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NATIVE AMERICAN ELDER HEALTH ISSUES

HEARING

BEFORE THE

COMMITTEE ON INDIAN AFFAIRS
UNITED STATES SENATE

ONE HUNDRED SEVENTH CONGRESS

SECOND SESSION

ON

OVERSIGHT HEARING TO EXAMINE THE LONG TERM CARE AND HEALTH CARE NEEDS OF NATIVE AMERICAN ELDERS

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NATIVE AMERICAN ELDER HEALTH ISSUES

WEDNESDAY, JULY 10, 2002

U.S. SENATE,
COMMITTEE ON INDIAN AFFAIRS,
Washington, DC.

The committee met, pursuant to other business, at 10:15 a.m. in room 485, Senate Russell Building, Hon. Daniel K. Inouye (chairman of the committee) presiding.

Present: Senators Inouye, Campbell, and Conrad.

STATEMENT OF HON. DANIEL K. INOUYE, U.S. SENATOR FROM HAWAII, CHAIRMAN, COMMITTEE ON INDIAN AFFAIRS

The CHAIRMAN. The committee meets this morning to receive testimony on an ongoing study that is being conducted by the National Resource Center on Native American Aging within the Center for Rural Health at the University of North Dakota School of Medicine and Health Sciences. This study examines the long term care and health care needs of America's Native American elders.

Despite the fact that the American Indian population is one of the fastest growing populations in the United States, the status of elderly Native Americans is, to put it simply, poor. As the testimony today will indicate, almost three out of five elderly Native Americans live well below the poverty level. Diseases such as diabetes afflict Indian elders at epidemic rates, and the mortality rate from diabetes is five times higher than the national average. Deaths associated with kidney disease are three times the national average among Native American elders.

These statistics are overwhelming and the need for age sensitive health care and for long term care is obvious. Unfortunately, the long term care options for most Native American elders are minimal at best and often require decisions that break families apart. With few long term care facilities available on most Indian reservations, elders requiring such care may have to be placed hundreds of miles from their homes and families. Poor families don't have the means to travel back and forth to visit their grandmothers and grandfathers, and sadly, we know that many families in Indian country are constrained in this way.

Home health care alternatives are also extremely limited in most tribal communities. So while families may ultimately decide that it is best to keep their loved ones at home, like most families across America, few have the professional training to adequately care for their elders. These are the tragic circumstances that many Native American elders face as they enter into their twilight years.

Today we hope that the testimony will shed some light not only on the conditions in Indian country as they affect the elderly, but what can be done to better address their needs. As one who qualifies under almost any definition as an elder, I take these matters very seriously. And I look forward to the constructive solutions that we anticipate will be forthcoming from the testimony received today.

And may I recognize the vice chairman.

STATEMENT OF HON. BEN NIGHTHORSE CAMPBELL, U.S. SENATOR FROM COLORADO, VICE CHAIRMAN, COMMITTEE ON INDIAN AFFAIRS

Senator CAMPBELL. Thank you, Mr. Chairman.

We don't normally make headlines in the New York Times and the Washington Post about the activities in this committee, but they are extremely important to one segment of the American population, and that's the Indian people. The hearing today is one of those that involves Native elders, a group revered in Indian cultures, but also a group that is often quiet and in the background when it comes to public debate. As the 2000 census makes clear, the Native population, like the U.S. population, is growing at a very fast pace.

I think that when we talk about the future of elders, I might mention that during the break I went to Montana, visited the Northern Cheyenne, where I happen to be a member. I was asking the tribal chairman up there about the growth of that tribe. There are about 8,000 enrolled in that tribe. But 75 percent are under 25 years old, which of course gives us a whole host of problems with education and jobs and all that. But those youngsters are some day going to be elders, too. And we don't seem to be ahead of the curve when we talk about what's going to happen in another 20 or 30 or 40 years about those young people now who are all going to have these problems. These include, as you know, diabetes, which leads to poor circulation, gangrene and then amputation of the lower extremities, things of that nature.

I think your comments about the difficulty of families visiting is really important. I know that in the case of that little community, Lame Deer, MT, one of the places that elders are put after the have had their legs amputated, which happens too often, is clear in Glendive, MT, about 100 miles away. That means if their family, their grandkids, their youngsters want to visit them, and they don't have transportation, they just don't see them any more, because it's just too far to go to be able to visit the elderly that are in the hospitals with their extremities cut off. That means they have a mighty lonely existence in the last years of their lives, which shouldn't be anything that anyone should have to go through. It seems to me one of the great things about growing older is your ability to be close to your kids and your grandkids. But when they suffer these debilitating problems brought on by diabetes, that's not the way too many elderly Indian people finally go to their Maker.

Thank you, Mr. Chairman, for convening this hearing.

The CHAIRMAN. I thank you very much. You are so correct, your autumn years should be the happy years. But in too many cases, such is not the case.

We have two panels this morning. The first panel, Director of the Centers for Wellness and Community-Based Services, Administration on Aging, Edwin Walker. He will be accompanied by Dr. Yvonne Jackson, Director of the Office of American Indian, Alaska Native and Native Hawaiian Programs, Administration on Aging. And then we have the Area Director of the Bemidji Area Indian Health Service of Bemidji, Minnesota, Dr. Kathleen Annette, who will be accompanied by Dr. Craig Vanderwagen, Acting Chief Medical Officer, Indian Health Service, Rockville, and Dr. Bruce Finke, Elder Specialist.

Dr. Walker.

STATEMENT OF EDWIN WALKER, DIRECTOR, CENTERS FOR WELLNESS AND COMMUNITY-BASED SERVICES, ADMINISTRATION ON AGING, ACCOMPANIED BY YVONNE JACKSON, DIRECTOR, OFFICE FOR AMERICAN INDIAN, ALASKA NATIVE AND NATIVE HAWAIIAN PROGRAMS

Mr. WALKER. Good morning, Mr. Chairman and members of the committee. On behalf of the U.S. Administration on Aging, I appreciate the opportunity to discuss the health concerns of Native elders and to provide some information about our programs. I commend this committee's commitment to Native Americans and the support you have shown for aging issues in Indian country.

As indicated, I am accompanied by Dr. Yvonne Jackson, the Director of our Office of American Indian, Alaska Native and Native Hawaiian Programs at the Administration on Aging. Josefina Carbonell, our Assistant Secretary for Aging, has identified health promotion and disease prevention among her priorities for the Administration on Aging. Our focus is on encouraging Americans of all ages to live healthier lives. Healthy living can prevent diseases and certain disabilities, and it can ensure that today's older persons, as well as our future generations, not only live longer, but also better.

Great strides have been made in improving the health status of American Indians and Alaska Natives. Yet, cardiovascular disease remains the leading cause of death for all populations in the United States, and one-half the adults have diabetes. Diabetes complications are some of the major causes of morbidity and mortality among older Indians. The Administration on Aging is working with the Indian Health Service, tribal health and social service departments and universities to assist in developing programs and services for preventing and controlling diabetes.

The AOA annually awards grants to provide supportive and nutrition services for American Indian, Alaska Native and Native Hawaiian elders. Our Older Americans Act Title VI program has been funding services in Indian communities throughout the country for the last 22 years, growing from services in 85 tribes in 1980 to over 300 tribes serving nearly 100,000 Native elders today.

Our programs provide a wide range of services, including congregate and home delivered meals, transportation to meal sites and doctor's appointments, wellness programs, home health services,

adult day care and family caregiver support, just to name a few. These services achieve the goal of assisting elders to remain in their homes and communities for as long as possible. In addition to our programs that directly assist the elderly, AOA now assists those who care for the elderly and the disabled through our Native American family caregiver support program.

In order to assist the tribes in developing home and community based services for their elders, AOA has awarded grants to two national resource centers, one at the University of Colorado and one at the University of North Dakota. AOA and the resource centers collaborated on a study that concluded that there is a wide disparity between the need for and the availability of home and community based long term care services. While emergency and acute primary health care is usually met, other services, such as mental health, home health, personal care and transportation are only moderately met, and services such as adult day care, respite care and assisted living are unmet.

In response to requests for assistance from tribes, we asked our resource center at the University of North Dakota to develop a needs assessment tool that provides tribes with an accurate picture of the health status of their elders. Although the resource center will discuss the results of the needs assessment in detail, I would like to highlight just some of the data noteworthy in developing home and community based services.

Nearly 30 percent of Indian elders live alone. As compared to elders in the general population, a greater percentage of Indian elders consider their health to be fair or poor. Many more Indian elders are overweight, and yet may be less aware of their overweight status since they consider their weight to be just about right. Most Indian elders indicated they would be willing to go to an assisted living facility, while only 18 percent of the elders indicated they would be willing to use a nursing home.

