



National Resource Center on Native American Aging
Center for Rural Health
University of North Dakota School of Medicine
& Health Sciences

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Administration on Aging Training & Listening Session

**October 27-29, 2003
John Ascuaga's Nugget Hotel
Sparks, NV**

Applying Research to Long-Term Care



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Purpose of the Project

- The purpose of this project was to assist tribes in collecting data they could use to build infrastructure in their communities.
- Multiple methods are used throughout the study, but the main method of data collection is the survey instrument (administered face-to-face with the elders).

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Population

- Native American elders residing primarily on reservations
- Individuals age 55 and over living on or around Indian areas.
- Age 55 is considered comparable to 65 and over in the general population

Sampling Design

- Get everyone in small populations
- Sample in large populations
- Systematic random sampling
 - Use a list of names or addresses
 - Determine proportion
 - Select every nth name based on the proportion

Data is collected on

- General health status
- Activities of Daily Living (ADL's)
- Instrumental Activities of Daily Living (IADL's)
- Indicators of chronic disease
- Indicators of vision and hearing
- Tobacco and alcohol use
- Diet and exercise
- Weight and weight control
- Social supports

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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

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Tribal Name Data Comparison to Region IX Tribal Data (N=1,725) & National Data

Question	Response (s)	Tribal Data (55 and over)	Region IX (55 and over)	94' NLTCs (65 and over)
4. Because of a health or physical problem, do you have difficulty --	a. Bathing or showering?		19.8%	36.8%
	b. Dressing?		13.7%	15.8%
	c. Eating?		9.0%	8.1%
	d. Getting in or out of bed?		14.4%	22.1%
	e. Walking?		29.0%	33.7%
	f. Using the toilet, including getting to the toilet?		10.4%	22.8%
5. Because of a health or physical problem, do you have difficulty--	a. Preparing your own meals?		23.5%	19.7%
	b. Shopping for personal items (such as toilet items or medicines)?		20.6%	34.8%
	c. Managing your money (such as keeping track of expenses or paying your bills)?		13.1%	17.9%
	d. Using the telephone?		11.2%	9.6%
	e. Doing heavy housework (like scrubbing floors, or washing windows)?		46.0%	51.6%
	f. Doing light housework, (like doing dishes, straightening up, or light cleaning)?		21.1%	17.0%
	g. Getting outside?		17.8%	44.2%

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Local Communities Provide:

- Locating a list and selecting names for the sample
- Data collection
- Receiving the findings and getting them to the right people
- Local implementation and coordination

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Current Status of the Study

- 132 tribes from 88 different sites are represented in national file
- 9,296 Native elder participants
- Additional tribes are now collecting data
- At least one tribe from 11 of the 12 I.H.S. regional areas are represented
- 20 of the tribes and 1,725 Native elders are from Region IX

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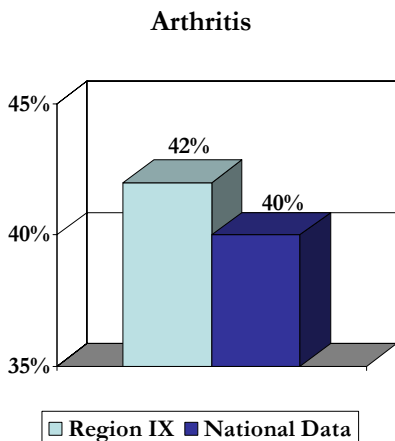
The Health of American Indian and Alaskan Native Elders



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Chronic Diseases – Arthritis (N=1,725)

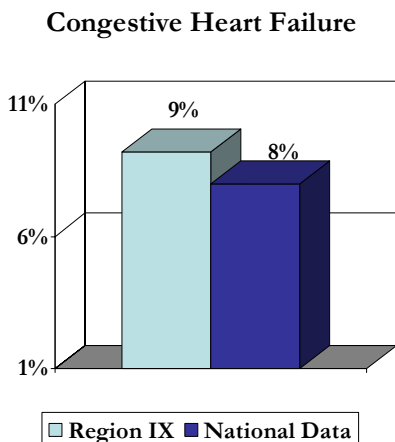


- Region IX Native elders were 5% more likely to experience arthritis than the U.S. general population.

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Chronic Diseases – Congestive Heart Failure (N=1,725)

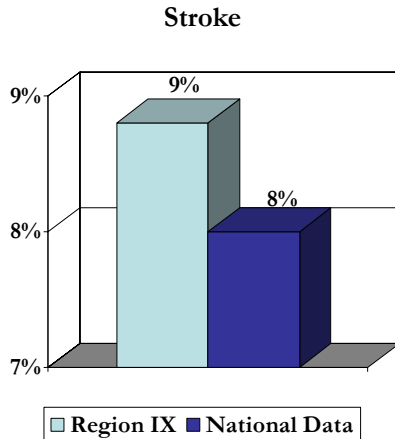


- Region IX Native elders were 13% more likely to experience congestive heart failure than the general U.S. population.

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Chronic Diseases – Stroke (N=1,725)

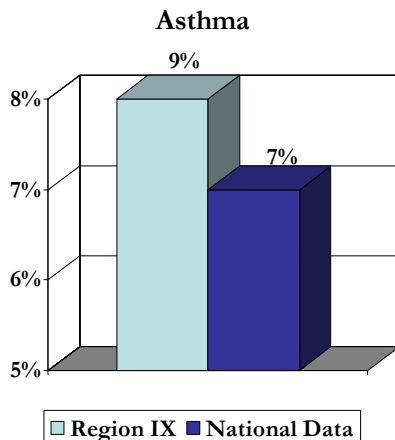


- Region IX Native elders were 10% more likely to experience a stroke than the general population.

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Chronic Diseases – Asthma (N=1,725)

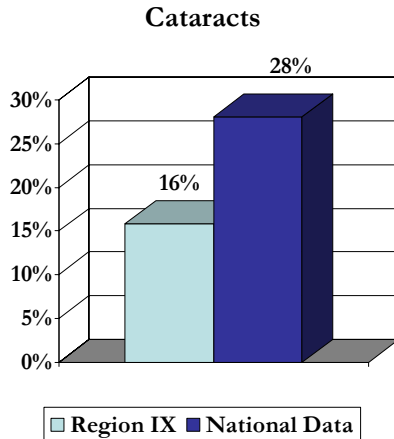


- Region IX Native elders were 24% more likely to experience asthma than the U.S. general population.

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Chronic Diseases – Cataracts (N=1,725)

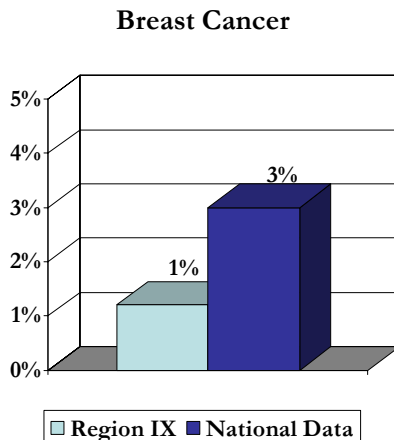


- Region IX Native elders were 24% less likely to experience cataracts than the general population.

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Chronic Diseases – Breast Cancer (N=1,725)



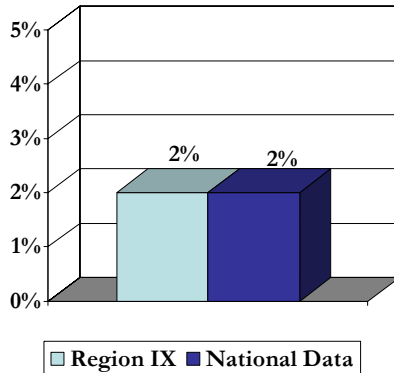
- Region IX Native elders were 60% less likely to experience breast cancer than the U.S. general population.

