Challenges and Solutions to Accessing Data that Benefits Tribal Communities

Collette Adamsen, PhD  
NRCNAA Director  
Turtle Mountain Band of Chippewa Indians

&

Cole Ward, MS  
NRCNAA Research Specialist  
Sisseton-Wahpeton Oyate

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Overview

In this session we will discuss the following topics:

- Background and history of the National Resource Center on Native American Aging (NRCNAA).
- The NRCNAA research model utilized when working with Title VI programs.
- Discuss how tribes can assess their needs using the “Identifying our Needs: A Survey of Elders.”
- Informing tribes on how to effectively utilize their data.
- Provide data visual representation of Cycle VI tribal aggregated data from the “Identifying our Needs: A Survey of Elders VI.”
- Benefits of data and how it can be utilized at the local, state, tribal, and federal level.
National Resource Center on Native American Aging (NRCNAA)

The NRCNAA is one of three centers that are funded through the Administration for Community Living (ACL). The other two centers are:

- The National Resource Center for American Indian, Alaska Native and Native Hawaiian Elders (Alaska)
- National Resource Center for Native Hawaiian Elders (Hawaii)

The NRCNAA was established in 1994

- Center for Rural Health, University of North Dakota, School of Medicine & Heath Sciences.

Mission and Vision

**Mission**
Identify and increase awareness of evolving Native elder health and social issues.

**Vision**
To empower Native people to develop community based solution.

Honoring and helping to maintain cultural values.
NRCNAA Programs and Resources

- *Identifying Our Needs: A Survey of Elders*
- WELL (Wise Elders Living Longer) Balanced Program
- Native Elder Caregiver Curriculum (NECC)
- Service Locator Map
- Heroes Project

Data Challenges

- Data not being readily available to tribes.
- Significant gaps in data.
- National data sets are skewed due to misclassification of race/ethnicity.
- Small sample size in some cases.
- Unreliable

(Urban Indian Health Commission, 2007)
**Why is data important?**

- Today, many decisions are based on data; therefore, populations with little or no data are easily overlooked (Urban Indian Health Commission, 2007).
- Provides an accurate picture of the Native elder population
  - Collecting custom fit data
  - Helps set goals and priorities
  - Identifies specific areas of health and social needs
    - Resource allocation
  - Relevant actionable data
    - Assists policymakers, tribal leadership, directorship, and management make decisions based on facts and numbers.

**Why is data important?**

- Fulfill Title VI grant requirements
- Other funding opportunities
  - Secure funding and additional resources for Native elders

*MOST IMPORTANT*
USE THE DATA
Identifying Our Needs: A Survey of Elders

- Assesses the health and social needs of Native Elders in Tribal Communities
- 3 year cycles
- Opportunity to collect information for their communities
- Technical assistance and training

Tribal Diversity

- NRCNAA research model addresses diversity between and within tribes.
  - Measurement of local needs
    - Unique fit to tribal community
  - Custom-fitting measure
    - ONE SIZE DOES NOT FIT ALL
Population

- Native elders that primarily reside on or within reservation areas, Alaskan villages, and Hawaiian homesteads.
- Age 55 years and older
- Important to note:
  - Age 55 years and over for Native elders is considered comparable to non-Native elders 65 years and older in the general population.

NRCNAA Research Model

- Tribal Resolution
- Elder Count
  - Send Surveys Guides
- Administer the Surveys
  - Trained Staff or Volunteer
- Tribe Owns Data
- Process Data
  - Results
**Needs Assessment Participation**

Cycle VI
- 18,134 Elders
- 267 tribes

Cycle V
- 17,049 Elders
- 262 tribes

Cycle IV
- 18,089 Elders
- 234 tribes

Cycle III
- 15,565 Elders
- 268 tribes

Cycle II
- 10,743 Elders
- 342 tribes

Cycle I
- 9,403 Elders
- 190 tribes

Total N = 89,436 surveys

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**Cycle VI Summary**

- Data collected in the time span of April 1, 2014 to March 31, 2017
- 18,134 AI/AN elders
- 164 sites
- 267 tribes
- Representation from:
  - 11 out of 12 Indian Health Service (IHS) Regions
  - 9 out of 10 Department of Health and Human Services (DHHS) regions
  - 28 out of 50 states