The feedback that we've received from the tribes who are using the needs assessment has been very, very positive. They are happy to have the data, but now they are requesting additional assistance in interpreting the data and in how to use the information in program planning. We are working with the staff of the resource center in order to provide this additional assistance.

Mr. Chairman, we are very proud at the Administration on Aging that we are able to provide services and assistance to American Indian, Alaska Native and Native Hawaiian elders and their families. We are committed to working with you and your colleagues to improve the quality of life in Indian country in the years ahead. Thank you very much, and Dr. Jackson and I would be happy to answer any questions that you have.

[Prepared statement of Mr. Walker appears in appendix.]

The CHAIRMAN. Thank you very much, Mr. Walker. May I now recognize Dr. Annette.

STATEMENT OF KATHLEEN ANNETTE, M.D., AREA DIRECTOR, BEMIDJI AREA, INDIAN HEALTH SERVICE, ACCOMPANIED BY CRAIG VANDERWAGEN, M.D., ACTING CHIEF MEDICAL OFFICER, INDIAN HEALTH SERVICE, BRUCE FINKE, M.D., ELDER SPECIALIST

Ms. ANNETTE. Good morning. My name is Kathleen Annette. Accompanying me is Dr. Craig Vanderwagen and Dr. Bruce Finke. Dr. Bruce Finke is a geriatric specialist in the Indian Health Service, and Dr. Vanderwagen is the chief medical officer.

I have a prepared statement, which you have, and I would like to take the opportunity now to summarize this for you.

The CHAIRMAN. Without objection.

Ms. ANNETTE. I am an American Indian physician, a family doctor who has worked on reservations off and on most of my life, and currently am an area director. I also have a mother who is currently in dialysis, diabetic and dealing with personally many of the issues that we're talking about today.

Who are these people that we're talking about, these Indian elderly? In the tradition of my people, the best way for me sometimes to explain this is really to tell you a story. And this is a true story. I have, or had, an 84 year old great aunt. She called me one 9day and said, as many of our elders do, it's your turn to come and take me to the clinic to pick up my pills.

So I picked up Aunt Mary and we headed to Cass Lake Indian Hospital, where she had received her care for 84 years of her life, and came to the one stop light in town. And the one stop light in town stays red and red and red. So we pulled up and wouldn't you know it, there was a very young couple that was necking at the stop light. I don't know how else to put it. And Aunt Mary looked, and I was embarrassed. She kept pushing me aside and she kept looking. She said, look at them, they're hot. I said, oh, Aunt Mary. She said, well, I used to be. [Laughter.]

This is an 84 year old elder. I took this story about—have any of you seen Wind Talkers? A wonderful, wonderful film about the Navajo code talkers. I told this story at a national meeting that I was attending where the code talkers brought in the colors. I was so proud. And they listened, and they came up to me afterwards, and I thought, gee, these wonderful elders are going to really give me some encouragement. And what they told me is they wanted to meet my Aunt Mary. [Laughter.]

But these are the people we're talking about in terms of elders. They're the ordinary Indian people that are at home dealing with issues every day, and they are Indian people that have had extraordinary experiences and contributions to this country.

What are they dealing with at home? When we ask them, and I think the North Dakota study is fantastic, and you'll hear more about that, it gives us some baseline data from 88 tribes, that is incomplete. It has to be expanded to more, and we'll have a much better data base and information to share with tribes.

The issues they bring to us and that we deal with in Indian Health Service is of course long term care. Are we involved in long term care? You bet we are. And the reason for that is long term care is a spectrum. It's a spectrum. It's a spectrum of services that

ought to be available. We are responsible for the hospital and clinic portions, along in partnership with tribes.

What is our responsibility? It's ongoing. We really need to work with coordination of services. And we find that's a real challenge at local, regional and national levels.

We also really must assure that when our doctors and nurses and providers provide geriatric care, the care we provide can't be good enough. Our care has to be outstanding. And whatever we do to provide that piece, we need to assure that our primary care providers have geriatric training as part of what they bring to our table when they come to serve our people.

These are the people we serve, these are people that have contributed so much to this Nation. Indian Health Service does have a role. We must partner with others. We must continue to do much of what we do and do it better. We have to partner with tribes and say, "what is it you really need". Because I think if we're going to have a successful program, we must work with the tribes to develop what that program ought to be. And again, we'll be talking at length I think with you in terms of the services that define long term care and how we can best design programs with tribes.

Thank you.

[Prepared statement of Ms. Annette appears in appendix.]

The CHAIRMAN. I thank you very much.

If I may ask, Mr. Walker, what gaps in Federal services have you identified in diabetes or nutrition programs that, if services were provided to fill these gaps would help alleviate the high incidence of diabetes?

Mr. WALKER. What we've noted is that, and as I mentioned, we do provide a nutrition program for the elders. What we've found is that we need to continue our educational efforts. We have some pilot projects, and Dr. Jackson can speak directly about those projects that include researchers pairing up with elders and tribes to discuss the types of foods that they eat. We had one case where they gathered foods, they tested the glycemic level in the foods to determine the rate at which glucose is generated, I guess, within the food. Then they incorporated new practices of preparing foods and which foods to use and eat into the Native culture.

Ms. JACKSON. A couple of years ago, we had some funding for some pilot breakfast projects. Some of the tribes, notably the Rosebud Sioux Tribe, decided they could best serve their elders, the diabetic elders, by serving a breakfast. Because they would find the elders would come to the site at lunch and hadn't had breakfast. And when they had their glucose monitored, they would be either really high or really low. So they for 1 year with funding from us, they provided breakfast for the elders.

The program was so successful that even when our funding ran out, the tribe picked up the funding of it. They have found that the elders that participate in the two meal a day program, their blood glucose levels are much better controlled.

So if we could find practices like that, programs like that that really made a difference, and then be able to expand those into other communities, I think we could see some real benefit in the health of the elders.

The CHAIRMAN. What would it cost if we carried out that practice on all of the reservations?

Ms. JACKSON. I don't even have a clue. We would have to look at that. Because some of our programs now are really struggling to provide one meal a day. The number of elders has increased so rapidly that the Indian programs differ from the non-Indian programs in that we find many of the non-Indian programs will cut off the number of people attending the meal site. If they're running short on money, then they say nobody else can come. The Indian programs, we don't say nobody else can come. We'll continue serving people and feeding people, and then we have to limit the number of days. So we'll feed everybody for 3 days a week, rather than serving fewer people 5 days a week.

So we're finding a number of our programs now, due to the funding level of the program, are only serving lunches 3 days a week, rather than the 5 days a week.

The CHAIRMAN. Mr. Walker, as you can imagine, none of us are experts here, so we have to depend upon you and other experts to provide us with the necessary statistics and information. Based upon that, we can act if moneys are needed.

When I became a member of this committee about 25 years ago, I was told that if an Indian elder reached the age of 50, the odds were that he had diabetes, and that the mortality rate for those with kidney problems were 3 times the national average. And apparently, it is still the same. Will any attempt be made by AOA to let us know what it could cost to bring these statistics above that of third world countries?

Mr. WALKER. Mr. Chairman, the Administration on Aging, and I'm sure the entire Department of Health and Human Services, would be very pleased to work with you in reviewing the statistics and discussing how we can best achieve better goals in addressing the health status of Native Americans.

The CHAIRMAN. Has any comprehensive study ever been made?

Mr. WALKER. Related to the?

The CHAIRMAN. The health of elders.

Ms. ANNETTE. From an Indian Health Service perspective, I think a comprehensive study as you speak of has not. I believe we have elements. And a coordinated effort to look at those elements will give us a better overall picture. And perhaps the gaps can be identified then and we can give you a better feel, I think, overall of what the need is. But I think the answer to that, to my knowledge, no.

The CHAIRMAN. What would it take for us to have this coordinated study to identify the gaps?

Ms. ANNETTE. I think that to look at this, it may be best to have, this is my idea, perhaps have an inter-agency group look at this along with tribes and sit down and say, what has been done, what needs to be asked. I think we have a beginning of that with the North Dakota study. We have some tools to take a look at that.

Again, it may be that from a tribal perspective, they would like to have data, to find out where are we today. It's similar to what you're asking for, Senator.

The CHAIRMAN. Do we need legislation to bring this about?

Mr. VANDERWAGEN. Mr. Chairman, I would think that legislation is probably not necessary. I know this Secretary, Secretary Thompson and Deputy Secretary Allen are very supportive of exploring ways we can eliminate disparities in health. This is one of the major initiatives I think that this Department is pushing forward at this time. So I believe that there is support within the executive branch for this kind of interest.

