

Conference Report

**Data Conference on American Indians/Alaska Natives
September 6 – 8, 2000
Denver, Colorado**

Background:

At the request of Deputy Secretary Thurm, IHS and HCFA expanded a planned data conference between the two agencies to include broader Department participation. What we believe is the first Department/Tribal conference on the subject of AI/AN data was held in Denver, September 6 – 8, 2000.

Purpose of the Conference:

The purpose of the conference was to bring experts together from the Department and Tribal organizations to learn about current data systems that support AI/AN issues, to hear from Tribal representatives about needs and problems, and to begin a process to improve the collection, use and dissemination of data for and about AI/AN people. We believe that purpose was fulfilled.

Attendance and Agenda:

There were 74 attendees from around the country. We had fourteen presentations on a broad range of data systems in place within DHHS and in Tribal health settings. Presenters from the Department included: ASPE, NCHS/CDC, AHRQ, HCFA, IHS. Guest presenters included: Inter-Tribal Council of Michigan, Northwest Tribal Epidemiology Center and the State of Colorado. Following the presentations each day, the conference participants engaged in discussion and a brainstorming exercise to identify key data-related issues that could be better addressed through improved cooperation and collaboration. The conference culminated in preliminary consensus on ways to provide both direct and indirect assistance to Tribes through data systems improvements.

Summary of Major Issues:

Direct Assistance to Tribes would improve through:

- Adding Tribal representatives to ongoing Data Councils, work groups and task forces
- Establishing an AI/AN Data User's Group
- Including an AI/AN Data Issues segment to websites
- Providing focused training and technical support in use of Department Data

Indirect Assistance to Tribes would improve through:

- Establishing a specific AI/AN research agenda
- Reconsidering sampling criteria to be more descriptive of the AI/AN population
- Improving the race classification in current databases

A full report of the recommendations is attached.

Summary of Key Issues:

Three discussion sessions were held during the conference to clarify issues with the presenters and suggest areas of improvement in the acquisition, access, processing and dissemination of data on behalf of American Indians and Alaska Natives. The suggested improvements fell into two general categories:

- Areas where the Department could improve its **direct assistance** to Tribes and
- Areas where the Department could make **indirect improvements** which would benefit Tribes

The following compilation of key issues and suggested areas of improvement are shown as they were presented by the conference attendees. No attempt has been made to judge the feasibility, cost/benefit or efficacy of any of the items.

Direct Assistance to Tribes

All Agencies:

1. Add Tribal representation to ongoing work groups, task forces, data committees etc.
2. Establish an AI/AN Data Users Group
 - a. Provide access to experts
 - b. Meet regularly to develop long term plans and strategies for improving AI/AN data
 - c. Meet ad hoc to address short term, tactical issues
3. Develop and conduct training on accessing, interpreting and using Department data and systems
 - a. Conduct needs assessment
 - b. Plan and budget for training programs targeted to AI/AN data needs
4. Establish or adapt websites to address AI/AN data issues
5. Ensure Urban Indian populations are considered and addressed
6. Provide specific training and technical assistance on the use of survey instruments
Assist Tribes to self-administer survey instruments to obtain community-level data
7. Develop and train on small area analyses to permit community-level profiling by Tribes

Indian Health Service

1. Assess the role of the Epidemiology Centers to consider
 - a. Developing a training program in the use of data, data analysis, research methods etc.
 - b. Assess Tribes' requirements, address concerns about level of service
 - c. Seek additional funding to enhance service to Tribes
 - d. Add additional centers
2. Develop specific training and technical assistance for HIPAA requirements
3. Seek and make available training programs such as the Johns Hopkins University program.
4. Provide full support for cost reporting
Needs a national work group including Tribal representation
Standardize cost center definition, etc.

Health Care Financing Administration

1. Work with states, Tribes, Tribal Organizations to release state-specific Medicaid data
2. Regional Offices: facilitate inclusion of state Indian Affairs Commissions (and the like) in data discussions, projects
3. Tribes/Tribal Organizations/IHS work with HCFA on small area studies (Medicare and Medicaid)

Office of the Assistant Secretary for Planning and Evaluation

1. Establish a task force on AI/AN Data; possibly a sub-group to the Data Council
2. Assist with training/technical assistance programs for HIPAA requirements:
Consider a Y2K-type rollout

Indirect Assistance to Tribes (benefits available through improved attention and coordination)

All Agencies

1. Establish an AI/AN-specific research agenda
 - a. Include Tribal representatives in development
 - b. Address AI/AN utilization and access to health services (among others)
2. Current researchers, share information and data more broadly with Tribes and Tribal orgs.
 - a. Conduct regular inter-agency conferences on AI/AN Data
 - b. Provide interpretive guidance on use of published data
3. Improve validity of race classification in current databases
4. Consider or reconsider sampling criteria; increase sample size or “oversample” AI/AN’s in national studies to provide usable comparisons
5. Coordinate a Department-wide effort to address racial health disparities
6. Develop and share best practices in “marketing” data and its applicability to Tribal health leaders, AI/AN communities

