not be panicked.

CDC recognizes that tribal leaders are on the front lines of that, not only because they are closer to their people, but also because they know their people in ways that CDC does not. Dr. Butler said that he could not emphasize enough how critical that partnership is. The distribution of antiviral drugs was another challenge with which tribes had to struggle, and he thanked them for being able to implement that as much as they were able to. He said he recognized a lot of familiar faces from the NIHB meeting, during which he remembered telling them how much vaccine was going to be available only to be very unpleasantly surprised later when it was not. That was a struggle, particularly in terms of dealing with getting the vaccine to the people who were most likely to benefit. He expressed appreciation for personal communications with some of the tribal leaders during that time in terms of working through some of the issues.

Dr. Butler acknowledged that some specific issues had been raised thus far during the Tribal Consultation Session that illustrated very important lessons to be learned. From this session, he confessed a certain mixture of both encouragement and discouragement. Encouragement in terms of the benefits of the planning—the engagement of tribal groups in pandemic preparedness has paid off tremendously, just as pandemic preparedness has paid off tremendously at all levels of government. Partnerships existed, even though they were not perfect and sometimes they failed, but they were partnerships that in many cases did not exist even 10 years ago. Conversely, he thought the tribal leaders were telling him things that they were getting tired of saying because the problem are the same ones with which they have struggled for years. CDC recognizes that. He encouraged them not to stop pushing. Government moves slowly sometimes. Change does occur. It just does not occur as quickly as everyone would like. The lack of collaboration, communication, and data sharing are particularly painful for Dr. Butler because they seem like issues that they should be able to solve. CDC will continue to work in that direction. He said that he would be happy to speak with them individually about other issues or individual issues, so he closed with the invitation for them to contact him through Dr. Bryan. Dr. Butler stressed that this was by no means is the end of the conversation, and that he was happy to talk with any of them anytime.

Ms. Christine Kosmos
Director, Division of State and Local Readiness (DSLRL)
Centers for Disease Control and Prevention (CDC)

In addition to what she spoke about with TCAC the previous day, Ms. Kosmos said she thought this was very helpful. She said that this opportunity to look “under the covers” to see how things went well and did not go well was an honor for her. It was also striking to her when Mr. Joseph spoke of the father who died and left young children. Putting a face on something like H1N1 brings it home for everyone, especially those who are parents and are really trying to do the best by their children. CDC now plans to reach out to states, tribes, and locals to learn what they need to in order to improve things and do them better. It is one thing to sit around and develop a plan based on best guesses, but it is a completely different story when that plan has to be implemented and the best laid ideas do not go the way that was anticipated. It is very important to revisit the things that went well, and the things that did not go well. She has been discussing with her staff the importance of cataloging the things that went well and the things that did not, and developing an action plan to resolve problems at all levels (e.g., federal, state, tribal, territorial, local). Ms. Kosmos said she was not going to tell them that every single one of the problems would get fix, because they would not. However, at the end of this they would have a blueprint to move forward and strategize on the best solutions for doing things better the next time. She agreed that, as Dr. Butler pointed out, having partnerships served them well when they worked well, though there remained room for improvement. Her division plans to ask the states to complete After Action Reports about what they think went well and did not at the local and tribal levels, and to provide information about what CDC can do on the federal side to improve the response. She expressed her gratitude for the tribal leaders’ input.

Chronic Disease and Environmental Health Topics

Moderators

J.T. Petherick, Session Moderator
Nick Burton, Session Moderator

Mr. Petherick quipped that being sandwiched between two Navajos made him think of something that Jerry Freddy, a Councilperson from the Navajo Nation, always talks about. Looking at Indian Country offers a peak at the future of what is coming down health-wise and society-wise nationally. This really made Mr. Petherick think about chronic disease. For example, the epidemic of diabetes hit Indian Country first, and hit it hard. Diabetes has now become a nationwide epidemic. Obesity in Indian Country relates back to many societal issues such as federal policy regarding food, taking away native lands, et cetera. The obesity epidemic has spread from Indian Country to the rest of the country, and CDC is now responding on a national level. Clearly, Indian Country has a great deal of valuable information to offer in terms of what needs to be done nationally to address diabetes, obesity, and other chronic diseases. He suggested that serious consideration be given to what is occurring in Indian Country, because it is very likely that if they do not learn from what is taking place and intervene in Indian Country, there will be a national problem. The list of examples is lengthy (e.g., meth, environmental contaminants, et cetera). There is an opportunity to help not only Indian Country, but also all of the US and the world to address chronic disease issues. He then invited tribal

leaders to provide testimony, make commentary, and / or ask questions regarding chronic disease and environmental health issues in their communities.

A few years ago, Mr. Petherick had the opportunity to visit the farm program at the Oneida Nation, which is by far a model that should be duplicated throughout Indian Country as well as throughout the world. The way that they activate their community; provide resources and technical assistance to allow their citizens to actually have access to organic foods, including meat, poultry, et cetera; and work with them to establish gardens in their own homes, is very powerful. Sustainability is a major issue. Many times programs are developed through the grant process, so certain communities are able to implement them, but then the funding ends and they must scramble to try to keep those programs going. One of the lost opportunities is the ability for communities that do receive funding to share best practices and lessons learned with all of Indian Country. One of the issues is that typically funding runs out and they are not able to do this, but also if a tribe is interested in a program that another tribe has implemented, someone must travel there on their own, utilizing their own resources to learn those programs. Frankly, it is impossible for a lot of tribes to do this. If someone heard about something promising at the Oneida Nation and started a dialogue with Vice Chairwoman Hughes, for example, she would be very open to welcoming and teaching them. Even if they could visit Oneida Nation to learn about what they are doing, most tribes are unlikely to have the resources, manpower, or capacity to implement such programs. Perhaps there should be grant opportunities that allow tribes without capacity to successfully implement similar programs.

Tribal Speakers

Ms. Kathy Hughes

Vice Chairwoman, Oneida Business Committee

Tribal Consultation Advisory Committee (TCAC) Co-Chair

Ms. Hughes reported that the Oneida Tribe of Wisconsin is located just outside of Green Bay. They have a membership of just a little over 16,000. The obvious four priorities in Indian Country currently include diabetes, obesity, cardiovascular disease (CVD), and cancer. Ms. Hughes noted that during this session, she planned to discuss primarily diabetes and nutrition, which lead to the community obesity problem. The Oneida Community Health Center has a user population of 13,716. Of those, the diabetes population is 2,145. That is a prevalence rate of 15.6%. This is likely to be an understated number because there is a tendency for individuals who may have problems not being checked until they absolutely have to because they go into a coma, for example. There is a fear of knowing what the problem is, so many people will not go in to be tested. Obesity, particularly in the younger population, is a growing concern. Of Head Start children, 44% are in the overweight or obese category. Head Start children are comprised of 3- and 4-year olds, so they are starting very young with a problem that must be tackled and corrected as quickly as possible.

Diabetes can no longer be considered a disease that only adults get. Increasingly more children, as young as 12 years old, are being diagnosed with Type 2 diabetes. In large part, they believe that there is a cultural component because they have gotten away from traditional means of sustenance. For Oneida, that was corn, beans, and squash. There are now unhealthy snacks and unhealthy lunch programs in schools. They are trying to address all of these issues, but not all Oneida children are in the Tribal School System, which makes the effort more challenging. At least in the Tribal School System, they are working to ensure that there is no access to soda or other vending machines, and all classrooms are required to have healthy snacks. Halloween used to be a major event for children from Head Start on up. Two years

ago, they converted Halloween to a healthy snack event. Rather than giving candy at Halloween, children are given graham cracker bears, cheddar cheese gold fish, and that sort of thing. They believe by starting younger, because that is where the problem is headed, they will be able to make a greater impact over the long haul.

Communication, education, and information are extremely important. Ms. Hughes grew up as a diabetic expecting to go on a needle, which she is now on—actually, she uses several needles throughout the day. She anticipated that at some point, amputations would begin occurring. Fortunately, that has not happened yet. She also anticipated that kidney disease would occur. Fortunately, that has not yet occurred. However, she grew up expecting all of that to occur. She is trying to educate her children and grandchildren specifically that this can be prevented, and that there are things that can be done to alleviate going down the diabetic trail. Amputations still occur in the clinic, but they have decreased. Unfortunately, renal failure remains a significant factor. That is probably a leading cause of most of the deaths in her community from diabetes, although cardiovascular disease from diabetes is also very high.

They have their own food programs, and have used those to introduce food items into the school system. They have their own Buffalo and Black Angus herds. They now require that Buffalo and Black Angus be used in the food lunch program, primarily Buffalo because they believe it is a healthier meat to eat. They are now trying to introduce this into the surrounding school systems, which is more of a challenge. In their nutrition department, there are registered dieticians on staff who hold regular classes on healthy cooking in order to teach young parents how to cook healthy meals. On a quarterly basis, there is a family cooking class and lunch and learn classes.

The Oneida Community Health Center strives to educate the community on diabetes and diabetes prevention awareness empowerment. Having individuals with knowledge goes a long way toward preventive maintenance and control of diabetes. One of the programs they instituted about a year ago was the Check the Neck Campaign for acanthosis nigricans [a skin condition characterized by dark, thick, velvety skin in body folds and creases. Most often, acanthosis nigricans affects your armpits, groin and neck: www.mayoclinic.com/health/acanthosis-nigricans/DS00653]. Everywhere in the community and schools there are Check the Neck posters. This was a very successful program because it brought attention to young people about what may be occurring, and they went home and told their parents that there might be a problem. Many of those young people went in and were tested as a result. It is an on-going program in the Oneida communities.

They also engage in partnership collaborations, through which they created the nutrition wheel. Products are included on the wheel that are very familiar to tribal members, such as their sustenance items (e.g., corn, beans, and squash). The corn they normally eat are on the wheel, so they know what the calories and carbs are in a cup of soup. This was created in collaboration with Merck Pharmaceutical Company. Merck provided almost 100% of the funding, working with Oneida's dieticians to developed the wheel. With CDC funding, they developed a calendar for 2010, which includes a lot of information about diabetes, eating healthy, and exercise. It also includes healthy recipes. This type of work is on-going and needed. The problem with many of the programs is that the tribes do not have the ability to sustain programs once funding is gone. Diabetes is an on-going and growing issue, which is becoming more prevalent in younger people. A program is needed that will provide sustainability to the programs that are already in place and are working, and this is a potential area in which CDC could be helpful. The special diabetes project has been one of the most

successful federally funded programs in the last decade, but it needs to continue on a cycle that will allow them to continue programs in a manner that is helpful and beneficial to the individual.

While they know funding is going to be restricted, CDC has a lot of resources together. Oneida worked with others to develop these two items (e.g., nutrition wheel and calendar), and there are many more informational materials that can be created. Working with CDC, they should be able to do much more than they are able to do currently with the minimal funding that they currently have. Even access to CDC personnel would be extremely beneficial in doing the work Oneida needs to do with the funding they already have.

Mr. Roger Trudell
Chairman, Santee Sioux Tribe of Nebraska
Aberdeen Area

Women, children, and infants are a very serious matter. One program they had for many years in the Aberdeen Area that is gradually phasing out is the Healthy Start Program. This has been one of the better and most successful programs that they have ever had in their region. Unfortunately, they have not been able to sustain it at the level it was originally funded. Therefore, they had to start eliminating services. Soon, even communities were eliminated. The success of it has probably dwindled along with the dollars. However, it made great strides in educating parents, especially high risk parents. Infant mortality was reduced and birth weights increased. Unfortunately, as funding is reduced or removed, the effectiveness of programs is also lost. There is a community called Milk's Camp about 100 miles from Rosebud Indian Health Service Hospital. In order to receive services, the people of Milk's Camp have to travel that 100 miles. When it became evident that they would have funding to continue the coverage area, communities such as Milk's Camp and others that were far away from the central resources, were dropped and had to find ways to get there themselves. This not only affected the Rosebud Reservation, but also affected others as well (e.g., Standing Rock, Cheyenne River, Pine Ridge, et cetera). Transportation is particularly a problem for young families who have not established themselves with employment, but have established themselves with families. Trying to take care of those families is very difficult on them. Programs like Healthy Start contributed substantially to the wellness of those families and their babies. They have discussed ways to be healthier people, and it basically needs to start with having healthy children and bringing them up in a healthy manner.