I don't know at the moment that there's a specific requirement necessarily for legislation. But that's something that probably needs to be studied a little more comprehensively. As we've suggested to you, we don't have a comprehensive look at what the impact of many of these issues are in aging Indian populations. With study, it may be that some legislative corrections may be needed.

The CHAIRMAN. What can we do to bring about this study?

Ms. ANNETTE. I think we certainly will, you have expressed to us such an interest that it's something——

The CHAIRMAN. How much would it cost?

Ms. ANNETTE. Good question.

The CHAIRMAN. We would try to provide it. But we do not know. You will have to tell us.

Ms. ANNETTE. I'm not prepared today to come up with that number. But I certainly will make sure that we coordinate with other agencies to get that information to you.

The CHAIRMAN. Will both of you get together and tell us what you need?

Mr. WALKER. Absolutely. And in fact, the Secretary operates the Department of Health and Human Services as one department. As a result, we are working better together, more so than we have ever done in the past.

Ms. ANNETTE. I would like to interject, we also have another piece of information that I believe we've provided for you, and that's a roundtable that was done really looking at long term care needs within Indian country.

The CHAIRMAN. I have the report here.

Ms. ANNETTE. You have the report.

The CHAIRMAN. Mr. Vice Chairman.

Senator CAMPBELL. Thank you, Mr. Chairman.

Before I ask a couple of questions, let me just maybe make a few comments. If you were to go into most committees here on the Hill, and you asked them what the word commodities brings to their mind, they wouldn't have a clue. But many of the people that come in this committee, they know what the word commodity means. Basically, what it means for anybody in the audience that's not here is Government surplus food that is given to Indian tribes that is primarily high starch, some of it is white cans with no labels, it's just written on the can what's inside. Surplus cheese, almost all the commodities have a high starch content or a high content of what creates cholesterol, as you know.

So it seems to me that when we do more studies or we talk about putting more money into the problem, we need to go back and address the underlying problem that got us there. If we don't change that, we can pour tons of money into it and it still won't correct it. We've got to deal, it seems to me, through education and recog-

nize that there is a lifestyle problem and maybe in some cases, a difference of heredity too.

But when I talk to elders about their elders, I don't know any that would tell you that their grandparents that lived before the turn of the century had a problem with diabetes. Maybe after the reservation system was initiated, but certainly not when they had plenty to do. They might have died of a lot of other things, but it wasn't diabetes. They had a different kind of a diet. And I think that has an awful lot to do with it.

I happen to live on the Southern Ute Reservation. They just built a very, very nice facility there that is comprised of, it's really a gymnasium but it's really a wellness center. Because they offer cooking classes and they do a number of things to try to teach people that just exercise alone isn't going to cut it. You've got to do a lot of other things, too. I think that's really important.

And that makes it all the more difficult, because you can educate young people about having a better diet, but if they don't have access to money, i.e., a job to buy what they need for a better diet, they're still reduced to living on commodities. So you have this kind of endless cycle that they can't get out of, and so it seems to me the health of Indian people is really related to a lot of things just based on the circumstances which keep them in that hole where they can't seem to get out.

Let me just ask a couple of questions. One of them is, I mentioned that maybe heredity plays a part and so on. The Native Alaskans, they still live, I think, to a higher degree, on subsistence and gathering, probably more than many in the lower 48. I know that having gone up there a number of times and eaten muktuk, high fat from a seal and whale and so on, which doesn't taste great, by the way, but I'm interested in knowing if there is any disparity between the elders in Alaska and the elders in the lower 48 on diabetes or diet related illnesses.

Ms. ANNETTE. Yes; there is, there has been. In the past, when Alaska Natives lived a life that you describe, their rates are much, much lower. What we have found is that as they become more acculturated, perhaps, with the western diet as we know it, the rates of diabetes are going up. So I guess that goes to really support the point that you've made, that it truly is lifestyle.

I'm really intrigued by the fact that you put, and it's so true, we have to put an emphasis on prevention. What I've found in some of our elders is they seem to think that they're beyond prevention at that point when some of these illnesses have hit. One of our education challenges is to say to the elders, "prevention never stops". There are ways we can maintain, get better, by doing some prevention, interventions throughout a person's lifetime. That's a challenge we have and that's a message we must get out to our elders. Prevention is always, always important, those activities.

Senator CAMPBELL. Along that line, I might also suggest that 50 years of commodities can't be turned around in a matter of 1 day or 2 days or 1 year. Some of the damage that's done by poor diets over the years, you just don't fix it by taking a couple of pills for 1 week. That's something that takes a long time.

Let me mention one other thing I wanted to get your opinion on, either you or maybe Mr. Walker. I understand that in the case of

the Pimas, there are American Pimas and Pimas that live in Mexico. The American Pimas, like many of us, they eat more processed foods, their kids probably watch more TV and have less exercise, like any other kid in America does now, compared to years ago when they had to work the land. But the Mexican Pimas have a higher corn diet and different lifestyle, probably not as many things that we have on this side of the border. Do you know of any difference between the Mexican Pimas related to diabetes and the American Pimas?

Mr. VANDERWAGEN. Yes; there are about 1,500 tribal members of the Tohono O'odham Nation that live in Sonora. We have in the last few years conducted some health fairs and health surveys in that population, because the Tohono O'odham Nation of course is, federally recognized and these are tribal members. In fact, the rates of diabetes are lower in Sonora than they are across the border in Arizona. Unfortunately, those folks are dying of accidents much more frequently, so we have a different set of issues to cope with there. But at least they don't view Spam as a traditional native food.

Ms. JACKSON. The research that's been done on the foods that they eat is what prompted us to work with Utah State University on doing the nutrient content of foods of the Utes in Utah and the northwest. Because down in the Pimas in Mexico, they're still eating much more of their traditional food. And even though it's corn, a high starch diet, the corn has a lower glycemic index than the bread that the Pimas on this side of the border are substituting for it.

So we're using the research that was done down there to hopefully incorporate more native foods in the Utes in Utah and the northwest tribes to again maintain their culture by eating more of the traditional foods, but also substituting some of the better foods for the commodity foods and the store-bought foods.

Senator CAMPBELL. Is it less processed, too?

Dr. YOUNG. Yes; a lot less processed.

Senator CAMPBELL. A few years ago, some of us on the committee tried to initiate a program with the surplus buffalo from the Federal herds to go to nutrition programs for Indian elders. We weren't very successful with that, but we are still trying. I know part of it has to do with low protein, too, in diets.

Let me ask one other thing. Since the University of Colorado was brought up, and I am from there, could you describe to me the kinds of activities that resource center is going to participate in? Mr. Walker?

Ms. JACKSON. The Resource Center in Colorado is developing a lot of training materials for health care professionals working with tribal members, and especially urban Indian elders. We find on the reservations there is much more cultural sensitivity. But in the urban areas, there is essentially no sensitivity to the needs of elders. They have developed one on diabetes, one on cancer, they've just developed one on depression and cardiovascular diseases and alcoholism. So their focus this next year is going to be on training professionals and paraprofessionals for working with Indian elders.

Senator CAMPBELL. Is that the center that's being developed at the old Fitzsimmons site?

Ms. JACKSON. Yes.

Senator CAMPBELL. Oh. Well, you'll have to come to the unveiling. They've named the thing after me. [Laughter.]

I wondered what the connection was. You'll have to come to that. It's a beautiful building, by the way.

Ms. JACKSON. That's what I understand.

Senator CAMPBELL. Maybe the last thing I mentioned, about the elder population and how many youngsters are coming up now, the 2000 census reported only 12 percent of the Indian elder population is 55 or older. It seems to me that logically, what we need to do is cultivate in youngsters lessons about exercise, good health habits, that kind of thing. Is that outside of the scope of your agencies, Mr. Walker?

Mr. WALKER. No; not really. What we are doing is broadening our scope. While we are certainly focused on the needs of the elderly, we believe that we need to prepare people to be older by giving out broad based messages about prevention, about lifestyle changes that need to take place that will impact the quality of life you have when you are older.

Senator CAMPBELL. Good. And perhaps one last question, you mentioned that you just awarded caregiver grants to 177 tribes. What was the total amount of the grants, and what was the average amount given for the grants?

Mr. WALKER. The total amount was $5.5 million, and the average award was about $18,000.

Senator CAMPBELL. Were those grants given on some competitive basis, or how do you give the grants?

Mr. WALKER. All federally recognized tribes are eligible to apply. And they indicate an interest in the ability to provide caregiver services and the statute prescribes five services that they choose from in terms of the provision to their elders and to family caregivers. So they have to meet those criteria.

