



Epidemiology Centre Tour Report

U.S. Indian Health Services

January 12 – 14, 2004

Background

The First Nations Centre (FNC) at NAHO was invited to attend along with five representatives of the First Nations Inuit Health Branch (FNIHB), Health Canada, a tour of the Epidemiology Program run by Indian Health Services (IHS)'s Office of Public Health. The tour included a visit to the Administrative Headquarters in Albuquerque, New Mexico, as well as to a tribally run Epicenter Project located on the Lac de Flambeau Reservation, Wisconsin.

The site visit was organized by FNIHB with the following objectives:

- Establish contacts, link into their networks and develop working relationships;
- Explore their model in such areas as structure, governance and funding;
- Examine their structure and how they are organized, scale, linkage with medical officers of health and their roles in the organization;
- Gain insight into their successes and problems, best practices and pitfalls;
- Develop the knowledge of how they collect and interface with the larger public health system on a range of surveillance type information topics (e.g., vital statistics, communicable diseases, hospitalizations, etc.) and how to deal with possible duplication in reporting and the sharing of information with partnering stakeholders;
- Gain added value of sharing specific expertise in addition to a geographic focus.

Although the FNC shared some of the FNIHB's tour objectives, the Center's intent was also to examine the Epidemiology Centre program to determine application to Canadian First Nations communities in the context of:

- Developing a First Nations Health Infostructure; and
- Implementing the principles of Ownership, Control Access and Possession of Health Information/data.

Indian Health Services (IHS), a federal agency of the U.S. Public Health Service in the Department of Health and Human Services, has the responsibility for delivering health services to federally recognized American Indians and Alaska Natives (AI/AN) through a system of direct IHS tribal and urban operated facilities and programs based on treaties, judicial determinations and Acts of

Congress. The mission of the IHS, in partnership with AI/AN, is to raise their physical, mental, social and spiritual health to the highest possible level.¹

The IHS is the principal federal health care provider and health advocate for Indian peoples and its goal is to raise their health status to the highest possible level. The IHS currently provides health services to approximately 1.5 million AI/AN who belong to more than 557 federally recognized Tribes in 35 states.²

It is foundation of the IHS to uphold the federal government's obligation to promote healthy AI/AN people, communities, and cultures and to honor and protect the inherent sovereign rights of Tribes.³

Epidemiology Program Overview

The Epi Program headquarters staff consists of 19 professional and support staff with expertise and training ranging from bachelor to doctoral levels, encompassing skill and interests in epidemiology, statistics, public health, medicine, computer technology, and business administration. The program staff is a collaborative team of IHS personnel, Centre for Disease Control (CDC) staff field assignees, and other independent contractors. One third of the staff is of American Indian descent representing Tribes from the Southwest and Northern Plains.⁴

The Epi Program areas of emphasis include sexually transmitted diseases, immunizations and vaccine preventable, enteric diseases, hepatitis, antimicrobial resistance, breast and cervical cancer screening, tobacco control, Hantavirus and cardiovascular disease. In addition, the Epi Program collaborates with the IHS National Diabetes Program to address issues such as increased tuberculosis linked mortality among AI/AN diabetics.⁵

The Epi Program has led IHS efforts to establish a network of tribal epidemiology centers. Originally, IHS funded four centers: the Alaska Native Health Board, Great Lakes Inter-tribal Council in Wisconsin, the Inter-tribal Council of Arizona and the Northwest Portland Area Health Board. Two additional centers have recently received funding: the Seattle Indian Health Board and the United Southeastern Tribes.⁶ The FNC was able to visit the Great Lakes Inter-tribal Council, WI.

¹ Indian Health Services, Information Resource Management Plan 2003 – 2008, May 5, 2003, pg. 1.

² http://www.ihs.gov/PublicInfo/PublicAffairs/Welcome_Info/IHSintro.asp

³ http://www.ihs.gov/PublicInfo/PublicAffairs/Welcome_Info/IHSintro.asp

⁴ Epi Program Activities and Accomplishments, Executive Summary.

⁵ Ibid.

⁶ Ibid.

Key Activities

Disease Prevention and Control

- Cancer Prevention and Control;
- Tobacco Control;
- Women's Health;
- Immunizations;
- Sexually Transmitted Disease/Chlamydia Control;
- Tuberculosis Control;
- Hepatitis Control;
- Hantavirus Program.

