



Center for
Rural Health

University of North Dakota
School of Medicine & Health Sciences

<http://medicine.nodak.edu/crh>

Using Data for Decisions, Advocacy, & Policy

Leander R. McDonald, PhD, Alan Allery, PhD,
Richard Ludtke, PhD, Kyle Muus, PhD, & Patricia
Moulton, PhD

Federal Interagency Taskforce Meeting
on Older American Indians

April 26, 2006

200 Independence Avenue, SW
Washington, DC



*Connecting resources and knowledge to strengthen
the health of people in rural communities.*



National Resource Center on Native American Aging

- Established in 1994, at the Center for Rural Health, University of North Dakota School of Medicine and Health Sciences
- Focuses on:
 - Education, Training, and Research
 - Community Development & Technical Assistance
 - Native Elder Health, Workforce, & Policy
- Web site: <http://medicine.nodak.edu/crh/nrcnaa>



Other AI Programs

- RAIN
- INPSYDE
- MSDP
- Native Media Center (Journal)
- Tribal College Partnerships in Teacher Education
- See AISS Brochure



Center *for* Rural Health

- Established in 1980, at the University of North Dakota - Grand Forks, ND
- Focuses on access, financing, quality, and information dissemination through:
 - Education, Training, and Awareness
 - Community Development & Technical Assistance
 - Native American Health
 - Rural Health Workforce
 - Rural Health Research
- Web site: <http://medicine.nodak.edu/crh>





The Needs Assessment Team

- Dr. Richard Ludtke, Ph.D.
- Dr. Kyle Muss, Ph.D.
- Dr. Leander “Russ” McDonald, Ph.D.
- Mrs. Francine McDonald, MPA
- Mrs. Crystal Kipp, Graduate Assistant
- Twyla Demaray, M.Ed.
- Ms. Kim Rullifson
- Dr. Alan Allery, Ph.D.



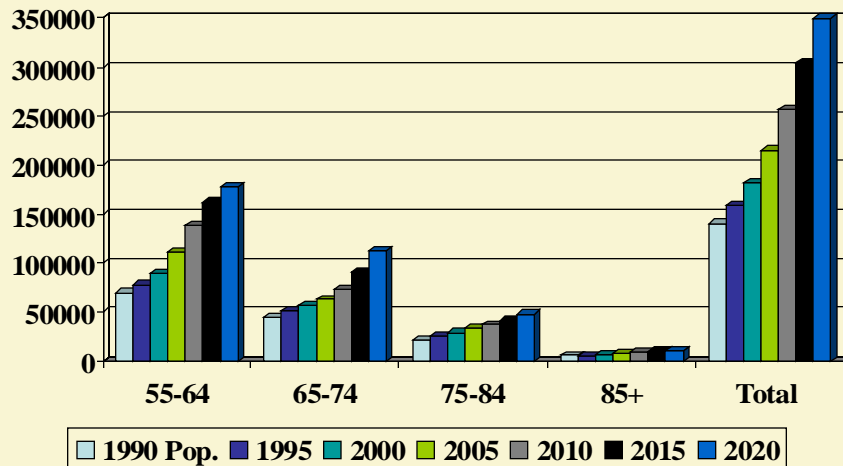
The Framework

- The Premise For The Elder Needs Assessment (Phase I and Phase II)
 - Value to American Indian Tribes and Communities
 - Valid design, methodology
 - Fair Subject Selection
 - Balanced Risks and Benefits
 - Independent from politics, etc.
 - Informed consent, tribal approval
 - Respect for American Indian elders





Native Elder Population Projections 1990-2020



McDonald, Alery, et al.



7



Regional Variances

- One size does not fit all
- Variation in regard to life expectancy and chronic disease
 - Ex. California Area life expectancy is close to the nations; however, Aberdeen Area is 64.3, a difference of 12.5 years.
 - Ex. Alaska Area has diabetes rate close to the general population at 14%; whereas, the majority of other regions are at 37% or higher.
- Once you seen one tribe you've only seen one tribe

McDonald, Alery, et al.



