Tribal Research Infrastructure Updates

4th Annual Health Research Summit
March 31, 2016
2012-2016 Tribal Partners

- Oglala Sioux Tribe
  - Kathryn Blindman
- Fond du Lac Band of Chippewa
  - Cody Bassett and Jordan Mallery
- Turtle Mountain Band of Chippewa Indians
  - Anita Frederick, Kylie Keplin and Ashley Parisien
- Sisseton Wahpeton Oyate
  - Heather Larsen
- Spirit Lake Nation
  - Bonita Morin
- Rosebud Sioux Tribe
  - Simone Bordeaux
## CRCAIH Tribal Partners’ IRBs

<table>
<thead>
<tr>
<th>External IRB/RRB</th>
<th>Tribal College IRB/RRB</th>
<th>Tribal IRB/RRB</th>
<th>Human Services IRB</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>• Sisseton Wahpeton Oyate Local Research Review Board [LRRB]</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Rosebud Sioux Tribe</td>
<td></td>
</tr>
</tbody>
</table>

This presentation is supported by the National Institute on Minority Health and Health Disparities of the National Institute of Health under Award Number u54MD008164 (PI – Elliott)
SPIRIT LAKE NATION

TURTLE MOUNTAIN BAND OF CHIPPEWA INDIANS

COMMUNITY HEALTH ASSESSMENT & DATA CHALLENGES
Community Assessment Process

Planning, Implementation and Dissemination

March 2016

This presentation is supported by the National Institute on Minority Health & Health Disparities of the National Institute of Health under Award U54MD008164.
Cankdeska Cikana Community College
Community Assessment Workgroup

• **Organizations [Collaboration of community partners]**

• Composition of the workgroup:
  The team consisted of tribal college programs, tribal college Administration and tribal programs.

• How the workgroup was identified:
  The stakeholders were critical to the success of the Community Needs Assessment Project. It met program requirements, program reporting requirements and program goals and objectives in general.

• Roles of the team members:
  Each workgroup member was called upon to identify the role they would like to take during this process; tasks were not assigned by someone else. The Assessment was a collaborative effort on the part of the members of the workgroup.

• How the team developed (e.g., size of the team, number of meetings):
  The Team composition was 15. Meetings were scheduled bi-weekly during planning process.
Overview of Assessment

• Assessment process
• Benefits of conducting an effort such as this:
  ▪ Provides new information
  ▪ Provides new data and stats
  ▪ Meet program requirements
  ▪ Collaboration efforts
  ▪ Engages community
  ▪ Future planning
The *Planning* process:
-walks communities through the assessment process.
-provides a snapshot of policy, systems and environmental change strategies - ‘assets’ and ‘needs’.
-frames and understands the current status of community health.
-allows communities to track progress so incremental changes can be noted.
LEARNING OPPORTUNITIES FOR OUR COMMUNITY TO GROW
Photovoice Purpose:

Strengths and Resources

picture of an area that may be deemed appropriate and highlight the reasons why

Areas for Improvements

picture of an area that may be deemed unacceptable and highlight the reasons why (e.g., difficult to access, solid waste, lack of pedestrian crossing)
Photovoice

Strengths and Resources

Area for Improvements
Success stories, challenges, and anecdotes from the process:
The overall implementation of the CNA was very successful, due to:

- the initial planning,
- the collaboration of the workgroup,
- the sites for all the sessions,
- individuals very respectful during the sessions,
- meals provided at each location both afternoon and evenings,
- evening sessions scheduled to accommodate working parents, and
- engaging children that attended with their parents (child care available and meals provided).

Transportation was a concern, however the workgroup decided to schedule sessions in the districts both during the day and evening that would support higher participation for each session.
Method

- Design
  - Cross-Sectional Anonymous Survey

- Instrument
  - Based on previous CCCC Health Surveys
  - Spirit Lake Comprehensive Community Assessment 2015
    - Revised by CCA Workgroup
    - 2012 BRFSS, Housing, and Childcare
Method

- Data Collection
- Interviews
  - Head Start Parent Interviews
    - Conducted May 28th – June 4th 2015
  - Community Interviews
    - Conducted Monday July 20th – Thursday July 23rd
      - 10am – 1pm and 4pm – 7pm Daily
  - Notified through mail, Flyers in community, & Local radio station
  - Face-to-Face interviews were recorded electronically on I-Pad
  - Incentive after completing survey $25 Wal-Mart gift card
Method

