

# **AT-RISK POPULATIONS PROJECT**

# TRIBAL ENGAGEMENT MEETINGS:

# **FINAL REPORT**

JUNE 2011

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# I. PURPOSE

Through a cooperative agreement with the Centers for Disease Control and Prevention (CDC), the Association of State and Territorial Health Officials (ASTHO) and the Center for Infectious Disease Research and Policy (CIDRAP) engaged tribal emergency planners, at-risk community members, and other key stakeholders to further develop model planning guidance for at-risk populations and pandemic influenza. The goal was to provide a unique opportunity for tribal officials and at-risk community members to have direct input on national policy and obtain key feedback on the needs of one of the target audiences for the guidance. ASTHO and CIDRAP used a multifaceted strategy to achieve this goal. A literature search was conducted to better understand this population and some of the unique challenges they face. A planning group was formed that included tribal members knowledgeable about health issues and other experts to assist with meeting development. At-risk individuals and national stakeholders were asked for their input. This report is a summary of the two meetings that occurred in February and April of 2009.

# **II. THE PROCESS**

The At-Risk Populations Project tribal engagement meetings were coordinated by ASTHO, CIDRAP and CDC. The goals of the engagements were to: 1) assess community values as they relate to at-risk population needs during an influenza pandemic; 2) gather input on what should be included in the guidance on assisting at-risk populations during a pandemic; and 3) obtain feedback on what will and will not work for tribes during a pandemic and suggestions for changes to better prepare at-risk populations prior to a pandemic outbreak.

A planning committee was formed and comprised staff from ASTHO, CIDRAP and CDC, and numerous subject matter experts. This group connected regularly via conference call to determine the best approach and method for reaching meeting goals.

Meeting participants were identified based on their role as an emergency planning official or member of an at-risk group. Additional participants were selected by identifying the agencies and organizations that support at-risk individuals. Care was taken to obtain permission to hold the meetings on tribal territory. The Albuquerque meeting was planned to coincide with CDC's Tribal Consultation Advisory Committee meeting, making it convenient for tribal leaders to attend. For the Mille Lacs meeting in April, each Minnesota reservation was asked to send key staff and to assist with locating potential participants. For this meeting, the facilitators and note-takers received initial training and materials prior to the event, as well as just-in-time training the day of the event.

#### **III. METHODS**

Two meetings took place. The first meeting was February 10, 2009, at the Isleta Casino and Resort in Albuquerque, N.M. It included 39 participants, many of whom were members of the Tribal Consultation Advisory Committee. The second meeting occurred on April 4, 2009, at the Mille Lacs Grand Casino in Onamia, MN, and included 66 participants.

Overall, participants were older, with few persons in the 18-30 age range. There was good representation of officials from numerous tribes in attendance at both meetings, but particularly at the Albuquerque meeting. These officials included chairpeople, health directors, and emergency preparedness coordinators. Diverse risk factors were mainly represented at the Mille Lacs meeting, including persons with chronic health conditions, limited incomes, physical limitations, the elderly and single parents. Dr. Joy Dorscher from the University of Minnesota Medical School Center of American Indian and Minority Health moderated both meetings. The Mille Lacs meeting participants received a \$50 stipend for their participation. Those who traveled more than 60 miles to attend the meeting were given the option of a free night's stay in the casino hotel and a separate travel stipend of \$50 to cover additional expenses.

Both meetings began similarly (see agendas in appendix A). The first presentation provided information on the basics of influenza; how it is spread; differences between seasonal, avian, and pandemic influenza; what could happen during a pandemic; government's plans for fighting pandemic influenza; and actions people can take to prepare. The second presentation discussed the guidance document and the At-Risk Populations Project. Question-and-answer sessions followed all presentations: experts noted the questions were sophisticated, reflecting an understanding of the complexities of addressing pandemic influenza. These presentations were followed by an opportunity for participants to share the preparedness activities tribes have conducted to recognize the achievements thus far.

In meetings, a great deal of time was spent addressing who participants believed were most at-risk. The definition of at-risk populations from the guidance was shared and participants were encouraged to consider factors that increase an individual's susceptibility to negative impacts of an influenza pandemic, versus being more susceptible to getting the disease itself.

Moderated discussions followed the presentations. Dr. Dorscher led the Albuquerque participants through a series of questions to identify obstacles tribes face in preparedness planning and to determine how tribes will use the guidance document. Finally, participants were asked to share revision suggestions that would make the guidance more useful for them. At the Mille Lacs meeting, participants studied three scenarios at their tables and answered questions. Upon completion, they were asked to identify two key statements made that day to share with the larger group. Meeting participants then voted whether they agree, disagree, or were neutral about the statements. This exercise yielded a total of 19 statements. These "pollable" statements addressed limited resources, communication methods, important planning issues, and potential solutions (see appendix C). Meeting facilitators then tabulated the responses to reflect the group's overall feedback and shared the results with them.

At both meetings, participants were asked to document any unshared questions or comments on notecards. These sentiments were combined with the rest of the feedback received during the meeting and are included in the meeting summaries. Discussions were facilitated chiefly in English; however, opening and closing invocations were given in the local spiritual leader's preferred language.

At the conclusion of both meetings, participants discussed the overall experience in a focus group, while facilitators and note-takers at the meetings offered their reflections in a post-meeting debriefing. Focus group participants agreed that the best part of the day was the information they received and the chance to learn from and talk with others. Albuquerque participants commented that they appreciated being consulted about at-risk pandemic planning. Both groups felt that they gained more knowledge as a result of the day and that additional discussions should be planned.

Although participants' responses to questions at each meeting represent only a snapshot of the opinions of a small number of people, those responses were considered in addition to the rich discussions captured by note-takers. Aspects that were appropriate and relevant were subsequently incorporated into the guidance document, *At-Risk Populations and Pandemic Influenza: Planning Guidance for State, Territorial, Tribal, and Local Health Departments.* 

# **IV. RESULTS**

### A. Themes

# **Planning Obstacles**

Meeting attendees listed limited funding, resources, personnel availability, and a lack of collaborative partnerships as the main factors that make emergency planning difficult. Participants mentioned that work is needed to build and strengthen relationships with Indian Health Service and with state and local emergency planners. Population distribution and geography were also identified as obstacles. Many tribes have very few residents per square mile, often spread over large distances.

#### Most At-Risk

Participants identified individuals living in rural communities, the elderly, people with chronic health conditions, and people with mobility issues as most at risk of negative consequences during an influenza pandemic. Other at-risk community members included single mothers, people with limited incomes, and others with no support systems.

#### **Communication Methods**

Participants at both meetings felt communication was an important issue, because many tribal members lack access to many common communication systems. Many identified trusted officials and community members as sources for reliable health information in an emergency. Included in this list were family members, local law enforcement, tribal leaders and community health representatives. Other identified modes of communication included radios, scanners, television, mail, phone and word of mouth.

# Transportation

Albuquerque and Mille Lacs attendees identified transportation as a key planning concern. Because most tribal nations are rural, transportation is essential to maintain access to adequate healthcare and prescription medications.

#### Stockpiling

Meeting participants expressed concern about stockpiling food, water and supplies. They mentioned low socioeconomic status and lack of resources as obstacles many would face. Participants suggested planners begin to address this concern now versus waiting until an emergency is imminent.

#### Registries

Although registries are a somewhat controversial issue with federal, state and local planners nationwide, tribal participants at both meetings felt they might work well on reservations. Participants commented that a registry would be a good method for storing up-to-date contact information, could help ensure that nobody is forgotten during an emergency, and may be more successful than in the general population, since most tribal planners already know most people residing on the reservation.