Assistant Secretary for Planning and Evaluation

1. Conduct a “Round II” of the Denver Data Conference to include other Department Operating Divisions. (CDC, NIH, HRSA, AoA, ACF...)
2. Work with Tribes to make website easier to access by non-technically trained

National Center for Health Statistics

1. Consider targeted surveys for AI/AN population
Possibly through pilots and use of university centers
2. Work with Tribes to gain consensus on a core set of indicators and a standard collection tool

to provide usable, comparable data on AI/AN's

3. Work with Tribes and States to improve quality/validity of state-level data

Agency for Health Care Research and Quality

1. Work collaboratively with Tribes/IHS to share expertise
2. Increase AI/AN sample size on NMEPS
3. Develop data workshops for Tribes.

Indian Health Service

1. Coordinate legislative efforts with HCFA
2. Advocate for a Data Subcommittee to the IHS/HCFA Steering Committee
3. Assign priority to a HCFA/IHS data sharing project to improve AI/AN classification on both agencies' data systems
4. Include Tribal representation on the Information Systems Advisory Committee
5. Strengthen the IHS Data Center
 - a. Provide universal interfaces for non-RPMS users
 - b. Provide training on RPMS utility
6. Establish a "Think Group" including Tribes to advise on financial management systems
 - a. Incentives for RPMS retention
 - b. Encourage cost reporting for its potential in managing revenue centers and assets

Health Care Financing Administration

1. Consider requirements on States to address Tribal needs during systems development and modification. Heavy federal support given to States for their Medicaid systems.
2. Assist Tribes in writing grant proposals; provide access and advice on HCFA data.
3. Research and make recommendations on ways for Tribes, IHS and Urban programs to gain greater access to Medicare/Medicaid/SCHIP eligibility (and dollars)
4. Work with National Governor's Association and State Medicaid Directors to facilitate access to state data.
5. Develop incentives for I/T/U system to move toward full cost reporting capability.
6. Establish an "Indian Desk" at HCFA headquarters for access to range of HCFA issues.
7. HCFA consider the IHS model for Tribal Consultation

List of Presentations:

Michigan Tribal Community Profiling Project

Presenter: Rick Haverkate, MPH
Health Services Director
Inter-Tribal Council of Michigan
Sault Ste. Marie, MI

HHS Data Council: Improving Information for Decision Making

Presenter: James Scanlon
Director, Division of Data Policy
Office of the Assistant Secretary for Planning and Evaluation
Washington, DC

Centers for Disease Control and Prevention

National Center for Health Statistics

Past, Present and Future

Presenter: Jenifer Madans, PhD
Associate Director for Science, NCHS
Hyattsville, MD

Medical Expenditure Panel Survey (MEPS)

Presenter: Nancy Kraus
Senior Survey Statistician
Agency for Health Care Research and Quality
Center for Cost and Financing Studies
Rockville, MD

Administrative Simplification:

Health Insurance Portability and Accountability Act Update

Presenter: William R. Braithwaite, MD, PhD, FACMI
Senior Advisor on Health Information Policy
Office of the Assistant Secretary for Planning and Evaluation
Washington, DC

Measuring Health Status Accurately in Indian Country

Presenter: Dee Robertson, MD
Director, Northwest Tribal Epidemiology Center
Northwest Portland Area Indian Health Board
Portland, OR

Racial Misclassification on State Death Certificates

Presenter: Paul Stehr-Green, DrPH
Consulting Epidemiologist
Northwest Tribal Epidemiology Center
Northwest Portland Area Indian Health Board
Portland, OR

Medicaid Systems and Data

Presenter: Rick Friedman
Director, Division of State Systems, Center for Medicaid and State Operations
Health Care Financing Administration
Baltimore, MD

Medicaid Management Information System (Colorado)

Presenter: John Wagner
Department of Health Care Policy and Financing
State of Colorado, Denver CO

Medicare/Medicaid Research Issues on behalf of American Indians/Alaska Natives

Presenter: Cliff Wiggins
Senior Operations Analyst
Office of the Director, Indian Health Service
Rockville, MD

Medicare Data Systems

Presenter: John Van Walker
Senior Advisor for Technology, Office of Information Systems
Health Care Financing Administration
Baltimore, MD

Information Available within the IHS's Data Systems

Presenter: Stanley P. Griffith, MD, FAAFP
Division of Information Resources
Indian Health Service, Albuquerque, NM

Indian Health Service Financial Systems

Presenter: George Anna Horton
Senior Fiscal Analyst
Indian Health Service, Rockville MD

IHS Business Office Systems

Presenter: Elmer Brewster
Business Office Coordinator,
Indian Health Service, Rockville MD

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