Building Tribal Data Capacity and Oversight – Tools and Resources

NCAI Policy Research Center
NCAI Pre Conference Data Data Institute

June 3, 2018
Overview

• Diabetes and Behavioral Health Comorbidities: Opportunities for Research and Policy

• Disaggregating American Indian & Alaska Native Data

• Using Science to Building Tribal Capacity for Data-Intensive Research
Mission

• The mission of the NCAI Policy Research Center is to provide tribal leaders with the best available knowledge to make strategically proactive policy decisions in a framework of Native wisdom that positively impact the future of Native peoples

• Vision: Supporting Indian Country in shaping its own Future
Fulfilling the Mission

Data on the Problem + Data on Solutions, Policies + Political players take action = Policy Change

Adapted from Kingdon, J. Agendas, Alternatives and Public Policies, 2nd ed. 1995
Fulfilling the Mission

Data on the Problem + Data on Solutions, Policies + Political players take action = Policy Change
13th Annual Tribal Leader/Scholar Form

- NCAI Mid Year Conference
- Tuesday - June 5, 2018

Visit [http://www.ncai.org/prc](http://www.ncai.org/prc)
Diabetes and Behavioral Health Comorbidities: Opportunities for Research and Policy

Yvette Roubideaux, MD MPH
NCAI Policy Research Center

June 3, 2018
Diabetes and Behavioral Health Comorbidities

• New Monograph - Outline
  • Diabetes in AIANs
  • Behavioral Health Conditions in AIANs
  • Comorbidities
  • Diabetes and Behavioral Health Comorbidity
  • Current Efforts to Address
  • Policy Recommendations
Policy Recommendations

• Promote awareness
• Share best and promising practices on how tribes can address these issues
• Support behavioral health integration into primary care
• Support more research, resources, and funding to address these issues
• Support local and cultural adaptation of programs, best and promising practices
• Encourage more federal interagency collaboration and federal, state, local collaboration with tribes
• Help raise awareness of the TBHA
DISAGGREGATING AMERICAN INDIAN & ALASKA NATIVE DATA

A Review of the Literature

NCAI Policy Research Center
May 2018
AI/AN DATA DISAGGREGATION

Six Driving Questions

1. What has been published?
2. Priority issues of concern?
3. Demographic variables that impact health outcomes that are important to collect?
4. What is the potential and importance?
5. What are the potential benefits?
6. What organizations could lead and inform this work?

Resources
19 academic, 23 policy, and 7 media literature resources + NCAI reports

Reviewers
20 Indian Country experts, scholars
FINDINGS

Data quality challenges
  • Racial misclassification
  • Exclusion of AI/AN people and tribal governments

Multiple “definitions of Indian” used by federal agencies;
  • Political pressures of formula (population-based) funding
  • Challenges to fulfilling the trust responsibility

Types of data disaggregation
  • Geography, age, gender, single vs. multi-race
  • Culture, environment, community, tribe
RECOMMENDATIONS

Inform the standardization of AI/AN data collection and reporting across federal agencies

Amend reporting practices and policies that inhibit the disaggregation of current data, where appropriate

Support regional intertribal entities in increasing data disaggregation and providing TA

Build tribal data capacity

Visit: http://www.ncai.org/prc
USING SCIENCE TO BUILDING TRIBAL CAPACITY FOR DATA-INTENSIVE RESEARCH

National Congress of American Indians

June 2018
Building Tribal Data Capacity (NSF Project)

- Tribes need accurate data to:
  - Meet the cultural, social, and economic needs of their people
  - Exercise tribal sovereignty
  - Improve service delivery

- Elements of NSF Project
  - Pilot grants for tribal censuses and surveys
  - Federal reporting requirements
  - Analysis of data on service areas
  - Tribal Data Practices Survey
Pilot Grants for Tribal Censuses/Surveys

- Pilot grants to conduct tribal censuses and surveys in their communities

- The Kalispel Tribe of Indians, the Pueblo of Laguna; the Nez Perce Tribe; the Sault Ste. Marie Tribe of Chippewa Indians; and the Rocky Mountain Tribal Epidemiology Center, serving tribes in Montana, Wyoming and Idaho
Lessons Learned

Some Lessons Learned and Best Practices

• Dedicated funding and staff needed

• Support of Tribal Leaders is crucial

• Planning for tribal data collection should carefully consider:
  • the purpose the collection,
  • definitions of the population and geography,
  • the use of external partners and ownership of data,
  • need for IT infrastructure, and timing.
Additional Lessons Learned

• Support of tribal program managers, elders, youth and cultural leaders in the community is also essential

• Thoughtful questionnaire development is needed

• Staff conducting the enumeration must be trained and retained; expertise is needed

• Data security, maintaining confidentiality and long term data storage are also essential
Major Recommendations

• Financial resources are needed for tribal planning and data collection.