#### **Service Disruption**

Mille Lacs participants expressed concern over day cares and schools potentially closing during an influenza pandemic. A lack of affordable childcare would directly impact their ability to continue working, which is the main source of income. The community center was identified as a place where crucial services are available. Attendees cited the center as the information hub and the place where many elders receive meals. Concern over shortages at local pharmacies, stores and gas stations was also mentioned, particularly as such stores might be many miles apart.

#### **Population Movement**

Meeting participants mentioned the possibility of an exodus of people moving from urban areas back to the tribal community during an emergency. This could additionally strain limited tribal resources, including access to services and availability of vaccines. Others felt that people may leave the reservation and head for urban areas where more resources exist.

# **Personal Preparedness**

Another common theme discussed at both meetings was a need to promote preparedness in the community. Younger generations are accustomed to a just-in-time society, and traditional self-sufficiency has been forgotten, a participant noted. Participants mentioned a need for promoting healthy families and communities that reclaim the ability to sustain individual and community needs.

#### Isolation

Mille Lacs attendees noted numerous benefits to living on a reservation during an emergency. They have an opportunity to better control the spread of disease. Their isolation could help keep them safe. There is also a greater sense of community and extended family networks to care for each other. Also, spiritual care is provided on the reservation.

#### **Traditional Healers**

Numerous questions arose about how traditional medicine might play a role during an influenza pandemic. Participants said they might call on traditional healers for advice on how to stay healthy, home remedies, health ceremonies, counseling and guidance.

# What Tribes Want Public Health Officials to Know

Participants at both meetings identified sovereignty and the true capacity of tribal governments as two concepts they wished public health officials better understood. Ignorance about sovereignty may be viewed as disrespect toward tribal governments. In addition, tribes could assist local health agencies with regional pandemic planning.

# V. SUMMARY

The ASTHO At-Risk Populations Project tribal engagement meetings achieved their objectives. A significant number of tribal officials and at-risk members came together to discuss who they felt was most at-risk, their potential needs during a pandemic, some potential solutions to those needs, and their recommendations for improving the guidance. Discussion was rich, and participants offered a variety of suggestions, many of which are being included in the guidance document.

The project also provided many lessons regarding the public engagement process with tribal populations. Reaching out to a specific population requires adequate planning time so that sufficient care is taken to identify and respect culturally specific considerations. For example, an opening and closing prayer was conducted at both meetings by local spiritual leaders. Small ceremonial offerings of tobacco were distributed as part of the facilitators' request that people participate in the meeting. The meeting location was also important. Holding the meetings on tribal territory not only made it more convenient, but also lent to a greater sense of comfort and ability to openly share thoughts and beliefs. Although participation was adequate, more representation from underrepresented tribes would have contributed to the richness of the insights provided. Nonetheless, the information provided was very useful for the guidance revision process. For a complete summary of each meeting, see appendix B and C.

**VI.** APPENDICES

**Appendix A: Meeting Agendas** 

# **AT-RISK POPULATIONS PROJECT**

# **TRIBAL CONSULTATION ADVISORY COMMITTEE ENGAGEMENT**

# AGENDA – FEBRUARY 10, 2009

8:00 – 8:30 AM	MORNING PRAYER CEREMONY REGISTRATION CONTINENTAL BREAKFAST	
8:30 – 9:00am	WELCOME AND INTRODUCTIONS	ANNA BUCHANAN Senior Director, Immunization and Infectious Disease, ASTHO CAPT PELAGIE (MIKE) SNESRUD Senior Tribal Liaison for Policy and Evaluation, CDC CAPT RALPH BRYAN Senior Tribal Liaison for Science and Public Health, CDC
9:00 — 9:15 ам	PANDEMIC INFLUENZA OVERVIEW AND PREPAREDNESS PLANNING	<b>CDR Scott Santibañez</b> Medical Officer, USPHS, CDC
9:15 – 9:30 ам	INTRODUCING THE GUIDANCE This session will describe what ASTHO and CIDRAP are, and the context and goals of the At-Risk Populations Project.	CAROLINE BARNHILL Senior Analyst, Infectious Disease, ASTHO AMY LAFRANCE Project Coordinator, CIDRAP
9:30 – 10:15 AM	MODERATED DISCUSSION ON TRIBAL ACCOMPLISHMENTS IN PREPAREDNESS PLANNING Learn about preparedness activities tribes have conducted that have proved successful.	ALL PARTICIPANTS
10:15 — 10:30ам	BREAK	

10:30 – 11:15AM	<b>MODERATED DISCUSSION:</b>	ALL PARTICIPANTS
	TRIBAL CHALLENGES IN	
	PREPAREDNESS PLANNING	
	Learn what issues tribes	
	face due to geography,	
	infrastructure, sovereignty,	
	healthcare availability and	
	access, affordability,	
	health disparities,	
	population growth, and	
	access to the Strategic	
	National Stockpile, etc.	
11:15 – 12:15рм	<b>MODERATED DISCUSSION:</b>	ALL PARTICIPANTS
	TRIBAL IMPLEMENTATION OF	
	THE GUIDANCE	
	Participants will discuss	
	how tribes may implement	
	the guidance document.	
12:15 – 12:30 РМ	WRAP-UP AND NEXT STEPS	Anna Buchanan
		Senior Director,
		Immunization and
		Infectious Disease, ASTHO
12:30 РМ	LUNCH AVAILABLE	
	Post-Meeting Activities	
12:30 – 12:45 рм	FOCUS GROUP ON MEETING	INTERESTED PARTICIPANTS
	PROCESS	
12:45 – 1:45 рм	DEBRIEFING	PLANNING COMMITTEE

# **AT-RISK POPULATIONS PROJECT**

# **MEETING WITH TRIBAL MEMBERS IN MINNESOTA**

# AGENDA - APRIL 4, 2009

8:00-8:30 AM	<b>REGISTRATION &amp; CONTINENTAL BREAKFAST</b>		
8:30-9:00am	WELCOME, INVOCATION, AND INTRODUCTIONS		
	Joy Dorscнer Director, University of Minnesota Medical School Center of American Indian and Minority Health		
	JOE NAYQUONABE		
	Mille Lacs Band of Ojibwe		
	Dr. Salina Rizvi		
	Mille Lacs Band of Ojibwe Health Service Dire	ctor	
	JAMES BLUMENSTOCK		
	Chief Program Officer, ASTHO		
	TOBY MERLIN		
	Deputy Director, Influenza Coordination Unit,	CDC	
	CAPT PELAGIE (MIKE) SNESRUD		
	Senior Tribal Liaison for Policy and Evaluation	, CDC	
	Amy Becker LaFrance		
	Project Coordinator, Center For Infectious Disease Research and Policy		
9:00 – 9:15 AM	Your Turn	JOY DORSCHER	
	What do you want to learn about pandemic influenza today?	Moderator	
9:15 – 9:35 AM	PANDEMIC INFLUENZA OVERVIEW AND	CDR SCOTT SANTIBAÑEZ	
	PREPAREDNESS PLANNING	Medical Officer, USPHS, CDC	
9:35 — 9:50 ам	QUESTIONS & ANSWERS	ALL PARTICIPANTS	
		Moderator: Joy Dorscher	
9:50-10:15 AM	Your Turn	ALL PARTICIPANTS	
	Recognizing the achievements of Minnesota Tribes	MODERATOR: JOY DORSCHER	
10:15 – 10:30AM	Вгеак		