*Cycle VII began April 1, 2017 and will end March 31, 2020*
Survey Needs Data

- General health status of elders
- Indicators of chronic health
- Activities of Daily Living (ADL’s)
- Screenings
- Indicators of visual, hearing, and dental
- Memory and Disability
- Health Care Access
- Tobacco and alcohol use patterns
- Diet, nutrition, and exercise
- Social support pattern and housing
- Social Functioning
- Use and acceptance of services
- Demographics

Identifying our Needs: A Survey of Elders VII
Identifying our Needs: A Survey of Elders VII

VISON, HEARING & DENTAL
42. How quickly do you react to see or hear things?
43. Do you have trouble seeing or hearing?
44. Do you have trouble seeing or hearing?
45. Do you have trouble seeing or hearing?
46. Do you have trouble seeing or hearing?

MEMORY & DISABILITY
47. Have you been diagnosed with Alzheimer's disease?
48. Have you been diagnosed with Alzheimer's disease?
49. How often do you forget things?
50. How often do you forget things?
51. How often do you forget things?

HEALTH CARE TOOLS
52. What type of health care coverage do you have?
53. What type of health care coverage do you have?
54. What type of health care coverage do you have?
55. What type of health care coverage do you have?

SOCIAL SUPPORT/HOUSING
56. Do you participate in social activities that include food, housing, or other needs?
57. Do you participate in social activities that include food, housing, or other needs?
58. Do you participate in social activities that include food, housing, or other needs?
59. Do you participate in social activities that include food, housing, or other needs?

WEIGHT & NUTRITION
60. How tall are you without shoes?
61. How tall are you without shoes?
62. How tall are you without shoes?
63. How tall are you without shoes?

ESCALD & ALCOHOL USE
64. Do you smoke tobacco?
65. Do you smoke tobacco?
66. Do you smoke tobacco?
67. Do you smoke tobacco?

11276 11276 11276 11276
### Identifying our Needs: A Survey of Elders VII

[Image of the National Resource Center on Native American Aging (NRCNAA) logo]

#### Comparison Sheet

**Tribe Name (N= ) Comparison Data to Aggregate Tribal Data and National Data**

<table>
<thead>
<tr>
<th>Question</th>
<th>Response(s)</th>
<th>Tribal Data (55 and over)</th>
<th>Aggregate Tribal Data (55 and over)</th>
<th>National Data* (55 and over)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Would you say your health in general is excellent, very good, good, fair, or poor?</td>
<td><strong>General Health Status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Excellent</td>
<td>13.8%</td>
<td></td>
<td>16.8%</td>
</tr>
<tr>
<td></td>
<td>Very Good</td>
<td>29.2%</td>
<td></td>
<td>22.2%</td>
</tr>
<tr>
<td></td>
<td>Good</td>
<td>32%</td>
<td></td>
<td>30.4%</td>
</tr>
<tr>
<td></td>
<td>Fair</td>
<td>16.8%</td>
<td></td>
<td>16.2%</td>
</tr>
<tr>
<td></td>
<td>Poor</td>
<td>7.8%</td>
<td></td>
<td>7.6%</td>
</tr>
</tbody>
</table>
Data: Caregiving Data

Caregiving by Native Elders Cycle VI

Chronic Disease Rates by Gender among Native Elders

<table>
<thead>
<tr>
<th>Disease</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Blood Pressure</td>
<td>56.7%</td>
<td>58.2%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>40.3%</td>
<td>39.7%</td>
</tr>
<tr>
<td>Arthritis</td>
<td>38.9%</td>
<td>50.2%</td>
</tr>
<tr>
<td>Depression</td>
<td>15.6%</td>
<td>9.8%</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>14.0%</td>
<td>2.9%</td>
</tr>
</tbody>
</table>
Cycle VI Tribal Aggregate Unmet Needs