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Chronic Diseases – Prostate Cancer (N=1,725)

Prostate Cancer



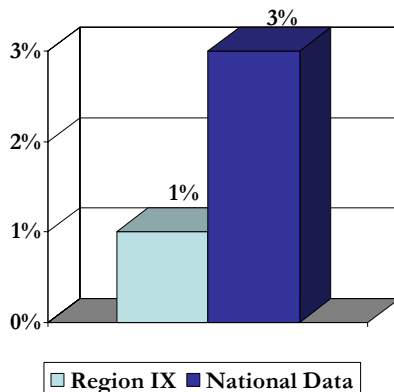
- Region IX Native elder men had prostate cancer at the same rates as the U.S. general population.

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Chronic Diseases – Colon/Rectal Cancer (N=1,725)

colon/rectal cancer



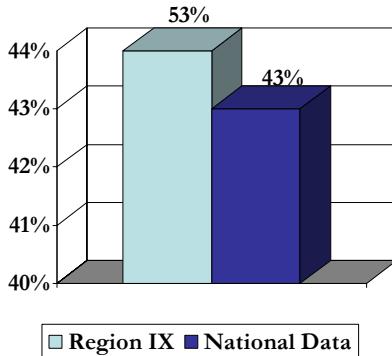
- Region IX Native elders were 67% less likely to experience colon/rectal cancer than the U.S. general population.

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Chronic Diseases – High Blood Pressure (N=1,725)

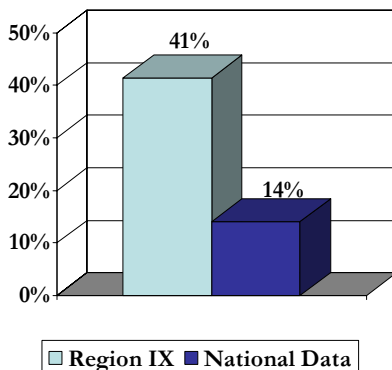
High Blood Pressure



- Region IX Native elders were 22% more likely to experience high blood pressure than the U.S. general population.

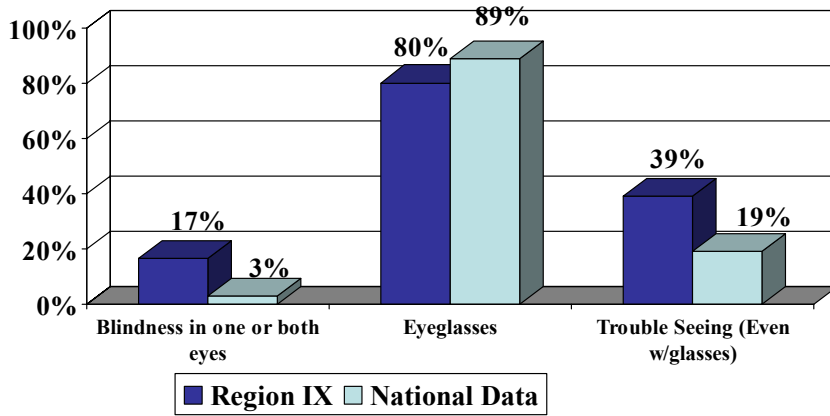
Chronic Diseases – Diabetes (N=1,725)

Diabetes



- Region IX Native elders were 196% more likely to experience diabetes than the U.S. general population.

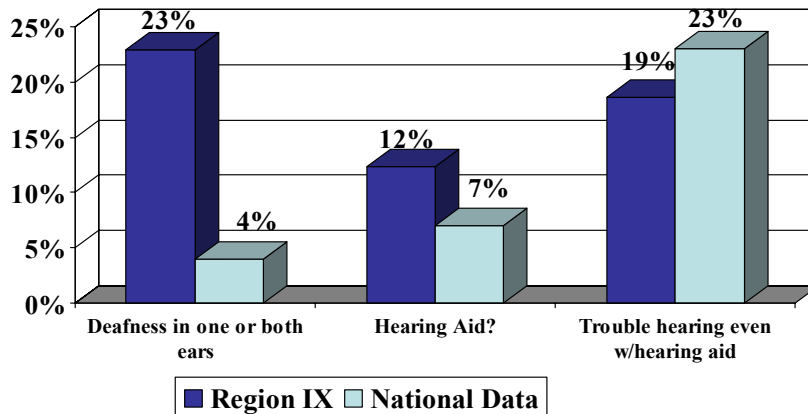
Vision (N=1,725)



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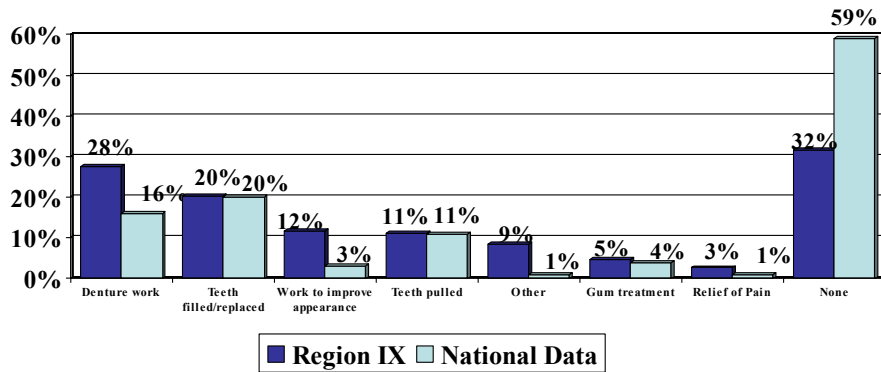
Hearing (N=1,725)



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Dental Services Needed (N=1,725)



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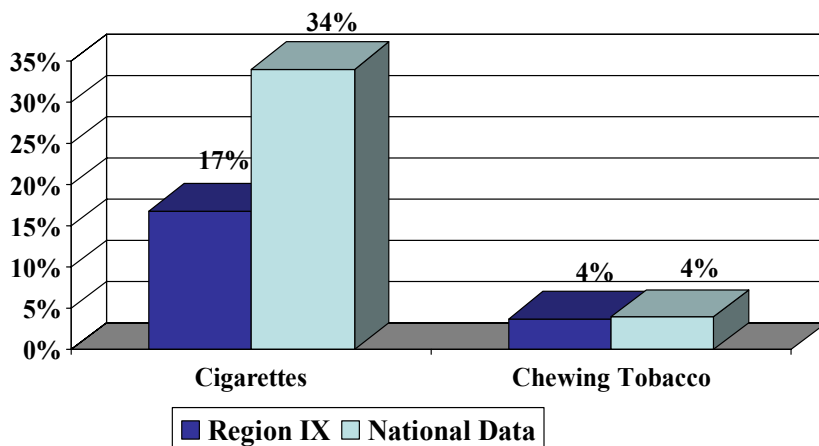
Behavioral Risk Factors



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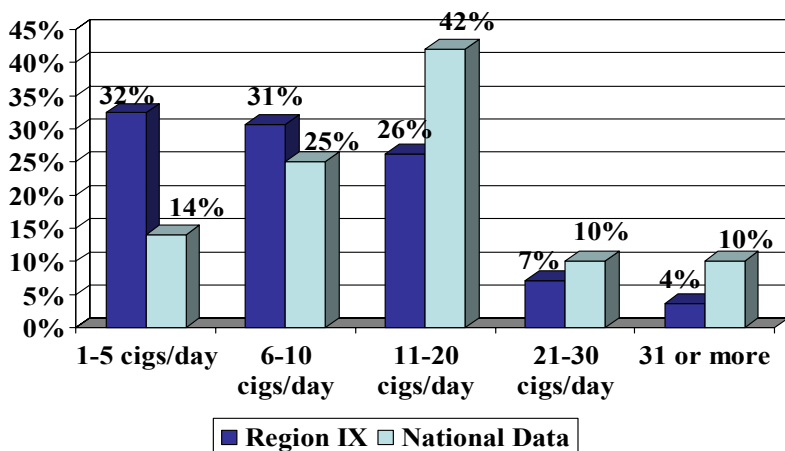
Tobacco Usage (N=1,725)