10:30 - 11:00AM	INTRODUCING THE GUIDANCE/ Q&A	CAROLINE BARNHILL
	This session will describe the project.	Senior Analyst, Infectious Disease, ASTHO
11:00-11:25AM	YOUR TURN	ALL PARTICIPANTS
	Scenario 1	Moderator: Joy Dorscher
11:25 — 12:10рм	LUNCH	
12:10 – 12:30рм	Your Turn	TALK AT YOUR TABLE
	Scenario 2	FACILITATOR AT TABLE
12:30- 12:50рм	Your Turn	TALK AT YOUR TABLE
	Scenario 3	FACILITATOR AT TABLE
12:50 – 1:30рм	DISCUSS MAJOR THEMES	ALL PARTICIPANTS
	Statements will be shared and displayed on a screen. Participants will use bingo daubers to vote on ballots at each table.	Moderator: Joy Dorscher
1:30 – 1:50pm	BREAK AND SNACK	
1:50 – 2:10 pm	VOTING RESULTS	JOY DORSCHER
2:10 – 2:15 pm	WRAP-UP AND NEXT STEPS	JAMES BLUMENSTOCK Chief Program Officer, ASTHO
2:15 – 2:25 рм	CLOSING INVOCATION	
2:25 – 3:15 PM	FOCUS GROUP DISCUSSION	INTERESTED PARTICIPANTS
	& PARTICIPANT STIPENDS PAID	
3:15 – 3:40 pm	DEBRIEFING	FACILITATORS, NOTE-TAKERS AND CIDRAP STAFF

# TRIBAL CONSULTATION ADVISORY COMMITTEE ENGAGEMENT MEETING SUMMARY

### FEBRUARY 10, 2009

**Date/Location**: The Association of State and Territorial Health Officials, in conjunction with the Centers for Disease Control and Prevention (CDC), and the Center for Infectious Disease Research and Policy (CIDRAP) held a meeting on Tuesday, February 10, 2009 from 8a.m. to 12:30 p.m. at the Isleta Casino and Resort in Albuquerque, NM.

**Purpose:** The purpose of the engagement meeting was to identify the needs of tribal members who are part of at-risk groups for inclusion in the At-Risk Populations Project Guidance revision.

**Attendees:** Attendees included members of CDC's Tribal Consultation Advisory Committee and other invited tribal agency representatives (see list at end of summary).

Morning Prayer: A local tribal leader led the group in morning prayer.

**Welcome and Introductions:** Anna DeBlois Buchanan, Senior Director, Immunization and Infectious Disease, ASTHO; Capt. Pelagie "Mike" Snesrud, Senior Tribal Liaison – Policy and Evaluation, CDC; and Capt. Ralph Bryan, Senior Tribal Liaison – Science and Public Health, CDC welcomed and introduced project staff. Toby Merlin, deputy director, CDC Influenza Coordination Unit thanked participants and provided a background to the At-Risk Populations Project. Ms. Buchanan reviewed the goals and agenda for the meeting. She emphasized the need for assistance in identifying who within tribes will be more vulnerable to negative consequences during a pandemic.

**Presentation—Pandemic Influenza Overview and Preparedness Planning:** Capt. Scott Santibañez, medical officer, CDC Influenza Coordination Unit, gave an overview of pandemic, seasonal, and avian influenzas and asked participants to think of people they knew who may be at risk during a pandemic. He described tools that fight influenza such as vaccines, antiviral medications, and community mitigation practices. He spoke about basic preparedness activities such as storing extra food and supplies; developing communication plans; practicing behaviors that help to keep people healthy; planning for children at home versus school/daycare; and making home and work environments safer. He emphasized the importance of planning for at-risk populations.

#### **Questions and Comments:**

- How long will a pandemic last? (Response: They occur in shorter waves but can last 12 to 18 months.)
- Many tribal members lack email, Internet, and other common communication systems, which could pose a problem during an emergency.
- Storage of food and water is a concern. It is important to get this information out to the community, so members know what steps to take. Some tribal radio stations could get messages to some remote populations. The New Mexico Department of Health is distributing

emergency preparedness handouts that include artwork by native artists. They are geared toward students and senior citizens.

• Registries are a controversial national issue. Within the Navajo nation, it might be easier to have a registry to identify people who are more at risk.

**PRESENTATION – INTRODUCING THE GUIDANCE:** Caroline Barnhill, Senior Analyst, Infectious Disease, ASTHO, reviewed the background of the At-Risk Populations Project and the guidance components. She highlighted that it is not a mandate, but rather a document intended to assist planners. Ms. Barnhill explained that ASTHO and CIDRAP are meeting with tribal leaders to help shape the document and emphasized that "at-risk populations" refers to people at greater risk of consequences in a pandemic, rather than at risk of infection.

#### **Questions and Comments:**

• It is too bad that the Panflu.gov Web site is not listed in the guidance. (Response: We have the CDC workbook listed within the tool section for assistance but will revisit adding panflu.gov.)

**MODERATED DISCUSSION – TRIBAL ACCOMPLISHMENTS IN PREPAREDNESS PLANNING:** Joy Dorscher, Director, University of Minnesota Medical School Center of American Indian and Minority Health, facilitated the discussion sessions of the meeting. Dr. Dorscher explained that meeting notes will be shared with Tribal Consultation Advisory Committee members and encouraged people to speak up directly or write comments on index cards.

#### 1) What Activities are Occurring in Your Community to Prepare for Pandemic Influenza?

- a) The Navajo Nation held two (2) mass vaccination exercises in 2006 and 2007 with county and federal representatives to test points of dispensing and in 2007 alternate sites. Their pandemic flu plan is constantly updated and will include memoranda of understanding with local communities and resources. Their planning comprises 110 chapter communities in three (3) states - Arizona, New Mexico and Utah. Community health representatives distribute emergency information, in addition to their many other tasks. Many members of their large nation are geographically isolated and do not speak English. The Navajo Bioterrorism Program has hired a public information officer who is fluent in Navajo. The Navajo Division of Health and Dine College are working together to develop new Navajo words for current terminology (e.g., "bioterrorism," "disease transmission," "avian flu"). They are also enhancing their communications plan, sending handouts home with schoolchildren to share with their parents and preparing their joint information center (JIC) plan. Recently, the state of Arizona recognized the Navajo Nation as a Strategic National Stockpile site, and is developing a memorandum of understanding to confirm this verbal acknowledgement. On March 24 to25, 2009, the Navajo Nation is hosting a pandemic flu conference related to the basic understanding of pandemic influenza and developing an emergency plan. They are also holding National Incident Management System trainings (700a, 100a, 200a) for the general public, executive employees, and response personnel. They find it difficult to bring people to the table because people have so many other obligations.
- b) Community health representatives are a major part of tribal outreach. They know where enrolled members live. Some tribes work with law enforcement and even use GPS mapping. Navajo Nation participants shared an example of community health representatives helping to deliver food and medical supplies during a snowstorm that eventually led to their use of GPS mapping for future emergencies.

c) The Oneida tribe began planning by having the tribal council take National Incident Management System training. Their emergency plans will continue to change as they have more discussions and test their plans. A tornado forced them to implement their plan two years ago. Property damage was the largest concern. They noted problems with communications systems and the need for sturdier vehicles to reach remote areas. The tribe has satellite phones so that they do not have to rely on cell phone towers, and they have a call-down process. Their greatest challenge is establishing a working relationship with the local government and emergency planners. Tribes often lack the resources needed to adequately respond to a major emergency, yet many tribes lack strong government relationships to obtain additional help. Oneida representatives suggested the need for regulation to outline the needed coordination and cooperation between local municipalities and tribes.