<table>
<thead>
<tr>
<th>Service</th>
<th>Would Use</th>
<th>Now Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home Repair/Modification</td>
<td>3.5%</td>
<td>1.5%</td>
</tr>
<tr>
<td>Home Delivered Meals</td>
<td>6.2%</td>
<td>0.5%</td>
</tr>
<tr>
<td>Transportation</td>
<td>4.2%</td>
<td>1.5%</td>
</tr>
<tr>
<td>Home Health Services</td>
<td>5.7%</td>
<td>2.2%</td>
</tr>
<tr>
<td>Financial Assistance</td>
<td>2.4%</td>
<td>0.4%</td>
</tr>
<tr>
<td>Caregiver Programs</td>
<td>1.3%</td>
<td>0.3%</td>
</tr>
<tr>
<td>Emergency Response Systems</td>
<td>1.6%</td>
<td>0.8%</td>
</tr>
<tr>
<td>Senior Center Programming</td>
<td>1.1%</td>
<td>0.3%</td>
</tr>
<tr>
<td>Legal Assistance</td>
<td>1.5%</td>
<td>0.5%</td>
</tr>
<tr>
<td>Adult Day Care</td>
<td>3.4%</td>
<td>0.5%</td>
</tr>
<tr>
<td>Assisted Living</td>
<td>4.6%</td>
<td>0.7%</td>
</tr>
<tr>
<td>L.T. Care Services</td>
<td>1.9%</td>
<td>0.2%</td>
</tr>
<tr>
<td>Information and Referral Asst.</td>
<td>1.4%</td>
<td>0.2%</td>
</tr>
<tr>
<td>Personal Care</td>
<td>2.7%</td>
<td>0.5%</td>
</tr>
<tr>
<td>Congregate Moats</td>
<td>2.9%</td>
<td>0.5%</td>
</tr>
<tr>
<td>Volunteer Services</td>
<td>2.5%</td>
<td>0.5%</td>
</tr>
<tr>
<td>Hospice Care</td>
<td>3.7%</td>
<td>0.5%</td>
</tr>
<tr>
<td>Grt. Asst. Housing</td>
<td>1.8%</td>
<td>0.3%</td>
</tr>
<tr>
<td>Telephone Reassurance</td>
<td>1.4%</td>
<td>0.3%</td>
</tr>
<tr>
<td>Nursing Facilities</td>
<td>1.2%</td>
<td>0.5%</td>
</tr>
<tr>
<td>Retirement Communities</td>
<td>1.7%</td>
<td>0.6%</td>
</tr>
<tr>
<td>Case Management</td>
<td>2.1%</td>
<td>0.7%</td>
</tr>
<tr>
<td>Elder Abuse Prevention Program</td>
<td>2.5%</td>
<td>0.6%</td>
</tr>
<tr>
<td>Employment Services</td>
<td>3.6%</td>
<td>0.7%</td>
</tr>
<tr>
<td>Shared Housing</td>
<td>4.7%</td>
<td>0.9%</td>
</tr>
</tbody>
</table>

Trending Data for Top 5 Chronic Diseases among AI/AN elders

- Diabetes: Cycle I 37.6%, Cycle II 46.3%, Cycle III 58.8%, Cycle IV 56.9%, Cycle V 52.3%, Cycle VI 48.7%
- High Blood Pressure: Cycle I 56.1%, Cycle II 51.0%, Cycle III 56.9%, Cycle IV 57.3%, Cycle V 58.2%, Cycle VI 56.5%
- Arthritis: Cycle I 47.1%, Cycle II 47.1%, Cycle III 45.1%, Cycle IV 44.9%, Cycle V 46.5%, Cycle VI 45.5%
- Cataracts: Cycle I 26.5%, Cycle II 24.4%, Cycle III 20.4%, Cycle IV 21.7%, Cycle V 21.9%, Cycle VI 19.4%
- Depression: Cycle I 0.0%, Cycle II 13.7%, Cycle III 12.2%, Cycle IV 13.8%, Cycle V 14.9%, Cycle VI 13.3%
Trending Data for Activities of Daily Living for AI/AN elders

**Cycle I**
- Bathing or Showering: 16.7%
- Dressing: 11.7%
- Eating: 7.3%
- Get In or out of bed: 13.0%
- Walking: 28.1%
- Using toilet: 8.9%

