Understanding Community Long-Term Services and Support Needs

Paula Carter, Ph.D.
(Turtle Mountain Band of Chippewa)

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National Resource Center on Native American Aging
Funded by Administration for Community Living
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The NRCNAA is one of three centers that are funded through the Administration on Community Living (ACL/AOA). 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)

NRCNAA established in 1994, at the Center for Rural Health, University of North Dakota School of Medicine and Health Sciences
Vision:

“All people, regardless of age and disability, live with dignity, make their own choices, and participate fully in society”.

Web site: http://www.acl.gov
NRCNAA MISSION

“Identify and increase awareness of evolving Native elder health and social needs”.

❖ Web site: www.nrcnaa.org
NRCNAA AIMS

- Empowerment of Native American leaders and service providers
- Honoring and maintaining cultural values while providing high-quality services
Tribal Participatory Model
Fisher & Ball (2003)

- Tribal Participatory Mechanisms:
  - Tribal Oversight
  - Tribal Resolution
  - Tribal Capacity Building
  - Culturally-Fit Method and Assessment
  - Applicable, Interpretable, and Usable Results
  - Tribal Data Ownership
Native Elder Population Projections 1990-2020
“Identifying Our Needs: A Survey of Elders”

- Assesses elders’ health and social needs
- Run in three year cycles and currently in cycle VI
- Tribes have the opportunity to collect information about their community
- Funded by ACL/AOA for past 20 years
Purpose of Needs Assessment

- Assists tribes in assessing options and developing an action plan to address local needs.
- Provides documentation required for planning and grant purposes including fulfilling requirements for tribes’ Title VI elder nutrition program grant applications.
- Provides documentation (Family caregivers percentages) to apply for elder caregivers grant applications.
LTSS needs assessment

- An ongoing, definitive, and “big picture” process
- A process where local interests or issues are defined.
- A method by which the nature and extent of needs can be both assessed and documented.
- A basis for planning that is evidence based.
Population

- Native American elders residing primarily on reservations, Alaskan villages and Hawaiian homesteads.
- Individuals age 55 and over living on or around Indian areas.
- Age 55 is considered comparable to 65 and over in the general population.
- Data is age adjusted.
Tribal Diversity

- NRCNA’s model addresses diversity between and within tribes:
  - Measures local community needs which are then unique to that community and fit only that particular community.
  - Model utilizes a custom-fitting measure.

One Size Does Not Fit All
Aggregated Representation

- Not a single representative sample of nation’s Native American Elders
  - Represents an aggregation of representative samples from participating tribes
  - Survey and methodology has stayed constant from Cycle II through Cycle V
Regional Variance

- NRCNAA model also addresses regional variance:
- Such as variance in life expectancy and chronic disease
  - California Indian Health Service Area life expectancy at 76.3 years is close to nations; however, Aberdeen Area is 64.3 a difference of 12 years.
  - Alaska Area has a diabetes rate slightly higher than the general population at 16%; whereas, the majority of other regions area at 37% or more.
Tribal Participatory Model
Fisher & Ball (2003)

- Tribal Participatory Mechanisms:
  - Tribal Oversight
  - Tribal Resolution
  - Tribal Capacity Building
  - Culturally-Fit Method and Assessment
  - Applicable, Interpretable, and Usable Results
  - Tribal Data Ownership
The Needs Assessment Survey

- The primary method of data collection is the survey instrument (administered face-to-face with the elders).

- A standardized assessment instrument
  - Surveys provided to the tribes by NRCNAA at no cost.
  - Surveys processed (optical scanner) by NRCNAA at no cost.

Sample Needs Assessment Survey

Identifying Our Needs: A Survey of Elders VI

1. Would you say your health in general is excellent, very good, good, fair, or poor?
   - Excellent
   - Very Good
   - Good
   - Fair
   - Poor

2. During the past 12 months, how many different times did you stay in the hospital overnight or longer?

3. Has a doctor ever told you that you had any of the following diseases . . . (Please mark all that apply)
   - Arthritis
   - Congestive Heart Failure
   - Stroke
   - Asthma
   - Cataracts
   - High Blood Pressure
   - Osteoporosis
   - Depression
   - Diabetes
   - Do you take oral medication?
   - Do you take insulin?
   - Are you on dialysis?
   - Was this only during a pregnancy? (For women only)
   - Are you a diabetic amputee?

4. How many falls, if any, have you had in the past year?

ACTIVITIES OF DAILY LIVING (ADL’S)

5. Because of a health or physical problem that lasted more than 3 months, did you have any difficulty... (Please mark all that apply)
   - Bathing or showering?
   - Dressing?
   - Eating?
   - Getting in or out of bed?
   - Walking?
   - Using the toilet, including getting to the toilet?