Ms. JACKSON. They're non-competitive, and everybody that applied received a grant.

Senator CAMPBELL. Everybody that applied received a grant? So that means about 300 and some odd tribes didn't apply, is that correct?

Mr. WALKER. That's correct.

Senator CAMPBELL. Do they know about it? One of the problems we have sometimes, we put things in place here, it's administered by the Administration, then we're told later by tribes that they didn't know, because there is a disconnect, an information disconnect about what is available to the tribes. Are all tribes aware that they can get these grants?

Ms. JACKSON. Only the tribes that receive the part A grants, the nutrition and supportive services, were eligible for the caregiver grants. We have 235 that receive the Part A. So those were the only ones eligible for the caregivers grants. And some didn't apply just because they didn't think they were ready to begin a new program at this time.

Senator CAMPBELL. I see. Thank you.

Thank you, Mr. Chairman.

The CHAIRMAN. I thank you very much.

If we may, we would like to submit questions for your consideration and response. Thank you very much.

Our next panel consists of the Director of Research, Center for Rural Health, University of North Dakota, Dr. Richard Ludtke; Researcher, Center for Rural Health, University of North Dakota, Leander "Russ" McDonald. He will be accompanied by Alan Allery, Director of National Resource Center on Native American Aging, University of North Dakota.

May I call upon Mr. Ludtke.

Mr. LUDTKE. If Dr. McDonald would start, please.

STATEMENT OF LEANDER "RUSS" MCDONALD, RESEARCHER, CENTER FOR RURAL HEALTH, UNIVERSITY OF NORTH DAKOTA, GRAND FORKS, ND, ACCOMPANIED BY ALAN ALLERY, DIRECTOR, NATIONAL RESOURCE CENTER ON NATIVE AMERICAN AGING

Mr. MCDONALD. Mr. Chairman and other members of the committee, I'm honored for the opportunity to speak on behalf of my elders. My name is Russ McDonald, my mother is an Arikara from the Three Affiliated Tribes and my father is a Dakota from the Spirit Lake Nation. Both reservations are located in North Dakota. I am a research analyst at the National Resource Center on Native American Aging. The Resource Center is located in the Center of Rural Health at the University of North Dakota School of Medicine and Health Sciences. Established in 1993 with funding from AOA, the Resource Center has a mission of providing research, training and technical assistance to the Nation's Native American elders.

Today we will be presenting new findings about prevalence of chronic disease, their effect on functional limitations and differences in life expectancy for Native American populations from a nationwide elders needs assessment project called Conducting Local Assessments: Locating the Needs of Elders. The project entails conducting a survey on reservations that voluntarily participate in this project and allows for comparison of elders on reservations with their national counterparts.

The results from the research not only provide us with new information about Native elders, but also gives each tribe data they can use to help guide them in developing long term care infrastructure for their communities. The data has been used by a number of tribal communities in their planning efforts, program development and grant application, primarily directed at addressing the need for long term care services within our community.

To date, we have 83 tribes with 8,560 Native elders having filed out the survey. Two additional tribes are being processed this week and will be added to the aggregate file upon completion.

With that background on the study, let me share with you a picture of elder health and long term care needs on our results. Life expectancy for Native Americans and Alaska Natives are low relative to the general population. In addition to important differences between Natives and the general population, it is also very important to note that there is a substantial variation across Native American and Alaska Native tribes in life expectancy across the Indian Health Service areas. Average life expectancy ranges from a low of 64.3 years of age in the Aberdeen area to a high of 76.3

years in the California area, a difference of 12 years. Life expectancy for the general population is 76.9 years.

Earlier this year, I attended the high school graduation at the Spirit Lake Reservation and watched as grandparents congratulated their grandchildren in accomplishing a major goal. When I graduated from high school in 1981, I had one grandmother still living at age 77. She died 2 years later. My other grandmother died during childbirth at age 37, with my two grandfathers dying both from heart attacks, one at age 62 and the other at age 64. So while the number of Native elders living to be old is increasing, old age is still rare on our reservations.

Chronic disease. While quantity of life is an important indicator of health for the general population, the health status of the aged is also an important focus. As populations, including Native Americans, age, there is a likelihood of developing chronic illness like arthritis or heart disease, which can impact both life span and quality of life. For example, the Native elders are 19.5 percent more likely than the general population to experience arthritis. Similarly, Native American elders are 48.7 percent more likely to experience congestive heart failure, 17.7 percent more likely to report high blood pressure, 17.5 percent more likely to have experienced a stroke, 44.3 percent more likely to report asthma, and 173 percent more likely to be afflicted with diabetes. Only cataracts are reportedly higher in the general population. So what we see here in this data is that the Native elder is sicker than their United States general counterparts but at least they're able to see a little bit better.

Our data, as seen in figures 1 through 6, suggests that chronic disease rates are higher among Native American elders in spite of their shorter life expectancy. These findings suggest that the disparate health conditions of the Native elder are the result of other factors, such as lifestyle, socioeconomic status and access to timely and adequate care. Furthermore, these findings, and the prevalence of chronic disease, like life expectancy, varies across Native American and Alaska Native tribes.

When the regional chronic disease rates in Native American and Alaska Native elders are compared, we see apparent differences between areas. Arthritis rates reported in the survey tended to be lower in the area of the southwest and high elsewhere. The same pattern holds true for congestive heart disease. High blood pressure tends to be reported at higher levels in the east and south. Asthma rates again appear lowest in the southwest. Diabetes, while high generally, produced lower rates for Alaska and the highest rates in the Phoenix area. Persons reporting having experienced a stroke were lowest in the Navajo and Phoenix areas, followed by the north central and northwest areas.

On the last, I'd like you to keep in mind this represents people who have been diagnosed with stroke and have survived. The areas with the lowest life expectancies tended to also report lower rates of stroke victims in their surveyed area. We believe these lower and average rates of chronic disease to be the result of lower life expectancy, rather than being indicative of better health status. Chronically ill elders in these regions have shorter life spans, resulting in regional chronic disease rates that are lower. In a sense,

only the strong and healthy survive to be elders, which in turn affects the chronic disease rates in the Midwest and Alaska regions.

My colleague, Dr. Ludtke, will address the issue of increasing numbers of Native Americans with functional limitations, reflecting a growth in the need for long term care services. He will also comment on strategies for decreasing the number of individuals with functional limitations.

I will be pleased to answer any questions now or after Dr. Ludtke has completed his remarks. Thank you, Mr. Chairman.

[Prepared statement of Mr. McDonald appears in appendix.]

The CHAIRMAN. Thank you.

Dr. Ludtke.

STATEMENT OF RICHARD L. LUDTKE, DIRECTOR OF RESEARCH, CENTER FOR RURAL HEALTH, UNIVERSITY OF NORTH DAKOTA

Mr. LUDTKE. Mr. Chairman and honored members of the committee, I'm also honored and grateful for this opportunity to speak.

Chronic disease varies widely, with some people minimally affected, while others have significant levels of disability. The level of disability is related to functional limitations in the population and used as a criterion for admission to nursing homes, assisted living, to community based care, long term care programs. Nearly all definitions of functional disability use information about activities of daily living and instrumental activities of daily living. Examples of the ADLs, activities of daily living, include such items as eating and walking. IADLs, on the other hand, focus on limitations like with cooking and shopping.

When ADLs and IADLs are combined, people can be classified into four levels of need. The associated care requirements can be identified as ranging from no long term care services needed to home and community based care, to assisted living, and to skilled nursing care, as seen in table 1. Using these categories, we are able to estimate the numbers of people at these different levels of need and determine the needs for different levels of long term care services. The prevalence of functional limitations increases with age and the severity of limitations also increases with age. Figure 1 contains the data from our surveys regarding functional limitation for Native American elders. It's clear that the rates for all levels, from moderate to severe, increase with age and that they do so most dramatically in the oldest cohorts.

As the population ages, there will be an increased need for long term care services. The number of people classified as elders in the Native American population is about to explode, with the arrival of those born during the baby boom as shown in figure 2. When one combines the population data with the measure of functional limitation, a picture of growth in need for long term care is generated.

The most dramatic growth will occur as a result of the large number of the baby boom cohorts in the next decade growth will expand the population of young old, and barring any change, will increase the need for moderate levels of care consistent with home and community based services that are greater than the other cohorts.