Partnering with other organizations, such as:

- Tribal health departments and boards, state health departments, private organizations and foundations, academic institutions and other federal agencies;
- CDC for collaborations with Tribal Epi Centers, public health infrastructures, and bio terrorism preparedness.

Training and Mentoring AI/AN Students

- Public Health;
- Capacity Building for tribal organizations in the areas of research methodology, public health practice, colposcopy for cancer screening and the development of leadership skills in cancer support groups.

Policy Development

- Develop guidelines for disease specific interventions;
- Interpret and implement U.S. Public Health Services recommendations.

Services Available

- Data management and reporting by assisting development of data collection capacity for several systems (ORYX, HEDIS, GPRA);
- Emergency response by leading, coordinating and facilitating public health response to outbreaks;
- Surveillance by developing, maintaining and monitoring disease surveillance systems;
- Liaison by coordinating public health activities of local, state and other federal health programs;
- Training through the provision of resident, medical and public health student rotations, fellowships to IHS or tribal staff, colposcopy instruction for health care providers and cancer support group leader instruction for tribal communities.

- Consultations to clinicians by providing or arranging expert consultation of public health importance and facilitating diagnostic testing at state or CDC;
- Applied epidemiological research;
- On-site team available

Epidemiology Center Visit Highlights

During the course of the day and a half visit, the Canadian contingent was shown a series of presentations that outlined some of the following initiatives and activities of the Headquarters Administrative Office for the Epidemiology Program. On the morning of the 2nd day, the FNC was able to present on some of its activities.⁷

Administrative Center Headquarters: Activities

1. Centers for Disease Control and the IHS Epidemiological Program

The CDC serves as the national focus for developing and applying disease prevention and control, environmental health, and health promotion and education activities.⁸ It is committed to improving the public health of the AI/AN and recognizes the unique relationship IHS has with AI/AN and the cultural diversity of the AI/AN communities. Within CDC, the Office of Minority Health, the Office of the Director (OMH/OD) has responsibility for coordinating the agency's program and policies that benefit AI/AN communities. To lead these efforts, two full-time professional staff positions have been established within the OMH/OD to help plan and coordinate CDC programs for AI/AN: the Senior Tribal Liaison for Policy and Evaluation and the Senior Tribal Liaison for Science and Public Health. These senior staff members provide direction to the Associate Director for Minority Health and serve as the official CDC points of contact for issues relating to AI/AN health. They also work closely with CDC offices that have programs and activities involving AI/AN communities.⁹

2. Sexually Transmitted Diseases in Indian Country

There are a number of challenges in STD Prevention and Control in Indian Country, such as poor data, low priority, ineligibility for CDC funding as it is state focused, involves multiple jurisdictions and lacks dedicated personnel. There is no national initiative in this area. It is projected that HIV may become a public health disaster in AI/AN communities due to high chlamydia and syphilis rates,

⁷ Please contact Allen DeLeary at 1-877-602-4445, extension 524, or adeleary@naho.ca, to receive a copy of the presentation.

⁸ <http://www.cdc.gov/aboutcdc.htm>.

⁹ Handout, CDC Senior Tribal Liaisons, Jan 2004.

low HIV screening, increased meth use, nominal prevention activities, and stigmatization. The Epidemiology Program works to increase collaboration between state and tribal organizations and other public health agencies, to build organizational capacity in STD prevention and control, to promote quality medical and laboratory services and to identify best practices in STD clinical management in tribal facilities.

Briefly, the IHS Epidemiology Program has established a STOP Chlamydia Initiative for enhancing data collection through the elimination of unnecessary variables and automating data entry and reporting processes. A Navajo/Zuni Syphilis/HIV Outbreak Initiative has been established to develop non-clinical training for CHRs, Health Educators and Behavioral Health Counselors. Demonstration projects are currently being developed to identify effective disease prevention and control strategies on reservations and for urban settings. The STD Infrastructure Project is being coordinated by the Phoenix Indian Medical Center to investigate local HIS facilities to prevent and control STD and syphilis in their services areas.