8



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

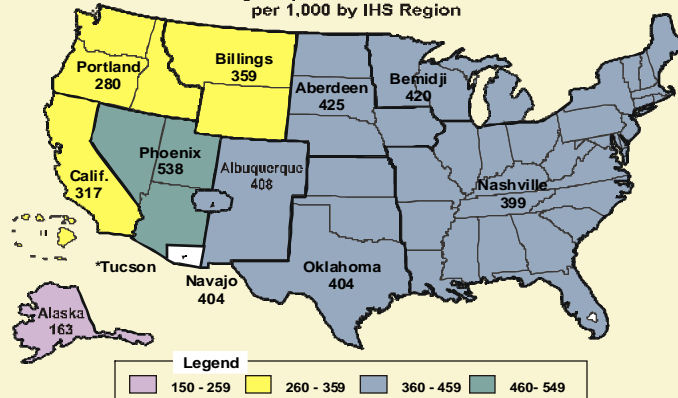
IHS Area	At Birth	At Age 55	At Age 65	At Age 75
Aberdeen	64.3	18.9	13.2	8.5
Benidji	65.7	18.7	12.7	10.1
Billings	67.0	20.2	13.9	8.9
Alaska	68.0	21.3	14.7	9.2
Tucson	68.4	22.2	15.8	10.0
Phoenix	69.8	22.6	16.1	10.6
Portland	71.7	23.1	16.0	10.1
Navajo	71.9	24.9	17.7	11.7
Nashville	72.2	22.8	16.3	10.5
Albuquerque	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
**U.S. All Races	76.8			

Source: I.H.S. Division of Statistics (1998); **National Center for Health Statistics (2000)



Diabetes Rates by Region

Native Elders 55 and Over
Age Adjusted Diabetes Rates
per 1,000 by IHS Region



Source: NRCNAA Needs Assessment Data, UND Center for Rural Health.
* No data are available.





Purpose of the Project

- The purpose of this project is 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).



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



Data is collected on

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



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



“Tribal Name” Data Comparison to Aggregate Tribal Data (N=9,296) and National Data

Question	Response (s)	Tribal Data (55 and over)	Aggregate Tribal Data (55 and over)	94' NLTCs (65 and over)
4. Because of a health or physical problem, do you have difficulty –	a. Bathing or showering?		16.7%	36.8%
	b. Dressing?		11.6%	15.8%
	c. Eating?		7.5%	8.1%
	d. Getting in or out of bed?		13.1%	22.1%
	e. Walking?		28.1%	33.7%
	f. Using the toilet, including getting to the toilet?		8.9%	22.8%
5. Because of a health or physical problem, do you have any difficulty--	a. Preparing your own meals?		18.1%	19.7%
	b. Shopping for personal items (such as toilet items or medicines)?		17.0%	34.8%
	c. Managing your money (such as keeping track of expenses or paying your bills)?		10.3%	17.9%
	d. Using the telephone?		8.0%	9.6%
	e. Doing heavy housework (like scrubbing floors, or washing windows)?		37.3%	51.6%
	f. Doing light housework, (like doing dishes, straightening up, or light cleaning)?		17.1%	17.0%
	g. Getting outside?		15.4%	44.2%



Local Communities Provide:

- Obtaining a resolution from their tribal councils
- 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





Current Status of Project

- **Cycle I**
 - 190 tribes from 87 different sites are represented in national file
 - 9,403 Native elder participants have filled out the survey
 - At least one tribe from 11 of the 12 I.H.S. Regional Areas is represented in the national file
- **Cycle II**
 - 254 tribes from 75 sites representing 10,521 Native elders have completed Cycle II
 - 17 tribes have resolutions on file and are now collecting data
 - All 12 I.H.S. Regional Areas are represented in the national file



Data Used for This Analysis

- Two Cycles of Matched Survey Data
- 38 IHS Service Areas have collected data in both cycles. These survey results are employed as replication studies.
- 4,148 Respondents in Cycle I
- 4,008 Respondents in Cycle II

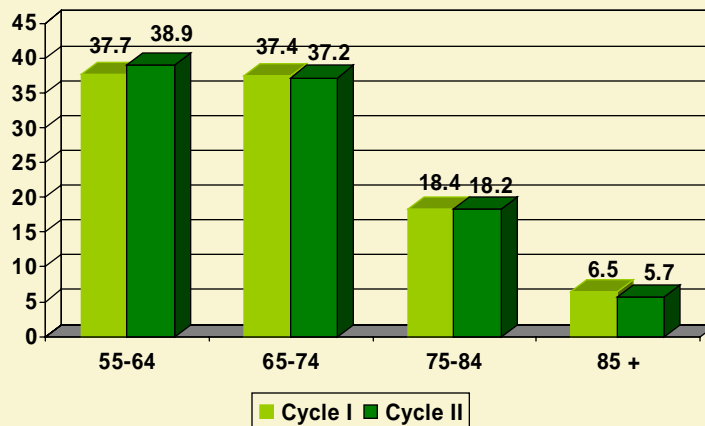


The Times – They are A Changing: Demographic Shifts

- Baby Boomers are changing the age distribution for elders
- Length of last residence is shorter
- Educational levels are improving
- More people age within marriages
- Incomes are gradually improving