**Cycle II**
- Bathing or Showering: 14.3%
- Dressing: 10.2%
- Eating: 5.4%
- Get In or out of bed: 11.6%
- Walking: 23.9%
- Using toilet: 8.1%

**Cycle III**
- Bathing or Showering: 16.1%
- Dressing: 11.5%
- Eating: 6.2%
- Get In or out of bed: 13.7%
- Walking: 31.2%
- Using toilet: 8.3%

**Cycle IV**
- Bathing or Showering: 15.8%
- Dressing: 11.4%
- Eating: 5.9%
- Get In or out of bed: 13.3%
- Walking: 30.7%
- Using toilet: 8.5%

**Cycle V**
- Bathing or Showering: 15.4%
- Dressing: 11.2%
- Eating: 6.3%
- Get In or out of bed: 13.6%
- Walking: 29.8%
- Using toilet: 8.4%

**Cycle VI**
- Bathing or Showering: 14.7%
- Dressing: 10.1%
- Eating: 4.4%
- Get In or out of bed: 12.0%
- Walking: 29.0%
- Using toilet: 7.5%

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Trending Data for Instrumental Activities of Daily Living for AI/AN elders

**Cycle I**
- Prepare Meals: 17.9%
- Shop Pers. Items: 17.0%
- Managing Money: 10.0%
- Using telephone: 8.0%
- Doing Heavy Housework: 37.5%
- Doing Light Housework: 17.2%
- Getting Outside: 15.4%

**Cycle II**
- Prepare Meals: 15.7%
- Shop Pers. Items: 15.2%
- Managing Money: 8.3%
- Using telephone: 5.2%
- Doing Heavy Housework: 31.0%
- Doing Light Housework: 14.8%
- Getting Outside: 12.6%

**Cycle III**
- Prepare Meals: 16.8%
- Shop Pers. Items: 14.0%
- Managing Money: 8.8%
- Using telephone: 5.8%
- Doing Heavy Housework: 36.1%
- Doing Light Housework: 16.2%
- Getting Outside: 13.2%

**Cycle IV**
- Prepare Meals: 16.3%
- Shop Pers. Items: 15.1%
- Managing Money: 8.7%
- Using telephone: 5.5%
- Doing Heavy Housework: 35.1%
- Doing Light Housework: 15.7%
- Getting Outside: 13.0%

**Cycle V**
- Prepare Meals: 15.8%
- Shop Pers. Items: 14.8%
- Managing Money: 8.5%
- Using telephone: 5.1%
- Doing Heavy Housework: 35.1%
- Doing Light Housework: 15.6%
- Getting Outside: 12.8%

**Cycle VI**
- Prepare Meals: 14.9%
- Shop Pers. Items: 12.6%
- Managing Money: 8.3%
- Using telephone: 4.0%
- Doing Heavy Housework: 34.9%
- Doing Light Housework: 15.2%
- Getting Outside: 12.1%
## Top Chronic Diseases for Native Elders by Region and Tribal Aggregate