6. Because of a health or physical problem that lasted longer than 3 months, did you have any difficulty...
   (Please mark all that apply)
   - Preparing your own meals?
   - Shopping for personal items (such as toilet items or medicines)?
   - Using the telephone?
   - Doing heavy housework (such as scrubbing floors, or washing windows)?
   - Doing light housework (such as doing dishes, straightening up, or light clean up)?
   - Getting outside?

SCREENING

7. About how long ago has it been since you last visited a doctor/hospital care provider for a routine check-up?
   - Never had a checkup
   - Within the past year
   - Within the past 5 years
   - Within the past 3 years
   - 1 or more years ago

8. How long has it been since you had your blood stool tested for blood using a home kit?
   - Never had a checkup
   - Within the past year
   - Within the past 5 years
   - Within the past 3 years
   - 1 or more years ago

9. (FOR WOMEN ONLY) How long has it been since you had your last mammogram?
   - Never had a checkup
   - Within the past year
   - Within the past 5 years
   - Within the past 3 years
   - 1 or more years ago

10. (FOR WOMEN ONLY) How long has it been since you had your last pap smear?
    - Never had a checkup
    - Within the past year
    - Within the past 5 years
    - Within the past 3 years
    - 1 or more years ago

11. (FOR MEN ONLY) How long has it been since you had your last PSA, prostate-specific antigen test, a blood test used to check MEN for prostate cancer?
    - Never had a checkup
    - Within the past year
    - Within the past 5 years
    - Within the past 3 years
    - 1 or more years ago
VISON, HEARING & DENTAL

12. Do you have total blindness in one or both eyes?
   - Yes  
   - No

13. Do you use glasses or contact lenses?
   - Yes  
   - No

14. Do you have trouble seeing (even when wearing corrective lenses)?
   - Yes  
   - No

15. Have you seen an optometrist (eye doctor) in the past year?
   - Yes  
   - No

16. Do you now have total deafness?
   - Yes  
   - No

17. Do you use a hearing aid?
   - Yes  
   - No

18. Do you have trouble hearing (even when wearing your hearing aid)?
   - Yes  
   - No

19. Have you had a hearing test in the past year?
   - Yes  
   - No

20. Have you seen a dentist or dental hygienist in the past year?
   - Yes  
   - No

21. What type of dental care do you need now? (Please mark all that apply)
   - Teeth filled or replaced (for example, fillings, crowns, and/or bridges)
   - Teeth pulled
   - Gum treatment
   - Denture work (new dentures)
   - Relief of pain
   - Work to improve appearance (for example, braces or bonding)
   - Other
   - None

MEMORY & DISABILITY

22. Have you been diagnosed with Alzheimer's disease, dementia or other problems with memory or thinking?
   - Yes  
   - No

23. Has someone you are helping care for been diagnosed with Alzheimer's disease, dementia or other problems with memory or thinking?
   - Yes  
   - No

24. Is the person I am helping care for was diagnosed in a timely way once we started noticing problems.
   - Yes  
   - No

25. I know what to do to help myself or the person I am caring for and I know where to get help if I need it.
   - Yes  
   - No

26. The people helping me care for myself or me if I'm a caregiver feel well supported.
   - Yes  
   - No

27. My wishes for the kind of care I want to get are listened to and respected.
   - Yes  
   - No

28. Are you disabled?
   - Yes  
   - No

29. How were you disabled?
   - Congenital (from birth)
   - In military service
   - Due to chronic disease
   - Due to accident/injury

HEALTH CARE ACCESS

30. What type of health care coverage do you have? (Please mark all that apply)
   - Medicare
   - Medicaid
   - Private Insurance: Health/Medical
   - Private Insurance: Long-term care
   - Other

31. Do you have one person you think of as your personal doctor or health care provider?
   - Yes, only one
   - More than one
   - Don't know/not sure

32. When you are sick or need professional advice about your health, to which of the following places do you usually go? (Please mark all that apply)
   - A doctor's office
   - A clinic
   - A hospital outpatient department
   - A hospital emergency room
   - Urgent care center
   - Community health aide
   - Traditional healer
   - Other:

33. Have any of the following kept you from medical care in the past 12 months? (Please mark all that apply)
   - Cost
   - Distance
   - Office wasn't open when I could get there
   - Too long a wait for an appointment
   - No one spoke my language
   - No child care
   - No transportation
   - No access for people with disabilities
   - Too long a wait in waiting room
   - None