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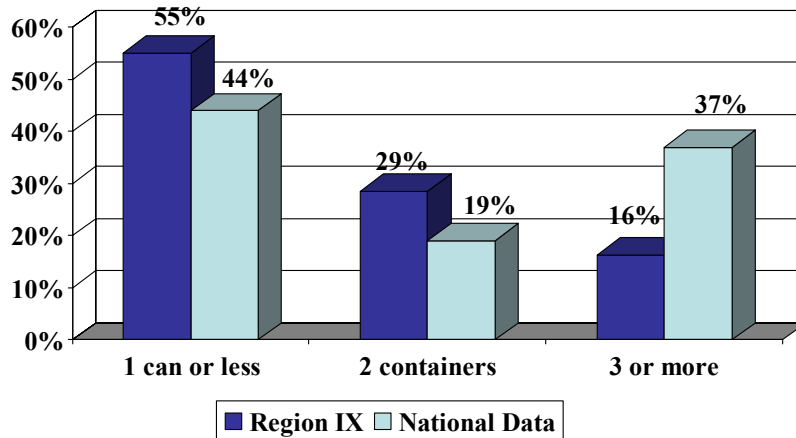
Cigarettes Smoked a Day (N=1,725)



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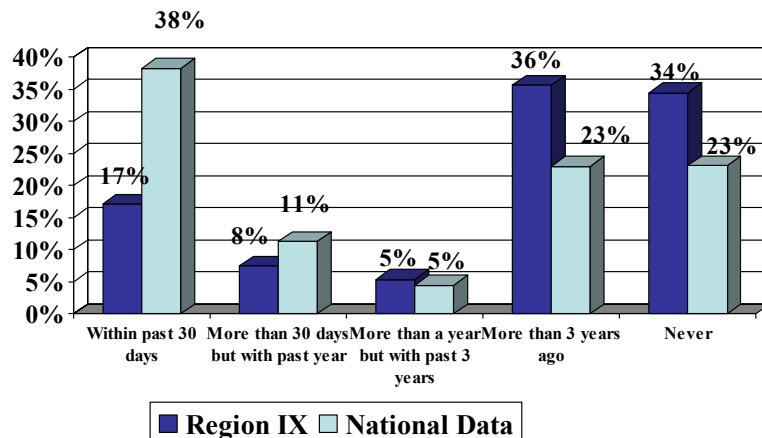
Chewing Tobacco (N=1,725)



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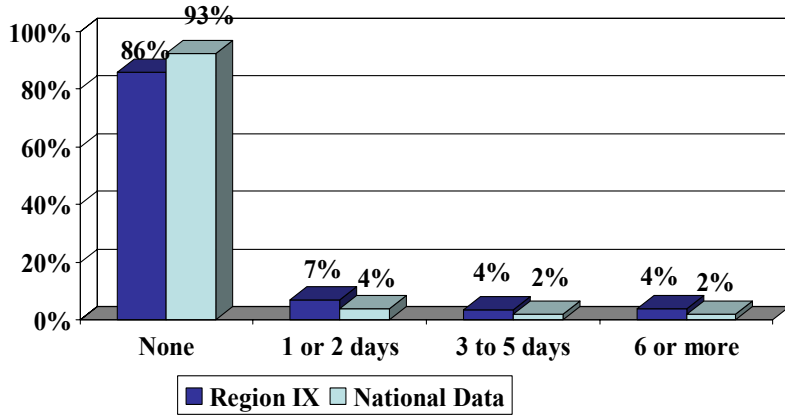
How long since last drink of alcoholic beverage? (N=1,725)



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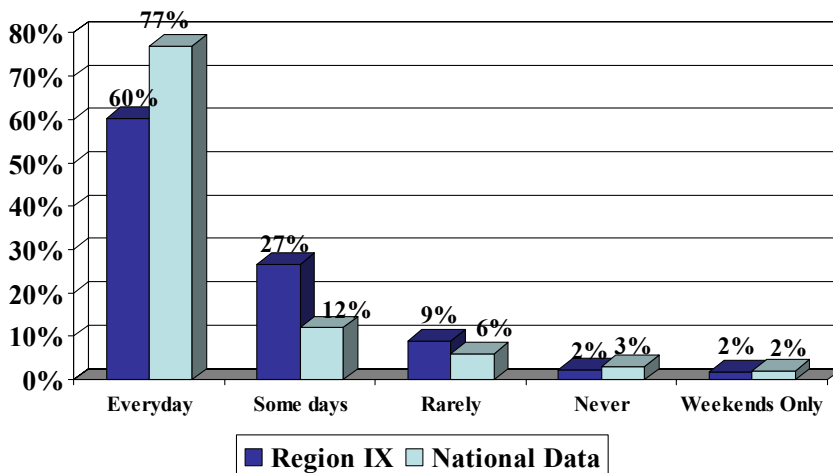
Binge Drinking (N=1,725) (5 or more drinks on one occasion)



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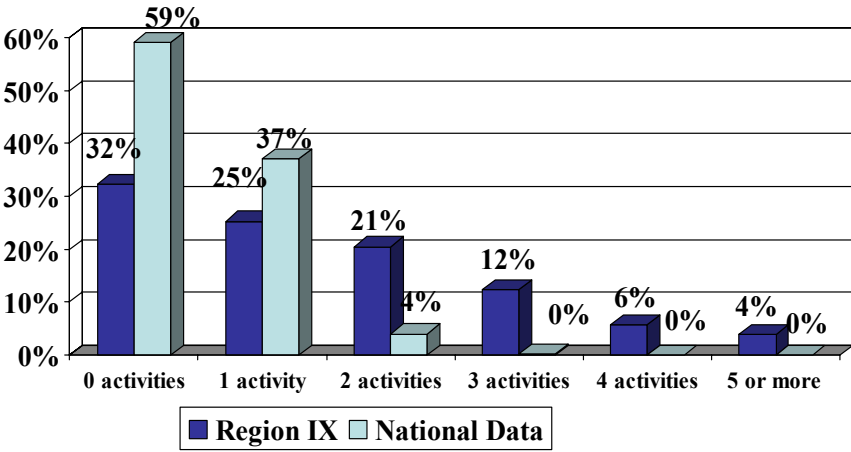
Breakfast (N=1,725)



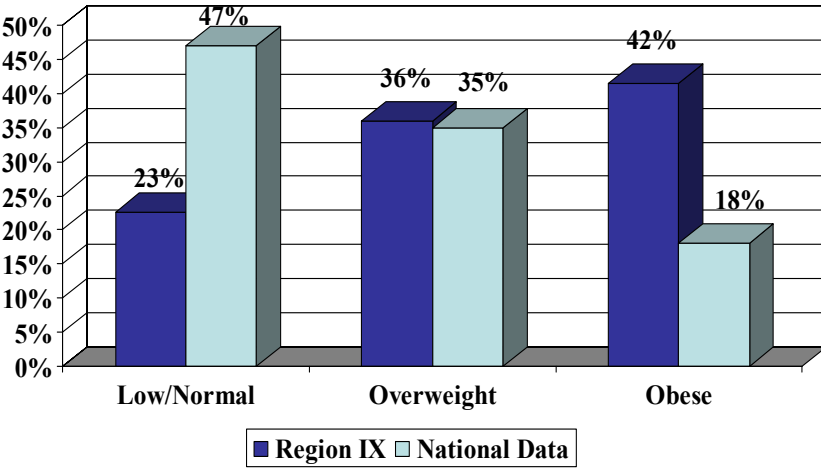
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Exercise (N=1,725)



Body Mass Index (N=1,725)



Functional Limitations



Functional Limitations

- The majority of definitions concerning functional limitations or disability refer to activities of daily living (ADL's) and instrumental activities of daily living (IADL's) as indicators of functionality.