<table>
<thead>
<tr>
<th>Region</th>
<th>Diabetes</th>
<th>High Blood Pressure</th>
<th>Arthritis</th>
<th>Cataracts</th>
<th>Depression</th>
<th>Asthma</th>
</tr>
</thead>
<tbody>
<tr>
<td>National</td>
<td>18%</td>
<td>55.2%</td>
<td>47.4%</td>
<td>40.2%</td>
<td>17.2%</td>
<td>12%</td>
</tr>
<tr>
<td>Tribal Aggregate</td>
<td><strong>48.7%</strong></td>
<td><em>56.5%</em></td>
<td><em><strong>45.3%</strong></em></td>
<td>19.4%</td>
<td>13.3%</td>
<td>12.6%</td>
</tr>
<tr>
<td>Region 1</td>
<td><em><strong>47.9%</strong></em></td>
<td><em>55.2%</em></td>
<td><strong>49.3%</strong></td>
<td>12.7%</td>
<td>15%</td>
<td>13.8%</td>
</tr>
<tr>
<td>Region 2</td>
<td><em><strong>45.7%</strong></em></td>
<td><em>56%</em></td>
<td><strong>51.4%</strong></td>
<td>18.4%</td>
<td>14.7%</td>
<td>16%</td>
</tr>
<tr>
<td>Region 4</td>
<td><strong>57.8%</strong></td>
<td><em>64.3%</em></td>
<td><em><strong>47.1%</strong></em></td>
<td>23.5%</td>
<td>12.2%</td>
<td>12.1%</td>
</tr>
<tr>
<td>Region 5</td>
<td><strong>52.4%</strong></td>
<td><em>57.2%</em></td>
<td><em><strong>48.7%</strong></em></td>
<td>21.6%</td>
<td>17.6%</td>
<td>14.6%</td>
</tr>
<tr>
<td>Region 6</td>
<td><strong>52.5%</strong></td>
<td><strong>43.1%</strong></td>
<td><em><strong>43%</strong></em></td>
<td>17.8%</td>
<td>12.3%</td>
<td>10.3%</td>
</tr>
<tr>
<td>Region 7</td>
<td><em>63.7%</em></td>
<td><strong>60.6%</strong></td>
<td><em><strong>58.2%</strong></em></td>
<td>20.9%</td>
<td>12.6%</td>
<td>12.3%</td>
</tr>
<tr>
<td>Region 8</td>
<td><strong>48.3%</strong></td>
<td><em>55.4%</em></td>
<td><strong>45.4%</strong></td>
<td>15.8%</td>
<td>10%</td>
<td>12.8%</td>
</tr>
<tr>
<td>Region 9</td>
<td><em><strong>53%</strong></em></td>
<td><strong>57.1%</strong></td>
<td><em><strong>56.7%</strong></em></td>
<td>19.6%</td>
<td>10.7%</td>
<td>12.6%</td>
</tr>
<tr>
<td>Region 10</td>
<td><em><strong>33.8%</strong></em></td>
<td><em>54%</em></td>
<td><em><strong>47.2%</strong></em></td>
<td>22.2%</td>
<td>15.1%</td>
<td>13.9%</td>
</tr>
</tbody>
</table>

### Participation by DHHS Regions for Cycle VI

- Region 1: 426, 3%
- Region 2: 407, 2%
- Region 3: 3497, 10%
- Region 4: 537, 1%
- Region 5: 2223, 15%
- Region 6: 4056, 27%
- Region 7: 396, 3%
- Region 8: 2134, 12%
- Region 9: 2889, 16%
- Region 10: 3476, 19%
Map of DHHS Regions

Identifying Our Needs: A Survey of Elders VI
Urban vs. Rural Data

- RUCA codes for *Identifying Our Needs: A Survey of Elders VI* data
- AI/AN/NH elders who utilize Title VI services who reside within, near, or a certain radius of a defined urban area
  - Important to note: May live on the reservation or off the reservation, but reside in a certain proximity of an urban area.
RUCA Map Census Division Nine: Pacific


California Tribes

Urban vs. Rural Comparisons
Identifying Our Needs: A Survey of Elders Data

nrcnaa.org

Identifying Our Needs: A Survey of Elders VI
Urban and Rural Populations

N = 18,134

nrcnaa.org
Self Reported Health Status

Top 5 Chronic Conditions
Barriers to Health Care Services

<table>
<thead>
<tr>
<th>Barriers to Health Care Services</th>
<th>Urban</th>
<th>Rural</th>
</tr>
</thead>
<tbody>
<tr>
<td>No transportation</td>
<td>91.9%</td>
<td>94.3%</td>
</tr>
<tr>
<td>Cost</td>
<td>9.1%</td>
<td>10.0%</td>
</tr>
<tr>
<td>Long waits in clinic</td>
<td>8.5%</td>
<td>12.8%</td>
</tr>
<tr>
<td>Distance</td>
<td>7.7%</td>
<td>12.4%</td>
</tr>
<tr>
<td>Long waits in office</td>
<td>6.4%</td>
<td>12.3%</td>
</tr>
<tr>
<td>No access to office</td>
<td>2.2%</td>
<td>2.6%</td>
</tr>
<tr>
<td>No child care</td>
<td>0.3%</td>
<td>0.4%</td>
</tr>
<tr>
<td>No disabled access</td>
<td>0.3%</td>
<td>0.4%</td>
</tr>
<tr>
<td>No one speaks my language</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
</tbody>
</table>