Another issue is that their relatives at Cheyenne River have been without electricity for several days. Mr. Trudell's latest understanding was that, as of the evening before, they remained without power and were having to move some of their elderly people into wherever they could find shelter for them. The plumbing is frozen and they cannot use the facilities, so relocation continues. They have a request out to other tribes in the Aberdeen Area to try to assist them with items for babies and dry goods that will not spoil, so that they can get supplies out to families with babies. Hopefully, someone or some agency will help. His little tribe is in the process of determining what they can do to provide diapers, grocery items, et cetera. It would be excellent if agencies would also step up to help.

For the record, Mr. Trudell submitted the following report that was prepared by the Aberdeen Area Tribal Chairmen's Health Board Epidemiology Center:



The Chronic Disease Burden of Northern Plains American Indians

Recent statistics show substantial disparities in health between Northern Plains American Indians (NPAI) and the rest of the US. In particular, NPAI suffer disproportionately from the burden of chronic disease compared to their American Indian and Alaska Native (AI/AN) counterparts. The major chronic conditions most affecting AI throughout the Northern Plains region include cardiovascular disease (heart disease and stroke), cancer, diabetes, and needs related to oral, and behavioral, health. These diseases are among the leading causes of premature death and disability throughout the region. The determinants of chronic disease begin early in development and extend throughout the lifespan. Consequently, adequate preconception and prenatal care for women of childbearing age are important determinants of healthy birth outcomes and subsequent risk for disease in children. Chronic diseases share many of the same risk factors. Modifiable risk factors include unhealthy diet, tobacco use, and lack of physical activity. Over the years, the Aberdeen Area Office of the Indian Health Service, Tribal Health Care and the Aberdeen Area Tribal Chairmen's Health Board have developed programs to address chronic disease throughout the region. Yet, health disparities persist. A major factor is the lack of adequate and coordinated funding streams that enable the development of vital infrastructure for improving the health and well-being of Northern Plains tribal communities. The chronic disease burden among Northern Plains American Indians has been documented in the following areas:

Maternal and Child Health

- Infant mortality in the Aberdeen IHS Area of North Dakota, South Dakota, Iowa and Nebraska is the highest of all IHS service areas.¹ According to unpublished data provided by state departments of health for 2001 through 2005, infant mortality rates for AI/AN within regional states range from 9.45 to 14.37 per 1,000 live births. Sudden Infant Death Syndrome is a leading cause of infant death for AI/AN populations in the region.²

¹ US Department of Health and Human Services, Indian Health Service. (2008). *Regional Differences in Indian Health, 2002-2003 Edition*. Washington, DC: US Government Printing Office.

² Rinki C, Irving J. An Overview of Vital Statistics for American Indians in Nebraska, North Dakota, and South Dakota Key Data from the Birth and Infant Death Files. Oral presentation at the Aberdeen Area Indian Health Service Perinatal Infant Mortality Review. May 21, 2007.

- AI women participants in the 2007 South Dakota Tribal Pregnancy Risk Assessment Monitoring System (PRAMS) Project have reported high rates of intimate partner violence, which can lead to the delivery of pre-term or low birth weight infants.³ Reports of physical abuse during pregnancy were nearly 2-5 times higher among AI women in South Dakota than PRAMS participants in other states across the nation (13.3% vs 2.8-6.5%, respectively) (J Irving, personal communication, January 20, 2010).⁴
- Over one-quarter of South Dakota AI women (27.6%) reported high levels of postpartum depressive symptoms in the PRAMS Project. Prevalence of depressive symptoms was nearly double the rate reported by PRAMS participants in other states (15.7%) (J Irving, personal communication, January 20, 2010).
- Rates of self-reported binge drinking and smoking before, during, and after pregnancy among AI women exceed estimates for the US population (J Irving, personal communication, January 20, 2010).
- The majority of funding for maternal and child public health infrastructure flows to states from the Maternal and Child Health Bureau of the Health Resources and Services Administration through the Maternal and Child Health Block Grant. There is currently no mechanism for tribes to receive these funds directly from MCHB, nor any guidance for tribes to receive a portion of the funds that are awarded to states. Therefore, funding for the improvement of tribal maternal and child public health system infrastructure is dependent on tribal-state relationships.

Cardiovascular Disease

- Heart disease and stroke are the first and sixth leading causes of death for AI/AN nationally; death rates in the Northern Plains region mirror national rates and trends for these diseases.⁵
- AI/AN die from heart diseases at younger ages than other racial and ethnic groups in the United States. Over one-third of those who die of heart disease do so before age 65.⁶
- The Aberdeen Area ranks second of the 12 IHS service areas for heart disease deaths with rates that are 40% higher than the rate for all races in the US.⁷
- Overall mortality due to stroke among AI in the Aberdeen Area is only slightly higher than the US population; however, among the higher risk age groups (ages 35 to 74) rates of death from stroke are significantly higher than the US all races estimate and reflect a 2-fold increase over all IHS areas.⁸

³ Silverman, JG, Decker, MR, Reed, E, & Raj, A. (2006). Intimate partner violence victimization prior to and during pregnancy among women residing in 26 U.S. states: Associations with maternal and neonatal health. *American Journal of Obstetrics and Gynecology*, 195:140-148.

⁴ Centers for Disease Control and Prevention. (2008). PRAMS and physical violence. Retrieved from www.cdc.gov/reproductivehealth/ProductsPubs/PDFs/Physical%20Violence.pdf.

⁵ US Department of Health and Human Services, Indian Health Service. (2009). *Trends in Indian Health, 2002-2003 Edition*. Washington, DC: US Government Printing Office.

⁶ SS Oh, JB Croft, KJ Greenlund, C Ayala, ZJ Zheng, GA Mensah, WH Giles. Disparities in Premature Deaths from Heart Disease—50 States and the District of Columbia. *MMWR* 2004;53:121–25. <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5306a2.htm>.

⁷ US Department of Health and Human Services, Indian Health Service. (2008). *Regional Differences in Indian Health, 2002-2003 Edition*. Washington, DC: US Government Printing Office.

⁸ Ibid.

- Cigarette smoking, a risk factor for both heart disease and stroke, is higher among AI in the Northern Plains than for AI living in any other region in the US.⁹
- High rates of diabetes and hypertension also contribute to overall risk for cardiovascular disease among AI across the Northern Plains region.

Cancer

- NPAI are consistently diagnosed with higher rates of cancer than persons of other races, and AI from other regions. Incidence rates of all cancers in South Dakota (519.3 per 100,000) and North Dakota (576.1 per 100,000) AI from 1999 to 2004 were higher than all races in the US (475.8 per 100,000).¹⁰
- Cancer mortality rates are significantly higher among AI from the Northern Plains than all other races in the US. The age-adjusted mortality rate from 1999 to 2003 among AI in the Aberdeen Area for all-site cancer was 273.8 per 100,000 compared to 185.7 per 100,000 for Non-Hispanic Whites in the US, thereby reflecting a 47% difference in mortality.¹¹
- Incidence of lung, colorectal, stomach, and liver cancer are significantly higher among NPAI men and women than the US population, and in AI from other regions. Prostate cancer in men is the most common form of cancer in AI males; it is also diagnosed more often in men who live in the Plains states than in AI males living elsewhere in the US.¹²
- NPAI cancers are diagnosed at a later stage of progression than US Non-Hispanic Whites.¹³
- The prevalence of risk behaviors associated with cancer, such as binge drinking, obesity, and smoking among NPAI is significantly higher than among Whites in the same region and among AI/AN populations in other regions.¹⁴
- From 1997-2006, there was no statistically significant improvement among NPAI for cancer risk behaviors or cancer screening use, and there was a significant increase in the obesity rate.¹⁵
- Improvements in rates for screening for colorectal and other cancers are needed to reduce the significant disparity that exists in screening rates between NPAI and Non-Hispanic Whites across the Northern Plains region.¹⁶

⁹ Centers for Disease Control and Prevention. Surveillance for health behaviors of American Indians and Alaska Natives: findings from the Behavioral Risk Factor Surveillance System, 1997–2000. In: CDC Surveillance Summaries (August 1). *MMWR* 2003;52(No. SS–7). <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5207a1.htm> .

¹⁰ Iowa, Nebraska, North Dakota, and South Dakota cancer incidence information reported by respective state cancer registries via personal communication.

¹¹ SEER Program (www.seer.cancer.gov) SEER*Stat Database: Mortality - All COD, Public-Use With State, Total US (1990-2003), National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2006. Underlying mortality data provided by NCHS (www.cdc.gov/nchs).

¹² Espey, DK, et al. (2007). Annual report to the nation on the status of cancer, 1975-2004, featuring cancer in American Indians and Alaska Natives. *Cancer*. 110(10): 2119-2152.

¹³ Ibid.

¹⁴ Watanabe-Galloway, S, Duran, T, Flom, N, Frerichs, L, Kennedy, F, Smith, C, and Jaiyeola, A. (Submitted for publication). Cancer-related disparities and opportunities for intervention in Northern Plains American Indian communities: Trend analysis of BRFSS data.

¹⁵ Ibid.

¹⁶ Ibid.

Diabetes

- Diabetes disproportionately affects AI/AN compared with other racial/ethnic groups.
- Examination of recent trends point to increasing prevalence of diabetes in AI/AN populations during the past 16 years.^{17,18} For example, the age-adjusted prevalence of diabetes increased among all US adults, from 4.8% to 7.3% between 1994 and 2002; whereas, the age-adjusted prevalence of diabetes among AI/AN adults increased 33.2%, from 11.5% to 15.3%¹⁹ with an overall age-adjusted prevalence for AI/AN adults more than twice that of US adults.
- Diabetes prevalence increases with age up to approximately 65 years for adults. For a given age, the prevalence of diagnosed diabetes is 2 to 3 times higher for AI/AN adults than for US adults.
- Approximately 30% of AI/ANs aged ≥ 55 years were diagnosed with diabetes in a 2002 study.²⁰
- Diabetes is associated with severe and costly complications (e.g., blindness, kidney failure, lower-extremity amputation, and cardiovascular disease), disability, decreased quality of life, and premature death that continue to affect AI/ANs disproportionately.²¹

Oral Health

- Dental caries (tooth decay) is the single most prevalent chronic disease of all AI children.
- In the general population, dental caries (tooth decay) is 5 to 8 times more common than childhood asthma, the second most common chronic disease in children.
- Early childhood caries (ECC) is an especially virulent form of caries that affects infants, toddlers and preschool children. If not treated properly, ECC may lead to serious long-term effects that interfere with normal growth and development, such as the inability to get proper nutrition, impaired hearing and speech, and learning difficulties.
- The highest levels of ECC occur in AI/AN more often than in any other racial or ethnic group. Across the US, approximately 18% of 2 to 4-year olds are diagnosed with tooth decay. Seventy-six percent of AI/AN children in the same age group report a history of decay (A Jaiyeola, personal communication, January 14, 2008).
- Despite ongoing efforts to prevent ECC through community water fluoridation and health education programs, dental decay rates in AI/AN preschool children have actually increased between 1991 and 1999.

¹⁷ Valway S, Freeman W, Kaufman S, Welty T, Helgeson SD, Gohdes D. Prevalence of diagnosed diabetes among American Indians and Alaska Natives. 1987. *Diabetes Care* 1993;16(suppl 1):271-276.