Activities of Daily Living (ADL's)

- Eating
- Walking
- Using the toilet
- Dressing
- Bathing
- Getting in/out of bed

Instrumental Activities of Daily Living (IADL's)

- Cooking
- Shopping
- Managing money
- Using a telephone
- Light housework
- Heavy housework
- Getting outside

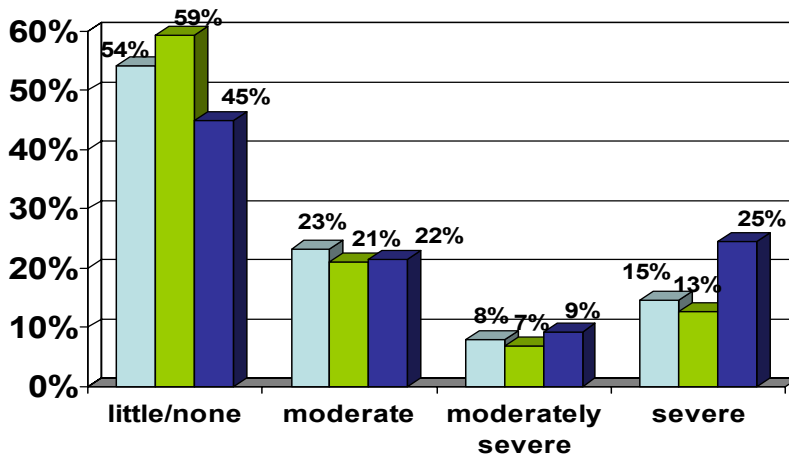
Functional Limitation Categories

Categories	Limitations	Recommended Services
Little or none	No ADL limitations, up to one IADL limitation	No Services Required
Moderate	One ADL limitation with fewer than IADLs	Home and Community Based Services
Moderately Severe	2 ADL limitations	Assisted Living
Severe	3 or more ADL limitations	Skilled Nursing Facility

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Rates of Functional Limitation



Region IX U.S. Native Elders U.S. General Population

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Rates of Functional Limitation: Region IX Native Elderly and U.S. by Age

Functional Limitation	65-74		75-84		85 and over	
	Native American	U.S.	Native American	U.S.	Native American	U.S.
Little or none	56.6%	61.4%	47.2%	46.7%	31.1%	20.8%
Moderate	22.1%	16.6%	27.6%	23.2%	24.6%	23.5%
Moderately Severe	8.3%	6.6%	7.5%	8.5%	16.4%	13.8%
Severe	13.0%	15.4%	17.7%	21.6%	27.9%	41.9%

U.S. Data Source: 1994 National Long Term Care Study

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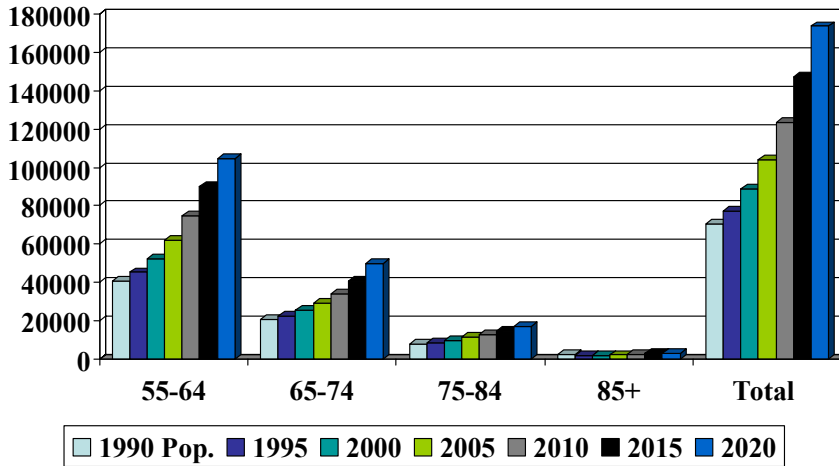
Life Expectancy at Birth, ages 55, 65 and 75 by IHS Area

IHS Area	At Birth	At Age 55	At Age 65	At Age 75
Aberdeen	64.3	18.9	13.2	8.5
Bemidji	65.7	18.7	12.7	10.1
Billings	67.0	20.2	13.9	8.9
Alaska	68.0	21.3	14.7	9.2
Tucson	68.4	22.2	15.8	10.0
Phoenix	69.8	22.6	16.1	10.6
Portland	71.7	23.1	16.0	10.1
Navajo	71.9	24.9	17.7	11.7
Nashville	72.2	22.8	16.3	10.5
Albuquerque	72.7	25.4	19.6	12.2
Oklahoma	74.2	25.7	18.2	13.1
California	76.3	26.9	19.4	13.3
All Indians	71.1	23.5	16.7	11.2

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Region IX Native Elder Population Projections 1990-2020



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Functional Limitation Levels Applied to Services and Personnel

Level Functional Limitation	Service Goals	Services with best fit	Personnel required
Little or none (54%)	Health promotion, preventive care, maintaining vitality	No caregiver services required Health Promotion/Prevention	Health educators, physical trainers, therapists
Moderate (23%) This category represents entry level functional limitations and requires assistance usually consistent with remaining in one's home.	Supportive services to aid persons in remaining in own domicile. Train and support informal providers and buffer them with respite and contact services for a range of possible tasks.	Informal care – w/supports Chronic Disease Management Home & community based <ul style="list-style-type: none"> •Day/night care* •Durable medical* equipment •Home health care* •Homemaker services* •Physical therapy •Occupational therapy •Medication assistance* •Speech therapy •Mental health services •Transportation services* •Nutritional services* •Personal care* •Respite care* * Require local providers	Family and friends Trainer for skills Facility staff – LPN/CNA Rental source RN, LPN, CNA, PT, OT... Cleaning and chore assts. PT, PT aides, tele-health OT, OT aids, tele-health Medication aide Speech therapist Psychologist, Psychiatrist, Psych. Social Worker, Van driver Dietician, aide Trained attendants Trained respite providers or institutional site

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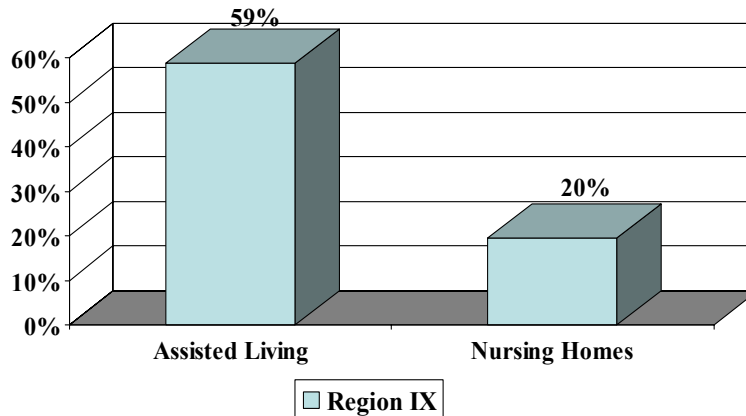
Functional Limitation Levels Applied to Services and Personnel Cont...

Level Functional Limitation	Service Goals	Services with best fit	Personnel required
Moderately Severe (8%)	The goal for this level of care is to provide housekeeping and meals along with a modest level of oversight. People may contact for services from the home and community based services in addition to the basic services found in these settings. Assisted living establishes the goal for this cluster in that it	Congregate care Basic care facilities Assisted Living	Institutional staff as required by state regulations
Severe (18%) With 3 or more ADLs, this level tends to become prime candidates for skilled nursing care. They represent care needs with	seeks to maintain resident control over services. Skilled nursing care is the most fully institutional and is reserved for those with medical needs necessitating this level of care.	Skilled Nursing Care	Institutional staff as required by state regulations
Extremely Severe (2%) Individuals in this category.	End of life care occurs at all points on the above continuum, but is concentrated at the higher levels of limitation. The goal is physical and emotional comfort.	Hospice Care	*Hospice volunteers and coordinator

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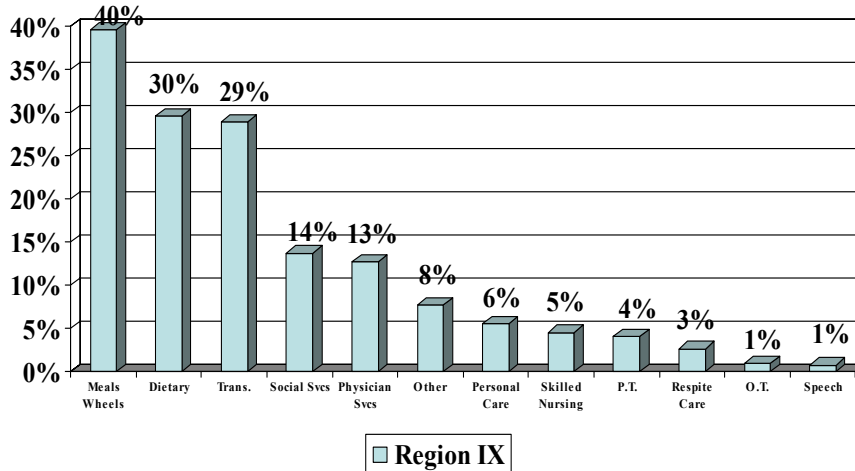
Acceptance of Nursing Homes & Assisted Living (N=1,725)