Life expectancy for Native elders has been growing rapidly and should be expected to grow in the future. Population projections using IHS life tables and census data show that as of the year 2000, the Nation has approximately 218,000 Native American elders with functional limitations of a moderate or greater level. As the population ages, the number of elders with functional limitations will grow assuming the same rates of disability are continued. By the year 2010, as shown in Figure 3, we can expect a 51 percent increase, or approximately 329,000 Native elders, to have functional limitations of moderate or more severe levels. The large number of people becoming elders and the earlier ages of onset from any chronic diseases that produce functional limitations creates a conservative estimate in the growth of functional limitations to the end of the decade.

The health and vitality of future elders depends on a healthy lifestyle, including good diet, regular exercise, and refraining from drinking and smoking. If people take care of themselves, they can reduce the need for long term care services. Access to preventive and other health services is important for delaying the onset of illness, as well as effectively treating disease. If we reduce only 10 percent of the Native American and Alaska Native limitations, we would see a significant decrease in the demand for long term care services.

Figure 4 presents the changes in the numbers of people with each level of limitation that would occur if we had a 10-percent across the board reduction in functional limitation. That could occur with improved health promotion and access to state of the art health care.

The recommendations that we derived from these observations is that we need an initiative to develop an intervention and health promotion models leading to improved outcomes for Native Americans and Alaska Natives as they enter their elder years. There is a need for the development of long term care, it requires solutions that are tailored in terms of both the types of care that work best and the means by which local communities can realistically produce the type of care required.

There is a need for increased support for targeted research on Native American aging and related educational and capacity building programs. These are essential to help fill the gaps in information and help tribes anticipate emerging health care needs.

Three points of relevance to the Native American and Alaska Native people concerning long term care include the need to reduce chronic diseases and functional limitations, to eliminate disparities across tribes, between Native American elders and the general population, and to increase life expectancy. And lastly, to address the shortages and lack of long term care options in Indian country.

I thank you for this opportunity to speak and would entertain any questions, along with Mr. McDonald.

[Prepared statement of Mr. Ludtke appears in appendix.]

The CHAIRMAN. Thank you very much.

Senator Conrad, do you have any statement you'd like to make?

STATEMENT OF HON. KENT CONRAD, U.S. SENATOR FROM NORTH DAKOTA

Senator CONRAD. Just very briefly, Mr. Chairman.

First of all, I want to thank you very much for holding this hearing. I especially want to welcome Dr. Ludtke and appreciate the work that he did on this survey. It is really sobering to look at the statistics that are revealed here. When compared to the general U.S. population, Native elders are almost 20 percent more likely to have experienced a stroke, 50 percent more likely to have experienced congestive heart failure, more than 40 percent more likely to report asthma, and perhaps most stunning of all, 170 percent more likely to be afflicted by diabetes.

All of us have known before this survey was done that these statistics would probably be alarming. And they are. When it comes to life expectancy in the Aberdeen area, which includes my home State of North Dakota, we have the lowest life expectancy of any area for Native Americans, 64 years compared to nearly 77 for the general population.

Mr. Chairman, these statistics cry out for action. This is going to require a dedication of resources and a commitment of effort. Unfortunately, we see in the President's budget that there is not that commitment. And it is, I think, deplorable. But it's not just the President's responsibility. Fundamentally, the responsibility lies right here in the Congress of the United States. We have the obligation to dedicate the resources to make a meaningful difference. And there has been a failure to do so.

Mr. Chairman, I hope this hearing will be the beginning of a change in the level of attention and the level of commitment by the Congress to address these issues, and once and for all, to make a meaningful change.

I also want to thank Mr. McDonald for his contribution to this study. I'm also pleased that Fred Baker, the chairman of the Mandan, Hidatsa and Arikara Elders Organization is here to share with us some of the experiences of Native elders in North Dakota. I'd like also, Mr. Chairman, just briefly, to recognize two other people who are here today, Alan Allery, the Director of the National Resource Center on Native American Aging, and Dr. Mary Wakefield, from the Center for Rural Health in North Dakota. Dr. Wakefield is my former chief of staff, and she has made a tremendous contribution to these issues, not only in North Dakota, but here in Washington. I know of no one with greater credibility to speak on these issues than Mary Wakefield. I am so pleased that she has gone home to North Dakota to make a contribution at our Center for Rural Health there.

Let me say, Mr. Chairman, if I could, that you and the vice chairman have been outspoken on the need to make a difference on these issues. We appreciate your leadership. I think we've got to find some way to convince our colleagues that more of the same just isn't going to get the job done. I don't know what it's going to take to put a focus on these issues in a way that moves our colleagues.

I was just at one of our reservations over this break. We had terrible fires break out on the Standing Rock Sioux Reservation, more than 40,000 acres burned. While I was there for an emergency

meeting, with people who had lost their homes as well as with the leaders of the reservation and Federal officials who were part of the response team, it really struck me once again, as I left that hall, a young woman came up to me and said, Senator, something has got to be done. We are having suicide on this reservation among young people in numbers we have never seen before. She said, there is a sense of hopelessness and despair, a sense that there is no future. Now, that is a condemnation of what is occurring. And we have an obligation to respond.

I thank the chairman, and I thank the witnesses as well.

The CHAIRMAN. I thank you very much, Senator.

If I may ask a question of Mr. McDonald, you have accumulated much data. Do you share this with the Federal Government?

Mr. MCDONALD. The descriptive statistics from the study are posted on our web site underneath the research icon. So the numbers are available to the general public. Those statistics are from the aggregate data file.

The CHAIRMAN. Do you know whether the Federal Government is making use of that?

Mr. MCDONALD. No, sir; I'm not aware.

Mr. LUDTKE. Can I respond to that? These are being shared as widely as we can. They are submitted to the Administration on Aging. Each publication is submitted to the Administration on Aging . They have been shared with the Indian Health Service, and Dr. Finke has used them. So we are making every effort to get them to the appropriate agencies.

The CHAIRMAN. Senator Conrad said we cannot do the same thing for the same problem year after year. But since we are not experts in this field, can you tell us what we can do? We are awaiting your suggestions.

Mr. LUDTKE. I think there are a number of things that we can do. When we work with some of the tribes or State organizations and they receive our data, they would like to carry it forward, and they look to us for assistance. We're frankly equipped to give some of the information and the data, but not the counsel on how to develop long term care programs. I think we could develop a concerted effort to assist people in developing long term care programs on reservations. I think we could develop demonstration projects that are unique and culturally compatible with reservations. And these could be tied to our research and educational efforts. I think these are possibilities for responding that would, I think, have a short start time and produce great results.

The CHAIRMAN. Have you looked into the possibility of submitting such a request to the Government?

Mr. LUDTKE. We have only talked about it. We have considered it if we could find the vehicle, we would submit.

The CHAIRMAN. There is your vehicle right there. [Laughter.]

Mr. McDonald, have you looked into the possibility of what Dr. Ludtke has stated?

Mr. MCDONALD. We've talked about it a little bit within the office, but as far as going further with it, we're still in that process of thinking of what could be developed first, before seeking assistance for that.

I'd like to maybe have Alan comment on that. He's the director of the Resource Center.

Mr. ALLERY. Just a brief comment. We are going to be meeting with some Federal agencies this afternoon to discuss possibilities further. But the Indian Health Service is the primary health care provider for American Indians. And certainly, additional support for health promotion activities would make a huge difference in the health status of elders.

The CHAIRMAN. Well, my concern is that, as a member of this committee, we have been giving these impassioned speeches year after year about the dismal health conditions in Indian country. And it is the same every year. Some day, I hope we can give speeches saying that we have done something about it. And there isn't much we legislators can do unless we know what to do. And no one has suggested to us what we can do, other than add 10 percent or add 5 percent. And even at that, we are not aware, or we are not certain what it will accomplish.

But apparently, you people have some scientific data that could be put to use. If you come up with a pilot program of sorts, I can assure you we'll look at it very seriously and put it on the right vehicle, as you say.

Mr. ALLERY. We would like the opportunity to translate the research into action by working with various groups on model projects, including specific tribes, perhaps, in North Dakota and other States that would develop some models, some ideas that others could replicate.

The CHAIRMAN. Mr. Vice Chairman.

Senator CAMPBELL. Thank you, Mr. Chairman.

This by the way, is tremendously informative. Probably also predictable. I might say, Senator Conrad mentioned something maybe along the line I was talking to, that we've got to really get ahead of this curve, this population growth. We're not putting enough resources in it, but I don't know if we'll ever be able to put enough resources in it, because the underlying problem is growing faster than even the resources that are available. Before Senator Conrad came in, we talked about the population growth and the baby boomers were mentioned and the post-baby boomers, the boomers of the baby boomers.