¹⁸ Burrows NR, Geiss LS, Engalgau MM, Acton KJ. Prevalence of diabetes among Native Americans and Alaska Natives, 1990--1997: An increasing burden. *Diabetes Care* 2000;23:1786--90.

¹⁹ Centers for Disease Control and Prevention. Diabetes Prevalence Among American Indians and Alaska Natives and the Overall Population --- United States, 1994--2002. *MMWR* August 1, 2003 / 52(30):702-704.

<http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5230a3.htm>.

²⁰ Harris, MI. Summary. In: Harris MI, Cowie CC, Stern MP, et al., eds. *Diabetes in America*, 2nd ed. Washington, DC: US Department of Health and Human Services, Public Health Service, National Institutes of Health, 1995 (DHHS publication no. NIH 95-1468).

²¹ Ibid.

Behavioral Health

Behavioral health refers to the diagnosis and treatment needs related to mental health and substance abuse. Analysis of available data reflect significant behavioral health needs of Native Americans living in the Aberdeen IHS Service Area.

- **Substance Abuse.** National survey data reveal that American Indians/Alaska Natives (AI/AN) share a disproportionate burden of substance abuse when compared to other racial groups. There are 3 major classes of substance addiction: Tobacco, alcohol, and illicit drugs.

There are limited reliable prevalence estimates of tobacco use among Northern Plains American Indians. However, statistically significant disparities in smoking prevalence for the general population and AI living in Northern Plains states have been noted. Prevalence rate ratios vary from 2.2:1 to 2.7:1, respectively.²² The impact of nicotine addiction in tribal communities also exerts a multiplier effect with respect to secondhand exposure and its deleterious consequences.

Alcohol continues to be the most frequently abused substance in Northern Plains tribal communities. Both NPAI men and women recently reported higher estimates of alcohol use and lifetime prevalence of DSM-III-R alcohol dependence than the US population. NPAI respondents to the survey also reported initiation of alcohol use at a younger age than the general population.²³

With few exceptions, illicit drug use among Native Americans in the US is also higher than for the general population. A recent public health concern expressed by many tribal authorities in the Northern Plains is the impact that methamphetamine production, trafficking and use is having on reservation communities. However, no population-based data are currently available to support increasing trends either in the prevalence of methamphetamine use and dependence, or, treatment admissions in the Aberdeen Area.

- **Mental Health.** Suicide risk constitutes the single greatest mental health threat in Northern Plains American Indian communities. The Aberdeen Area has consistently ranked as having one of the highest suicide rates of all 12 IHS service areas. Area-specific estimates of suicide rates are not publicly available. However, it may be reasonable to assume that suicide rates in the Aberdeen Area are comparable to national AI/AN data which suggest that suicide rates among AI/AN persons, ages 15 to 34 (21.4 per 100,000), are 1.9 times higher than the national average of 11.5 per 100,000.²⁴ This rate is over 4 times higher than that of the Healthy People 2010 goal of 5 suicides per 100,000 persons.²⁵ Risk for suicide is concentrated among adolescents and young adults. **Suicide is consistently ranked as the second leading cause of death among AI/AN individuals, ages 15-34.** In general, nearly all suicidal behavior may be attributed to a major mental disorder, such as anxiety or mood disorder, and/or drug and alcohol abuse. This is also true of Native populations.

²² Kennedy, F. *Northern Plains Smoke-Free Homes Campaign* presentation, 2006.

²³ Spicer, P, Beals, J, Croy, C, Mitchell, C, Novins, D, Moore, L, Manson, S, the American Indian Service Utilization, Psychiatric Epidemiology, Risk and Protective Factors Project Team, The prevalence of DSM-III-R alcohol dependence in two American Indian populations. *Alcoholism: Clinical & Experimental Research*. 27(11):1785-1797, November 2003.

²⁴ Centers for Disease Control and Prevention (CDC). *Web-based Injury Statistics Query and Reporting System (WISQARS)* [Online]. (2005). National Center for Injury Prevention and Control, CDC (producer). Available from URL: www.cdc.gov/ncipc/wisqars/default.htm.

²⁵ Office of Disease Prevention and Health Promotion, US Department of Health and Human Services. *Healthy People 2010*.

Retrieved on January 17, 2008 from http://www.healthypeople.gov/Document/HTML/Volume2/18Mental.htm#_Toc486932699.

Other risk factors specific to American Indian populations include childhood trauma, domestic violence, racial discrimination, historical trauma, and low socioeconomic status. Targeting these underlying risk determinants with evidence-based assessment and intervention strategies may be an important next step in addressing the behavioral health of AI/AN people in the Northern Plains.

- Many AI/AN in the Aberdeen Area are unable to access mental health or addiction treatment services. Significant gaps in service delivery and barriers to service access play a role in the behavioral health disparities that continue to plague the Aberdeen Area. The lack of a coordinated, integrated delivery system further compounds the ability of many persons in need of treatment to access such services throughout the Northern Plains.

Ms. Candida Hunter
Councilwoman, Hualapai

Ms. Hunter indicated that the Hualapai Tribe is located in Northwest Arizona. Of their boundary, 108 miles is the Grand Canyon. She reported on some of their issues regarding cardiovascular disease, diabetes, and obesity. In 1984, Hualapai Tribe had no cases of diabetes in anyone under the age of 21. Currently, 25% of Hualapai Tribal members are diagnosed with diabetes before the age of 44 and the average age for diagnosis is 40. Of those diagnosed with diabetes, 87% are obese, 3% are on dialysis, and 30% have cardiovascular disease or significant risk factors. For people to receive dialysis, they have to travel 50 miles one way, leave at 3:00 AM to 4:00 AM depending on how many are going to receive services. There is also a low number of eye, foot, and dental exams occurring. The statistics indicate that the early onset of diabetes increases the chances of neuropathy and kidney failure. Compared to non-White Hispanics, neuropathy for the Hualapai is three times higher, kidney failure is seven times higher, and cardiovascular disease is two times higher.

The Hualapai Tribe has had programs such as the Special Diabetes Program for Indians (SDPI), The Healthy Heart, and other projects that have been funded. The interventions that they have used have been helpful. One example is The Healthy Heart intervention for which they recruited seven participants with cardiovascular disease, diabetes, or high risk factors. The participants received case management and education sessions, which included nutrition, how to care for their disease, and exercise mentoring. Of the seven participants, 25% lost 7% of their body weight and significantly reduced their blood pressure and HbA1c levels, and 10% were able to discontinue the use of medications. These are just statistics, but Ms. Hunter agreed that it was about putting faces to these statistics. Both of her parents have diabetes, her father has high blood pressure, her brother is at high risk of getting diabetes, and she has a daughter and nieces and nephews. These health issues cause stress on families.

Ms. Hunter works with youth a lot and one of the ways she believes CDC can help tribes is by providing dollars for capacity building so that they can educate their youth about various employment opportunities in the health field, and encourage them to become doctors who learn about disease and prevention. A problem that they have at their IHS and with a lot of positions in Indian Country is that people will come to work off the time they need to pay for their education loans back, and then they leave. This causes great hardship to their communities because it leaves a gap. They have gone as many as six months without a fulltime pharmacist in their clinic. The people who have diabetes and cardiovascular disease may not receive their medication. They may have to travel 50 miles away to the emergency room. There must be prevention efforts. It is also important to communicate to tribes about the funding that is available. They have a Health Director who is proactive in everything she does, and she is

always looking for grants. They applied for the CPPW grant, which is the first grant they have seen from CDC. When this grant came to their attention, they wondered how well CDC was communicating to tribes. As a newly elected official, Ms. Hunter is learning and indicated that she was thankful to be in attendance at the TCAC Meeting and Tribal Council Session. While it had been helpful, she encouraged better communication from CDC to tribes. Sustainable funding is very important. The programs they have had have helped their communities. They were able to open a fitness center and staff it, and the staff help people manage their diabetes, but once the grant is gone, it is not clear whether the tribe can take it over and whether their general fund could pay for it. Ms. Hunter recognized that this was part of planning also, but she wondered whether they could acquire sustainable funding and have something like Head Start or Women, Infants, and Children (WIC) funding that as long as requirements are met, funding is continued. When funding is lost, interventions and their successes decline. Earlier Dr. Frieden said that he wanted to look at facts. While maybe not everyone in Indian Country has them, the Hualapai Tribe does have facts. If everyone in Indian Country was given the funding and technical assistance, they could provide facts as well.

They just need the opportunity. In closing, Ms. Hunter expressed her gratitude for the opportunity to attend and present, and encouraged the government-to-government relationships. While they often referred to themselves as tribes and communities, they are really nations. It is good to realize that they while they all have a lot of the same issues, they are different nations that have specific ways in which they need to address those issues. For CDC to help fund, encourage, and sustain some innovative interventions would be helpful.

Ms. Dee Sabattus
Interim Tribal Health Program Support (THPS) Director
United South and Eastern Tribes, Inc.
Nashville Area

Ms. Dee Sabattus reported that United South and Eastern Tribes, Inc. represents 25 tribes along the East Coast who reside in 12 different states. Working on state-tribal relationships can be hard at times, particularly because a lot of their member tribes have less than 500 members. Thus, they are like a tiny sliver when it comes to the states. With respect to their future leaders, United South and Eastern Tribes, Inc. recently conducted an analysis of its area tribal data regarding diabetes and obesity. They found that 50% of the children are either overweight or obese, with a majority of children being obese. After conducting this analysis, they wondered how they would battle this and what the next steps should be. When the ARRA funding was announced, they were excited, but it was not clear how they could compete with other eligible groups for these funding opportunities. In the ARRA / CPPW funding opportunity, they are competing again large cities, the definition of which is "a jurisdiction with a population of over 1 million" and urban areas, the definition of which is "a population with more than 500,000." Then tribal communities and federally recognized tribes are listed. Area-wide for Nashville, the Native American / Alaska Native population is approximately 50,000. Without a specific set-aside, it is not clear how tribes can compete with large cities, states, universities, et cetera. Hopefully in the end, one or more tribal applicants will receive funding. At least whoever does can work on some of these programs and best practices, and share them with Indian Country what they have learned about how to reduce obesity rates among their children. Have 50% overweight children with a majority of them obese is sad. The need assistance, but it is not clear how to acquire this.

**Cathy Abramson, Board Member
Sault Tribe of Chippewa Indians
National Indian Health Board (NIHB)**

Ms. Abramson indicated that she was speaking on behalf of all tribal nations. She first identified the problem and then offered some solutions.

Concerted efforts by tobacco control partners and policy changes at the local, state, and federal levels in the past 10 years have reduced tobacco use rates in the United States. Unfortunately, those gains have not significantly lowered rates in specific priority populations, communities of color, which includes our American Indian and Alaska Native Population; lesbian, gay, bisexual, transgender (LGBT) communities; and those with low socioeconomic status (SES).

American Indians and Alaska Natives (AI / AN) adults have one of the highest smoking prevalences among ethnic / racial groups and suffer disproportionately from tobacco-related morbidity and mortality.

The tobacco industry continues to target priority populations with their tobacco products by tailoring their marketing strategies and developing new products.

The CDC Office on Smoking and Health (OSH) has funded the National Networks on Tobacco Control for Priority Populations since 2001, with many significant accomplishments. The National Native Commercial Tobacco Abuse Prevention Network is one of them.