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Type of Services Utilized (N=1,725)



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National Family Caregiver Support Program: North Dakota's American Indian Caregivers

Collaborators:

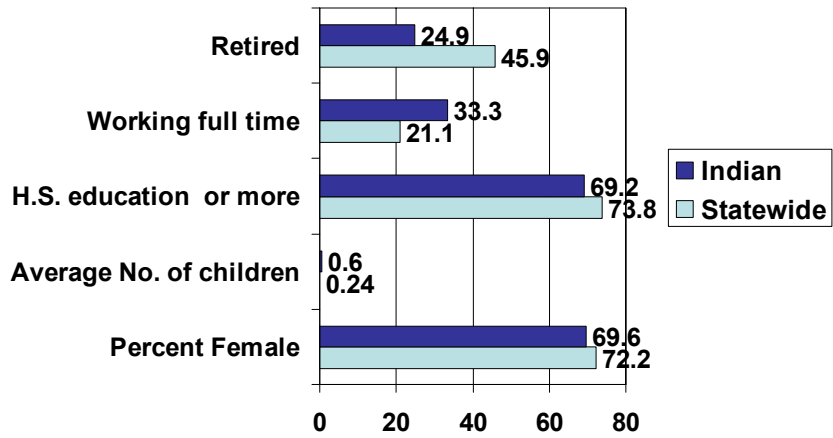
- North Dakota Data Center, North Dakota State University
- Center for Rural Health, University of North Dakota School of Medicine and Health Sciences
- Department of Child Development and Family Science

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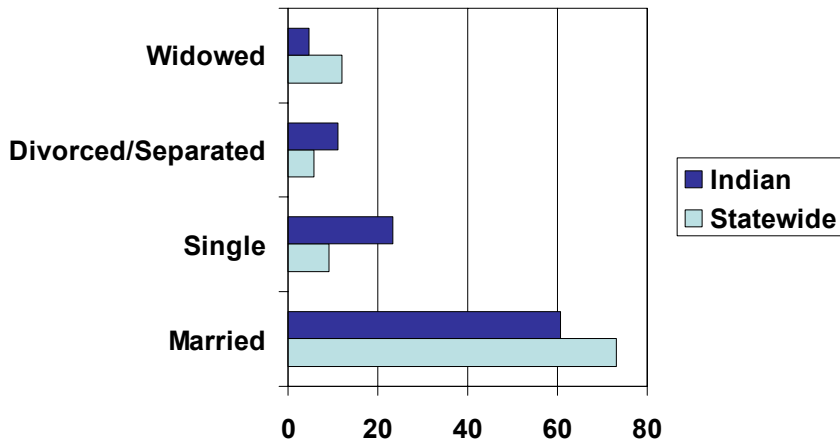
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North Dakota State University

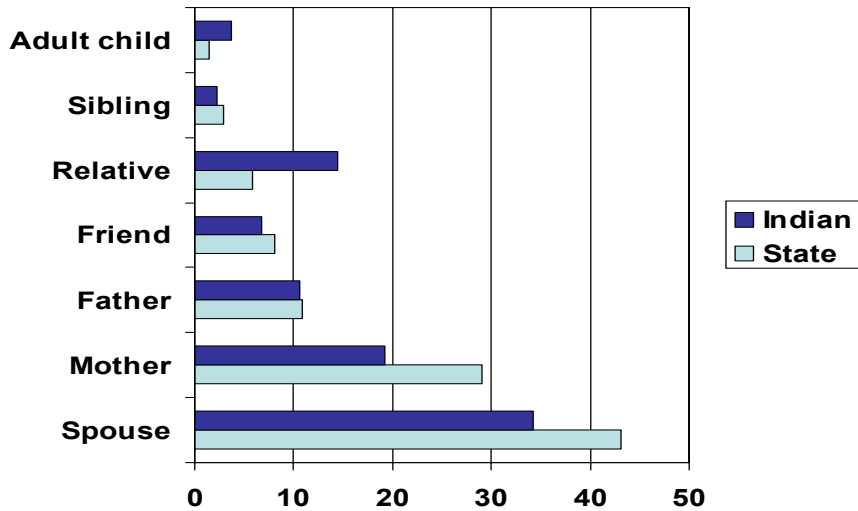
THE CAREGIVERS



CAREGIVERS: CONT.

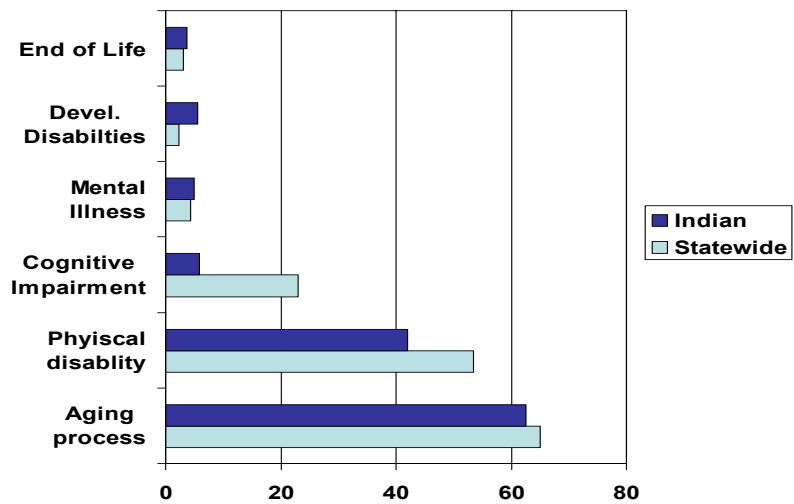


CAREGIVER RECIPIENTS



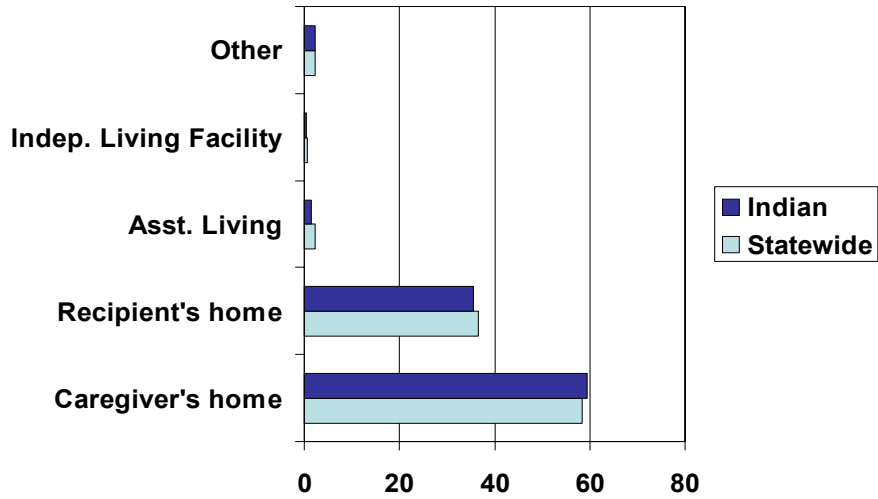
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MAIN REASONS FOR CARE