And I'm not a scientist or a doctor, but I think in mighty simple terms. I envision this problem like the shape of a pyramid. You have the traditional number of people, and this is pretty well, I think, alluded to in your study, traditional number of people, X amount at that apex of the pyramid. Then you have the adults that are on the reservations now, or Indian people, nationally growing at a huge rate. Then you have the youngsters. I mentioned before Senator Conrad came in that on the Cheyenne Reservation, 75 percent are under 25 years old.

Well, if we have that kind of a growth rate, and I imagine on many reservations it is the same, if you envision that pyramid I was talking about, and turn it over, that's where we have the problem. The apex is down at the bottom now, and we have a number of people that are elders down there that have existing problems and that we have got to deal with. But as you go higher on that inverted pyramid, the base is getting bigger and bigger, and the

baby boomer and the post- baby boomers is where the real problem is going to be in another 20 or 30 years.

I don't know how we get ahead of that, because it's just not going to be resolved by more resources from the Federal Government. Somehow, we've got to get to the underlying problem of unemployment, lack of opportunity, all the things that reservations face now that are somewhat similar to the things we would see in developing countries. It's something we simply have got to not just continue to play catch-up with, but try to get ahead and recognize the problem we're going to face in another 20 years. It's going to be huge compared to now.

Senator Conrad mentioned the suicide rate. I don't know if that was in the study or not. But I'm told on some reservations that almost half the teenage girls try to commit suicide before they are out of their teen years, and about a third of the boys. I'm not sure if that's a valid number or not, but I know having been out to reservations a lot, it's higher than the national average. And I'd like to know a little bit about the problems that people are facing that are related to suicidal tendencies. We're talking primarily with seniors here, so maybe somebody could deal with that, if you could. Was there anything done in the study that related suicide to bad health in seniors, the elders?

Mr. MCDONALD. No; we had nothing on the mental health.

Senator CAMPBELL. Nothing on that.

Mr. MCDONALD. No; and I think what you're seeing with the elder population is that when we talk about suicides happening on the reservation areas, that tends to be with the younger population. With the older population, I think at least for my people, is that we don't kill ourselves.

Senator CAMPBELL. Well, we shouldn't, and traditionally they didn't. But they are now. A lot of young people are now. I know some tribes traditionally, they felt that suicide for men was not a way you could go to the next world, you would lose your way to the next world if you did that. And it was an absolute no-no. They might have died a lot of ways, but they didn't kill themselves. But they are now, as you know, youngsters are. It's non-traditional, but it's happening.

So you don't have any, really anything to compare suicide rates for Indian elders with the national population?

Mr. MCDONALD. No; and from our discussions with the tribe that we've been working with over the past few years, this is not an issue that has come out of the focus groups that we've had or other groups.

Senator CAMPBELL. Have you found any, in your study, any concrete suggestions you could give the committee on improving lifestyle habits to reduce some of the statistics you have in here?

Mr. ALLERY. One of the groups that we worked with in Minnesota, the groups of tribes in Minnesota developed a wisdom steps program, which encompassed almost all elders in all the tribes in Minnesota. And in working with the National Resource Center, they were able to parlay their elder needs assessment into a $250,000-grant from the Share projects at the University of Pennsylvania. Their progress has been substantial. The last session that I went to, they had over 400 elders exercising, walking at least 2

miles a day. So that was, that's kind of how the National Resource Center works with many groups. We depend on the tribes to take the initiative. And we work closely with them and the data is actually theirs. They can use it for planning their own projects and developing programs that meet the needs of their elders.

Mr. LUDTKE. Could I followup on that for just one comment?

Senator CAMPBELL. Yes.

Mr. LUDTKE. In the data we have questions that reflect on lifestyle issues. They weren't included as part of the report this morning, but it's very interesting to observe that the Native elders exercise more than the general population. The Native elders drink far less than the general population. But in the area of diet, they have greater problems.

As we looked at the lifestyle comparisons, we were kind of stricken with the notion that they seemed to have relatively good lifestyles, yet relatively poor outcomes. We're left with the conclusion that that had to revert back to diet, and the very thing you were talking about earlier.

Senator CAMPBELL. Well, we've got to try to help, because it's the right thing to do. But I also happen to think those elders are one of the most valuable resources that tribes have. Because those youngsters that are in that population boom, one of the problems they're having is relating and finding and learning about the old ways. The elders are the key, they're the link. If we lose them, I think we've lost something that is just simply not replaceable.

Thank you, Mr. Chairman.

The CHAIRMAN. Your discussion on suicide reminded me of a trip that I took to Alaska for the first time 10 years ago. At that time, I was advised that the suicide rate among young men between the ages of 19 and 23 was 14 times the national norm. I think that is unacceptable.

Senator Conrad.

Senator CONRAD. I'd like to go back to the question of what can be done. In your analysis, did you do any separation based on economic circumstances for the health of elders? In other words, did you look at different income categories and then look at how that might relate to health?

Mr. LUDTKE. We haven't. There is a great deal of analysis yet to be done. We struggle to find the time to get the information back to the tribes to this point, so we haven't done extensive analysis.

One observation on the economic variable is that there's not a great deal of variability. My guess is that as we apply that, we'll find the absence of variability on that income variable, that a large percentage of the population is below the poverty line.

Senator CONRAD. The two of you have spent more time with this data than anybody else. Are there things that you observed, are there things that kind of tickled your fancy, if you will, as you looked at this data as to clues that might make a difference?

Mr. MCDONALD. I think somebody was talking about commodities earlier. I was raised on commodities, too, as you can tell. But one of the things is that the highest thing, Dr. Ludtke mentioned already, is the higher rates of exercise for Native elders. So they exercise at higher rates, but they also have higher rates of BMI, or they are more likely to fall into overweight and obese categories.

Therefore, the only thing I could think of that would otherwise affect their higher BMI would be the nutritionals. So I think there would have to be something to provide better nutrition and also maybe continue exercising, for those who already are, and maybe increase exercise for those people who aren't.

Senator CAMPBELL. Would the Senator yield for a moment?

Senator CONRAD. Yes.

Senator CAMPBELL. You asked a question about different socioeconomic backgrounds for elders. From my own experience, you rarely find an elder with much money, because it's not a traditional thing to accumulate money. If anything, they give it away. They have giveaways, they do things to share it. So you don't have much individual wealth among elders anywhere, Indian elders. Not that I know of. But that doesn't mean the tribes can't accumulate some wealth through different kinds of opportunities, and provide some of the programs that the elders need.

Thank you.

Senator CONRAD. In terms of diet, did you make observations with respect to dietary differences between the elders and the Indian population and elderly people in other populations? Is there some clue there as to what they're consuming that is different from others in healthier populations?

Mr. MCDONALD. Somebody talked about Alaska, and they are still eating much of their traditional foods, like fish and wild game and that type of thing. And what we're seeing is that that region tended to have lower rates in some areas.

Senator CONRAD. Lower rates of?

Mr. MCDONALD. Of chronic disease.

Mr. LUDTKE. The information that we gathered on nutrition was relatively scant and survey data often tends to be scant, we often ask one or two questions. What did happen was that we were triggered to look at nutrition as kind of a key variable. So if we have an opportunity to do a second generation instrument, we plan to expand that significantly.

We think this is an area that needs attention. We think health promotion needs to be directed at nutrition. We think nutrition and low incomes are at odds with one another. It's very difficult to have a nutritious diet if you don't have an adequate income. It's difficult to buy fresh fruits and vegetables. And people will end up on processed foods, which are less healthy.

Senator CONRAD. Thank you.

The CHAIRMAN. Thank you very much. Like the first panel, we'd like to submit question to you for your consideration and response. On behalf of the Committee, I thank you very much.

Our final panel consists of the executive director of the National Indian Council on Aging of Albuquerque, Dave Baldridge; and the chairman of the Mandan, Hidatsa and Arikara Elders Organization of the Three Affiliated Tribes of North Dakota, Fred Baker.

Mr. Baldridge, welcome, sir.

STATEMENT OF DAVE BALDRIDGE, EXECUTIVE DIRECTOR, NATIONAL INDIAN COUNCIL ON AGING

Mr. BALDRIDGE. Thank you, Mr. Chairman. I believe that over the time I've been in this business I've heard you make some of the

most eloquent statements about Indian country since Chief Joseph, probably, so it's a great honor to have you listen to us this morning.

I know you need no one to tell you anything about the Federal trust responsibility or that nowhere are the disparities in minority health care so great, nowhere is the mandate to the Federal Government so compelling as with the well being of Indian elders. Today we're glad for this chance to bring your attention to a few of them.

First, long term care. The need for long term care services in Indian country is great. It continues to grow. And while it's recognized that there is no national overall policy regarding long term care for the Nation's elderly and disabled, it's also true that billions of dollars in Federal and State funds are spent on long term care, particularly for nursing home and home and community based services under Medicaid. It's important to understand that there are virtually no funds available to Indian country for long term care.