The National Native Commercial Tobacco Abuse Prevention Network has identified the following priorities in need of support by the CDC:

- Assure that the American Indian and Alaskan Native (AI / AN) Adult Tobacco Survey (ATS) is implemented fully in all AI / AN communities in reservations, community service areas, and in urban settings. Provide funding directly to Tribal communities and Tribal Support Centers to implement the AI / AN ATS. The Adult Tobacco Survey is an actual tribal-specific tobacco survey designed to obtain needed data related to the use of tobacco use within a tribal community, both in a traditional way and for commercial use. Without this data the tribes are not able to effectively implement the educational programming needed to decrease the use of commercial tobacco, provide statistics on the use of commercial tobacco products within the tribal community when applying for grants, et cetera.
- Increase funding for the all of the National Networks so that they can adequately provide community-competent technical assistance, training, and materials to meet current demand with state departments of health.
- Increase funding for access to NRTs, and other cessation classes in priority populations. Assure that all state Medicaid programs and IHS services provide NRTs, and that those are available for at least 6 weeks of treatment.
- Provide funding for community leadership development to build the capacity of priority population communities and of emerging and established advocates to implement tobacco control prevention and policy change (e.g., Clean Indoor Air, implementation of FDA authority, illegal marketing, smoke-free apartments).

- ❑ Strengthen the community health infrastructure so that priority populations can better integrate tobacco into other chronic disease management.
- ❑ Provide funding directly to tribes and tribal support centers to address commercial tobacco abuse prevention and control priorities for the Tribes. Tribal communities need control to determine and address priorities and proper funding to support effective tobacco program infrastructure. In many instances, Tribes are funded by state and private grants who have set objectives FOR tribal communities based on reporting and programmatic requirements set by THEIR funders. Tribes need to have the funds to employ full-time tobacco specialists to implement projects based on objectives IDENTIFIED BY EACH SPECIFIC TRIBAL COMMUNITY / CONSORTIA to save from working around agendas of other agencies.

In addressing these issues, it is of the utmost importance that we acknowledge the need to respect sovereignty issues when dealing with the issue of commercial tobacco, and to respect the right of native people to use tobacco ceremonially / religiously. Our tribal leadership continue to learn about and realize the devastation that the use of commercial tobacco has on a tribal member / family / community. We appreciate the support of the CDC in continuing these efforts.

**Andy Joseph, Jr., Colville Tribes
Northwest Portland Area Indian Health Board
Chair, HHS Chair Tribe Council, NIHB**

Mr. Joseph reported that currently, the State of Washington plans to cut their budget by \$2 billion. To him, this meant that there would be reductions in various services such as tobacco awareness and other chronic disease programs. There is a lot of cancer affecting his people right now, and tobacco is probably one of the leading causes. Cancer does not care what color someone's skin is. He worries about all of the people in states who have to deal with secondhand smoke. Three people in his family currently have cancer, his dad and two of his sisters. One of his sisters had radiation the previous day. It is very stressful to know that many of his people are dying. His tribe had to deal with its budget as well. Last year, their death benefits rose from \$150,000 up to \$287,000—a 48% increase in the death rate on his reservation. Any chronic disease and tobacco programs will help change those rates. Some states will need that help. Definitely, the tribes with the highest disparities will need help from the federal government to ensure that they try to prevent these illnesses that will cost the government more money in the long run. He worries about his sister's children also, and her grandchildren. Many of their grandparents are raising their grandchildren because of other problems such as meth, other drugs, and other things that are impacting their people. They need to use all of their resources to provide wraparound services that will benefit other programs.

He agreed with Ms. Sebattus about applying for grants. Some tribes cannot afford to hire good grant writers. Some tribes are so small they do not qualify to apply. In the Portland area, several tribes are very small. Sometimes they will try to combine their numbers to have enough to be permitted to apply. He expressed his wish for the HHS departments to review how IHS submits their funds to tribes, which goes by user count population, as a funding mechanism. Then tribes would not have to compete against one another or large cities for funding. Responding to a request to clarify the term "user count population" Mr. Joseph responded that IHS is not a broken system. It probably scored the highest out of all of the HHS departments in terms of providing services. The problem with IHS is that they are underfunded, otherwise they would be able to take care of a lot of tribal needs. The different HHS departments should look

at IHS in terms of how to distribute their funds per user count, which is the population of every tribe. There would be a smaller user count for smaller tribes, and a larger user count for big tribes such as Navajo Nation. The funds would be divided according to user count population, or equally per person. There are different areas that are like Alaska in which services cost a lot more because of the distance people have to travel. It is all calculated out in a formula so that it helps everyone. To Mr. Joseph, it would be wiser to distribute funds through the same system so that they did not have to fight states and counties for their funding, and states and counties could not take advantage of their numbers. IHS is a federal system, so they would not have to deal with states and counties. Tribes made their agreements with the federal government, not the states.

**Mr. Joe Finkbonner, Executive Director
Northwest Portland Area Indian Health Board (NPAIHB)**

Adding to what Mr. Joseph discussed regarding user population, Mr. Finkbonner indicated that “user population” is an IHS term used to identify unique patients who visit clinics. This is a three-year running total over which they review patient utilization of facilities. If there are patients who would use multiple facilities, they are scientifically assigned to the clinic that is closest to their address zip code. An example would be that if someone lived in Whatcom County who accessed both Lummi and Nooksack, if their address was closer to Nooksack, they would be assigned to Nooksack as a unique user population even though they may use a predominant amount of the services at Lummi depending upon what resources are available at both clinics.

**Mr. Chester Antone
Tohono O’odham Legislative Councilman
Tribal Consultation Advisory Committee (TCAC) Co-Chair**

Mr. Antone requested of Dr. Sinks that the tribal leader’s documents be kept on file regarding the water and international boundary that were submitted in January 2008 and again in February of 2008. They discussed the possibility of infectious disease at that time should that wall have gone up. The wall did go up, but they still saw H1N1 come into the US, so he requested that this be kept at the forefront, given that some of the same environmental concerns raised at that time continue to exist.

**Mr. Derek Valdo
National Congress of American Indians (NCAI)
Southwest Area Pueblo of Acoma**

Mr. Valdo offered testimony regarding the environmental health hazards of mining within Indian Country. The most undeveloped resources in the US exist now on Indian lands, particularly uranium. He was pleased and displeased watching the State of the Union Address the previous evening and the proliferation of nuclear power plants. He was upset with that because he lives in the uranium capitol of the US. His home land is the Pueblo of Acoma approximately 60 miles west of Albuquerque. The Mount Taylor Range is there where the Jackpile Mine and Homestead Mines were mined in the early 1940s and 1960s. Mr. Valdo reminded everyone that in his opening statement earlier in the day he talked about the past, present, and future. There are numerous environmental health issues from the past. Their Navajo brothers and sisters are dealing with these issues consistently. Mr. Valdo offered support to their requests for studies on the health effects of uranium in their community from old mining from over 500 mines. Some things have not been cleaned up. The groundwater is contaminated. The Southwest Area

Pueblo of Acoma is downstream, so it does not look very good for them. They really would like the data to help them make better decisions as they move forward. Are really small populations of 500, 1000, or 15,000 really going to win for the needs of 300 million Americans and their dependence on energy? Probably not. Will he be successful in fighting every request to mine the land around his reservation knowing that any waste and debris is going to pollute his community?

His people have been that area since about 700 AD, and he would like to say that his grandchildren will be there thinking about the future for the next 700 years. By 2710, he would like for his people still to be there. They are tied to the land. When asked where they are from or what they do, they always relate back to their homelands. Uranium mining is critical in their area. Mr. Valdo said that he looked to CDC as the scientists, capacity, and infrastructure that can help the little guy. If the recent recession taught them anything, special interests and big business may not have the right interests at heart, and there could be another situation. He reached out with the perspective that Indian Country needs CDC's scientists and expertise as the arm and appendage of their body—that they all exist together as one within this community. Anytime the price of uranium goes above \$20, it is no good for Indian Country because it makes it more profitable for the energy companies. Unfortunately, he does not have a big pocketbook to fight them consistently. He tries to look at all possible scenarios and possible outcomes, and tries to plan for the best and worst. He asked CDC to help all of them. People are getting sick from the mines. Mr. Valdo's mom has colon cancer, which puts a face with the statistics. They must remember that the people have been there for many years and existed in harmony with the land and environment. They must go through this together educated so that they can be accountability and leave this earth for the future generations to come, because they are just renting the earth from the future.

Mr. Valdo was very impressed to hear that 80% of CDC's staff have a Bachelor's Degree or higher education. That is awesome compared to 2% in his community. They do not have that expertise, capacity, or bodies to help fight the good fight. He said he was reaching out as a common person, as someone who has been in the Pueblo of Acoma for a few years. He wants his people to be there for the next few hundred years. Uranium mining is not going to allow that if they do not learn from the past. He thanked CDC staff again for taking time to listen to the tribal leaders during this session to hear all of the needs there are. Though there are many needs, he believes they can work together as partners to leverage resources to come to some joint solutions.

Ms. Cynthia Manuel
Council Woman, Tohono O'odham Nation
National Indian Health Board (NIHB) Board Member

Regarding what Mr. Antone spoke of regarding the border, Ms. Manuel reported that about three years ago they were going to build a chemical plant right on the other side of the boundary. They were able to stop this with the Mexican government because of the water tables. Now there has been a lot of farming on the Mexican side of the boundary, and they have heard that there has been an increase in cancer in the area. They do not know whether it is from the pesticides or what it is from. She requested that CDC let them know and help them in some way if they saw the numbers go up do that they could work together.

CDC Respondents

Dr. Tom Sinks, Deputy Director National Center for Environmental Health (NCEH) / Agency for Toxic Substances and Disease Registry (ATSDR)

Dr. Sinks responded to the environmental issues that were raised. Regarding the on-going emergency response issue in the community that was experiencing problems because of extreme weather, he suggested to Dr. Bryan contacting the individual in the Secretary's office, Kevin Yeskey, who deals with emergency response issues and connects to the Federal Emergency Management Association (FEMA).

This should be very doable if the tribe makes a request through FEMA. The good news for Mr. Valdo is that the first increase in the ATSDR appropriation that has occurred in eight years was \$2 million provided specifically to ATSDR by US Representative Henry Waxman (D-California) to evaluate the health effects of non-occupational exposure to uranium in the New Mexico area near the uranium mines. That is good news; however, Dr. Sinks stressed that they certainly should not wait to clean up uranium contamination and wait for the health studies to demonstrate the problem. If contamination is known to be there and something can be done about it, EPA and others responsible for clean up should be moving ahead to clean up. It is one thing to conduct the science to determine whether there are health effects, but preventing on-going exposure is really the urgent priority. There are five agencies involved with Representative Waxman in dealing with a large plan for how to deal with Uranium in the New Mexico area.

Dr. Sinks heard from Mr. Antone and Ms. Manuel last year. He is familiar with the border, although he was not sure they were doing anything active at this point. Annabelle Allison is the major contact with all of the tribes. If there is something they can do, she will let him know.

Stephen Babb, Public Health Analyst (On Behalf of Ms. Dana Shelton) Office on Smoking and Health (OSH) National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) Centers for Disease Control and Prevention (CDC)

Mr. Babb thanked the tribal leaders for the opportunity to hear from them, and for their thoughtful comments. He heard a number of issues loud and clear, which he will definitely take back to their office. He acknowledged that the tribal leaders are the experts in the circumstances of their communities, the unique issues that they face, and the unique strengths that they have (e.g., sense of rootedness, closeness to the land, sense of family and community). He said he also recognized that each community is different and that one size does not fit all. Even rates of tobacco use differ among tribes and communities. He acknowledged the distinction between commercial and ceremonial tobacco use, which is something that CDC keeps very clear. At the same time, CDC knows that tribes are affected by some of the same forces that affect all Americans, including tobacco marketing. Probably some of the same interventions and solutions that have worked in other populations would work in tribal communities with some unique tailoring to make them fit the particular contexts and circumstances.