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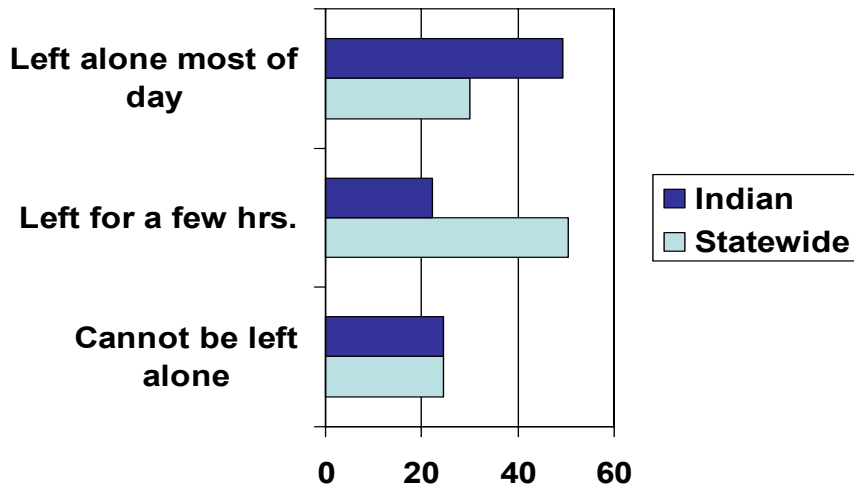
LOCATION OF CARE



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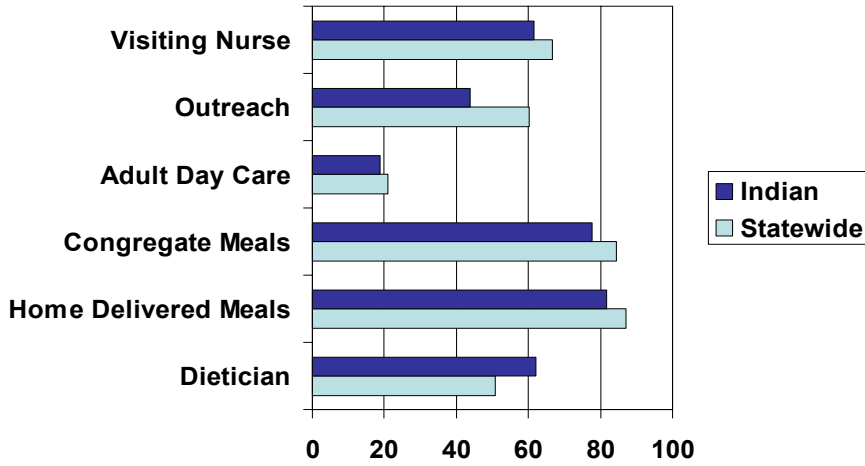
AMOUNT OF CARE REQUIRED



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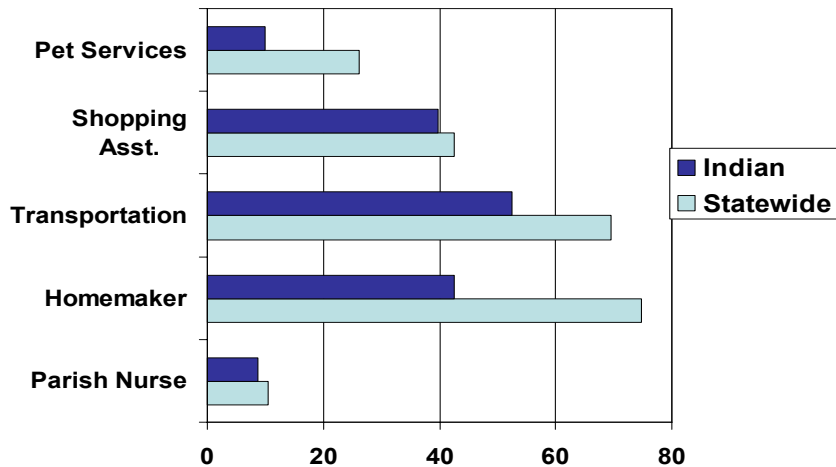
AVAILABILITY: SERVICES FOR RECIPIENT



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AVAILABILITY: SERVICES FOR RECIPIENT cont.



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SERVICE WANTS FOR ELDERS AMONG THOSE LACKING THEM

STATEWIDE

- 1 – Outreach
- 2 – Visiting nurse
- 3 – Day centers
- 4 – Homemaker
- 5 – Transportation
- 6 – Congregate meals

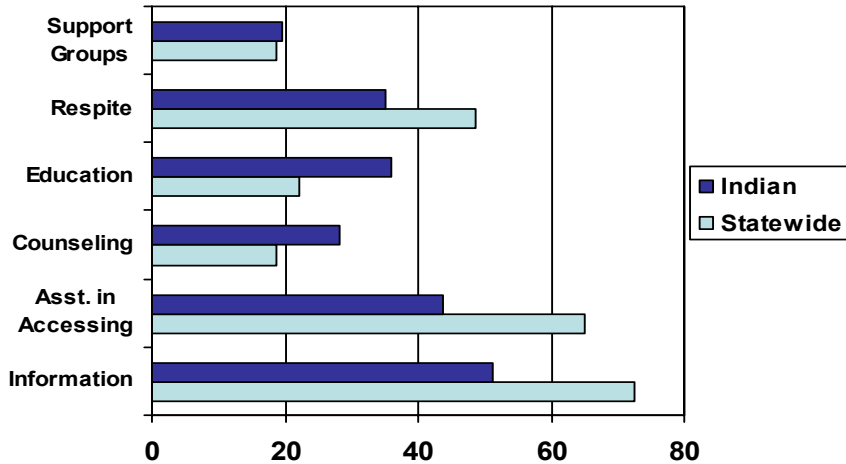
RESERVATION AREAS

- 1 – Visiting nurse
- 2 – Homemaker
- 3 – Outreach
- 4 – Transportation
- 5 – Congregate meals
- 6 – Shopping asst.

Use rates for available services

	Statewide	Reservation
Dietician	37.7%	61.3%
Home Del. Meals	54.1%	63.1%
Congregate Meals	38.6%	42.5%
Visiting Nurse	54.0%	69.5%
Homemaker Services	39.7%	42.3%
Transportation	32.8%	51.5%

AVAILABILITY OF SERVICES FOR CAREGIVER



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SERVICE WANTS FOR CAREGIVERS AMONG THOSE LACKING THEM

STATEWIDE

- Information - 68.5%
- Respite care – 51.1%
- Asst. w/access – 48.4%
- Support groups – 38.2%
- Education – 33.7%
- Counseling – 30.1%

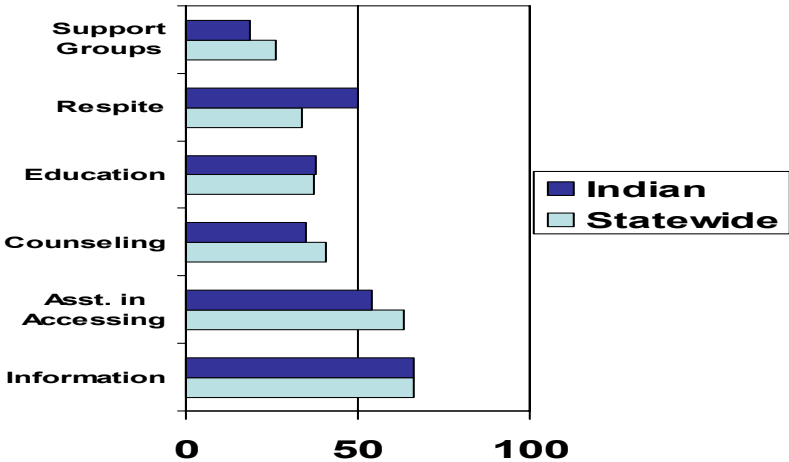
RESERVATION AREAS

- Information – 69.1%
- Education – 66.7%
- Asst. w/access – 58.9%
- Respite care – 47.1%
- Counseling – 36.9%
- Support groups – 35.9%

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USE OF AVAILABLE SERVICES BY CAREGIVERS



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INFORMATION CONSIDERED VALUABLE

	Statewide	Reservations
About conditions	38.2%	32.9%
End of life	27.0%	20.1%
Legal changes	37.6%	15.1%
Info-line access	36.8%	18.3%
Someone to arrange services	29.1%	16.4%
Counseling/support group	29.1%	22.4%
Respite/day care	39.1%	19.6%
Grief counseling	15.5%	12.8%

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VALUABLE INFORMATION CONT.