States have the ability through Medicaid waivers and CMS has the authority to approve requests to establish Indian only waivers especially for home and community based long term care services. We understand that no further legislative authority is necessary, yet States are not seeking these waivers and we hope this committee could provide leadership in working with tribes and receptive States to put such waivered services in place.

We're also extremely concerned that senior health insurance counseling and assistance services, SHIP program, is still not available for older Indians. Such funding is provided to all States, but inexcusably, there's no counterpart for Indian country, no analog. Despite our repeated requests, we're not aware that CMS or DHHS has addressed this issue. Perhaps the Committee could help us inquire of CMS.

Of the issues that elders face, those not related directly to their health are generally legislated through the Older Americans Act. I would like to talk to you about some issues that are certainly related to long term care, such as elder abuse. Title VII of the Older Americans Act, the vulnerable elder rights protection, was created in 1992. It includes subtitle B, which authorizes a program to assist Indian country to prioritize and carry out elder rights activities. Yet funds have never been appropriated, although they have been appropriated for States for similar purposes. These programs seldom reach Indian elders. Tribe have little or not access to the agencies, departments, ombudsmen or other programs that are available to States. Further, tribes have no additional source of mandated Federal funding for elder protection activities.

So we request that you not overlook basic protections like this that are available to most of the Nation. A demonstration grant program for Indian country of a million dollars would begin to address this very serious issue.

I would note on the side that our elders are living longer, but they're living longer with the amputations and the blindness and the renal failure that go with the diabetes. That's putting extraordinary burdens on their family caregivers. And we know that 90 percent of care for elders is given by adult children in homes and

communities. So we think that may be a factor in abuse and that long term care is certainly related there.

Title VI, as you've heard this morning, is an especially important program in Indian country. The 238 programs funded there are a primary source of services provided to reservation elders. Since 1980, title VI funding has been so inadequate for most of the years that its services have never really been "comparable to those provided under title III" as the OAA often indicated. Nevertheless, this program still is the cornerstone of Federal Services, including diabetes and health education for our elders. Current funding for projects ranges from about $71,000 to a top end of $174,000 per program. But we need an immediate increase of more than $30 million nationally to keep title VI directors able to deal with their great responsibilities.

That's related to title IV of the Act, research and demonstration grants. This title has historically provided annual training for our title VI program directors. However, since 1995, these activities have not been funded. The reality is that title VI remains without a national infrastructure, no paid staff, without a national training program at any level, without the capacity for regional or national meetings, and even without the capacity for its estimated programs to communicate with each other, its 238 programs.

We urge you to sponsor a capacity building initiative directed by NICOA, hopefully, to engender skill building, communication, greater economic self sufficiency for title VI programs. We request the sponsorship of $600,000 for training title VI directors, so badly needed, and developing their capabilities to better serve our elders.

And I'll conclude, we're very proud of some of our partnerships and projects with diabetes, which is front and center for all of us. We're connecting some tribes through a project with the Administration on Aging with the United States Renal Disease System, so they can look at ESRD. For CDC, we're conducting a grassroots diabetes education program for Indian elders. As the NIH recently published in the New England Journal of Medicine its DPPS study, showing that interventions really make a difference in diabetes, we are creating an atlas of diabetes for CDC, we are in the fifth year of an interactive atlas of Indian elder health for the IHS. These data projects are being extremely productive.

So thank you again.

[Prepared statement of Mr. Baldridge appears in appendix.]

The CHAIRMAN. Thank you very much, Mr. Baldridge.

Mr. Baker.

STATEMENT OF FREDERICK BAKER, CHAIRMAN, MANDAN, HIDATSA AND ARIKARA ELDERS ORGANIZATION, THREE AFFILIATED TRIBES, NORTH DAKOTA

Mr. BAKER. Thank you, Mr. Chairman and honored members of the committee. Thank you for allowing me to speak before this distinguished group regarding the concerns of the Indian elders of North Dakota, and in particular the elders of the Mandan, Hidatsa and Arikara Tribes.

My name is Frederick Baker. I am chairman of the Mandan, Hidatsa and Arikara Elders Organization, an organization that was officially chartered and sanctioned by the Three Affiliated

Tribes Business Council to represent the concerns of our elder population and provide some direct services. I have been appointed to the Governor's Committee on Aging of the State of North Dakota.

The elders of the Fort Berthold Reservation are those folks who are 60 years and older. We were born between the years 1905 and 1942. Our oldest member is 97 years old. There are approximately 573 of us that are in this age range; 307 of us live on the Fort Berthold Reservation, 74 live outside the reservation but in North Dakota, and 192 of us are sharing the virtues of North Dakota with other States. [Laughter.]

Mr. BAKER. As an age group, we have endured and survived great change. Most of us were born in dire poverty. Most of us saw family members die from causes of the frustrations of poverty, such as alcohol, despair, poor to non-existent health care. Most of us are products of off-reservation boarding schools. Many of us were given a one way ticket to urban communities, such as Los Angeles, Chicago, Dallas, with virtually no preparation of urban survival skills and very limited financial resources. Many of us still bear the scars of that experience.

Our age group also went to war in defense of our country. Many of us walked the jungles of the South Pacific, landed at Normandy, defended the frozen ridges of Korea, and saw the monsoons of the Mekong Delta. Many of us returned maimed in body and sometimes in spirit. Many of us were returned for burial.

Without question, the most devastating event for us was the Garrison Dam. It was almost as devastating as the smallpox epidemics of 1781 and 1837. Prior to the Garrison Dam, we were settled in communities such as Independence, lucky Mound, Nishu, Shell Creek, Elbowoods, Beaver Creek. We were raising our own food, just like we had been for centuries. Beef replaced the buffalo as our major protein supply, and we proved to be excellent cowboys. The River, Missouri, and its bottomlands provided us good soil for our gardens and crops, shelter for ourselves and our livestock, timber to build our homes. But especially, it allowed us to practice our cultural traditions. These traditions helped us to be independent and develop our own systems of caring for ourselves and one another. We didn't need social programs. We took care of our children, our elders, our ill. We had our own system of law and order.

The Garrison Dam changed all that. We were forced to move from the bottomlands up into the hills, where the quality of the land was such that it was very difficult to raise gardens. It took many more acres to raise livestock. Our homogeneous communities were broken up and replaced by isolation. We did not have access to capital, except the meager amounts of credit that was offered through the Bureau of Indian Affairs. Most of this credit was just enough to get one into serious difficulty.

Unfortunately, many of our people died in the process of relocating from the Garrison Dam. Many of us turned to alcohol, and ourselves and our families suffered as a result. Terms like unemployment, welfare, foster care, spouse abuse, child abuse, elder abuse, alcoholics, alcoholism, juvenile delinquency, low rent housing became part of our vocabulary. Our languages are in danger of being lost, and we get confused between poverty culture and Indian Culture.

We have never had the mental health resources to deal adequately with the problems that were posed to us through the Garrison Dam.

Despite these difficulties, some members of our age group were the first in their families to earn a college degree, to enter professions such as education, nursing, social work, medicine. We face many of the same problems today. Among those are inadequate medical care, poor or substandard housing, lack of specialized home health care, elder abuse issues, inadequate transportation, and our reservation is large, and because of the Garrison Dam, we're scattered, large traveling distances, inadequate meal service. Our written testimony will more clearly document these problems.

Let me highlight just a few things. The average health care expenditure in the United States is approximately $3,500 to what at Fort Berthold is $1,300; 75 percent of our elders have some type of a depression problem. A lot of it is caused by people who as a result of diabetes feel that their quality of life is over. All of North Dakota is seeing a return of elders who are seriously or terminally ill. Hence, the drain on the already limited Medicaid resources is critical.

Set-aside for Indian reservations for meal sites under title VI of the Older Americans Act only is enough to meet a part of the needs. At the present time there are six communities in Forth Berthold, one is being served through title VI, the other five are being served by what resources we can muster as a tribe. Housing is badly needed for elders, and especially assistance is needed repairing homes. Many elders live in very crowded conditions, because their children or grandchildren have no housing, and therefore move in with them. Our elders will not ask their children or grandchildren to move out.

Elderly abuse is rampant and needs to be addressed. And Social Security is something that we are trying to deal with and also needs to be addressed. We are receiving a lot less than the national average, because of some issues regarding reporting and so forth.

Thank you for your time. I would be glad to answer any questions that you may have.

[Prepared statement of Mr. Baker appears in appendix.]

The CHAIRMAN. I thank you very much, Mr. Baker.