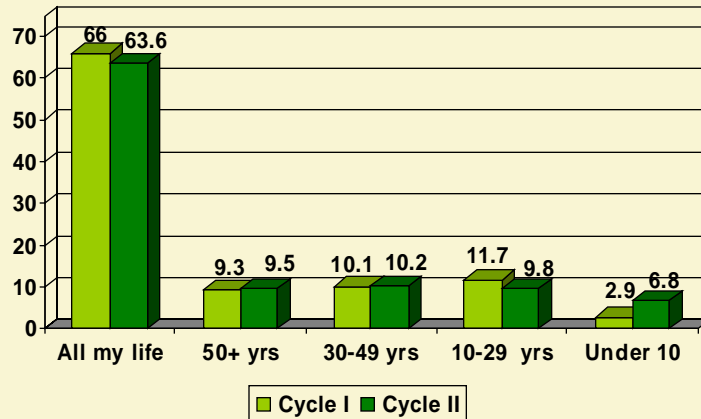


Age Distributions: Cycle I and II





Length of Current Residence: Cycle I and II



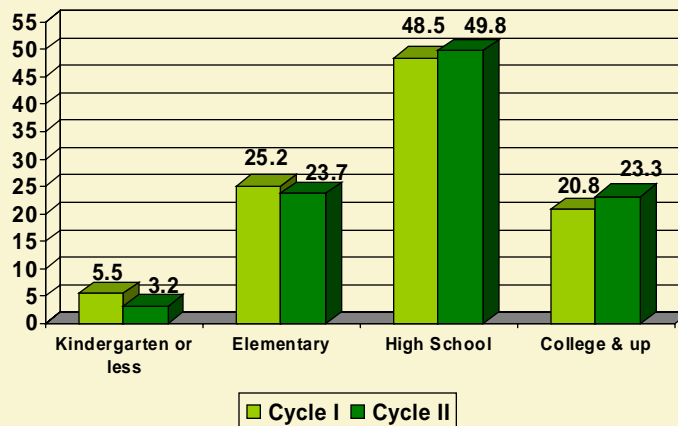
McDonald, Alery, et al.



21



Education: Cycle I and II



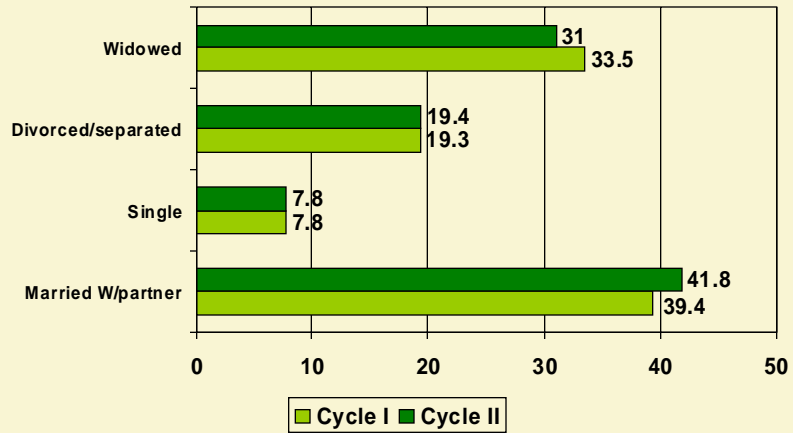
McDonald, Alery, et al.



22



Marital Status: Cycle I and II



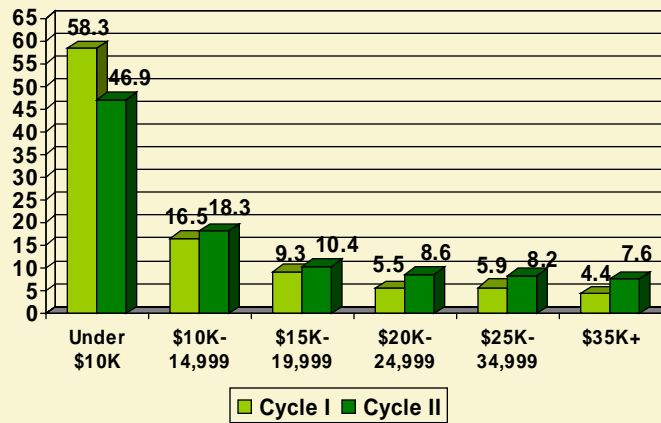
McDonald, Alery, et al.