• Flexibility in the use of existing program planning funds should be permitted.

• Intertribal sharing of technical expertise is important.

• Federal agencies should partner with tribes in the collection of data for federal purposes, including the BIA American Indian Population and Labor Force Report.
Federal Reporting Requirements

• A major portion of tribal capacity is consumed by meeting the reporting requirements of federal programs

• Over 2400 separate data fields required by 12 federal programs

• An analysis by the project estimated that reporting for just 10 programs and 2 program consolidation initiatives costs tribes nearly $12 million a year
Federal Reporting Requirements - Recommendations

• Standardization of reporting requirements across federal agencies is encouraged

• Program integration, as in self governance or 477 programs reduces reporting costs significantly

• Exploration of how federal reporting requirements burden can be reduced and how they can serve tribal policymaking
The Geospatial Dimensions of Tribal Data

• The connection between a people and the land they share together is fundamental to the concept of a nation.

• To improve data for decision-making and governance, tribal leaders at the local level and public policy-makers at the state, regional, and federal level must take into account tribal geospatial considerations.
Objectives of Geospatial Data project

• In reviewing tribal service area geography, several basic questions arise:

  • What are the types of tribal service areas already in use at the tribal level?

  • How are the types of tribally-defined service areas and the types of service areas used by federal funding agencies different than the Census Bureau's tribal geographic areas?

  • What are near-reservation areas and congressionally mandated service areas?
Methods

- Selected service areas for largest federal programs in terms of population and dollars:
  - Bureau of Indian Affairs
  - Indian Health Service
  - Employment and Training
  - HUD
  - TANF
  - Tribal Child Care Programs

- Reviewed Federal Regulations
Recommendations

• Federal agencies should consult with tribes on service populations and services areas

• Understanding federal and tribal definitions of services areas and their impact on programs and services is critical
THE STATE OF TRIBAL DATA CAPACITY IN INDIAN COUNTRY:

KEY FINDINGS FROM THE SURVEY OF TRIBAL DATA PRACTICES

Desi Rodriguez-Lonebear, PhD Candidate
(Citizen of the Northern Cheyenne Nation)
Sociology, University of Arizona USA & Demography, University of Waikato New Zealand

NCAI Policy Research Center NSF Grant Team
Funded by NSF grant #SMA-1439605 to NCAI
PROJECT OBJECTIVES

The Tribal Data Practices Survey (TDPS) focused on assessing tribal data capacity related to tribal censuses, surveys and use of data for tribal governance purposes, and sought to understand:

1) The types of data or information tribes currently use;

2) How tribes access, collect, manage, and report these data; and

3) What types of data tribes need for governance purposes.
METHODS

Sample:

• Target population: elected or appointed leaders of federally recognized tribes or their staff designees to respond on behalf of their tribe.

Survey/Measures

• 25 questions focused on various aspects of tribal data capacity

• Developed after interviews, focus groups with tribal leaders and others
SURVEY ADMINISTRATION


• Mail survey to tribal representatives with stamped return envelope

• Follow up email reminders
RESULTS

• A total of 253 surveys were completed
  – 207 surveys were collected on iPads during the NCAI Annual Convention
  – 43 surveys were collected online, 3 were returned by mail
  – Respondents - Tribal leaders, tribal staff, other

• Final sample = 197 responses (57% leader/42% tribal staff) from 122 federally recognized tribes (22%) who provided a valid tribal name and who consented to take the survey.

• Analysis at the tribal level required weighting multiple responses from individual tribes

• Tribes from all BIA regions represented (12-44%); 68% had < 5000 members
DATA FOR TRIBAL GOVERNANCE

• 83% of the tribes who responded to the survey indicated that it is extremely important for tribes to collect or have access to data on their tribal populations for governance purposes.
CURRENT TRIBAL DATA PRACTICES

• 43% of tribes have conducted a tribal census or survey of their members in the last five years.

• The majority of tribes currently collect or use data on:
  
  – their tribal citizens living on tribal lands (85%);
  
  – on tribal citizens living off tribal lands (72%); and
  
  – on other Indians or non-Indians living on their tribal lands (51% and 38%, respectively)
### WHAT KINDS OF EXTERNAL DATA ARE TRIBES USING?