He heard loud and clear the importance of sovereignty, and CDC is very aware and respectful of that. He heard the messages regarding sustainability of funding. OSH provides funding through the Tribal Support Centers. A new FOA is expected to be published for that later in the year, as well as one of their National Networks and an MOU with the IHS. Therefore, those sources of funding are expected to continue. Mr. Babb also heard the importance of continuing collection and using the data from the American Indian Adult Tobacco Survey, and OHS recognizes that the best data in the world is not valuable if it is not translated into action and used to inform program and policy. He commended tribal leaders for the exciting initiatives that are underway in a number of tribal communities pertaining to tobacco control, and specifically regarding smoke-free policies. Though often not framed in this way, indoor secondhand tobacco smoke is one of the most important environmental contaminants. A number of tribal communities are making strong efforts to address that, which is commendable.

Dr. William Dietz, Director

Division of Nutrition, Physical Activity, and Obesity (DNPAO)

**National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP)
Centers for Disease Control and Prevention (CDC)**

Dr. Dietz said that the personal face the tribal leaders put on the suffering of their tribes was moving to me, and as a result he felt frustrated—as frustrated as he felt about how to address the obesity epidemic in the broad population. During their comments, he found himself thinking about Lord Jeffrey Amherst, who distributed smallpox with his blankets and wiped out some of the New England tribes, and how the broader culture and its influence in Indian Country is doing much the same thing. The “blankets” being distributed “taste good” (e.g., soft drinks, fast food, fried bread, television) and the diseases that those “blankets” carry with them cannot be seen. The frustration is in figuring out how to restore the traditional diets of the Iroquois Nation in a way that does not look backwards, but looks forward.

One of themes Dr. Dietz said he wanted to address directly was the emphasis the tribal leaders placed on programmatic efforts. The Division of Nutrition, Physical Activity, and Obesity (DNPAO) funds 25 states and spends about 10 to 20 cents per person in those states. A program cannot be run on 10 to 20 cents, so their focus has shifted to policy changes like those that are happening in the United Nations—the kinds of things that are being done in schools such as eliminating vending machines, eliminating sugar sweetened beverages, and required the consumption of local beef. Those are policy initiatives. Those are not costly. They require political will. While this is not a prescription or possibility for many of the small tribes, the larger tribes could profitably think about the policies that would influence what their people consume and how they can be active. That requires the same political will that DNPAO is struggling to create around addressing the obesity epidemic nationally. That is not going to happen with big federal programs, particularly given the budget caps indicated in the State of the Union Address. It will happen if they can create a broad movement across this country to invest in the kind of environmental restoration described by the tribal leaders. As the tribal leaders were talking, he was thinking about DNPAO’s programs which are trying to do much the same (e.g., school gardens, farm to market programs, supermarkets in inner cities, access to physicians, et cetera). A policy he thought of for new mothers while they were talking regarded whether they know if the hospitals in Indian Country are baby-friendly, meaning that formula is not the first thing that is offered to a mother. That is a policy initiative. It is an achievable outcome which could substantially change the onset of early childhood obesity, not to mention weight gain and diabetes during pregnancy, all of which predispose infants to early childhood obesity.

In closing, Dr. Dietz expressed again his frustration at not being able to have a lengthy conversation with the tribal leaders about this, because he does believe this is what they need. He said that he would love that opportunity and recognized that this short time period was not sufficient for them to begin to think together about what they could do to solve this problem. Rather than money, he thought the answer was political will, policy, and a thoughtful perspective on how one builds permanent change. He heard the word "sustainability" numerous times. Programs are difficult to sustain as tribal leaders pointed out. They require an on-going infusion of money; whereas, a policy, once in place, does not require a continuing infusion of cash.

**Jennifer Tucker, Team Lead LEG and Partnership (On Behalf of Dr. Wayne Giles)
Coordinating Center for Health Promotion (CCHP)
National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP)
Centers for Disease Control and Prevention (CDC)**

Ms. Tucker indicated that Dr. Wayne Giles sent his apologies for not being able to attend, but indicated that he really enjoyed his time with the TCAC on Tuesday morning. Dr. Ursula Bauer, who was in attendance earlier in the morning, once again sent her appreciation for the morning's session and being able to hear the testimonies and discussion.

While this was an excellent opportunity to learn, Ms. Tucker said she shared Dr. Dietz's frustration. The issue regarding the need for resources was loud and clear. It was very frustrated for her to have to say that they do not have an answer for that. CDC's budget is driven by Congressional appropriations. They are so thankful this year to have the ARRA funding for the CPPW program. This is the first time that CDC has had an influx of dollars for that amount of money to support states, tribes, cities, urban areas, et cetera. Unfortunately, it is very competitive. As Dr. Frieden said that morning, it is CDC's hope that this is going to be a pilot and more funding will come. Over 250 applications were received for the ARRA / CPPW funding, but NCCDPHP will only be able to award approximately 30 applicants. They feel the tribal leaders' frustration because they wish they could award them all. They wish they had programs in all of the states, cities, and tribes. That just echoes what Dr. Dietz said, that during this time of tight resources, they are really going to have to focus on opportunities in policy and environmental change.

Ms. Tucker assured tribal leaders that she would take back the many issues they raised, and she said she looked forward to continuing the discussion. Consideration must be given to how tribal leaders and NCCDPHP can spend more time on this to determine what the opportunities are and how to move forward.

Injuries, Suicide, and Youth / Family / Intimate Partner Violence

Moderators

Mr. Joe Finkbonner, Session Moderator

CDR Holly Billie, Session Moderator

Mr. Finkbonner introduced the designated tribal speakers, and CDR Billie introduced the CDC staff. Mr. Finkbonner then invited tribal leaders to provide testimony, make commentary, or ask questions regarding injuries, suicide, and youth / family / intimate partner violence.

Tribal Speakers

Mr. Chester Antone

Tohono O'odham Legislative Councilman

Tribal Consultation Advisory Committee (TCAC) Co-Chair

Mr. Antone offered testimony to reiterate the importance of prevention of suicide in general. While there are many youth incidences of suicide, there is also a movement toward the elder population. Though it has been only one or two, this is still significant in his area. Over the holidays, they experienced five suicides on the reservation. One of these was a young man in his late 30s whose family did not want the cause to be known. Another was a young lady about 27 who was the former Miss Tohono O'odham Nation, whose family really had no choice about it being known because it was reported in the newspaper. Copies of the article were distributed to those present.

The issue of suicide has been a problem for a while. Last year, when Mr. Antone attended NCAI Executive Session, he happened to walk into a meeting of the National Congress of American Indians' Youth Suicide Task Force. Therefore, he thought he would make some efforts in that area as well. He sat on the Health Research Advisory Council (HRAC) for HHS. At that time, as they discussed this issue, his tribe understood that they would probably be the ones who had to make the effort within their tribe because they know their community. It is a sensitive issue. Some districts will not discuss it at their meetings, while others are more open. Discussing this issue requires a different way of doing things. The task at hand is very great. It was determined that research must be within the community and by the community. They decided that community-based participatory research (CBPR) would be the best approach. The HRAC submitted testimony last year and added as an addition to that the issue of youth suicide. They received assistance from the IHS for statistics. This year they are heading in the same direction to keep this issue at the forefront, and will most likely develop another addendum. People from national organizations are currently working on testimony.

In Tulsa, Oklahoma, Mr. Antone reported to the HRAC that he refrained from writing a letter that he had been tasked to do that would go up to Secretary Sebelius regarding this issue because they needed to know what everyone was doing (e.g., NCIA, NIHB, HRAC, TCAC, et cetera). They need to come together on that issue in order to move something forward. He said that the best example of collaboration he could think of was a recent meeting in Maryland between CDC, IH S, and SAMHSA because this issue crosses over many agencies. It is their hope to provide the message that everyone is collaborating on this issue within Indian Country and the appropriate federal agencies that are tasked to deal with this issue. Some recommendations are to come out regarding suicide in Native American communities, as well as in Hispanic communities because they have some similarities. Tribal and federal partners need to continue to work together on and deal with the issue of suicide in whatever way they can.

Mr. Roger Trudell
Chairman, Santee Sioux Tribe of Nebraska
Aberdeen Area

Mr. Trudell noted that whatever begins up the Missouri River is going to come all the way down the Missouri River and works its way back up. The most recent suicides in his area were at Rosebud and Crow Creek. They have been fortunate not to have many suicides, but when they do occur, they impact them a great deal because they are a small tribe. In a large city, when someone takes their own life it will probably make the news for one day. Among tribes, it shuts down whole communities because it affects many families. It takes families and communities a long time to recover. There is no pattern in terms of who may commit suicide. They have parents who have never taken a drink in their lives and parents who have been drinking their whole lives whose children commit suicide.

It is not clear why tribal children today hate their elders so much that they do not want to be them, so they kill themselves. Mr. Trudell does not understand this, because when he was growing up, he admired his grandfather and wanted to be like him. In his mind, his grandfather was a decent man. He could not say that about his father, and he probably was not a great father himself, but because he was raised by a grandfather he knows more about being a grandfather. Today's youth want to be someone else, they want to be other cultures and learn their songs, and they do not want to learn the tribal language or songs. While it is fine to have a broad spectrum of life, everyone should know who they are and why they are that person. He wonders whether they are not teaching their young people the way they should be, what they are missing, and why their young children do not want to be them. He has no answers. Although suggestions are made to bring people in to talk to them for a day or two, they pay a lot of money for this, and once these people are finished, they pack up and go home, but the problem remains. They must find ways to address what is wrong with them as a people. They cannot simply say that a child is crazy and took his own life. Somewhere they have failed, and he will be the first one to admit it. They must find away to figure out what the problem is, and they need serious help in trying to overcome it.

Ms. Kathy Hughes
Vice Chairwoman, Oneida Business Committee
Tribal Consultation Advisory Committee (TCAC) Co-Chair

Referencing the Youth Family and Intimate Partner Violence Program, Ms. Hughes indicated that the Oneida Nation is involved in the joint program with the IHS, Bureau of Indian Affairs (BIA), Department of Justice (DOJ), and CDC. She said she thinks that they have a very good program, although she is not exactly sure what the relationship is with CDC. Oneida Nation began the program several years ago. They have groups that meet on a regular basis. The subject matter is one that people do not want to talk about. It is not an item for public discussion, but on their reservation, the group that has been very active and effective has made it known that if violence occurs, it will be made public on the reservation and someone will have to stand for the consequences. In most cases, it is men who are violent against women. They have a court system that is working with the group on the reservation so that when men go to court, they are usually referred back to the reservation and back to the group where they are required to participate in certain activities. They do not stand them up in front of a large group and call attention to them in that way, but they do make it known that the program exists and that through the surrounding court systems, the police department knows where to take them and the judge knows where to send them back to. It has been a very successful program from the Oneida Nation's perspective. Since they had been talking about so many things that were not working, she wanted to let everyone know that some things are working.

Ms. Cynthia Manuel
Council Woman, Tohono O'odham Nation
National Indian Health Board (NIHB) Board Member

Ms. Manuel reported that two years ago during Thanksgiving, three girls in one school and two girls in another school who were about 13 years old committed suicide. It has been hard and they do not know what else to do. They have gotten various behavioral programs together to talk to the people, but maybe they were not talking to the right people. She talked to Miss Tohono O'odham Nation two days before she committed suicide and she looked and sounded okay, and then two days later Ms. Manuel received a call from her brother that the young lady committed suicide and she just could not believe it. She was always with her family. She taught her nieces about culture and tradition. She was very traditional. She was a singer, a dancer, and tribal queen. She was a pretty girl with long hair. It was just unbelievable that she took her own life. Even her mother could not explain why. They need help. Maybe there is something that Tohono O'odham Nation does not know or is not doing to take care of all of the suicides in their area that someone else can help them with. She agreed with what Mr. Trudell said about youth not wanting to be like their elders. She wonders about all of the youth, and even the elders now, and why they commit suicide. She has a scanner that she listens to on the weekends, and there is so much violence. Recently someone tried to kill his wife and children. They complain that the Border Patrol should be at the border and not out, but luckily Border Patrol was the first responder there and they picked him up. They would be happy to hear about any kind of help that might work that they are not doing.