TOBACCO & ALCOHOL USAGE

34. Do you smoke tobacco now?
   - Yes, everyday
   - Yes, some days (e.g. ceremonial, social)
   - No (if no, skip to question #36)

35. How many cigarettes do you smoke per day?
36. Do you use chewing tobacco or snuff?
   - Yes
   - No

37. How many containers of snuff or chewing tobacco per week do you use?

38. The next few questions are about drinks of alcoholic beverages. By a “drink,” we mean a can or bottle of beer, a glass of wine or a wine cooler, a shot of liquor, or a mixed drink with liquor in it. How long has it been since you last drank an alcoholic beverage?
   - Within the past 30 days
   - More than 30 days ago but within the past 12 months
   - More than 12 months ago but within the past 3 years
   - More than 3 years ago
   - I have never had an alcoholic drink in my life (skip to question #31)

39. During the past 30 days, how many days did you have five or more drinks on the same occasion? (By “occasion,” we mean at the same time or within a couple hours of each other).
   - None
   - 1 or 2 days
   - 3 to 5 days
   - 6 or more days

40. How tall are you without shoes?

41. How much do you weigh today?

42. Are you presently trying to lose or gain weight?
   - Yes, trying to lose weight
   - Yes, trying to gain weight
   - No

43. Over the past 30 days, what vigorous exercises did you do? (Please mark all that apply)
   - Aerobics
   - Bicycling or bicycling on a stationary bike
   - Gardening
   - Jogging
   - Running
   - Walking
   - Swimming
   - Weight Lifting
   - Yard Work
   - Traditional Dancing
   - (Pow-wow, Hula)

Please mark all that apply to your nutritional health.
   - I have an illness or condition that made me change the kind and/or amount of food I eat.
   - I eat fewer than 2 meals per day.
   - I eat few fruits or vegetables or milk products.
   - I have 3 or more drinks of beer, liquor or wine almost everyday.
   - I have tooth or mouth problems that make it hard for me to eat.
   - I don’t always have enough money to buy the food I need.
   - I eat alone most of the time.
   - I take 3 or more different prescribed or over-the-counter drugs a day.
   - Without wanting to, I have lost or gained 10 pounds in the last 6 months.
   - I am not always physically able to shop, cook and/or feed myself.

44. Do you participate in cultural practices that include traditional food, music, and customs?
   - All of the time
   - Most of the time
   - A good bit of the time
   - Some of the time
   - A little of the time
   - None of the time

45. How often do you get out and socialize? (attend church, religious meetings, clubs, organizations you belong to or cultural activities/traditional ceremonies)?

46. How long have you lived at your present address?
   - Less than 5 years
   - 5-10 years
   - Over 10 years

47. What type of housing do you presently have?
   - Single family residence
   - An apartment
   - Sleeping room/boarding house
   - Retirement home
   - *A health facility (available medical personnel)
   - Homeless
   - Other

*(If retirement home/health facility is marked, skip to question #53.)*

48. Are you living with family members, non-family members, or alone?
   - With family members
   - With non-family members
   - With both family and non-family members
   - Alone

49. How many (including yourself) live in your household?

50. Do you have a family member who provides care for you?
   - Yes
   - No

51. Do you take care of grandchildren?
   - Yes
   - No

52. Are you the primary caregiver of grandchildren?
   - Yes
   - No

53. During the past month, how much of the time were you a happy person?
   - All of the time
   - Most of the time
   - A good bit of the time
   - Some of the time
   - A little of the time
   - None of the time

54. How much of the time, during the past month, have you felt calm and peaceful?
   - All of the time
   - Most of the time
   - A good bit of the time
   - Some of the time
   - A little of the time
   - None of the time
55. How much of the time, during the past month, have you been a very nervous person?
   ☐ All of the time  ☐ Most of the time  ☐ A good bit of the time  ☐ A little of the time  ☐ None of the time

56. How much of the time, during the past month, have you felt downhearted and blue?
   ☐ All of the time  ☐ Most of the time  ☐ A good bit of the time  ☐ A little of the time  ☐ None of the time

57. How much of the time, during the past month, have you felt so down in the dumps that nothing could cheer you up?
   ☐ All of the time  ☐ Most of the time  ☐ A good bit of the time  ☐ A little of the time  ☐ None of the time

58. We would like to ask the extent to which you feel you can personally influence things by what you do or say. How much influence do you feel over your life in general?
   ☐ Almost no influence  ☐ Little influence  ☐ Some influence  ☐ A lot of influence  ☐ Total influence

59. Are you now using, or if at some point you became unable to meet your own needs, would you be willing to use the following services? [Please mark all that apply]
   (Interviewer, please see guide for definitions).