- Sample
  - 258 residents of the reservation representing their households completed the survey.
  - 70% Female
  - Average Age 40
    - Ages ranging from 16–89
  - 80% Lived in the community for 18+ years
  - 46% Never-Married; 34% Married or Member of Unmarried Couple
  - 28% Less than a HS Degree; 51% had a HS Degree; 22% had a college degree
  - 38% had an individual income under $5000; 73% under $20,000
  - Average number of people per family was 4.86
    - Number of People ranging from 0-19 people per family
Community Assets and Priorities

What are key assets:
- External resources
- People
- Economic development

Top priority areas for our Community Action Plan:
- Child Safety
- Housing
- Employment
Next Steps

- Next steps: Dissemination of results and on-going review, revisions, and updates to this document that will promote changes to existing services to benefit our community.

- Short term goal: Collection of new data and statistics initiated by the grassroots organizations.

- Long term goals: Collection of on-going data and stats that promote and support changes and improvements for our community.

- Developing the Community Action Plan

- Lesson learned: collaboration makes things happen.

- Improvements for continuing review: One-stop-point for review and continuing comments

- Support for on-going efforts (e.g., time, input, resources)
Community Health Assessment
Telling OUR story of Health & Wellness

Kylie Keplin
Tribal Nations Research Group-Director of Community Innovation
Why do we need a community health assessment?

- TMBCI has never conducted their own CHA
- Establish base line information that we will track and use to discern areas of concern and improvement over time through primary and secondary data collection
- Data driven decision making
- WE prioritize OUR health concerns
- Develop our own Plan of Action to meet our concerns
Potential Use & Benefits

- Health Services Planning
- Health Program Development
- Resource Allocation
- Describing services available in the community
- Verifying community health concerns
- Identifying and prioritizing health issues
- Monitoring trends on significant health issues over a period of time
- Public Health Accreditation
Multisector Coalition
Develop the CHA & Methodology

Market through advertising and recruitment

Coalition

Collect Information and identify priorities

Community Health Strategic Plan
To promote health equity for enrolled members of Turtle Mountain Band of Chippewa Indians residing in or adjacent to Turtle Mountain Band of Chippewa Indians reservation through health promotion and disease prevention
Design
- Build the Community Health Survey
- Methodology-sample size, survey locations, etc.

Market
- Newspaper
- Radio
- Social Media

Cooperation
- Tribal Resolution
- Tribal Program Involvement
- Letters of Support

Administer
- Tribal Programs, Convenient & High Traffic Locations
- Focus Groups

Analyze
- Triangulate Data
- Qualitative & Quantitative Data
- Comparative Data-YRBS, BRFSS, PRAMS, etc.
Now what?

WE build a community health profile
WE prioritize our health needs and concerns
WE develop our own strategic plan
WE decide what our future holds
Turtle Mountain Band of Chippewa
Data to Knowledge in Tribal Communities

Tribal Nations Research Group

Anita Frederick
Turtle Mountain Band of Chippewa
Tribal Nations Research Group

**Mission**

"To improve the quality of life for all tribal members through culturally-competent, custom-fit research"

**Purpose**

The purpose of the Tribal Nations Research Group is promotion of high quality research relevant to the Turtle Mountain Band of Chippewa Indians. The research results provide custom fit data and data ownership, promotes public and private economic development and opportunity, and upholds positive images of Turtle Mountain Band of Chippewa Indians. The Group also provides quality research education materials designed to educate the community about research and the research process, according to the standards established by the TMBCI.
Tribal Nations Research Group

• Goal
  • Develop a statutory process to review, govern, maintain, and house all research, collection, database, or publication undertaken within the Turtle Mountain Community. To maintain data relevant to TMBCI and all subsidiaries.

• Relationship with TMBCI
  • Establish a formalized process to protect the people, culture, and natural resources of TMBCI.
  • Establish and manage the TMBCI Research Department.
    • Tribal RRB
    • Research Catalog
  • Establish a data center/repository that will be the official reporting entity for the TMBCI and subsidiaries.
  • Inform and educate the TMBCI community about the research process, data use, data ownership, and distribute updates about research.
Why?

- Establish our own benchmarks.
- Change for our community.
- Increase in communication.
- Everyone working toward a set of common goals.
How?

PHASE 1

TNRG & TMBCI partners

Research Review Board

Catalogue past research

Collect list of secondary data sources

Track Research Results

Develop a research database results, researcher, funding

Analyze secondary data information

Data Sharing/Use agreements

Understanding Prior Research - develop a research agenda

Find what is good, know what we need to collect
How?