#### 2) Who Do Tribes Trust to Provide Accurate Information About Emergencies, and Why?

- a) Northern California tribes purchased boxes for each household to receive messages from the National Weather Service because of the threat of fires. They also hired an environmental health safety officer to do community emergency response team training. They held a meeting with regional county officials about respecting sovereignty, but they felt that the emergency planners seemed more interested in talking about coordination. They were, however, able to discuss the differences between local and tribal planning, including how they will distribute medications.
- b) The guidance must not offer a "cookie cutter" approach to tribes because each tribe is unique.
- c) One Cherokee tribe, a fishing community, uses VHF (two-way) radios both in boats and homes. Tribal authorities are working on getting everyone into the habit of leaving VHF radios on yearround, not just during fishing season. HAM (amateur) radios are another alternative mode of communication.
- d) One participant noted it is important to consider how tribes within a region will communicate with each other in an emergency.
  - i) Ms. Buchanan noted that ASTHO welcomes suggestions from tribes on types of technical assistance they might need relevant to the at-risk populations project.
  - ii) Capt. Snesrud noted that a CDC team has written a paper on vulnerable populations in tribal communities.
  - iii) Capt. Bryan talked about a multipronged approach, with training and resource materials to facilitate local tribal partnerships.
- e) The Cheyenne River Nation has been holding monthly meetings and setting up an exercise to test their points of dispensing. They have been working closely with two local counties and have attended annual meetings at the state level with seven other tribes. These meetings resulted in sharing documents, which they hope will lead to a cohesive plan. For the first time, they are employing a homeland security coordinator. They recently had to activate the emergency preparedness team due to lowland flooding. They have also encountered droughts that caused disease.
- f) Another representative explained that Tribal Consultation Advisory Committee members may represent a large number of tribes. ASTHO and CDC may need to connect with, fund, and involve area Tribal Epidemiology Centers to help the tribes build collaborations, develop plans and create registries.

- g) The director of the Navajo Area Epidemiology Center explained that the need is great for resources and funds. The Tribal Epidemiology Centers lack resources and are vastly underfunded. The centers have the capability to assist tribes with many kinds of projects and issues, such as preparedness and surveillance work.
- h) Participants expressed distrust in "health care officials," claiming that many of them seem to only be interested in higher salaries and neglect care of elders. The Indian Health Service has not been sufficiently involved in tribal emergency preparedness planning. Without their participation, it will be extremely difficult for many tribes to adequately respond during public health emergencies, such as a pandemic. This is mainly because many healthcare facilities on tribal lands are run by the Indian Health Service. Consequently, during public health emergencies, tribes may not know when their local hospitals have reached surge capacity, when alternate sites for healthcare are being set up (or where), whom they should turn to during health emergencies, and so on. Indian Health Service must become an active partner in such planning with tribes whose healthcare facilities they still run.i) Dr. Dorscher confirmed that the generally trusted means of communication is person-to-person contact. This tends to be a time-consuming and costly method of communication.

#### **MODERATED DISCUSSION – TRIBAL CHALLENGES IN PREPAREDNESS PLANNING**

#### 1) What Factors Make It Difficult for You or Your Tribe to Prepare for a Flu Pandemic?

- a) Funding
- b) Personnel availability
- c) Getting the Indian Health Service to come to the table. Tribes need their expertise and supplies in an emergency. This year, a deliverable was taken away that had previously forced Indian Health Service to communicate with the tribe about what was happening. Insufficient Indian Health Service funding and a lack of medical doctors at its facilities further reduce access to health care.
- d) A fundamental difference among tribes is population distribution. The density on land in northern California is about eight people per square mile, while the population receiving health services from Indian Health Service is about half a person per square mile. Under the Indian Self-Determination and Education Assistance Act, tribes have many small operating units. A program may serve hundreds of people.
- e) Geography is an issue in Strategic National Stockpile material distribution, as tribal members may live in isolated areas without paved roads, slowing emergency response.
- f) Reliable modes of communication are difficult to identify. The Navajo Nation uses a microwave band (when available). Satellite phones often do not work when it is cloudy, and cell phone reception is spotty, especially in canyons. The 2000 U.S. Census data reported that only 40% of Navajos owned phones. The most reliable modes of communication at a given time might take priority over more generally trusted modes.
- g) Transportation is also an issue. In urban areas, people are going to try to get to the nearest facility, which will cause an influx at those facilities.

- h) Tribal governments often feel left out. Governors rarely visit and a mechanism for formal tribal representation to the state may not be in place. Tribes should be included and reflected in the government planning documents, and tribal leaders need to be included in planning.
- i) Many tribes are unclear about where federal agencies stand on stockpiling. Do the USDA, EPA, or FDA assist in this process? Many people simply cannot stockpile three months worth of food, water, supplies, and medications, or even shorter-term amounts. This is due to economic or resource limitations. For example, many people on Navajo Nation still haul water, because they do not have in-door plumbing or other access to potable water. It is difficult even to obtain a 30day supply of medicine through tribal clinics.
- j) Youth need to learn about self-sufficiency and planning/storing food for meals.
  - i) Capt. Bryan suggested better messaging about economical approaches to stockpiling.
  - ii) Dr. Merlin said the USDA has not been significantly involved in pandemic flu preparedness planning and that government stockpiling advice is not very practical. Yet, he added that some stockpiling is better than none.
- k) Some participants were unsure how to prioritize pandemic planning. The economy is taking center stage right now. It may be advisable to educate the entire country, possibly via a national educational campaign, on preparedness (similar to civilian "duck and cover" training for nuclear attacks).
- I) There is a need for appropriate orientation and training materials. Tribes need to promote healthy families that respect and care for each other. They need reminders of what to do as families, individuals, and communities to reclaim ownership of these issues.
- m) A suggestion was made to develop official recommendations from a formalized consultation with Tribal Consultation Advisory Committee on these concerns. An example of one of the recommendations would be to allow Northwest tribes to fish for salmon during the summer, so that they have food all winter long. Encouraging self-preservation is a form of stockpiling.
- n) In New Mexico, the emergency response act includes pandemic influenza but no mechanism for tribes to work together; they may need to develop memorandums of understanding. Tribes could develop a template to get other entities involved to work together and share resources.

# 2) What do Public Health Officials Need To Know When Working With Sovereign Nations?

- a) Some tribal facilities can handle some of these situations much better, more efficiently, and faster than some local public health agencies. Local governments often do not understand the tribal government's true capacity. Tribes could help with a lot of the planning and take a burden off of local health agencies, if they were included in the discussions.
- b) Lack of respect is a big issue. Nontribal governments often do not understand sovereignty. It is critical that the tribal nations have the support of CDC to push the states to work with tribes. Example: The regional corporations have more power in Alaska than the tribes. Tribes always seem to have to fight for issues around sovereignty.
- c) Many reservations include both tribal and nontribal residents, so tribal services may absorb care for many non-natives during a major emergency. Many non-natives live near a reservation and will also likely rely on reservation services when an emergency happens, such as during a quarantine scenario. Many tourists may have to be cared for by tribes during emergencies. How can resources be obtained to provide help to these populations?

- d) A participant noted that in her state, communication generally occurs between the state and tribal nations. One solution would be for tribes to become more involved with the general election process. Some representatives at the state level know the tribal members well. It is important to let politicians know that tribes have an influence via their employee and vendor base.
- e) Tribes differ in their capacity and their relationship to resources, such as control over land, healthcare capacity, language, isolation, economic well-being, weather, roads, and education.
- f) In 2003, Gov. Bill Richardson (NM) mandated that agencies have a tribal consultation plan for government-to-government relationships and receive education on sovereignty. The result was greater legislative involvement for tribes.