	Statewide	Reservations
Hotline – for emotional needs	14.4%	10.5%
Nursing home selection advice	22.3%	11.0%
Help with timing nursing home placement	23.8%	10.0%
Understanding payment for nursing care	31.3%	11.4%
Help dealing with agencies	31.0%	19.2%
Financial support	31.7%	19.6%
Tax breaks, subsidies	27.5%	11.9%

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IMPACTS OF CAREGIVING

	Statewide	Reservations
Changed location	15.2%	9.6%
Sold home to move in with recipient	4.0%	1.4%
Stopped working	7.2%	8.7%
Retired early	6.4%	2.3%
Taken less demanding job	3.1%	2.7%
Changed to part-time work	4.9%	2.7%
Reduced official work hours	5.7%	4.6%

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IMPACTS OF CAREGIVING CONT.

	Statewide	Reservations
Lost fringe benefits	3.5%	4.1%
Time conflicts: work/caregiving	14.7%	11.9%
Used vacation	14.0%	13.2%
Took leave of absence	3.8%	7.3%
Lost promotion	.5%	1.4%
Left work early or arrived late	17.2%	13.7%

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KEY SERVICES TO SUPPORT FAMILY CAREGIVING

- Home Health
- Personal Care
- Home Modification
- Nutrition
 - Dietician
 - Home Delivered Meals
 - Congregate Meals

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KEY SERVICES cont.

- Homemaker
- Chore
- Transportation
- Respite
- Day Care
- Outreach/case management

Native Elder Care Needs Assessment: Development of a Long Term Care Planning Tool Kit



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Sciences

Grant Background

- NRCNAA received grant in September, 2002
- Funded by Office of Rural Health Policy, Health Resources and Services Administration in Rockville, MD
- Result of testimony given by NRCNAA to Senate Committee on Indian Affairs in July 2002.

Purpose of the Project

- To assist tribes in interpreting long term care data that was obtained through a national Native Elder Care Needs Assessment conducted by NRCNAA.
- To assist tribes in using the long term care assessment data in the development of infrastructure and comprehensive services that respond to local needs and culture.

Planned Deliverables

- Develop a spectrum of long term care services/options for tribes to consider when planning, developing, and implementing their long term care efforts.
- Develop a web based and paper tool kit.

The Toolkit will:

- Be specifically geared towards American Indian and Alaska Native elderly.
- cover such items as community development, needs assessment, health promotion and preventive care services, home and community based services, assisted living, skilled nursing homes, and hospice care.

Focus Group Meeting

- Held in November 2002 in Denver, CO
- Invited participants for the focus group represented a wide range of geographic areas.
- Work with American Indian elderly, either through tribal elder programs, state elder programs, tribal elder care homes, or nursing homes off the reservation that serve American Indian elders.

Focus Group Meeting (Cont.)

- 12 participants
- 2 ½ day meeting
 - 1 day for agency information
 - 1 day for open discussion on LTC
 - ½ day for prioritizing

Focus Group Results

Priority list:

- Define the continuum of long term care service options
- How to conduct a needs assessment
- How to develop community interest and support
- Provide examples of programs
- Discuss the differing land and jurisdiction issues

Focus Group Results (Cont.)

What area of the long term care continuum should be the initial focus of the toolkit?

1. Prevention
2. Community based
3. In-home services

Planned Deliverable #1: Development of spectrum of long term care services/options

Functional Limitation Categories

Categories	Limitations
Little or none	No ADL limitations, up to one IADL limitation
Moderate	One ADL limitation OR 2 or more IADLs
Moderately Severe	2 ADL limitations
Severe	3 or more ADL limitations

Functional Limitation Levels Applied to Services and Personnel

Level Functional Limitation	Service Goals	Services with best fit	Personnel required
Little or none (54%)	Health promotion, preventive care, maintaining vitality	No caregiver services required Health Promotion/Prevention	Health educators, physical trainers, therapists
Moderate (23%) This category represents entry level functional limitations and requires assistance usually consistent with remaining in one's home.	Supportive services to aid persons in remaining in own domicile. Train and support informal providers and buffer them with respite and contact services for a range of possible tasks.	Informal care – w/supports Chronic Disease Management Home & community based •Day/night care* •Durable medical* equipment •Home health care* •Homemaker services* •Physical therapy •Occupational therapy •Medication assistance* •Speech therapy •Mental health services •Transportation services* •Nutritional services* •Personal care* •Respite care* * Require local providers	Family and friends Trainer for skills Facility staff – LPN/CNA Rental source RN, LPN, CNA, PT, OT... Cleaning and chore assts. PT, PT aides, tele-health OT, OT aids, tele-health Medication aide Speech therapist Psychologist, Psychiatrist, Psych. Social Worker, Van driver Dietician, aide Trained attendants Trained respite providers or institutional site

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Functional Limitation Levels Applied to Services and Personnel Cont...

Level Functional Limitation	Service Goals	Services with best fit	Personnel required
Moderately Severe (8%)	The goal for this level of care is to provide housekeeping and meals along with a modest level of oversight. People may contact for services from the home and community based services in addition to the basic services found in these settings. Assisted living establishes the goal for this cluster in that it seeks to maintain resident control over services.	Congregate care Basic care facilities Assisted Living	Institutional staff as required by state regulations
Severe (18%) With 3 or more ADL limitations, this level tends to become prime candidates for skilled nursing care. They represent care needs with relatively high levels of acuity.	Skilled nursing care is the most fully institutional and is reserved for those with medical needs necessitating this level of care.	Skilled Nursing Care	Institutional staff as required by state regulations
Terminal as special category	End of life care occurs at all points on the above continuum, but is concentrated at the higher levels of limitation. The goal is physical and emotional comfort.	Hospice Care*	Hospice volunteers and coordinator

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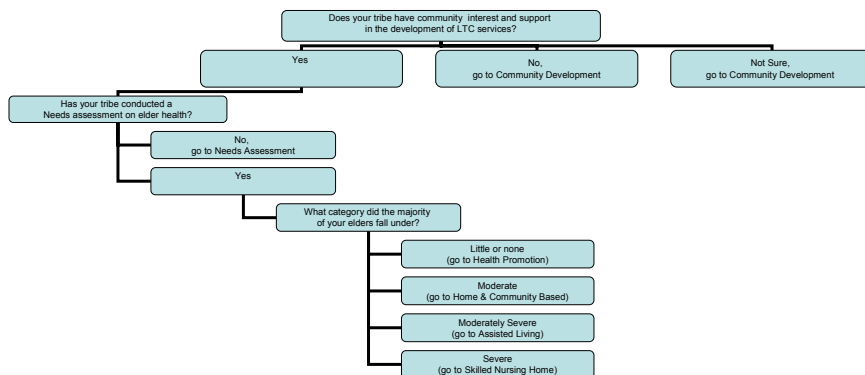
Planned Deliverable #2: Develop a web based and paper tool kit

Development of Product

Resource Book and Website

1. Introduction
2. Community Development
3. Needs Assessment
4. Health Promotion & Preventive Care
5. Home & Community Based Services
6. Assisted Living
7. Skilled Nursing Home
8. Hospice Care
9. Differing Land and Jurisdiction Issues
10. Definitions

Decision Tree



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Availability of Products

Website can be accessed through the UND Center for Rural Health website:

<http://www.med.und.nodak.edu/depts/rural/nrcnaa/toolkit/index.html>

Resource book will be sent to the 100+ tribes that have conducted NRCNAA's Elder Needs Assessment

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Reducing LTC Needs Through Health Promotion and Disease Prevention

Presented by:

**Alan Allery, Director
National Resource Center on
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Some Keys to Health Promotion and Prevention in American Indian Communities

- Culture
- Social Support
- Health Literacy
- Self Care for Chronic Disease
- Adherence to a program of change!