Mr. Reno Franklin
Chairman, National Indian Health Board (NIHB)
Chairman, California Rural Indian Health Board (CRIHB)

Mr. Franklin reported that in the really small community on his reservation, there was a cluster of attempted suicides in which five youth over the course of a couple of months tried to commit suicide. It was interesting because their elders got together and brought these youth back into the fold. A community effort was made to show these youth love and that the community cared about them, and helping them to plan out parts of their lives. They were lucky that this worked, and all of these youth survived whatever it was they were going through. In a small community, one suicide is devastating. One of their outreach workers, who was working with youth on their sister tribe's reservation about six to seven miles away, hung herself in front of her three-month old daughter. He was thinking about what Mr. Trudell was saying, because this was not a youth, it was the person who was talking to the youth about suicide. It makes no sense and is just confusing. The youth on the reservation fit the mold of the danger signs for obvious things, but did not. They are stuck with a community of youth up there who have now witnessed two murders and the suicide of the person who was helping them deal with the murders in a community with perhaps 200 people living there. He does not know what it is, but there is something going on. He did not know where this was just occurring in Indian Country, or how to deal with it. Their Behavioral Health Facility was tasked with talking to the youth and trying to make sense of it, but again, this was the girl who was supposed to be helping them in the first place. It is not clear whether what the staff are saying to them now even matters. There was a pretty serious trust breakdown when their counselor committed suicide.

Andy Joseph, Jr., Colville Tribes
Northwest Portland Area Indian Health Board
Chair, HHS Chair Tribe Council, NIHB

Mr. Joseph reported that about three years ago, his tribe ranked number one in the nation for suicides. They had a team dispatched through the Public Health Service system, for which Betty Hastings was the lead. In her final report, she stated that for a tribe their size and the amount of area that they cover, the funding that a tribe receives for 638 through IHS for mental health would only meet one third of the need. As he said before, IHS is a pretty good system, but it needs the resources to provide the care that would prevent a lot of the suicides that are occurring. They need psychiatrists, psychologists, and other mental health providers. It is difficult to bring people into rural areas. He has said in other testimonies that he has given, but sometimes it takes more than once for people to listen to the need. Suicide is a very serious issue. They had a completion a couple of months back. Their tribe is a timber tribe, and they had to shut down two of their saw mills, which meant that about 400 jobs in the mills and 200 jobs in the forests came to a stop. They are now on an alert status now because these individuals do not have funding to pay their bills. These types of situations could impact a lot of tribal people throughout the US. Other tribes are probably facing the same situations. He wished that all of the programs could work together to provide wrap-around service that would help each other to provide what is needed for survival. The government should consider constructing community centers and other places where young people could be. An average person might see 20 funerals in their lifetime. On an Indian Reservation such as his, it might be that many for a grade school child in one year's time. Their people have different ceremonies for how they take care of their people when they pass over, and their children have seen this more than anything, and it impacts them. The children of the young man who died from H1N1 will be stuck with that for the rest of their lives. It is like the Vietnam Soldiers who suffer from post traumatic stress disorder (PTSD), and it seems to be hereditary. Mr. Joseph watched the

State of the Union Address the previous evening, and he will be working toward asking Congress to exempt them from any freezes to their funding to prevent the government from having to care for young children the rest of their lives, because that is the path that they are taking.

Ms. Candida Hunter
Councilwoman, Hualapai

Ms. Hunter reported that suicide was the Hualapai Nation's third leading cause of death when they saw some statistics earlier in the week. They have Regional Behavioral Health and they are under Northern Arizona. A problem they have had is that they have had youth cut themselves or who have hurt themselves in other ways, and Regional Behavioral Health has said that they have suicidal risks and suicide ideation. However, they take them to the emergency department an hour away where they have to work with Mojave Mental Health, which will say there is not a problem. Mojave Mental Health does not listen to the tribes about the youth being a danger to themselves, and they do not receive support there. There is a real problem in the system in that they are trying to get help for youth who are known to be at risk, yet outside resources are shutting them out. As she mentioned earlier, Hualapai Nation has a very proactive director. They meet monthly or quarterly with their Regional Behavioral Health to try to address that issue, but they do not seem to be culturally sensitive. This is prevention and intervention that are not taking place, which could be contributing to the high suicide rates in Indian Country.

Lester Secatero, Chairman
Albuquerque Area Indian Health Board (AAIHB)

Mr. Secatero reported that they have also experienced problems with suicide. They had one young man who went to court with his relatives where the judge ruled against him, so he got a gun and killed four family members who were all related to Mr. Secatero. Mr. Secatero conducted the funeral with the four coffins, which was very tough for him. One of the churches gave them a room to conduct the funeral. Right after that, the chapter president took it upon himself to do something about it. He got together a variety of people, including law enforcement, the judge, social services, parents, caregivers, et cetera. About 50 people came together to form a committee called To'Hajiilee Community Action Team. They began meeting regularly and went to the state, from which they acquired \$20,000 per year. That is not much, but it paid for a part-time coordinator to run that program. They are housed in the Behavioral Health Center, publish a newspaper every month, and meet every two weeks. This program continues after 8 to 10 years. The coordinator is very active and wants to work with the youth. They host walks with free t-shirts, music, food, et cetera to bring people in. The police, EMS, and everybody gets involved in these walks. This program is working pretty good.

CDC Respondents

Dr. Mick Ballesteros, Associate Director for Science
National Center for Injury Prevention and Control (NCIPC)
Centers for Disease Control and Prevention (CDC)

Dr. Ballesteros thanked everyone for the opportunity for CDC staff to attend this session, and said that he was sorry that tribal communities had to deal with this issue. Everyone wishes that suicide was not an issue and that no one had to deal with it, but unfortunately it is a reality. Everyone acknowledges that it is a complex issue that does not have an easy solution. There

was a comment earlier about federal collaborations. In order to move forward, they must do better with those collaborations. NCIPC is working hard to do better with collaborations and will do better in that. They heard a lot during the day about limited resources, and collaborative efforts are the only way to leverage resources and build on successes from other federal agencies. NCIPC is working with other federal agencies such as SAMHSA and NIH to address some of these issues collectively. There was another comment about the difficulty of talking about some of these issues. There are similar challenges in some international settings, specifically in some Asian countries. They have made some progress in that area, so there may be some international models about how to encourage communities and societies to talk about and address some of these issues. He also encouraged everyone to keep thinking about injury and violence as a public health issue. As they talked about on Tuesday during TCAC, it is one of the challenges the field is experiencing, but public health has a lot to offer in terms of addressing the issue and prevention.

**Dr. Alex Crosby, Epidemiologist
Division of Violence Prevention (DVP)
National Center for Injury Prevention and Control (NCIPC)
Centers for Disease Control and Prevention (CDC)**

Dr. Crosby offered his gratitude for the opportunity to speak with tribal leaders. He agreed that the situations and incidents that they described are ones that must be taken very seriously. Trauma that occurs in a community, and as was mentioned especially in small communities, can have a very long-lasting effect and can affect generation after generation in terms of trying to address that.

Regarding some of the collaboration that Ms. Hughes mentioned, he noted that the second item on the one-page document that he distributed described a collaboration that NCIPC is trying to work with in regard to the DOJ Indian Health Service dealing with intimate partner violence (IPV) and violence against women. This page discusses some of the initial stages of that collaboration. As Dr. Ballesteros was saying, one of the things that NCIPC has tried to emphasize with that collaboration is that the different agencies have different perspectives, but it really does take a number of their strengths to really address the problem in a much more coordinated and comprehensive manner. In terms of interpersonal violence, the perspective of law enforcement often occurs after something has already happened. In order to emphasize prevention, public health tries to take a much stronger role to prevent these things before they start to occur by strengthening families, improving parenting skills, or getting children involved in their early years in pro-social activities. There are some examples, especially in youth violence prevention, that are successful. There may not be many specific examples that have been tried in Native American / Alaska Native communities, but there are some principles that Indian Country could use, test, and evaluate from these examples to see how well they work.

Mr. Trudell mentioned some of the problems within the community. With that in mind, Dr. Crosby said that while sometimes communities may feel dysfunctional, when addressing risk and protective factors of a particular health problem or disease, NCIPC examines the problem at multiple levels: What can be affected at the individual level? What about their peers and their families? What about their community? What about societally? How can we strengthen some of the clinical services? How can we prevent people from getting to the point of inflicting the injury? The community itself is not responsible for everything, because society has an influence as well. That can be the broader society or the whole US society. The programs and prevention activities that have demonstrated the most success try to address a broad range of things.

There is a slide that is used to talk about suicide prevention that shows someone standing on a ledge seemingly getting ready to jump off. A net can be put under them, but the best thing is to keep them from getting to that ledge in the first place. There are two very good examples of successful programs for suicide prevention in American Indian communities. The Life Skills Program developed by Teresa LaFromboise at Stanford University is a successful program implemented and evaluated in American Indian communities that has demonstrated success. The Natural Helpers Program was the result of a collaboration between NCIPC and IHS. This program was implemented in Dulce, New Mexico and was demonstrated to work. While these are the only two examples Dr. Crosby knows of, at least they can try to implement these.

There may be other opportunities for some of the tribes. The Garrett Lee Smith Memorial Act, which is operated out of SAMHSA, has funded 17 tribes and focuses primarily on youth suicide prevention. Those tend to be 3- to 4-year projects, so of course, the issue is sustainability at the end of those funds. However, during the years of funding they can get activities going. SAMHSA emphasizes working with programs that have a good track record, so there may be opportunities to apply for the funding through the Garrett Lee Smith Memorial Act.

As Mr. Joseph mentioned, some of the issues regarding stress in communities (e.g., the economy, loss of jobs, et cetera) is affecting the entire society in terms of homicides and suicides that are occurring in communities. Those are often in the context of intimate partner violence. What can we do to try to support communities and help people who are at risk *before* they start to engage in violent or adverse behavior (e.g., paying mortgages, daily support, et cetera). There are some examples of programs that try to do that, which have proven to be successful. It is important to do better in terms of making those things long-term and in getting them out to those who are at greatest risk. It is a matter of trying to do more with interventions that already exist and information that is already known.

**CDR Holly Billie, Senior Injury Prevention Specialist
National Center for Injury Prevention and Control (NCIPC)
Centers for Disease Control and Prevention (CDC)**

Responding primarily to what Ms. Manuel discussed, CDR Billie said she knew that when something like this occurs in a community, they just need something to grab onto. She has had the privilege of working with about 80 to 90 tribes in the 19 years she has been officially working with tribes. In the last five years or so, she has heard a real need from the tribes for people to focus on suicide prevention. She has spent 18 of those 19 years working with IHS at the community level. She discussed a couple of tribes and what they have done to try to address suicides in their communities. Most people do not know about these because they have not been written up in scientific journals or anything like that, but they are making progress in their communities. She did not mention the tribes by name because she did not have permission to talk about them, and because suicide is a very sensitive topic, but she wanted to highlight the approach that these tribes took. The common thread with these tribes was that they started something on their own without waiting for anybody from the outside to come in and do something grand.

One of the tribes was so frustrated by all of the suicides that were occurring, a small group started meeting in the community. This was not the behavioral health specialists or other professionals in the community. The group was comprised of local clergy, parents of youth who had completed suicides, and so forth. The group discussed what they wanted to do, and without having a lot of scientific statistics or background, they talked among themselves. This was very important because it is really hard to move forward with addressing any kind of issue if

people cannot talk about it. She has worked with tribes who could not even say the word "suicide" to those who were ready to do something about it. Where each tribe starts will vary depending upon their readiness to even talk about this. This particular tribe was ready to talk about it. They talked amongst themselves about what they could do to prevent suicide in the future and what they could do for those who needed immediate help. They talked about going into the schools, beginning with Head Start. Her group helped them review programs that were available. If they did not want to use an existing program, but wanted to send grandmas and grandpas to talk to small children about building self-esteem and how to solve their problems, that was fine. They decided to work in the schools and put programs in the Head Start, elementary, and high school where many of the native children attended.