#### MODERATED DISCUSSION - TRIBAL IMPLEMENTATION OF THE GUIDANCE

#### 1) Who Do You Consider Most At-Risk of Consequences of an Influenza Pandemic?

- a) Single parents who have a limited income may not be able to prepare ahead of time or need daycare.
- b) People with chemical addictions-routine programs may not be available for support.
- c) Patients with current medical needs; many have to travel significant distances to access services off the reservation.
- d) People with special diet restrictions (e.g., renal patients).
- e) People who will lack access to daily medications (e.g., blood pressure, diabetics, chronic pain).
- f) Homeless/transient population.
- g) Tourist population.
- h) Gamblers.
- i) Businesses-if casinos close, there will also be an economic impact on the reservation.
- j) Group homes for disabled people, nursing homes, those that rely on assisted living, homecare.
- k) Families who are fleeing reservations (refugees due to the emergency). Where do they go?

# 2) What do You Feel You Need in Order To Advance Your Planning Level of Pandemic Preparedness? What Does Your Community Need?

- a) Continuation of planning and building partnerships.
- b) Training for tribal councils and health boards and increasing awareness of what could possibly happen.
- c) Access to the tribal services infrastructure that is present on the reservation for people residing off the reservation.
- d) Home dialysis or a traveling dialysis unit.
- e) Child care/school emergency planning.
- f) Transportation for people with chronic medical conditions that need care (community health representatives can only do so much). Often healthcare is many hours away.

- g) What about the addicted and those who suffer from chronic pain? Do we stockpile needles and drugs for them? What domino effect might occur if the supply chain is disrupted for an extended period of time? What if 12-step programs are discontinued for a year? What happens when people become desperate?
- h) Resources should be better coordinated. We need to look at what resources we already have that we could better use during an emergency, such as Army Reserve offices, staff, and supplies.

i) A significant coordination effort needs to take place nationally, such as with the Department of Defense and the Department of Transportation to control our borders/ports, to support all citizens, to share and best use all resources to sustain life. Has ASTHO/CDC communicated with DOD on a pandemic flu plan for civilian employees of these installations? A lot of tribal members work at these facilities.

- j) The Substance Abuse and Mental Health Services Administration has had years of tribal involvement.
- k) Tribal members value their livestock and may need support for animals as well.
- I) Workforce development, such as training tribal workers (e.g., community health representatives) to further assist during emergencies (i.e., to assist with triage, giving vaccines).
- m) More nurses or others trained in health within the community.
- n) Community resiliency programs will be needed.

#### 3) Discuss The Current Draft of The Guidance and Its Features.

- a) Is this useful for tribal preparedness planning?
- b) What might make it more useful?
  - i) Consider terms, such as *social distancing*. Cultures are different and also may not understand these terms. Other cultural issues such as gatherings at funerals, need to be considered. How can we maintain cultural practices and safety?
  - ii) Geography is so important in a way that others need to understand; the issues are different.
  - iii) Site visits are highly encouraged!

**Wrap-Up and Next Steps:** Ms. Buchanan concluded by thanking everyone for coming and affirming that the CDC, ASTHO and CIDRAP will take heed of what was said during the meeting. She noted that they had heard some new things and things that they had heard frequently during this project. Next steps will be to distribute notes to Tribal Consultation Advisory Committee members. She welcomed any and all comments after the meeting.

NAME AGENC		Agency
1	Alicia Reft	Karluk Ira Tribal Council
2	Amy Becker LaFrance	CIDRAP
3	Amy Groom	CDC NCIRD Immunization Services Division/Indian Health Service
4	Andrea Petersen	CIDRAP
5	Anna Buchanan	ASTHO
6	Ardys Cook	Cheyenne River
7	Audrey Soliman	National Indian Health Board

#### **Meeting Attendees**

8	Brenda Granillo	Arizona Center for Public Health Preparedness
9	Bruce Everett	CDC Division of Strategic National Stockpile
10	Caroline Barnhill	ASTHO
11	Chester Antone	Tohono O'Odham Legislative Council
12	Cheyenne Jim	Navajo
13	Claudia Miron	CDC
14	Davis Filfred	Navajo Nation
15	Deborah Klaus	Navajo Epidemiology Center, Navajo Division of Health
16	Derek Valdo	Pueblo of Acoma
17	Dixie LeCompte	Cheyenne River
18	Dixie Padilla	Salt River Pima-Maricopa Indian Community
19	Donald Warne	Aberdeen Area Tribal Chairman's Health Board
20	Doug Taren	Arizona Center for Public Health Preparedness
21	Elaine Dado	Northwest Portland Area Indian Health Board
22	Jeff Burgess	Arizona Center for Public Health Preparedness
23	Jefferson Keel	Chickasaw Nation/National Congress of American Indians
24	Jerry Freddie	Navajo Nation
25	Jim Crouch	California Rural Indian Health Board
26	Joan Murphy	New Mexico Department of Health Bureau of Health Emergency
		Management
27	Joe Baca	New Mexico Department of Health Bureau of Health Emergency
		Management
28	Joe Finkbonner	Northwest Portland Area Indian Health Board
29	Joy Dorscher	University of MN Medical School Center of American Indian and
		Minority Health
30	Kathy Hughes	Oneida Business Committee
31	Lester Secatero	Albuquerque Area Indian Health Board/ToHajiilee Band of Navajos
32	Linda Holt	Suquamish Tribe/Northwest Portland Area Indian Health Board/TCAC
33	Martha Ellison	Navajo Nation
34	Mike Rousseau	Cheyenne River
35	Natalie Vestin	CIDRAP
36	Pelagie "Mike" Snesrud	CDC
37	PingPing Yang	CIDRAP
38	Priscilla Thomas	Navajo Bioterrorism Program
39	Ralph Bryan	CDC
40	Raven Murray	National Indian Health Board
41	Reno Franklin	NIHB
42	Roger Trudell	Santee Sioux Tribe of Nebraska
43	Rosemary Yazzie	Albuquerque Area Indian Health Board
44	Scott Santibañez	CDC Influenza Coordination Unit
45	Toby Merlin	CDC Influenza Coordination Unit
46	Vicki Tall Chief	University of Oklahoma Health Sciences Center, College of Public Health
47	Virginia Daniels	Albuquerque Area Indian Health Board
48	Wanda King	CDC – COTPER
49	Weston Cornelius	United South and Eastern Tribes

# **Appendix C: Mille Lacs Meeting Summary**

# AT-RISK POPULATIONS PROJECT TRIBAL COMMUNITY MEETING SUMMARY

# August 14, 2009

**Date/Location:** The Association of State and Territorial Health Officials, in conjunction with the Centers for Disease Control and Prevention (CDC), and the Center for Infectious Disease Research and Policy (CIDRAP) held a meeting on Saturday, April 4, 2009 from 8 a.m. to 3:15 p.m. at the Grand Casino Mille Lacs near Onamia, MN.

**Purpose:** The purpose of the meeting was to identify the needs of tribal members who are part of at-risk groups for inclusion in the At-Risk Populations Project Guidance revision.

**Attendees:** The 49 attendees included urban and rural members of Minnesota and other tribes, and invited tribal agency representatives.