   Now Using  Would Use
   ☐ Adult Day Care  ☐ Home Delivered Meals
   ☐ Caregiver Program  ☐ Congregate Meals
   ☐ Case Management  ☐ Personal Care
   ☐ Elder Abuse Prevention Programs  ☐ Respite Care
   ☐ Employment Services  ☐ Assisted Living
   ☐ Financial Assistance  ☐ Retirement Communities
   ☐ Home Health Services  ☐ Nursing Facilities
   ☐ Home Repair/Modification  ☐ Government Assisted Housing
   ☐ Information and Referral/Assistance  ☐ Shared Housing
   ☐ Legal Assistance  ☐ Senior Center Programs
   ☐ Volunteer Services  ☐ Telephone Reassurance
   ☐ Long Term Care Services

60. Gender
   ☐ Male  ☐ Female

61. Age
   ☐ Enter Age

62. Current marital status
   ☐ Married or living with partner  ☐ Single/never married
   ☐ Divorced or separated  ☐ Widowed

63. What is your personal annual income?
   ☐ Under $5,000  ☐ $5,000 - $9,999
   ☐ $10,000 - $14,999  ☐ $15,000 - $19,999
   ☐ $20,000 - $24,999  ☐ $25,000 - $34,999
   ☐ $35,000 - $48,999  ☐ $50,000 or more

64. Have you been employed full or part-time during the past 12 months?
   ☐ Full-time  ☐ Part-time  ☐ No

65. What is the highest grade or year of school you completed?
   Never attended or kindergarten only
   Elementary  ☐  ☐  ☐  ☐  ☐  ☐  ☐
   High School  ☐  ☐  ☐  ☐  ☐  ☐  ☐
   College/Technical School  ☐  ☐  ☐  ☐  ☐  ☐  ☐
   Graduate/Professional School  ☐  ☐  ☐  ☐  ☐  ☐  ☐

66. What zip code and county/borough do you currently reside?
   ☐ Zip Code

67. Are you American Indian, Alaska Native, Native Hawaiian, mixed race or other?
   ☐ American Indian  ☐ Native Hawaiian
   ☐ Alaska Native  ☐ Other
   ☐ Descendent (Grandparent or parent is an enrolled tribal member)

68. Do you reside on/in a reservation, trust land, Alaska village, or Hawaiian homestead?
   ☐ Yes  ☐ No

69. Are you an enrolled member of a federally recognized tribe?
   ☐ Yes  ☐ No
   Tribal Affiliation:

70. Have you ever served on active duty in the U.S. Armed Forces, Military Reserves, or National Guard?
   ☐ Yes  ☐ No
Survey Needs Data

- General health status of elders
- Indicators of chronic health
- Indicators of visual, hearing, and dental
- Tobacco and alcohol use patterns
- Diet, nutrition, and exercise
- Social support patterns, housing and work
- Health care access
- Unmet needs
- Use and acceptance of services
National Resource Center Provides:

- Survey instruments – a standardized tool
- Assistance with sampling
- Training on data collection
- Technical support
- Data entry
- Data analysis
- Statistical profiles of your elders
- Comparisons with national norms
Local Communities Provide:

- A resolution from their tribal councils
- A number or count of the elders in the community
- Data collection
- A repository for the findings and are responsible for getting them to the right people
- Local implementation and coordination
Post Data Collection

- NRCNAA receives completed surveys from participating tribes.
  - Surveys are scanned and coded for statistical analysis
  - A data file is created for each tribal participant
  - Standard measures are created (such as Body Mass Index, ADL and IADL limitations, chronic diseases and service uses).
Result Tabulations

- NRCNAA prepares comparison sheets for all participating tribes:
  - Includes each tribe’s data, national data, and data for all Native American elders (tribal aggregate).

- Sample comparison sheet can be seen at: [http://ruralhealth.und.edu/projects/nrcnaa/pdf/comparison.pdf](http://ruralhealth.und.edu/projects/nrcnaa/pdf/comparison.pdf)

- The comparison sheets allow a context for interpretation:
  - Helps to determine whether each tribe’s elders are healthier or less healthy than the norm or whether they have more chronic disease.
ACL/AOA Regional Map
Visualizing Disparities

Data Comparison

Comparisons between our tribe, regions and the U.S. general population provide documentation of disparities on specific diseases where American Indian people appeared to be at greater risk than others in the nation. This information assists in identifying diseases where health promotion efforts will assist in making significant improvements in health status for our elders. The table on the next slide presents these diseases.
## NRCNAA Data Use Template