In addition to that, they decided to get ready for any kind of funding that came along. Slowly, over about six months and without a professional grant writer, they thought out what they wanted in their community and what they would want to do should funding become available. They then brought in others to help them along. Basically, they decided to try to get information into the community about how to recognize signs of someone who may be thinking about taking their life, and then what to do once this recognition was made. A small amount of funding did become available in the amount of \$15,000 and they were ready. With this money, they were able to put into place some of the programs they envisioned. They also had other issues they had to deal with. That particular tribe did not trust the IHS provider who was charged with taking care of this problem and helping people who needed to talk. It took a long time for that issue to come out, but once it was finally out on the table, it became a major issue.

Another tribe CDR Billie worked with asked the youth, because it was the youth who were taking their own lives from ages 10 to 19. They got someone from the outside to come in to ask their youth why they thought this was occurring and what they thought they could do about it, what they thought the teachers could do about it, and what they thought the families could do about it. Wonderful information came out of this, and they responded to that information by bringing in resources. This tribe also wrote a mini-grant and was able to acquire about \$15,000 to start a program at their school to help youth recognize signs and train the teachers and parents about how to respond.

In closing, CDR Billie encouraged tribal leaders to start talking about suicide. Only they will know what approach will work in their communities. She also encouraged them to bring together people who really care about the issue. It is surprising who will come to something like this. In the first tribe she spoke of, people came to the meetings who they thought were just there to take pictures, which was what they had been doing in this group for a while. But it turned out that they had been attempters, and they came forth and shared their stories, bringing new life and new energy to the group. Thus, there are programs being tried with success among tribes, which she wanted to let tribal leaders know.

Open Tribal Testimony / Discussion

Ms. Kathy Hughes, Session Moderator
CAPT Pelagie “Mike” Snesrud, Session Moderator

During this session, Tribal leaders were again invited to provide testimony, make commentary, and / or ask questions regarding public health priorities in their communities.

Larry Curley, Executive Director
Indian Health Board of Nevada (IHBN)

Mr. Curley said that over the last three days he had heard many ideas, issues, weaknesses, and challenges that now lie in front of CDC as they consider this Tribal Consultation Session seriously. As Indian Tribes, and specifically from where he is in Nevada, they are looking to CDC to take a very firm and clear stand and direction on where the agency needs to go on behalf of Indian Tribes across this country. There are many issues from suicide prevention to environmental health. It is a broad category and field, but as he saw it, this Tribal Consultation Session has provided CDC with information to move ahead in some of those areas. From his view, additional things must also occur. There are agencies across the federal government that have roles and some tangential and perhaps even impinging and overlapping activities, for example, Department of Homeland Security (DHS) and the area of all-hazards programs. Programs with the H1N1 pandemic all fit together. Better and clearer coordination between CDC and DHS is paramount. In terms of what he sees, there was discussion over the last two days about tribes being treated as states. His concern about this is that at some point, someone who is brilliant is going to ask, “So, you want to be treated as states? Well, then you better start putting together systems and programs that are like states.” When that day comes, and it will, Mr. Curley looks at that as a challenge to CDC to begin to work with tribes to develop tribal capacity to establish and implement those kinds of systems within the tribes so that they are treated as and function like states—that their health departments have licensing credentials, standard development, standardization. This also fits the idea of self-government and self-determination. Those functions will truly make self-determination a reality, not just a word. He sees CDC as responsible for providing that kind of technical assistance, that kind of training to tribes, as they begin to move forward.

In addition, Mr. Curley reported that IHBN has one of the SAMHSA Garrett Lee Smith Memorial Act grants. They know that other tribes are facing the same issues as the tribes in Nevada. Nevada is looking to their youth to provide the answers, and they are working with the youth to give them those answers because they talk with none another. Reflecting on the pyramid Dr. Frieden talked about earlier in the day, the variables at the bottom impinge upon the problems related to suicide prevention (e.g., housing, poor education, et cetera). All of those variables affect the behavior of individuals. At the very top are the least effective services, such as counseling. Mr. Curley’s belief is that if they are going to save someone from doing something, they better replace it with something that is meaningful for them to do: Now what? At least in Nevada, they are focusing on the “now what” part of the suicide prevention programs.

**Kristin Hill, Director
Great Lakes Inter-Tribal Epidemiology Center (GLITEC)**

Ms. Hill thanked members of the TCAC for permitting her to submit her testimony. She indicated that the Great Lakes Inter-Tribal Epidemiology Center (GLITEC) is located on the Lac du Flambeau Reservation in Northern Wisconsin, which is a 12 square mile reservation located just a few miles from the Upper Peninsula of Michigan. She said she was especially privileged to be able to submit her testimony because she felt that she had been in such wonderful company over the last three days, and she thanked them for that opportunity. She said that much of her testimony was the result of being a tribal organization attempting to apply for grants that are published by many of the federal agencies, including CDC. She acknowledged that very eloquent testimony had been presented throughout the day from members of TCAC and other representatives pertaining to the barriers and difficulties in trying to compete for federal funds. In addition to the following testimony which she submitted, Ms. Hill offered eight recommendations that may be of assistance.

American Indian / Alaska Native (AI / AN) Tribal Officials and health care representatives serving AI / AN communities are eager to apply for competitive funding awards offered from federal, state and local agencies. AI / AN health care providers have recognized AI / AN inclusion on RFA lists describing eligible entities and appreciate participation in application rigor. Tribal programs and AI / AN organizations have been successful in receiving grant awards and benefit from expanding tribal programs and resources.

In spite of increased inclusion, many tribal applications fall short of meeting application reviewer criteria. As tribal communities continue to brace against economic stress, the burden of health care need continues to outpace available resources. Tribal communities now define their own problems, strengths, and deficiencies. Tribal staff are frequently crisis-driven, limiting time to think and plan. Health staff frequently wear "multiple hats" and are responsible for several programs at one time. Many tribal communities remain distant from academic resources and struggle to provide the scientific inductive / deductive narratives often required. Mainstream culture preference for prescribed and analytical evaluation frameworks clash with traditional "indigenous ways of knowing."

While working throughout the Indian Health Service Bemidji Area Tribes, Service Units, and Urban Health Programs, GLITEC staff participate in grant applications to support its program objectives and are increasingly asked to assist area tribes with application technical assistance. In this regard, GLITEC recognizes the impact of grant requirements which are inappropriate or unrealistic for tribal communities, limiting their ability to compete fairly. In the course of working with several CDC staff over the last four years, Ms. Hill has been witness to CDC's desire and commitment to bring needed resources to tribal communities to address health disparities resulting from long-standing inequity.

The following recommendations propose content and process improvements that would result in greater application success for Tribal communities. Ms. Hill said that she noticed that everyone had begun to engage in a language of “equality” and to use the word “equity.” While those two words are often interchanged, from her perspective, they do not mean the same thing. If they look at trying to achieve equity as treating everybody equally, they will fall short. She believes equity is not served well by treating everyone equally, but rather by guaranteeing conditions whereby disadvantaged groups can fairly compete:

1. Establish a cohort of AI / AN representatives who can participate in developing an RFA in which AI/AN communities/organizations will be eligible. At the minimum, maintain AI / AN consultants who will review the RFA prior to distribution.
2. Ensure that AI / AN representatives serve as reviewers for AI / AN applications.
3. Be prepared to negotiate alternatives to prescriptive grant requirements that reflect cultural norms and practices. This should not be viewed as minimizing expectations to accommodate a minority population but to create successful cultural alternatives.
4. Offer technical assistance as needed in addition to periodic technical assistance conference calls and web-based Q & A sites. Be available and present with AI / AN applicants. Frequently when tribal organizations call in to ask for technical assistance, they are referred to a Q & A website. This is not sufficient. They can read—they need someone to be present with American Indian people in order to understand their issues, concerns, and barriers to being able to apply and how they are trying to deal with some of the things that are published in the RFA.
5. Attempt to provide sufficient time from RFA release to due date. Quick turnaround eliminates many tribal communities and is counterproductive to gathering community involvement and support which is so critical.
6. Consider a minimum funding performance period of 3 to 5 years. Funding periods shorter than this are simply not sufficient to achieve results. While they are not turning funding away, in the proactive design of request for proposals, it is important to think in terms of the time period of 3 to 5 years as a minimum.
7. Emphasize and offer culturally sensitive evaluation alternatives such as qualitative methodology and use of storytelling techniques. Consideration must be given to the ways in which American Indians express themselves in terms of evaluation and what that might look like to be able to demonstrate the results everyone is looking for.
8. Initiate a consultation style feedback process to notify and discuss grant review scores. A “letter” listing reviewer comments is not sufficient to foster understanding, support learning, and advance tribal community skill.

In conclusion, Ms. Hill again offered her gratitude for the opportunity to present testimony and recommendations.

Consultation Summarization and Next Steps

Mr. Derek Valdo National Congress of American Indians (NCAI) Southwest Area Pueblo of Acoma

On behalf of the Tribal Nations present, Mr. Valdo expressed gratitude to those who stayed through the end to listen to the stories. The stories are long, sometimes they are redundant, and perhaps there are no answers. Tribes want to help themselves, but they are not afraid to ask for help because they may not have all of the answers. He always thinks about the team concept: Together everyone achieves more. When other partners are involved who bring in outside ideas, it helps to see “through the forest.” When thinking about the priorities that Dr. Frieden outlined in the morning in terms of more surveillance and knowledge, data is king and it is imperative in these times. Supporting states, tribes, locals, and territories will take many forms. Tribes also want to be part of increasing the impact on global health as well. They want to be part of the global solution and believe they can bring added value to this goal. In terms of health care reform, there is already a national health care system in place, but it is underfunded. They complain about IHS a lot, but if it had a lot more money, it would probably do more, better. With respect to increasing policy impact, tribes are sovereign nations. They need to implement culturally relevant policies and procedures that will help protect their people. They must put things in place that they believe will work within tribal communities, keeping in mind that one size does not fit all.

In closing, Mr. Valdo encouraged everyone to think about how they could set up some battles to win, taking baby steps to move forward as they identify areas in which they can make an impact, prove some successes, and look for ways to leverage and multiply those successes in order to move forward and go to bed at the end of the day with a good heart, happy mind, an clear conscience. He stressed to the tribes present that one thing which would help them would be to align their priorities with the six priorities Dr. Frieden outlined. Tribes do not have hospitals, so they do not have to worry about reducing hospital infections. They could scratch that one, but they could still align themselves with the other five in terms of thinking about priorities. This would give them a better chance to obtain some resources. In terms of accountability, he expressed his hope that the TCAC could help to open doors for the tribes. He invited tribal leaders to rely on TCAC as their partners as well. While TCAC members may not always have the answer, they can probably direct them to someone who does have the answer. The message Mr. Valdo left them with was that it is not always “you and I.” It is “us and we.”

**Illeana Arias, PhD, Principal Deputy Director
Office of the Director (OD)
Centers for Disease Control and Prevention (CDC)**

Dr. Arias reiterated what Mr. Valdo said. She expressed her incredible disappointment that she was unable to join them throughout the day. It is clear that this dialogue must be maintained in order to really understand the needs and, more importantly than that, figure out what must be done to respond to those needs in an effective way. Although she was unable to take part all day, she said she did take solace and comfort in thinking about the fact that what she personally believed that the real hard work, the real important work, would occur after this meeting. They clearly heard what the tribal leaders pointed out to them, their perspectives, and their requests and suggestions ranging from considering name and organizational changes to increasing support and access to and collaboration with staff. All of this will be taken into consideration, but not in the usual way that CDC takes issues into account and then issues a report a year later. Dr. Arias said she thought the critical thing would be to maintain contact on a more frequent basis in order to really address those issues and others in a very substantive way. One of the things that was very clear to her was that essentially the tribes' agenda is CDC's agenda and vice versa, which is incredibly great, because then anything the CDC does can benefit tribes and what tribes do can benefit CDC and they will not be working at odds.