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Culture is evidenced in a person's and/or a group's:

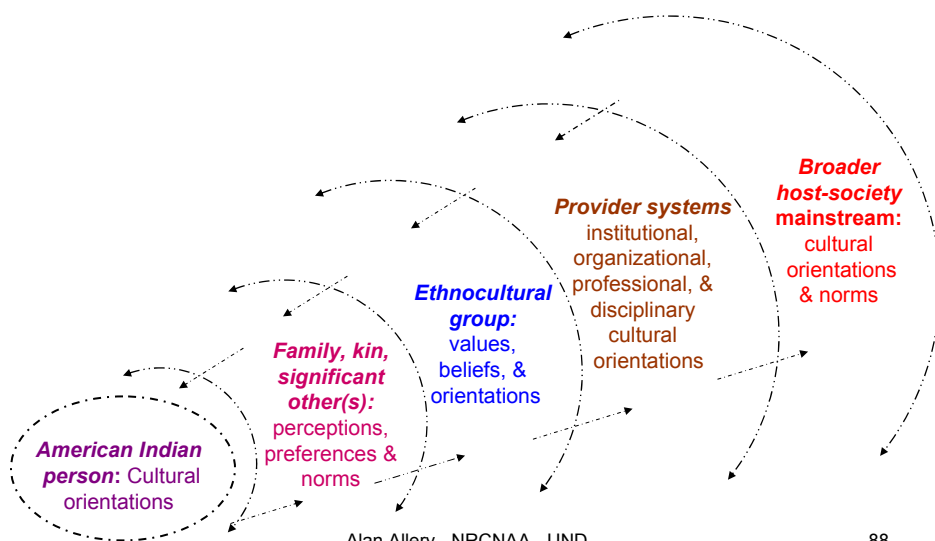
❖ language, symbols, communication patterns

❖ relational patterns, customs, practices

❖ values, beliefs, normative expectations

❖ Source: Ray Valle on Culture

Cultural Influence



Health Literacy

- Understanding the language of health promotion and prevention.
- Understanding written and oral information.
- Acting/use procedures and directions such as regular schedules.
- We need to be committed to providing information in a way that American Indian people can understand and act upon in order to improve their health.

Self-management Support

What is self-management?

“The individual’s ability to manage the symptoms, treatment, physical and social consequences and lifestyle changes inherent in living with a chronic condition.”

Barlow et al, person Educ Couns 2002;48:177

Social Support and Adherence

- 50% of health promotion is promotion!
 - » Cooper Institute
- “Habit is habit and not to be flung out the window, but coaxed downstairs one step at a time.”
- Adherence is the most important factor in maintaining a new habit.

Factors that Influence Health Behaviors

- Wanting to do it!
 - Knowledge
 - Attitude
 - Beliefs
 - Values
 - Perceptions
- Being able to do it!
 - Skills
 - Resources
 - Facilities
- Reinforcement
 - Rewards
 - Support









Logo

- Moccasins identify with American Indian Community
- Tipped moccasins represent Aging
- Worn moccasins represent Life Experiences-Wisdom of Elders

Butterfly Symbol

- Dakota symbol for Everlasting Life

Four-colored Square

- Dakota symbol for Four Ages (Infancy, Youth, Middle,Old)

Floral Design

- An Ojibwe floral design



Wisdom Steps is a ...

Partnership between -
American Indian Communities
&
Minnesota Board on Aging



WISDOM STEPS Promotes Preventive Health

- Health Screenings
- Health Education
- Healthy Living Activities



Wisdom Steps.....

simple steps Elders can take to:

- 1) Assess Your Health
- 2) Find Ways to Improve Your Health
- 3) Be Aware of Health Resources/Services
- 4) Practice Healthy Living
- 5) Share Your Wisdom as Role Models



Wisdom Steps

Health Promotion
 Health Education
 Prevention



NRCNAA Elder Assessment

Elders in MN *identified* themselves....

- 36% live in poverty
- 39% are current smokers
- 41% do not exercise
- 46% have either fair or poor health
- 49% have arthritis
- 56% are overweight



Wisdom Steps

- Promotes Community Partnerships
- Motivates American Indian Elders to begin taking *Steps to Improve* their Health
- Encourages Coordinating Resources



“Wisdom Steps” has developed innovative model projects

- Health Screenings –
 - “Medicine Talk”
- Health Education -
 - “Medicare in American Indian Community”
 - “Diabetes Education” (being developed)
- Healthy Living Activities -
 - “We Walk Many Together”

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“Medicine Talk”

- Addresses Better Communication between Elders and Health Specialists and Pharmacists
- Review of Traditional, Prescription, and Over-The-Counter Medicines
- Provide Follow-up for Elders Needing Assistance with Medicine Management



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“We Walk Many Together”

- Promotes Participation in Walking and Exercise Programs of Your Choice

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Incentive Plan

Complete 2 of 3 Below Activities to qualify for Wisdom Steps Recognition:

- 1) Complete 5 Health Screenings
- 2) Attend Your Health Fair
- 3) Participate in an Organized Walk or Routine Exercise of Your Choice

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Wisdom Steps Recognition

Each Year, Elders Completing “Wisdom Steps” Incentive Plan will receive a:

- Wisdom Steps Pin (1st & 4th yr.)
- Charm
- Certificate

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Thank you, Elders

for

“Sharing Your Wisdom”

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Benefits of Walking

- Reduces risk of dying prematurely
- Reduces risk of disease
- Helps control weight/lose weight
- Builds Healthy Bones/Joints/Muscle
- Promotes psychological well being

How much?

- 10,000 steps a day
- Thirty minutes a day
- If you have diabetes consult a physician regarding foot care
- Other illnesses consult your physician
- You can't start with 10,000 steps a day
- Build it up over time

Health Walking

- Leisure walking
- 16-30 minutes per mile
- Think tall
- Eyes focused about 15 feet ahead
- Arms down swing naturally
- Place heel and roll to ball of foot
- Natural stride

Fitness Walking

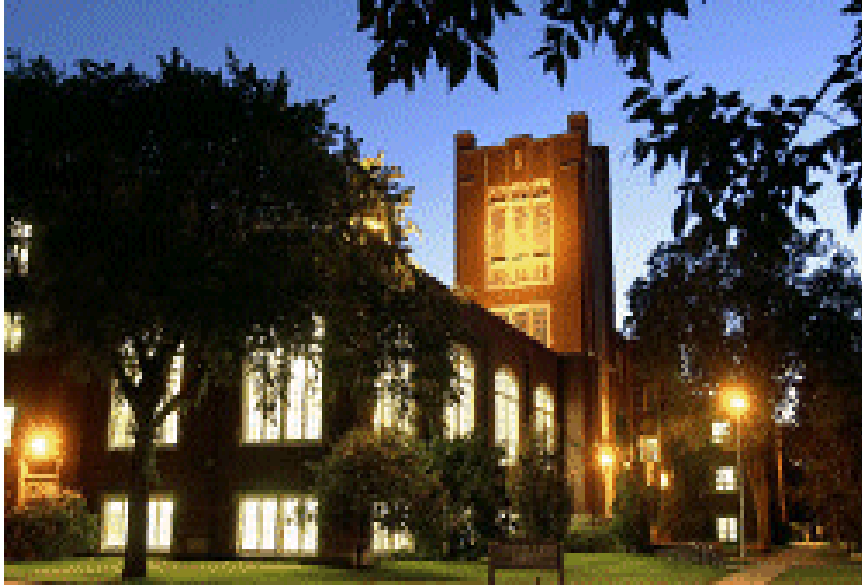
- Gradually move to fitness walking
- 13-15 minutes per mile
- Increased caloric use
- Think tall
- Walk straight forward

Walking Safety

- Shoes
- Clothing
- Hydration
- Stretching
- Precautions
 - Traffic
 - Sun protection
 - Clothing

NRCNAA Work Plan 2003-2004

- Continue Research on the Needs of Elders
 - More than numbers, Tribes should develop action plans – Tribal Specific Long Term Care Plans!
- Health Promotion Activities
 - Healthy People 2010 (Obesity & Physical Activity)
 - Monitoring Chronic Disease
 - Self Help Groups
- Communications to you!
- Health Literacy



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