3. Immunization

The goal of the Immunization Program is to improve the ability of Tribes, IHS, states and CDC to monitor and improve the immunization coverage among AI/AN children. IHS and Tribal programs manage their own immunization programs predominately through IHS or tribal funds. Emphasis is being placed on increasing use of IHS immunization software, improving data quality and facilitating IHS and tribal participation in state immunization registries.

Highlighted activities include:

- Immunization assessments by working with the Great Lakes Tribal Epidemiology Center and the IHS Bemidji Area Office to conduct immunization coverage assessments at nine sites. They examined the records of children 2 – 6 years of age and assessed their immunization status;
- Developing a new version of the Resource and Patient Management System (RPMS) immunization package;
- Facilitating data exchange with States by ensuring that IHS and tribal facilities can automatically exchange data with state immunization facilities. A module is being piloted in four states (AZ, UT, SD and WI).¹⁰

4. Cancer Data Linkage Project

The IHS Epidemiology Program is collaborating in a data linkage project that will lead to the first ever state-based estimates of cancer incidence for the AI/AN population. The project involves using information such as Social Security Numbers, name and date of birth to identify the same person in the IHS patient

¹⁰ IHS Handout, Immunizations, January 2004.

registration database and the cancer registry database. The CDC is funding a project to link IHS data with 25 state registries participating in the National Program of Cancer Registries (NPCR). The potential of this data linkage for improving other important data bases, such as birth and death records and other disease registries such as diabetes, is recognized.

5. Resource and Patient Management System (RPMS)

The system is an integrated software solution for the management of clinical and administrative information in health care facilities of various sizes and orientations. Flexible hardware configurations, over 35 software applications, and network communication components combine to provide a comprehensive clinical, financial, and administrative solution. RPMS developers, IHS support personnel, the National Patient Information Reporting System (NPIRS) and the Self-Determination Team work to make sure that RPMS is used to its up most capacity in helping a facility/clinic serve the health care needs of its community.¹¹

IHS has established the Information Systems Advisory Committee (ISAC) to guide the development of a ***co-owned and co-managed Indian health information infrastructure and information systems***. The goal of the ISAC is to assure the creation of flexible and dynamic information systems that assist in the management and delivery of health care. The ISAC will assist in insuring that information systems are available, accessible, useful, cost effective, and user friendly for local level providers, while continuing to create standardized aggregate data that supports advocacy for Indian health programs at the national level.¹²

6. Native American Research Centers for Health (NARCH)

The NARCH initiative supports partnerships of AI/AN Tribes or of tribal-based organizations such as the National Indian Health Board and Area Health Boards, with institutions that conduct intensive academic-level biomedical and behavioral research. The purposes of the NARCH initiative are:

- to encourage competitive research linked to reducing health disparities;
- to develop a cadre of American Indian scientists and health professionals engaged in biomedical, clinical, and behavioral research that is competitive to NIH funding; and,
- to increase the capacity of both research intensive institutions and American Indian organizations to work in partnership to reduce distrust by American Indian communities and people toward research.

¹¹ http://www.ihs.gov/CIO/Self-Determin/rpms/rpms_info.cfm.

¹² Ibid.

These purposes will be achieved by supporting research projects (including pilot projects), student development projects, and faculty development projects developed by each NARCH partnership.¹³

Great Lakes EpiCenter: Overview and Activities

Overview

The Great Lakes EpiCenter is an epidemiology project working through Great Lakes Inter-Tribal Council located in Lac du Flambeau Reservation, Wisconsin.¹⁴ A total of 34 Woodland Indian Tribes and three urban programs are served by this project, which is funded, in part, through a competitive grant from the IHS.¹⁵ The EpiCenter strives to be responsive to the health information and epidemiological needs of the Tribes in the Bemidji area by providing training and technical assistance in many areas of public health, program planning and evaluation, and health data collection, management, analysis and interpretation.

The FNC was able to present on its activities to the GLITC.

Key Program Objectives and Activities of the GLITC Epicenter¹⁶

1. Provide updated community health profiles to the 37 Tribes and urban Programs in the three state areas of Wisconsin, Michigan and Minnesota:
 - Annual update of birth and death files;
 - Annual update of sexually transmitted disease data;
 - Annual assistance with analysis of diabetes audits;
 - 2000 Census demographic information.¹⁷

2. Provide training and support on general epidemiological principles and management information systems in the Tri-state Area:
 - On-site training and group training in RPMS applications (patient registration, scheduling, CHR, case management, mental health/social services);
 - Ongoing telephone support/assistance with data retrieval for specific data requests and assistance with Epi info programming;
 - Community-based research (curriculum);
 - Assistance regarding survey development and sampling design.¹⁸

¹³ <http://grants.nih.gov/grants/guide/rfa-files/RFA-GM-00-007.html>.