Invocation: Joe Nayquonabe, local tribal elder

#### Welcome and Introductions:

- Joy Dorscher, Director, University of Minnesota Medical School Center of American Indian and Minority Health
- Salina Rizvi, Mille Lacs Band of Ojibwe Health Service Director
- James Blumenstock, Chief Program Officer, ASTHO
- Toby Merlin, Deputy Director, CDC Influenza Coordination Unit
- Capt. Pelagie "Mike" Snesrud, Senior Tribal Liaison–Policy and Evaluation, CDC
- Amy Becker LaFrance, Project Coordinator, CIDRAP

Dr. Dorscher reviewed the goals and agenda for the meeting. She emphasized the need for assistance in identifying who within tribes will be more vulnerable to negative consequences during a pandemic.

**Your Turn – What do You Want to Learn About Pandemic Influenza Today?** (Participants were asked to pose their pressing questions. Asterisks in the comments below indicate that multiple persons made the same statement or asked the same question. Each asterisk represents an additional individual)

- What is the difference between seasonal flu, bird flu and pandemic? Do we have bird flu in America and is there an immunization? \*\*
- What is a pandemic flu? What does it mean? Why should we care?
- Who will let us know if there is a pandemic?
- Who monitors the flu to get information to the community?\*
- People who have had regular flu shots have had serious side effects. If there is a vaccination, how would that affect us?\*
- How are we determining who is at risk or vulnerable in our community?
- What is real truth about pandemic flu? What are the odds of something like that occurring today? Is it a real threat, and should we be concerned?
- What are the best ways to protect children?

- How are immunizations distributed in the case of the flu? Ethics—who gets immunized and when?
- If there is pandemic flu, how will communities be told about it? How will agencies get information?
- Will there be different vaccines for immune-compromised individuals?
- Where will the virus emerge?
- How does the virus start?
- If someone coughs in Wal-Mart, how far and long will droplets stay in air to travel?
- How are symptoms and aftereffects different from seasonal and bird flu?
- How will we notice symptoms?
- What is the viral potency of bird flu? Will it affect travel restrictions?
- What are the chances the tribe will be the last to get vaccine?
- For the people who need medicines, insurance will only let you get so much of a drug, so how will you stockpile?
- Without violating culture and ceremony, how do you deal with the dead? How will the ceremonies be handled in a pandemic?
- Who will deliver medicines to sick people at home (if they can't get to the pharmacy)?
- How would you be able to share medicines? How do you know where the medicines are coming from?
- What about those who have chronic illness and pandemic flu, what kind of care would they require?
- How long do we stockpile for? Are we talking nuclear bomb shelters from the 1950s?
- Traditional healers use herbal means. Are they educated to distribute vaccine?

# Presentation – Pandemic Influenza Overview and Preparedness Planning: Capt. Scott Santibañez,

Medical Officer, CDC Influenza Coordination Unit, gave an overview of pandemic, seasonal and avian influenzas. He described tools that fight influenza such as vaccines, antiviral medications and community mitigation practices. He described basic preparedness activities and emphasized the importance of planning for at-risk populations.

# Q: What more can we do?

**A:** Vaccines, new medicines, communication; know who is at risk.

**Q:** Is there a magic number that makes it a pandemic? Who calls the shots?

**A:** There is no magic number that determines when a disease outbreak becomes a pandemic. It is based on a situation of worldwide, person-to-person spread. Experts also look at the rates of severe illness and death. The World Health Organization decides when a disease outbreak has reached pandemic status.

Q: What about health care? Will doctors close their doors?

A: Urge people to stay home to slow transmission and try to avoid overloading the system.

Q: What kinds of birds?

A: Mostly poultry in Asia that people raise and live with.

Q: If it starts in Asia, don't we have time to prepare?

A: There may be some lag time, but a pandemic could start in the United States.

**Q:** Does it start in one person?

A: Don't know the specifics of mutation. It could start in one person, mutate and spread.

Q: What is the velocity of a sneeze, and how long do the drops stay in the air?

**A:** Stay 3 to 6 feet away (large droplets). Flu is different from TB; TB spreads more easily. Flu can live on surfaces for 24 to 48 hours.

#### Q: Who is at risk?

A: Depends on the community.

Q: Bird flu vs. seasonal flu?

A: Bird flu is more serious in humans due to no immunity.

**Q:** When is someone contagious?

A: When you start feeling sick is when you're most contagious.

Q: What are the vaccine side effects?

**A:** The potential vaccine side effects differ for the nasal spray and the shot. The intranasal dose is a live virus that can cause a mild headache, sore throat, cough or runny nose. The shot contains killed virus; therefore, it cannot cause infection. It does create an immune response, however, and side effects can include mild soreness at the site, low-grade fever or aches. Those who are allergic to eggs should talk to their doctor before getting the shot. There are also rare side effects such as Guillain-Barre Syndrome. In general, the benefits greatly outweigh the small number of adverse side effects that may occur.

**Q:** If the initial supply of vaccine is limited, how will we decide who gets it?

**A:** To see who the recommended priority groups are to receive vaccine, visit <u>http://www.flu.gov/faq/vaccines/2004.html</u>. First responders and healthcare workers are among the recommended priority groups, so that they will be able to continue to help others who are sick. [Since the meeting, the novel H1N1 virus has caused a pandemic and vaccine development is under way. Due to the nature of this particular virus, the Advisory Committee on Immunization Practices has issued recommendations on priority groups for the initial available doses of vaccine. As additional vaccine becomes available, the entire U.S. population will be offered the vaccine. The priority groups include: pregnant women, household contacts and caregivers for children younger than 6 months of age, healthcare and emergency medical services personnel, all people from 6 months through 24 years of age, and persons aged 25 through 64 who have health conditions associated with higher risk of medical complications from influenza. The full advisory committee recommendations can be found at: <u>http://www.cdc.gov/h1n1flu/vaccination/acip.htm</u>.]

#### Your Turn – Recognizing the Achievements of Tribes

- Monte Fronk discussed Mille Lacs preparedness.
  - o Minnesota is pro-tribal
  - Relationships are good here.
  - A tribal liaison needs to be in the multiagency coordination.
  - Pan flu and all-hazards module in emergency plans.
  - Mille Lacs is involved in two regions.
    - Mass distribution work.
- Vicki Tallchief discussed Oklahoma tribal preparedness.
  - Held pandemic flu trainings with tribes.
  - Formed a tribal coalition of 39 people that meet monthly to share information.
- Additional points that were shared.
  - MDH and tribes: Local tribal public health has the best access to patients.
  - State needs and wants to be connected.
  - Need to be in contact with the region.
  - Developing plans and partnerships.

**Presentation–Introducing the Guidance:** Caroline Barnhill, Senior Analyst, infectious disease, ASTHO, reviewed the background of the At-Risk Populations Project and the guidance components.

Scenario Discussions-Dr. Dorscher facilitated the table discussion sessions.

**Scenario 1:** Imagine that a new strain of flu is making people sick all over the world. Several cases have been diagnosed in the United States. Experts are saying this flu could spread to your town or neighborhood in a couple of weeks.

### 1) Who would have the hardest time getting ready for and getting through a flu pandemic?

- Rural communities.\*\*\*
- Elderly.\*\*\*
- People with mobility issues.\*\*\*
- Businesses and employees that rely on them.\*
- Single mothers.\*
- People with limited income\* can't stockpile supplies.
- People with transportation issues.
- Those isolated from emotional support infrastructure/people alone with no one to help them.
- Those with chronic health problems because of their medical needs and prescriptions.
- Traditional healers—may be exposed multiple times.
- Homeless.
- Traditional healers need to be included in planning discussions. They are also a group to give consideration to when allocating vaccines: "If elderly have chronic conditions, this would make flu harder."