23



Income Levels: Cycle I and II



McDonald, Alery, et al.



24



Center for
Rural Health

University of North Dakota
School of Medicine & Health Sciences

<http://medicine.nodak.edu/crh>

The Health of America's Indian Elders: Change in Chronic Diseases



*Connecting resources and knowledge to strengthen
the health of people in rural communities.*



Chronic Disease: Change from Cycle I to Cycle II

- Hypertension****(Higher)
- Arthritis****(Higher)
- Asthma****(Higher)
- Cataract****(Higher)
- Prostate Cancer****(Down!) BUT When age was controlled there was no difference

****All represent statistically significant changes.



Chronic Diseases: No Change from Cycle I to Cycle II

- Diabetes (38%)
- Cataract (21%)
- CHF (12%)
- Stroke (9%)
- Cancers (other than Prostate)

McDonald, Alery, et al.



27



Center for
Rural Health

University of North Dakota
School of Medicine & Health Sciences

<http://medicine.nodak.edu/crh>

Functional Limitations



*Connecting resources and knowledge to strengthen
the health of people in rural communities.*



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.



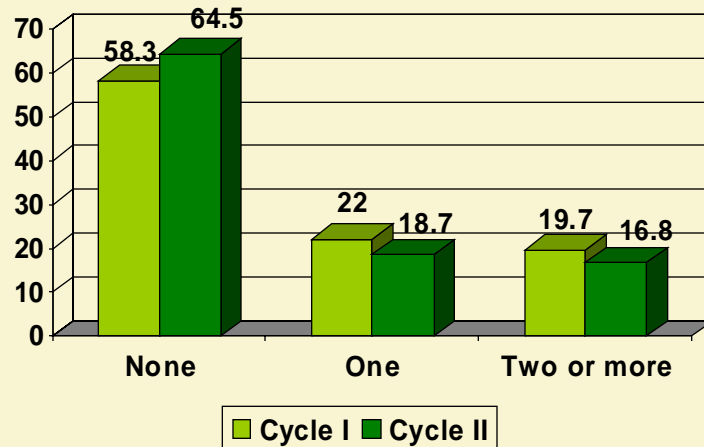
Functional Limitation Categories

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





Rates of Functional Limitation: Cycle I and Cycle II



McDonald, Alery, et al.



31



Component Changes in Functional Limitations: IADLs AND ADLs

- IADLs declined significantly for all age groups – an across the board gain
- ADLs declined significantly **only** for the 65-74 cohort

McDonald, Alery, et al.



32



Functional Limitation Levels Applied to Services and Personnel

Level Functional Limitation	Service Goals	Services with best fit	Personnel required
Little or none (65%)	Health promotion, preventive care, maintaining vitality	No caregiver services required Health Promotion/Prevention	Health educators, physical trainers, therapists
Moderate (18%) 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* •Home maker 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

McDonald, Alery, et al.



33



Functional Limitation Levels Applied to Services and Personnel Cont.

Level Functional Limitation	Service Goals	Services with best fit	Personnel required
Moderately Severe (6%)	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 (12%) With 3 or more ADLs, 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

McDonald, Alery, et al.



34



Center for
Rural Health

University of North Dakota
School of Medicine & Health Sciences

<http://medicine.nodak.edu/crh>

Health Risk Behaviors: Are they changing?



*Connecting resources and knowledge to strengthen
the health of people in rural communities.*



Smoking

- No significant change in the proportion of elders who smoke
- The volume (number of cigarettes smoked) dropped significantly overall, but the decline was not present when age was controlled.
- The overall drop was a function of the mix by age – not behavior.



Chewing Tobacco

- Smokeless tobacco use was up significantly
- The increase was due to more use among the young elders – the older elders use did not change



Drinking Behavior

- A slight increase in the proportion who had consumed alcohol in the past 30 days.
- This appears due to increased use among the younger elders.
- Aging appears to diminish drinking behavior with higher proportions indicating no alcohol in the past three years (abstinence).