Smoking Tobacco

<table>
<thead>
<tr>
<th>Smoking Status</th>
<th>Urban</th>
<th>Rural</th>
</tr>
</thead>
<tbody>
<tr>
<td>No smoking</td>
<td>78.7%</td>
<td>72.4%</td>
</tr>
<tr>
<td>Yes, everyday</td>
<td>14.6%</td>
<td>10.7%</td>
</tr>
<tr>
<td>Yes, some days</td>
<td>6.7%</td>
<td>6.8%</td>
</tr>
</tbody>
</table>
Alcohol Consumption Patterns

- 5 yrs. Age
- Never initiated
- Within 30 days
- >30 days within 12 mos.
- >12 mos. within 3 yrs.

Urban
- 38.2%
- 23.7%
- 22.5%
- 9.6%
- 5.6%

Rural
- 41.4%
- 18.5%
- 23.7%
- 9.7%
- 6.6%

Nutritional Health

- Skin/moist shrug/day
- Free fluid/waste/mills
- B/changement, food heat
- Eat alone
- Few/2 meals/day
- Phy. Unable to shop/ord/food sel.
- Lost/gain 10 lbs. in past 6 mos.
- Not enough money/food needed
- Toothy/mouth prob. diff to eat
- 3 or more alk.
drinks every day

Urban
- 10.0%
- 15.0%
- 20.0%
- 25.0%
- 30.0%
- 35.0%

Rural
- 10.0%
- 15.0%
- 20.0%
- 25.0%
- 30.0%
Exercise

![Exercise Chart]

Housing Type

![Housing Type Chart]

NRCAAA.org

23
AI/AN/NH elders residing with family members, non-family members, or alone

- Urban: 66.7% with family, 27.8% alone, 3.7% with non-family, 1.8% other
- Rural: 63.6% with family, 30.2% alone, 3.7% with non-family, 2.5% other

Participate in Cultural Practices

- Urban: Yes 73.1%, No 26.9%
- Rural: Yes 72.8%, No 27.2%
## Income

<table>
<thead>
<tr>
<th>Income Level</th>
<th>Urban</th>
<th>Rural</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;$15,000</td>
<td>44.0%</td>
<td>49.3%</td>
</tr>
<tr>
<td>$15,000-$49,999</td>
<td>36.5%</td>
<td>33.1%</td>
</tr>
<tr>
<td>$50,000 or higher</td>
<td>19.5%</td>
<td>17.5%</td>
</tr>
</tbody>
</table>

## Utilization of Data for the AI/AN/NH Population

- **Local Level**
  - Renewal of Title VI Grants
  - Strengthen Grant Proposals
  - Document health and social disparities
  - Tribal planning and infrastructure
  - Empowers the tribe with information to identify and address health needs

- **National Level**
  - Training for Native elder service providers
  - Advocating for resources and funding at the state, regional, and national level
  - Filling the research gap for Native elder information
  - Training Native researchers in aging field
  - Decision-making and policy
Summary of Data Process

- *Partnership with the Tribe*
  - Open communication and transparency about the research and data
- *Building Tribal Capacity*
  - People within the community administering surveys and assisting in conducting the research.

Summary of the Data Process

- *Obtaining proper permission to conduct research within tribal community*
  - Tribal community permissions
    - Tribal Resolutions
    - Tribal IRB or RRBs
    - Verbal consent from participating AI/AN/NH elder
- *Benefits to the partners (tribe and researcher)*
  - Data assists in bringing additional resources or funding to address health and social issues or disparities. Helps to change policy relating to the AI/AN elder population. Provides an invaluable rich data source.
- *Tribe owns*
The NRCNAA Team

Collette Adamsen, PhD, Program Director

Erica Gunville, M.S., Project Coordinator

Cole Ward, M.A., Research Specialist

Contact Information

For more information contact:
National Resource Center on Native American Aging
Center for Rural Health
School of Medicine and Health Sciences
Grand Forks, ND 58202-9037
Tel: 800-896-7628
Fax: (701) 777-6779
http://www.nrcnaa.org
Questions?

References