PHASE 2

Evaluate:
- Technology
- Policy
- Communication
- Resources

Programs/Services of TMBCI

Tribal Enterprise

Government Agencies

Private Independent Business

Data Warehouse

Analyze

Find Patterns

Tribal Members-Community

Tribal Leadership

Community services and programs
RESULTS

• Data
  • Research database
  • Demographic Information
  • Data sovereignty
  • Data protection

• Better understanding of our community and the needs of our community.

• Educated and informed community

• Increase in communication across the community, stakeholders, and constituents.

• Stronger decision making.

• Improved planning.

• Targeted resources

• Overall improvement in our people, resources, and finances.

• Respect for research
Items to remember...

- When collecting data in tribal communities, always have respect for the community, the people, their culture, and their lands;
- Tribal/Reservation communities have qualified individuals available to help you understand the data needs, reach out to them;
- If you collect the data, do something with the data.
  - inform policy,
  - inform leaders,
  - Inform the community.
To learn more about TNRG
Please visit our website:

http://www.tnrg.org
FOND DU LAC BAND OF LAKE SUPERIOR CHIPPEWA

TRIBAL-CONDUCTED RESEARCH
OPIOIDS IN INDIAN COUNTRY

Presented by Cody Bassett
Fond du Lac Human Services Division
Neonatal abstinence (NAS) highly prevalent

Over 25% of all Minnesota NAS newborns are American Indian

American Indian newborns are 7.4 times more likely to be born with NAS

American Indian women 8.7 times more likely to be diagnosed with maternal opiate dependency or abuse
**METHODOLOGY**

- Community Specialists
- Incentive: $25 Gift Card
- Survey
  - 59-item
  - Multiple sections covering opioid, methadone, and treatment histories

- 62 Participants
  - 30 men, 32 women
- 54 Enrolled with a federally recognized tribe
  - Remaining participants were identified as descendents of a band member
83.9% of study participants had taken methadone but only 32.3% ever being clients at a methadone clinic.

<table>
<thead>
<tr>
<th>Source</th>
<th>Percentage (%)</th>
<th>n=52</th>
</tr>
</thead>
<tbody>
<tr>
<td>Methadone Clinic</td>
<td>14.3%</td>
<td></td>
</tr>
<tr>
<td>Prescribed for Pain</td>
<td>0.0%</td>
<td></td>
</tr>
<tr>
<td>Purchased from a Dealer</td>
<td>10.2%</td>
<td></td>
</tr>
<tr>
<td>Given by Dealer</td>
<td>16.3%</td>
<td></td>
</tr>
<tr>
<td>Given by Friend/Family</td>
<td>59.2%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>0.0%</td>
<td></td>
</tr>
</tbody>
</table>

75.5% was freely given.
Key points:

- **Age 16:** 75% already had marijuana/alcohol and 50% had already started using illegal drugs.

- **Age 18:** 50% had an opioid prescription for pain.

- **Age 22.5:** 75% had an opioid prescription for pain, 50% had methadone.
Half of participants in MMT reported receiving doses above 100 mg/d.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Percentage (%); n=20</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prescribed opioids while in MMT</td>
<td>75.0%</td>
</tr>
<tr>
<td>Taken Benzodiazepines while in MMT</td>
<td>65.0%</td>
</tr>
<tr>
<td>Prescribed methadone for pain while in MMT</td>
<td>25.0%</td>
</tr>
<tr>
<td>Take Home Doses Stolen</td>
<td>25.0%</td>
</tr>
</tbody>
</table>
65% of those who received take-home doses reported diverting.

<table>
<thead>
<tr>
<th>Characteristics of Diversion among MMT clients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diversion</td>
</tr>
<tr>
<td>Giving it away</td>
</tr>
<tr>
<td>Selling</td>
</tr>
<tr>
<td>Trade</td>
</tr>
<tr>
<td>All of the Above</td>
</tr>
</tbody>
</table>
OUTCOMES

- This study exposed the risky behaviors and diversion that are much more common than believed.

- Revealed the efficacy and dangers of current MMT practices.

- The six resolutions were passed and call for action to combat this epidemic.

- These results lead to position paper from MACSSA and the current efforts to shape MAT policy in the state of Minnesota.
Cody Bassett
codybassett@fdlrez.com
QUESTIONS & ANSWERS