#### 2) How would you get reliable health information?

- Television \*\*\*\*\*\* (One participant commented that this was particularly true for elders).
- Local law enforcement.\*\*\*\*\*
- Radio.\*\*
- Scanners.\*\*
- Government Web sites.\*\*
- Internet.\*
- Information hubs to collect information from the state/county and distribute it to the community.
- Community health representatives over the phone.\*\*
- Mail delivery of fliers.\*\*
- Local health centers/officers.\*
- "Moccasin hotline"—Tribal elders get information out by phone.
- Door-to-door messengers-"We're so remote, we would need door to door."
- Comments:
  - No cell phones in rural areas\*/cells phones don't work\*—"When 35w collapsed, cell phones didn't work."
  - Elders do not have/use computers/text messaging.
  - o "We don't know who the health experts are, but we know law enforcement.
  - o "I think a lot of people will just Google it. They don't know where to look online."
  - o *"I can't* trust TV or radio."
  - "We had thought about broadcasting information over scanners. Many families in our area have scanners in their home."
  - Tornado in Granite Falls—no cell phones or telephones. Contaminated water. Sirens didn't go off. "In this emergency we had no TV; we listened to the scanners and information from law enforcement."

- 3) What experiences with past events might help you prepare for a pandemic?
  - National guard.\*
  - Snail mail and fliers.\*
  - Comment: Communication must be multipronged to reach everyone. Multiple media needed to communicate.\*
  - Law enforcement.
  - Text messaging.
  - Stocked up at the grocery store.
  - Listened to police scanners during past emergencies.
  - People went door to door.
  - No TV, radio or cell phones in rural areas so mail carriers and mailed fliers are important.
  - Desperate and needy may attempt to get supplies of medication and immunizations
  - "The scanner was our only means of getting information in our community (during a past emergency)."
- 4) If a local agency or government were creating a list of people who may need extra help, would you sign up?
  - List may contain private information, which is a concern (if the list is compromised).\*\*
  - May provide reassurance to people if they know they are particularly vulnerable.\*
  - Two lists are needed: one for those who need help and another for those who are willing to give help.\*
  - Yes. Single moms to receive immediate help for any type of emergency.
  - "A registry would help avoid pandemonium during an emergency."
  - Identify people who need help on a regular basis. clarify what type of help they need before the emergency
  - List will help officials determine who should be closely monitored because of needs, medical conditions, etc.
  - Registry might provide a false sense of security.
  - Local registries can be more effective because at-risk people are known and there is a level of trust.
  - There should be a tiered approach—have registries at local, then county level
  - "I'm a single mother with no transport. I would love to sign up before the pandemic to have that extra help available.
  - "If I were to sign up I would want it to be local. I can imagine that if I called (at state level), there
    would be a lot of other people on the phone as well."
  - How can the census help with planning in relation to the creation of these lists? Who coordinates the lists? How do we prioritize people on the list?

**Scenario 2:** Imagine that the flu pandemic has arrived. Several people are sick. The tribal council has decided to change or cancel social activities to limit the spread of the flu. Schools, daycares, businesses and community centers may all be closed. Other meetings or events on and off of reservations might be canceled.

# 1) How would the closings affect you?

- Day cares and schools—If they close, and other places don't, have to bring child to work or will be unable to work.\*\*\*\*\*
- Access to meals will be compromised if community center is closed.\*\*\* (these centers have dinners for elders). Community center is also a common place to congregate.
- Unable to get supplies if there are closings.\*\*

- Affects jobs and paychecks.\*
- The government should ensure people do not lose their health care or their insurance.\*
- If schools close, there will be nowhere to go. No after-school activities/athletics.
- Affects children's socialization with others.
- Community services closing will negatively affect people.
- Lack of transportation—no one to take adults and children elsewhere in case of emergency.
- If drug stores close, people won't be able to get their medication.
- Entertainment centers will be hard hit—much of the population is transient, visiting the casino.
- Gas and electricity service may be disrupted.
- There may be an exodus of people moving from the Twin Cities back to the tribal community.
- If you're working in an essential job but have small children, you would have to stay home even though people need your help.
- Will be difficult to meet the dietary needs of those who have special needs such as those with allergies or small children.
- Regional office closures could close local offices.
- Health departments lack space to keep individuals affected by the flu separate from individuals at health department for other reasons.
- The tribe has fewer resources than counties, state and federal government. The trickledown effect may not work as there are not enough resources.
- There may be problems with infection if people run child care out of homes.
- "In Prairie Island, we are an island. . . we do not have the resources. [People] will have to fend for themselves."
- Mille Lacs has a nutrition program where meals are delivered to those who cannot get to an assisted living facility.

# 2) How could you interact with people?

- Landline/telephone.\*\*\*\*
- Fliers.\*\*
- Email and Internet.\*
- Social networking sites.
- Postal service.
- Try whatever you can until something works.
- Through community-based organizations and other agencies.
- Will not interact with other people in person. Most likely will stay home and keep family and children at home.
- People need to be told to stay in their area to seek care.

#### 3) What is the impact of living on the reservation (or off the reservation)?

- Reservation can't handle influx of urban band members as far as services or vaccines.\*\*
- However, the isolation may also be a challenge when there is an emergency.\* People live far away from each other and some check up on each other, but some don't.
- On the reservation people keep in close contact. There are extended family networks.\*
- Smaller communities are very dependent on a few businesses; customers would flood individual businesses and stores would be filled all at once and this could lead to shortages.\*
- "On a reservation you don't have access to large stores with many supplies."\*
- Living on the reservation—there will be better control of the spread of disease.
- The isolation could be a benefit, and it's kind of safe.
- On the reservation there is spiritual care.
- Off the reservation—less contact with the community

- In the city you check in with neighbors only if you know them.
- In the city, it will be hard for people with fixed incomes to prepare.
- People will leave the community (reservation) because there are more resources elsewhere.
- Reservation has only one clinic and one community center.
- Small public health staff at the reservation would be easily overwhelmed since resources are limited.
- Fragmented system of communication on the reservation.
- Some people have scanners and phones, but others don't; the best form of communication is through word of mouth.
- On a reservation—difficult to access fuel.
- Increased worry about family members being treated and cared for.
- Off the reservation—people feel they can always go home to the reservation, but this may not necessarily be true; the reservation may be closed off.
- Burial rites would be compromised on the reservation—a very big impact.
- Comment—Planning document should clearly state who the people should listen to: tribal government, Indian Health Service, CDC, federal government, since there will be multiple sources of information.

#### 4) What services do you rely on the most that might be affected?

- Prescriptions/pharmacy.\*\*\*
- Smaller tribal clinics<sup>\*\*</sup> —will have to travel further to reach the next clinic.
- Public transportation.\*
- Grocery stores.\*
- Meal programs\* (like meals on wheels)/food services\* particularly casino and gas station.
- Clinics and health centers.
- Ambulance services\* —blood sugar and blood pressuring monitoring service would be disrupted.
- Public health.
- WIC.
- Government center—very quick to close for any emergency.
- Nuclear power plant (especially as concerns heating during the winter).
- Casino may be the only place still open—has been through different natural disasters. Remains open even when it shouldn't.
- "Oh God, in my town we have one grocery store."

**Scenario 3:** Imagine that the flu pandemic has reached its peak. Many people in your community are sick or have been sick. Some have passed on. Community organizations are not able to provide many of the services they normally would offer. Some workers are sick or much stay home to care for sick family members; others are still working and face increased workloads. Drugstores, clinics and grocery stores are sometimes short of supplies.