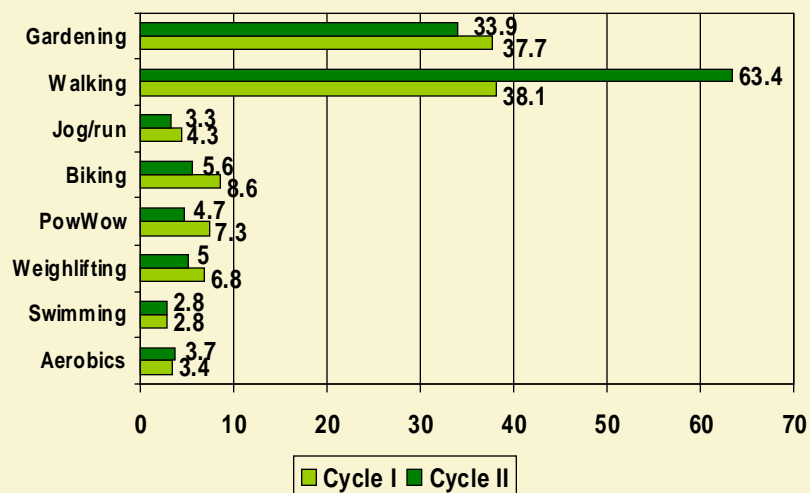


Binge Drinking

- Overall no significant change was reported in binge drinking
- Aging did produce a significant decline in binge drinking. 19.1% of those 55 to 63 reported binge drinking in past 30 days compared with only 6% of those 85 and over.



Exercise: Cycle I & Cycle II



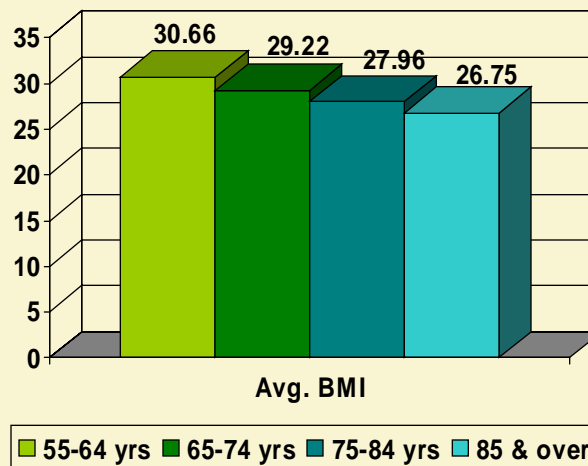


Exercise Change and Age

- Weight Lifting – Down for 55–64 age group
- Powwow – Down for 55-64 & 65-74 age groups
- Biking - Down for 55-64 & 65-74 age groups
- Jogging - Down for 55-64 & 65-74 age groups
- Walking – **Up dramatically for all ages!!**
- Gardening – Down for 55-64 & 65-74 age groups



Average BMI Scores by Age: Cycle II



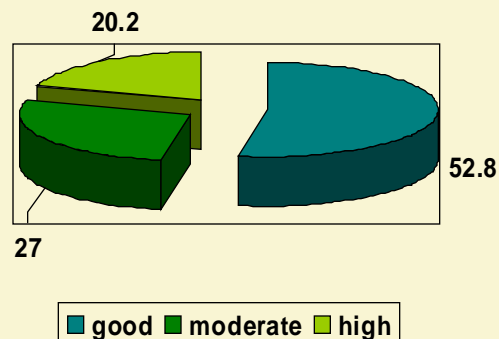


Growing Problem of Weight

- The average BMI score increased from 29.1 to 29.6 from cycle I to cycle II
- Age is related to BMI with the younger elders having the highest BMI scores – the 55-64 age group's average BMI fell in the obese category



Nutritional Risk Levels among Elders: Cycle II





Conclusions

- Native elder populations are **now** dramatically growing.
- Tribal recognition of age 55 for elder status includes those elders from the boom generation.
- Education and incomes are improving over time with new cohorts bringing new advantages.
- With the demographic shift, more elders live with a spouse and fewer are widowed.



Conclusions cont.

- Chronic diseases prevalence is mixed with several increasing and others steady.
- Declining rates were not found.
- Increases may well relate to risk factors.
 - Exercise – Walking increased dramatically, but nearly all other exercises decreased.
 - Weight issues increased – young old are heaviest.
 - Smoking and drinking were unchanged.





Recommendations

- Recognize the demographic shift in the interpretation of results may produce statistical artifacts that exaggerate the health and functionality of the elders.
- Lifestyle modification continues to merit attention. Positive results for walking provide a major source of encouragement.
- Chronic disease self management will be essential to avoiding future functional limitations as this population grows older.



Data Use Examples





Products

- All participating tribes receive a comparison sheet that contains their data with comparisons from national data files.
- Each of the tribes are able to use the document to identify disparities for use in planning efforts.
- Population Projections were developed for I.H.S. Service Units when possible.