When she began working at CDC, Dr. Arias first served as a Branch Chief in the Division of Violence Prevention (DVP). As complex as violence prevention is, she had a very narrow focus on violence prevention. She then became Director of NCIPC and had to expand to include unintentional injuries as well. Even though it was very broad, and was dealing with all injuries, it was still just injuries. As Principal Deputy of CDC, it is that and so much more that she confessed she did not even know existed. One thing that has been incredibly helpful is that CDC has a Director who recognizes the complexity of what it is they are dealing with, and the complexity of the demands on public health, on CDC, and on those as the community level, and who emphasizes the importance of prioritizing and focuses. One thing that will be incredibly helpful to CDC is to identify the top 1 to 3 or 3 to 5 things that the agency and tribes need to focus on together, and then very quickly after identifying those, roll up their sleeves to come up with very specific, articulate, action plans that are actually going to get them where it is they need to go. And then, of course, what happens after that is just doing it. That sounds difficult and is daunting, but if they have a good plan that is very clear about what needs to be accomplished, the probability of success will be very high. There are successes to build on and that is good, but a lot more needs to be done. With that in mind, Dr. Arias reiterated that she was looking forward to continuing to work with tribal leaders on a more frequent basis to identify the issues and quickly develop actionable plans that will actually get them all where they want to be. She thanked them for their patience with CDC's presentations, their time, their input, and their feedback on how it is CDC is helping, how it is that CDC is failing to help, and what it is that CDC can do to in order to improve upon that.

Closing / Adjournment

Ms. Kathy Hughes
Vice Chairwoman, Oneida Business Committee
Tribal Consultation Advisory Committee (TCAC) Co-Chair

In closing, on behalf of TCAC Ms. Hughes thanked everyone for enduring three very intense days. She stressed that this Tribal Consultation Session included a very good exchange of information and discussion, in large part because of CDC participation. She expressed great appreciation for that. She announced that the next meeting would be in July 2010 at a location to be announced. With no further comments offered or business posed, Ms. Hughes called for Chester Antone to offer the closing prayer.

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Attendant Roster

Tribal Consultation Advisory Committee (TCAC) Members

Chester Antone, Tucson, TCAC Chair (Tohono O'odham Nation, Councilman)
Roselyn Begay, Navajo Nation (Division of Health, Program Evaluation Manager)
Joe Finkbonner, Portland (Northwest Portland Area Indian Health Board, Executive Director)
Reno Franklin, California (California Rural Indian Health Board, Chairman)
Kathy Hughes, Bemidji, TCAC Co-Chair (Oneida Business Committee)
Cynthia Manuel, NIHB (Tohono O'odham Nation, Councilwoman)
Michael Peercy, Tribal Self-Governance Advisory Committee, Choctaw Nation of Oklahoma, Epidemiologist
J.T. Petherick, Oklahoma (Cherokee Nation, Health Legislative Officer)
Alicia Reft, Alaska (Karluk Ira Tribal Council)
Dee Sabattus, Nashville (United South and Eastern Tribes, Inc., Interim THPS Director)
Lester Secatero, Albuquerque (Albuquerque Area Indian Health Board, Chairman)
Roger Trudell, Aberdeen (Santee Sioux Tribe of Nebraska, Chairman)
Derek Valdo, NCAI (from Pueblo of Acoma, National Congress of American Indians)

Other Elected Tribal Leaders

Cathy Abramson, Sault Tribe of Chippewa Indians, Board Member
Candida Hunter, Hualapai, Councilwoman
Joyce Jones, Karluk IRA Tribal Council, Vice-President
Andy Joseph, Jr., Colville Tribes, Northwest Portland Area Indian Health Board Chair, HHS Chair Tribe Council, NIHB
Buford L. Rolin, Poarch Band of Creek Indians, Tribal Chairman

Other Tribal Organizations / Tribal Health Boards / Tribal Health Professionals

Stacy Bohlen, NIHB, Executive Director
Michael Bristow (Osage Tribe of Oklahoma)
Jessica Burger, NIHB, Deputy Director
Bridget Canniff, Northwest Portland Area Indian Health Board, Tribal Epi Center Consortium, Project Director
Kristal Chichlowska, Colville Confederated Tribes, California Tribal Epidemiology Center, Director
Alan Crawford (former AI CDC employee)
Feliciano Cruz, Pascua Yaqui Tribe, Public Health Emergency Preparedness Coordinator
Larry Curley, Indian Health Board of Nevada, Executive Director
Elaine Dado, Northwest Portland Area Indian Health Board
Maria Garcia, Pascua Yaqui Tribe, Program Manager Alternative Medicine
Tim Gilbert, Alaska Native Tribal Health Consortium, Senior Director, Community Health
Kristin Hill, Great Lakes Inter-Tribal Epidemiology Center, Director
Lyle Ignace, Coeur D'Alene, Indian Health Service, Medical Officer
Luke Johnson, Fort Mojave Indian Tribe, Public Health Emergency Preparedness Coordinator
Angela Kaslow, CRIHB, Director, Family and Community Health Services
Deborah Klaus, Navajo Division of Health, Director / Senior Epidemiologist, Navajo Epi Center

Steven Matles, Indian Health Board of Nevada, Deputy Director
Jackie McCormick, Northwest Portland Area Indian Health Board
Ruth Ojanen, Board Member, Norton Sound Health Corporation
Michael Peercy, Choctaw Nation of Oklahoma, Epidemiologist
Geoffrey Roth, National Council of Urban Indian Health, Executive Director
Paul Saufkie, Hopi Tribe, Public Health Emergency Preparedness Coordinator
Audrey Solimon, NIHB, Senior Advisor, Public Health Programs
Berda Willson, Norton Sound Health Corporation, Board Secretary

Centers for Disease Control and Prevention

Thomas Frieden, Director, CDC; Administrator, ATSDR
Larry Alonzo, Commander, US Public Health Service
Annabelle Allison, Environmental Health Specialist, NCEH / ATSDR
Ileana Arias, Principal Deputy Director, CDC
Samra Ashenafi, Health Communications Specialist, Global Health
Lynn Austin, Chief Management Official for Terrorism Preparedness and Emergency Response
Mark Austin, Plans Chief, Office of Public Health Preparedness and Response
Aneel Advani, Associate Director for Informatics
Stephen Babb, Public Health Analyst, NCCDPHP / OSH / OD
Mick Ballesteros, Associate Director for Science, National Center for Injury Prevention and Control
Ursula Bauer, Director, National Center for Chronic Disease Prevention and Health Promotion
Holly Billie, Senior Injury Prevention Specialist, National Center for Injury Prevention and Control
Lisa Briseno, Health Communication Specialist, NCEH / ATSDR Office of Communication
Kristen Brusuelas, Chief of Government Relations, State and Local Services
Ralph Bryan, Senior Tribal Liaison for Science and Public Health
Nick Burton, Public Health Analyst, OD / NCCDPHP
Maggie Byrne, Public Health Analyst, NCEH / ATSDR
Jay Butler, Director 2009 H1N1 Influenza Vaccine Task Force
Sabrina Chapple, Project Officer, Wisewoman Program / NCCDPHP
Daniel Chapman, Psychiatric Epidemiologist, NCCDPHP
Pyone Cho, Epidemiologist, NCCDPHP
Monique Colbert, Office of Public Health Preparedness and Response
Janet Collins, Associate Director for Program
Alex Crosby, Epidemiologists, Division of Violence Prevention, NCIPC
Larry Cseh, ATSDR, Environmental Health Scientist
Sean Cucchi, Associate Director for Policy, NCCDPHP
Rob Curlee, Deputy Director, Financial Management Office
Scott Damon, Health Communications Lead, Air Pollution and Respiratory Disease, NCEH / ATSDR
Veronica Davison, Public Health Advisory, NCCDPHP
Lori de Ravello, IHS / Division of Epidemiology & Disease Prevention, Public Health Advisor
Clark Denny, Health Scientists, Birth Defects Center
Bill Dietz, Director, Division of Nutrition, Physical Activity, and Obesity / NCCDPHP
Henry Falk, Director, National Center for Environmental Health / ATSDR
Sherry Farr, Epidemiologist, NCCDPHP
Roseanne Farris, NCCDPHP / DNPAO, Branch Chief
Kevin Fenton, Director, National Center for HIV, Viral Hepatitis, STD, and TB Prevention
Helen Flowers, Science Team Leader, NCEH / ATSDR

Divia Patrick Forbes, NCHHSTP / OD / OHE, Public Health Analyst
Constance Harrison Franklin, NIOSH / OD, Public Health Analyst
Michael Franklin, Senior Public Health Analyst, Financial Management Office
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Yvonne Green, Director, Women's Health
Ingrid Hall, Team Lead, NCCDPHP
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John Hustedt, Prevention Specialist
Robin Ikeda, Acting Deputy Director, National Center for Injury Prevention and Control
Sakina Jaffer, Public Health Analyst
Valerie Kokor, Public Health Advisory, Office of Public Health Preparedness and Response
Christine Kosmos, Director, Division of State and Local Readiness
John Krebs, Health Scientist, Vector Borne Diseases
Crayton Lankford, Director, Financial Management Office
Kari Leech, Water Engineer, NCEH / EHSB / Global Water, Sanitation, and Hygiene
Sarah Lewis, Health Communications Specialist, Diabetes Programs
Colleen Martin, Epidemiologist, NCEH / ATSDR
Kathleen McDavid Harrison, Associate Director for Health Equity, NCHHSTP
Judith McDivitt, Director, National Diabetes Education Program
Marian McDonald, Associate Director for the Office of Minority and Women's Health
Matthew Murphy, Epidemiologist, NCEH / ATSDR
Pamela Myers, Surveillance Partners Coordinator
James Nelson, Diversity Officer
Demetrius Parker, Marketing Communications Lead for Cultural Communications
Patricia Patrick, Public Health Advisory
Peter Penny, Procurement Analyst, DHHS/CDC/OD/OCOO/PGO/OPOE
Zina Peters, Health Marketing Communications Specialist, Global Health
Steve Redd, Director, Influenza Coordinating Unit
Bob Ruiz, Acting Director, EEO and Diversity
Dan Rutz, Global Health Communication Team Lead, Center for Global Health
Marjorie Santos, Health Education Specialist, NCCDPHP
Dawn Satterfield, Native Diabetes Wellness Program
Magon Saunders, Public Health Advisor, DDT
Puja Seth, Post-Doctoral Fellow, NCHHSTP
Tanya Sharpe, Deputy Director, NCHHSTP, Office of Health Equity
Arlene Sherman, Committee Management Specialist
Dana Shelton, Acting Director, Office of Health and Smoking
Tom Sinks, Deputy Director, National Center for Environmental Health / ATSDR
Mike Snesrud, Senior Tribal Liaison for Policy and Evaluation
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Myra Tucker, Tribal Liaison
Karen White, Acting Deputy Director, Office of State and Local Support

Lorraine Whitehair, Division of Nutrition, Physical Activity, and Obesity / NCCDPHP
Walter Williams, Office of Minority Health and Health Disparities

Other Federal Guests

Karen Ashton, Executive Officer, Region IV

Admiral Clara Cobb, OS / HHS Region IV Director

Stacey Ecoffey, Principal Advisory for Tribal Affairs, Intergovernmental Affairs, HHS

Ronald Demaray, IH S, Acting Director, Office of Direct Service and Contracting with Tribes

Deric Gilliard, Region IV, Intergovernmental Affairs

Lawrence Shorty, Public Health Advisor, US Department of Agriculture, Office of Tribal
Relations

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