#### 1) Who will you count on for help in your community? Outside of your community?

- Family.\*\*\*
- Community health representatives.\*\*\*
- Police/law enforcement.\*\*\*
- Local leaders like the mayor and commissioner.\*\*\*
- Hospitals/clinics.\*
- Neighbors/members of your lodge/circle.

- Women's shelter.
- Workforce.
- Community center.
- Tribal government.
- Food shelf.
- Casino.
- National groups.
- Other districts.
- Civilians from other counties.
- Those living in urban areas who might go home to help.
- Medical personnel.
- Clinic emergency response team—this would be a separate on-call team to help.
- Health planners and commissioners.
- Traditional healers.
- Church.
- Information hotline.
- City council members.
- Comments
  - Everyone should look out for themselves.
  - Stockpiling of medication is a big issue especially for those with chronic illnesses such as diabetes. \*
  - When you're in a small community, community health representatives and police are given the information.
  - You can't count on contracts you have with nontribal organizations (e.g. bus companies, clinics). They will take care of their priorities first and tribal members second.
  - When we plan we assume optimal circumstances—law enforcement, first responders may not respond during an emergency.
  - Employees on the reservation are often not band members, so who decided which band members get immunized? Everyone has a different idea of who is at risk . . .tribal leaders should make the decision.
  - "I would hope healthy people will step up...have a neighbor-watch-a-neighbor system where you check in with certain people everyday."
  - Concerns about how tribal boundaries are located and how the county would handle that—in Cass Lake, there is no clinic, would people have to go 12 miles to Bemidji? How would people get there?
  - "If this got bad, we have a small clinic, and we have a lot of sick people; where are they going to go? Care would have to be centralized like a school gym."
- 2) How will you manage if you can't easily get more medicines? If you can't go to your normal doctor's appointments?
  - Cut pills in half/split doses.\*\*
  - Conserve more/cut back.\*\*
  - Ask for larger quantities of meds to prepare for disruption.\*\*
  - There should be drug exchange between clinics and the Indian Health Service to control shortages.
  - Would rely on traditional medicine\*\* (would call for advice on how to stay healthy, home remedies, ceremonies for health) — "we have so many medicines out in those woods."
  - Prayer.\*

- Share medicine.
- Try to get everything done in one doctor's appointment.
- Call the nurses.
- Call the doctor to see if they can do house visits (especially for kids) or consultations over the phone.
- Medicine from local service unit at Indian Health Service hospital.
- Community health representatives could deliver medicines.
- Tribe won't be able to provide medical services so people will leave the community.
- Those who don't trust local hospital will go to Mayo clinic.
- Unsure how traditional medicine will be used—younger people are less attached to it
- "I don't know what I would do. I've never thought about it. I don't think people do think about these things."
- 3) What could you, your family or your community do to make the situation better?
  - Education with an emphasis on the lack of services and the need for preparedness.\*\*
  - Stock up on food/stockpile.\*\*
  - Form emergency plans/prepare emergency kit.\*
  - Talk to people about where they can get treatment.\*
  - Post plan at community and government center.
  - Practice drills at government and community center and schools.
  - Prepare a first-aid kit
  - Create a community team with well-defined roles who can communicate information.
  - Create a "flu center" where sick people can be kept away from the healthy that will serve as a centralized place to get vaccines and other medications.
  - Pray.
  - Help each other—healthy will have to take care of the sick.
  - Focus on prevention—if we can keep ourselves well, we can keep our communities well.
  - Wash hands, take shoes off, use sanitizer at home and office—hand washing is the number one way to prevent disease spread.
  - "Clip N' Save" feature in the newspaper to encourage being prepared.
  - "We are all going to have to be caregivers in this situation."

# **Additional Comments**

- Use a red/yellow/green flagging system for each household to notify the public if help is needed.
- Role of traditional healers—use plants and animal parts to heal and treat. Use intuition, gifts to
  determine patients' problems and appropriate therapies. They also offer counseling and
  guidance as an integrative part of health.
- Personal awareness and preparedness is key, but people are not ready or willing to deal with pandemic issues because they have everyday issues to deal with.
- "In the Leech Lake area, the system is already broken. There is an eight-mile radius that is served by few resources. These are focused upon low-income individuals who make up a huge percentage of the Leech Lake area."
- "In Leech Lake area, many houses are crowded. I would find it hard to believe that someone would get their own room if they got sick."
- Mail may not work—some people have to drive to the post box and may not be able to do so if they are sick.

**Voting on Major Themes**—Dr. Dorscher facilitated the voting process by clarifying key statements made throughout the day by each table and asking the entire group to vote on them.

STATEMENT	AGREE	NOT SURE/	DISAGREE
	(green)	NEUTRAL (yellow)	(red)
If I could eat only one food, it would be fry bread.	3 (7%)	6 (15%)	32 (78%)
We should be aware of and prepared for any emergency that could possibly happen.	38 (83%)	8 (17%)	0
The postal service or mailbox is the best vehicle to provide supplies, information and medication in an emergency.	5 (11%)	11 (24%)	29 (64%)
The correct information needs to come to the tribal members in a way they understand and from someone they trust.	38 (84%)	7 (16%)	0
Emergency education of the community should come from the elders.	6 (13%)	10 (22%)	29 (64%)
People will share medications in an emergency even if they know it is wrong or dangerous.	33 (73%)	7 (16%)	5 (11%)
Traditional healers should be prioritized and protected so that they may be able to help our people.	27 (60%)	17 (38%)	1 (2%)
It is important to have a plan ahead of time; families and communities should discuss the possibility of a pandemic, stockpile, and perhaps drill to prepare for an emergency.	40 (89%)	4 (9%)	1 (2%)
The current tribal infrastructure is not capable of dealing with everyday needs; housing, social and healthcare issues facing us are overwhelming/taxing limited resources.	31 (72%)	11 (26%)	1 (2%)
Transportation, medication and information are the most important issues to consider during an emergency.	9 (20%)	22 (49%)	14 (31%)
Tribal/community members should branch out into the community to form even the simplest of relationships to help in an emergency (pharmacists, child care, etc.).	36 (80%)	3 (7%)	6 (13%)
A red, yellow, green flag system should be used at each household to notify emergency personnel if help is needed.	34 (76%)	11 (24%)	0
A Minnesota state tribal alliance should be created to help plan for disaster preparedness.	32 (71%)	5 (11%)	8 (18%)
We need to develop a local plan using local resources so people trust that the community can deal with the situation.	31 (70%)	13 (30%)	0

No matter what else happens, prayer is something an individual can always do.	31 (70%)	12 (27%)	1 (2%)
In the event of a pandemic, community health			
representatives are an important part in getting information out on prevention and are vital in helping			
to identify who needs help.	35 (78%)	10 (22%)	0
During a pandemic, it is vital to maintain a line of			
communication that can be used for community			
education about current developments and to			
encourage preparedness.	38 (84%)	4 (9%)	3 (7%)
Personal awareness and preparedness education are key, but people are not ready/willing to deal with			
these issues because everyday issues are the focus.	30 (67%)	11 (24%)	4 (9%)
Dissemination of detailed, step-by-step information for			
caregivers (people taking care of family members at			
home) is vital.	38 (86%)	5 (11%)	1 (2%)

**Wrap-Up and Next Steps:** James Blumenstock concluded the day by reviewing some of the key messages that were shared and highlighting the next steps in the At-Risk Populations Project. **Closing Invocation:** Pat Bellanger, tribal elder, gave the closing remarks for the day.