Combining Data with Population Projections

- 38% of Native Elders in the nation currently have diabetes
- 2000 Native Elders = 182,057
 $.38 \times 182,057 = \mathbf{69,182}$
- 2020 Native Elders = 349,109
 $.38 \times 349,109 = \mathbf{132,661}$



Community Level Data Uses

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



State & National Advocacy & Policy Examples

- South Dakota State Legislative Research Committee
- Senate Committee on Indian Affairs
- National Indian Council on Aging
- National Congress of American Indians
- White House Conference on Aging



Policy Recommendations



Policy Recommendation # 1: Disease Prevention Efforts Including Health Promotion, Screening and Wellness Programs

- **Federal agencies including the Indian Health Service (IHS), Administration on Aging (AoA), Centers for Disease Control (CDC), Health Resources and Services Administration (HRSA), Bureau of Indian Affairs (BIA), Administration on Native Americans (ANA) and the Agency for Healthcare Research and Quality (AHRQ) should allocate resources to develop and evaluate wellness programs that focus on healthy eating choices and physical activity for Native Americans using a multigenerational approach.**



Policy Recommendation # 1: Disease Prevention Efforts Including Health Promotion, Screening and Wellness Programs Cont...

- **An interagency team comprised of the IHS, ANA, CDC, BIA, AoA, and the Department of Education should be created with the charge of developing a collaborative model for health promotion.**
- **Health screenings not already supported for elders (55 years or older) should become the responsibility of IHS and the Centers for Medicare and Medicaid Services (CMS) as a part of targeted health promotion programs.**



Policy Recommendation # 1: Disease Prevention Efforts Including Health Promotion, Screening and Wellness Programs Cont...

- **Designated funding within Health and Human Services should be provided to enable tribal health organizations and IHS to implement coordinated community screening and referral programs for Native American elders. These programs should be designed to remedy access to dental, hearing, and vision screenings.**



Policy Recommendation #2: Chronic Disease Management Programs to Prevent Co-morbidity and Increase Access to Services

- **A joint CMS, CDC, ANA and IHS disease management demonstration program should target the most prevalent chronic diseases in Native elders including diabetes, arthritis and high blood pressure.**
- **The Environmental Protection Agency's work in air quality and asthma management should target urban Native elders.**



Policy Recommendation #3: Increase Availability of Home/Community Based Long-term Care Services in Rural Areas

- **The health and human services community and faith based programs along with the Office of Rural Health Policy (ORHP) and AHRQ should support initiatives that seek innovative designs for providing home and community based long-term care services and support for Native elders living in rural areas.**
- **Congress should reauthorize the Indian Health Care Improvement Act (IHCIA).**



Policy Recommendation #4: Increasing Availability of Health Care and other Services in Rural Reservation Areas

- **The AoA Office for American Indian, Alaska Native, and Native Hawaiian Programs should advocate with states and other federal agencies to increase senior centers for frontier Native Elders.**
- **A special initiative under Housing and Urban Development (HUD) should provide assessments, on a regular basis, of Native elder's current housing environment in relationship to their health needs.**
- **Congress should increase funds for the Native American Housing Assistance and Self-Determination Act (NAHASDA) to improve plumbing and sanitation conditions for rural Native Elders.**



Policy Recommendation #5: Increase Incomes and Access to Health Insurance and Medicare for Future Generations of Native Elders'

- **A special initiative under the Department of Education to create and evaluate model programs to increase student retention and academic success in American Indian children.**
- **The IHS should provide a evidence based demonstration project focused on encouraging healthy lifestyles among American Indian youth.**





How can we collaborate to make better use of the data set?

- Our agreement with tribal government is not to give the raw or aggregate data to other agencies.....however, we can query our data for other agencies, do cross tabulations with other agency data, etc.
- We want to enhance/encourage data driven decision making by tribes, agencies, etc. regarding older American Indians.



Special Thanks.....

- Honorable Josephina Carbonell
Assistant Secretary
Administration on Aging
- Dr. Yvonne Jackson, Director, Office for
American Indian, Alaskan Native, and
Native Hawaiian Programs
- Margaret Graves, Project Officer,
Administration on Aging





Center for
Rural Health

University of North Dakota
School of Medicine & Health Sciences

<http://medicine.nodak.edu/crh>



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: (701) 777-6780

Fax: (701) 777-6779

<http://medicine.nodak.edu/crh>



*Connecting resources and knowledge to strengthen
the health of people in rural communities.*