- Chronic diseases with higher rates than the nation

<table>
<thead>
<tr>
<th>Condition</th>
<th>All Tribes</th>
<th>Nation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congestive heart failure</td>
<td>9.1%</td>
<td>8.2%</td>
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<tr>
<td>Stroke</td>
<td>7.8%</td>
<td>6.3%</td>
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<tr>
<td>Asthma</td>
<td>13.6%</td>
<td>12.0%</td>
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<tr>
<td>High blood pressure</td>
<td>58.2%</td>
<td>55.2%</td>
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<tr>
<td>Diabetes</td>
<td>40.7%</td>
<td>18.0%</td>
</tr>
<tr>
<td>Cervical cancer</td>
<td>1.6%</td>
<td>0.3%</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>10.6%</td>
<td>4.6%</td>
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</tbody>
</table>
Visualizing Unmet Needs

59. Are you now using, or if at some point you became unable to meet your own needs, would you be willing to use the following services? (Please mark all that apply)

(Interviewer, please see guide for definitions).

<table>
<thead>
<tr>
<th>Now Using</th>
<th>Would Use</th>
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- Adult Day Care
- Caregiver Program
- Case Management
- Elder Abuse Prevention Programs
- Emergency Response Systems
- Employment Services
- Financial Assistance
- Home Health Services
- Home Repair/Modification
- Information and Referral/Assistance
- Legal Assistance
- Home Delivered Meals
- Congregate Meals
- Personal Care
- Respite Care
- Assisted Living
- Retirement Communities
- Nursing Facilities
- Government Assisted Housing
- Shared Housing
- Senior Center Programs
- Telephone Reassurance
- Transportation
- Volunteer Services
- Long Term Care Services
Cycle V Tribal Aggregate Unmet Need

- Volunteer Services
- Transportation
- Telephone Reassurance
- Senior Center Programs
- Shared Housing
- Government Housing
- Nursing Facilities
- Retirement communities
- Assisted Living
- Respite Care
- Personal Care
- Congregate Meals
- Home Delivered Meals
- Legal Assistance
- Information and Referral
- Home Modification
- Home Repair
- Home Health Services
- Financial Assistance
- Employment Services
- Emergency Response
- Elder Abuse prevention
- Case Management
- Caregiver Program
- Adult Daycare

Now Use ▶ Would Use ▢
Community Level Data Uses

- Renewal of Title VI Native Elder Nutrition and Caregiving Grants
- Strengthening of grant proposals
- Documentation of health disparities
- Documentation of need for health promotion, home and community based services, and assisted living
Regional and National Data Use

- The applications for data at these levels are numerous and focus on:
  - Training for increasing skills for Native elder service providers
  - Advocating for resources at the state, regional, and national level
Regional and National Data Use continued

- Developing policy for informing national Native elder organizations
- Filling the research gap for Native elder related publication
- Training Native researchers in the aging field
Examples of Application of Assessment Data

- Tribal support for service program justification
- Proposals
  - Health Care Center
  - New Gym
- Tracking
- Gain partnerships
- Information sharing with community & government
- Identifying needs and resources
- Assessing mental health needs
- Enhancing Tribal Leadership
Service Locator for Native American Elders

The NRCNAA maintains a web-based service locator for Native American elders. Services vary by location, but some examples include help with chores, personal care, home-delivered meals, financial assistance, senior citizens programs and assisted living. You can search by service or by area or both. Please visit us online at http://ruralhealth.und.edu/projects/nrcnaa/servicelocator.php to check for services available in your area.
Past Cycles I-V

Cycle I
9,403 Elders

Cycle II
10,743 Elders

Cycle III
15,565 Elders

Cycle IV
18,089 Elders

Cycle V
17,049 Elders
Regional Participation

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Current Status of Needs Assessment

- **Cycle V (ended March 31, 2014)**
  - 262 Tribes/Alaska Native Villages/Hawaiian Homelands from 142 sites
  - 17,049 Native elder participants have filled out the needs assessment survey
  - 10 I.H.S. Regional Areas are represented in the national file.
The Needs Assessment Team

- Paula Morin-Carter, PhD., NCRNAA Director
- Collette Adamsen, M.S., Project Coordinator
- Patty Stensland, B.A., Research Specialist
- Ann Miller-Administrative Assistant
- Cole Ward-Graduate Research Assistant
- Jacque Gray, Ph.D., Associate Professor
- Marilyn Klug, Ph.D., Biostatistician
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.nrcnnaa.org](http://www.nrcnnaa.org)
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