¹⁴ Great Lakes Inter-tribal Council Epicenter Pamphlet, January 2004.

¹⁵ <http://www.glitc.org/epicenter/default.php>.

¹⁶ Great Lakes Epicenter, Project Pamphlet, January 2004.

¹⁷ Great Lakes Epicenter Handout, Powerpoint Presentation, January 2004.

¹⁸ Ibid.

3. Provide ongoing coordination with identified tribal, local, and state and federal partners concerning health information needs:
 - Agreements in place with the state health department in the Tri-state area;
 - Data Advisory Committee with membership including Tribe and state partners;
 - EpiCenter staff participating in a variety of statewide workgroups, such as Epidemiology Task Force, DM Advisory Council, and Data Steering Committee;
 - Planning and coordination of area wide DM activities annually.¹⁹

4. Provide ongoing communication of Great Lakes Epicenter activities to identified partners:
 - GLITC EpiCenter Newsletter published quarterly;
 - Regular communication between GLITC EpiCenter and Bemidji IHS office;
 - GLITC EpiCenter staff available to attend Tribal and Urban meetings upon request.

5. Provide support and technical assistance to epidemiological/prevention projects within the Tri-state area:
 - Wisconsin statewide AI/AN youth tobacco survey of middle school youth conducted;
 - Successful grant development to conduct a youth tobacco survey in Michigan;
 - Prepared and distributed a CD-ROM for Bemidji Area Tribes on bio terrorism and bio terrorism preparedness;
 - In coordination with the IHS National Epidemiology Program, participated in a national immunization surveillance project.²⁰

6. Develop and maintain general administrative systems to support the GLITC Epicenter:
 - Ongoing development of policies and procedures as needed
 - Coordinate and monitor EpiCenter's multiple funding sources.²¹

¹⁹ Ibid.

²⁰ Great Lakes Epicenter Handout, Powerpoint Presentation, January 2004.

²¹ Ibid.

Five Highlighted Projects for the GLITC Epicenter

Michigan Youth Tobacco Survey

- Reason: No statewide information regarding youth tobacco use in the AI/AN population.
- Purpose: Survey schools in Michigan that have a large AI/AN student population.
- Method: Work with interested Tribes so the following will occur:
- Project reviewed and supported locally;
 - Survey administration training;
 - CDC will scan the completed surveys;
 - GLITC EpiCenter will provide the analysis.
- Outcome: Statewide prevalence reports as well as tribal specific prevalence reports.²²

Community-Based Research

- Purpose: Provide training at the local level in the areas of basic, applied research methods.
- Method: Literature review of community-based research curricula. Survey tribal staff in the tri-state area to determine topics of general interest. Plan the curriculum based on literature review and survey results. Conduct three-day training sessions in each state.
- Outcome: Community-based research curriculum that assists interested Tribes in local research activities.²³

Bemidji Area Surveillance Project

- Partners: National IHS Diabetes Management Program and Bemidji Area Office.²⁴
- Objectives: Improve the Diabetes Registry and build a foundation for measuring Quality of Care for the Diabetes community in the Tribal and urban AI population for the Tri-state area. Provide RPMS training for Tribal and Urban programs in Tri-state area to improve the quality of diabetes care. Accurately estimate area prevalence rates for diabetes. Utilize collected diabetes data to improve health outcomes for AI in the Bemidji area. Prevent diabetes for high risk individuals through primary prevention

²² Ibid.

²³ Ibid.

²⁴ Great Lakes Epicenter Handout, Powerpoint Presentation, January 2004.

Great Lake Native American Research Center for Health (GLNARCH)

Objectives: Encourage cooperative research linked to reducing health disparities. Increase the number of AI/AN students, scientists, health professionals and organizations engaged in biomedical, clinical and behavioral research. Build capacity of both academic institutions and GLITC to reduce distrust by AI/AN communities towards research.