<table>
<thead>
<tr>
<th>Data Source</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>U.S. Census Bureau</td>
<td>70%</td>
</tr>
<tr>
<td>Bureau of Indian Affairs</td>
<td>68%</td>
</tr>
<tr>
<td>HUD – Department of Housing and Urban Development</td>
<td>61%</td>
</tr>
<tr>
<td>State Agency</td>
<td>30%</td>
</tr>
<tr>
<td>County Agency</td>
<td>21%</td>
</tr>
<tr>
<td>University and Colleges</td>
<td>24%</td>
</tr>
<tr>
<td>Other Federal Agency</td>
<td>14%</td>
</tr>
<tr>
<td>Pantribal Organizations (e.g. tribal epidemiology centers)</td>
<td>13%</td>
</tr>
<tr>
<td>Other Source</td>
<td>10%</td>
</tr>
<tr>
<td>Missing</td>
<td>7%</td>
</tr>
</tbody>
</table>
## HOW ARE TRIBES USING DATA?

<table>
<thead>
<tr>
<th>Response</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete federal grant or other required reporting</td>
<td>76%</td>
</tr>
<tr>
<td>Communicate with tribal members</td>
<td>69%</td>
</tr>
<tr>
<td>Service delivery</td>
<td>61%</td>
</tr>
<tr>
<td>Set tribal priorities and strategic goals</td>
<td>60%</td>
</tr>
<tr>
<td>Develop a budget</td>
<td>56%</td>
</tr>
<tr>
<td>Communicate with others outside the tribe</td>
<td>38%</td>
</tr>
<tr>
<td>Other</td>
<td>6%</td>
</tr>
<tr>
<td>I don’t know</td>
<td>4%</td>
</tr>
<tr>
<td>Missing</td>
<td>3%</td>
</tr>
</tbody>
</table>
HOW ARE TRIBES FUNDING DATA PRACTICES?

• Tribal money and federal grants/contracts were by far the main sources of funding for:
  
  – Conducting tribal censuses or surveys (54% and 38%)
  
  – Collecting and maintaining Tribal Enrollment data (71% and 39%)
  
  – Collecting and maintaining data on participants in services programs (73% and 62%)

• Other sources of funding (state grants and contracts, foundations, non-profit organizations, etc.) used much less (mostly less than 10%)
HOW ARE TRIBES MANAGING DATA?

<table>
<thead>
<tr>
<th>Response</th>
<th>Percent</th>
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</thead>
<tbody>
<tr>
<td>Tribe has a central data office or hub – a main office where the tribe’s data are managed</td>
<td>74%</td>
</tr>
<tr>
<td>Data sharing about participants in service programs occurs between tribal departments or tribal agencies</td>
<td>64%</td>
</tr>
<tr>
<td>Tribe has an IRB or committee that approves research conducted with tribal members or conducted on tribal lands</td>
<td>28%</td>
</tr>
</tbody>
</table>
## HOW ARE TRIBES PROTECTING DATA?

<table>
<thead>
<tr>
<th>Response</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employee confidentiality training</td>
<td>64%</td>
</tr>
<tr>
<td>Authorization by tribal members</td>
<td>52%</td>
</tr>
<tr>
<td>Tribal ordinance or code governing tribal data and information</td>
<td>49%</td>
</tr>
<tr>
<td>Data security infrastructure</td>
<td>48%</td>
</tr>
<tr>
<td>No privacy protection is currently in place</td>
<td>3%</td>
</tr>
<tr>
<td>I don't know</td>
<td>9%</td>
</tr>
<tr>
<td>Other</td>
<td>6%</td>
</tr>
<tr>
<td>Missing</td>
<td>3%</td>
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TRIBAL DATA NEEDS

Tribes identified the following data need areas:

1. Tribal language fluency and/or other cultural information (61%)
2. Education level (58%)
3. Health status (57%)
4. Housing (57%)
5. Demographics (57%)
6. Employment status (56%)
7. Income (52%)
CONCERNS ABOUT GOVERNMENT DATA COLLECTION

• Over 80% percent of tribes indicated they were concerned or very concerned about:
  – The accuracy of U.S. Census tribal population data
  – The usefulness of Census data to tribes
  – How the federal government uses Census data on tribal populations
  – Tribal input into Census decision-making.

• Beyond the U.S. Census, 89 percent of tribes are concerned about the accuracy of other federal, state, or local government data on tribes
RECOMMENDATIONS

• Federal funding and technical assistance for tribes to develop their capacity to conduct tribal censuses and surveys

• Exploration of other sources of funding, including prioritizing tribal investment and cost-sharing

• Increased federal tribal partnerships on data, including greater access, sharing and efforts to improve accuracy

• Increased efforts to train students and tribal citizens in data collection efforts, research, STEM fields

• Continued efforts to build capacity in tribes to regulate and oversee data collection efforts in their communities
Questions?
Visit our Exhibit!
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