Partners:

- GLITC
- Wisconsin Tribes
- University of Wisconsin
- University of Wisconsin Medical School
- Mayo Clinic
- Indian Health Service
- NIH

Projects: Youth Obesity Prevention
Reproductive Outcomes and Cost Effectiveness
Protective Effects of Traditional Diets
Cancer Surveillance²⁵

BioTerrorism/Emergency Response

Objectives:

- Assist Tribes within the state of Wisconsin to prepare and implement emergency response plans;
- Assist coordination/collaboration efforts between Tribes and counties and states;
- Assist with statewide bioterrorism training;
- Assist with the development of tribal level surveillance systems;
- Provide surveillance expertise and assistance upon request.²⁶

Observations of the Epidemiology Center Visits

Epi Centers

Although the existing Epi Centers are funded by the U.S. Government, the Federal Government and the Tribes acknowledge that they are not funded to their potential. The Epi Centers are encouraged and have partnered with the CDC, States and the Native American Research Centers for Health (NARCH). Additionally, it is recognized that the success of the Epi Centers are predicated upon the nature and willingness of Tribes to share their health information and data.

²⁵ Ibid.

²⁶ Ibid.

Sovereignty of Tribes

With the recognition of the sovereignty of Tribes, information of the Tribe, whether it is health-related or any other form, is accepted by the Federal Government as the sole property of the Tribe, to be shared at the Tribe's discretion with the U.S. Government, State or Municipal Government or any other organization requesting tribal information. Increasingly, all levels of government, value the sharing of information for a multiplicity of health and health related purposes, ranging from surveillance, public health and safety concerns to lobbying congress for increased resources. Ownership, Control, Access and Possession²⁷ – principles espoused by First Nations in Canada to reflect their rights of self-determination with respect to information – is not a contentious issue, but rather a common practice, of sovereign Tribes.

Treaty Right to Health

The provision of comprehensive health care to AI/AN is recognized by the Federal Government as a treaty right. Although, it is a recognized right, and furthermore, is a trust responsibility of the government, it is still subject to congressional appropriations for financial support. The Tribe visited as part of the tour, the Lac de Flambeau Ojibway, stated that funding levels are not enough to meet the needs of their constituency.

Compacts and Contracts

A Tribe under compact is a Tribe considered sovereign. The Canadian equivalent would be a First Nation operating under a Self-Government Agreement. It is a comprehensive arrangement that includes authorities formerly under the Federal Government as well as the State Government. A Tribe under compact is a Tribe administering IHS programs and services at the community level. The Canadian equivalent would be a First Nation operating a Health Transfer agreement.

Sexually Transmitted Diseases

Similarly in the U.S. as in Canada, there is a rise in STDs across respective Aboriginal populations, particular in chlamydia and HIV. Canada appears to be more vigilant in addressing this disease area as, only in the last fiscal year under Harkin Amendment SA 1626, an Act of Congress, \$1,000,000.00 was allocated for STD prevention and control to AI/AN Tribes.

Health Information and Health Data

The U.S. Tribes and Federal and State Governments face the same challenges with respect to the lack of accurate data on AI/AN populations, data that is often not shared or comparable across jurisdictions.

²⁷ For more information on OCAP, please refer to Brian Schnarch's article in the first issue of the Journal on Aboriginal Health published by the National Aboriginal Health Organization in January 2004 (www.naho.ca).

GLITC EpiCenter

The impressive operations of the Center would require more time for study. Notwithstanding, there are similar activities to those undertaken by the FNC in the areas of tobacco surveys, health careers and community-based research training.

Next Steps

1. Share information with the GLITC particular to the First Nations Regional Longitudinal Health Survey (RHS) initiative and the community-based skills enhancement workshops relating to health research and information. In particular, the GLITC and other Tribes might be interested in the workshops aimed at youth. They were keenly interested in the Data Warriors aspect as part of their own health career initiatives.
2. Return for additional site visits to the EpiCenters in Portland, Seattle, Alaska and Arizona as these centers serve large urban AI populations.
3. Meet with representatives of the National Indian Health Board to solicit their opinions on the success of the Epidemiology Program. The Board would be able to provide a more balanced opinion particular to Treaty Right to Health and how OCAP manifests itself in law and application for the sovereign Tribes.