Mr. Baldridge, can a Native American elder residing in an urban area have access to State social services, or does he have to rely upon American Indian Alaska Native type programs?

Mr. BALDRIDGE. We know that probably 50 percent of Indian people, including elders, are now urban. We understand from the Seattle Urban Indian program that they are seeing third generation urban Indians. Yet we know less about this population than any Indian population or probably other minority population in the country. They tend to not live in ethnic neighborhoods. They tend to be transient, they tend apparently to have frequently substance abuse or alcohol problems.

So in answer briefly is, I think they fall through the cracks very, very frequently. But they do rely on State programs and of course, the non–ITU services that are available in cities. I don't know that the Indian Health Care Delivery System reaches them much at all.

The CHAIRMAN. You indicated that the title VI moneys are inadequate. About how much more would you suggest is needed?

Mr. BALDRIDGE. In 1992, we had $14 million. Currently I believe we are at about $27 million. One of the staffers from the House side back a few years ago estimated that it would take $30 million just to get original title VI programs back to their 1980 levels of service; $35 million would, I think, make a huge dent in the ability of these programs to serve their elders. Many of them still are able to provide only a few communal meals a week, and very few home services or supplemental services. It's a very pale shadow of the services available through area agencies on aging.

The CHAIRMAN. Well, I can assure you I will look into that, because I must confess, I have no idea how much the Government requested for this program. But I would gather it must be much, much lower than $35 million.

Mr. BALDRIDGE. I believe we're at $27.5 million or so right now. And certainly more money is at the top of our list of needs.

The CHAIRMAN. Mr. Baker, do you have any suggestions as to what we as Members of Congress can do?

Mr. BAKER. Well, I think first of all, some of the things that we're trying to do is try to access or have our people access those programs that are available that don't come through the normal Indian programs, so to speak. Because we are citizens of the State of North Dakota and as such, have the right to those programs. I think a lot of tribes, a lot of people do not think that they're entitled to those programs. So we're trying to do that.

Obviously, there is a need for more funding. One of the things, I think there needs to be some type of Congressional action, perhaps, regarding elderly abuse in terms of its programs to try to deal with elderly abuse. I think it's one of those issues that is kind of quietly not mentioned, yet it exists in many ways. So I think those are perhaps some issues that might be addressed.

The CHAIRMAN. In your presentation, you remarked that many in your generation put on the uniform and participated in the wars of this Nation. I think we should recall that in the last century, on a per capita basis, more native people put on the uniform to serve our country in every war of the last century than any other ethnic group. That is saying a lot. More Indians per capita served than German-Americans or Italian-Americans or Chinese-Americans or Japanese-Americans. And I have said many times, couple that with the fact that you have given up much of your land suggests to me that you have already paid your dues. The least we can do is to make certain that you receive what you are entitled to.

Mr. Vice Chairman.

Senator CAMPBELL. Thank you, Mr. Chairman.

Let me ask Mr. Baldridge a question or two, but I wanted to say to Mr. Baker first, I thought your testimony was poignant. Depressing. Absolutely true. It needed to be said. I just wish more people here of our colleagues in the Senate could have heard your testimony.

You mentioned elder abuse. I was talking to one of my staff here, that I had an elderly gentleman at home, at Northern Cheyenne, tell me one time that he doesn't turn his lights on a night time because he's afraid somebody will know he's there and come and beat

him up. That's just a tragic kind of a thing to know about. Yet at the same time, that certainly wasn't a traditional value of Indian people anywhere. Elders were always respected and trusted and learned from and revered. But I suppose it's on the rise because of poverty and lack of opportunities and so on. So we have this dichotomy, this strange relationship between what Indian people believe and want to believe from a traditional standpoint and sometimes what is actually happening. I just wanted to mention that.

But I wanted to ask Mr. Baldridge a couple of questions. Three out of five, as I understand it, three out of five Indian elders are living at or below 200 percent of the poverty level. But more tribes are trying to develop their economies, certainly some of the gaming tribes have had some success. In the Great Lakes region, some of them have had great success, too. I have visited them.

Have you seen any increased resources from those successful tribes that have gone toward elder care?

Mr. BALDRIDGE. Yes, sir; I can. One comes to mind, certainly, Sandia Pueblo, which just went into debt enormously for a new casino. Yet with their gaming revenues over the last decade, they have developed a very fine clinic. They're putting all of their tribal members, including elders, through secondary education and higher education at no cost. And their health care has improved enormously because of that.

Other Pueblos around Albuquerque, with successful gaming operations, have created partnerships with hotel chains to create resort golf course, and it's interesting that our seemingly more business wise tribes are developing initiatives with States and private industry that are benefitting not just the elders but all the tribal members. So we're really encouraged by those tribes that are gaming.

Senator CAMPBELL. I have talked to a number of them, and I don't know of one single tribe I've talked with that has gaming that has not dedicated a portion of their new-found income towards senior programs. And I'm gratified that that is actually happening.

Some in fact have even broadened it. I live with the Southern Utes in Colorado. They are negotiating with the county to build a huge hospital and health care facility that will take care of everybody, not just Indian people. So they have been, in most cases, I think, very, very generous with some of the new money that the successful tribes have made.

Statistics from the IHS indicate Indian youth are the most likely to commit suicide. I may have mentioned, asked this earlier about suicide, I did, in fact, I think. But I asked it of another panel. Do you have any comparative statistics to deal with Indians or non–Indian comparison in suicide?

Mr. BALDRIDGE. What little data we've seen from IHS seems to indicate that once Indian people reach the age of 75, their longevity is much greater than that of other races. I believe that we see low suicide statistics for elders as well.

However, I visit from my tribe a medicine man, Crosson Smith, and I asked him, what's the greatest problem we face as Indian people. He said, we're losing our kids. It's what you all have said to us. Indian teens, with 17 to 19 times the alcohol and substance average of the Nation, suicide 7 or 8 times, we're winning some

battles with the medicine, but we're losing our kids. And it's a challenge for our elders and all of us.

Senator CAMPBELL. All the more reason we need to take care of them.

Several tribal groups have submitted testimony that they are being shut out of operating elder care facilities because the IHS doesn't fund it. They can't get direct reimbursement from Medicare or Medicaid for such facilities. And the states won't license a facility for the tribes so they can get different reimbursements from the State.

Do you have any comments on those issues?

Mr. BALDRIDGE. Yes, sir. I believe South Dakota, we often see, is the worst case State, where there is a more than 10 year moratorium on building nursing homes. The tribes there very desperately want and deserve nursing homes on their own reservation lands. Yet the State I think says, gee, we're sorry, it's a Federal problem, but we have this moratorium, even though it's self-imposed. It's very much, I think, a critical situation for those tribes, a longstanding one, and one that CMS has made some effort to resolve, but it's a very difficult, as usual, interface between Federal policy and State regulatory authorities.

Senator CAMPBELL. In that case, even if you found all the money you couldn't get a license, because they have a moratorium on it.

Mr. BALDRIDGE. Exactly. It's a very difficult situation.

Senator CAMPBELL. Thank you for your testimony.

Mr. Chairman, thank you, I have no further questions.

The CHAIRMAN. Senator Conrad.

Senator CONRAD. Thank you, Mr. Chairman.

First of all, I'd like to welcome Mr. Baker here. He is a very valued and respected member of the Three Affiliated Tribes of North Dakota and a very respected member of our State. And I thought your testimony was outstanding. I thought you could have focused on the disaster that the Garrison Dam has been to the Indian people, not only of the Three Affiliated Tribes but of the Standing Rock Sioux Nation as well. Because it dramatically altered the way of life of the people. And the compensation that has been forthcoming, while welcome, has not been sufficient to reverse the damage that was done. So I think, Mr. Baker, you put the focus right where it belongs.

Let me ask you, if you could wave a wand, if you could come here and say, these are the things that must be done, what would be the list that you would give this Committee.

Mr. BAKER. Wow. I guess several things. One is probably some type of a way to go back, if we can go back, I look at it as probably going forward, to incorporate the traditional cultural values that we had with the attempt to become a part of the modern day society, through some type of language preservation, cultural preservation program of some type. I think that's the basis for a lot of our, perhaps the problems that have to do with respect for elders, the respect for ourselves.

Somewhere along the line, because of the things that have happened, I think we've lost respect, to some extent, for ourselves, and probably lost confidence in our ability to deal with the issues. I think that's one of the things that I would somehow, and I think

maybe some of these other things would kind of fall into place. Certainly we need some type of an increased health care facility, those kinds of issues need to be addressed. Certainly employment, although we're trying hard to do that, employment issues, trying to find some type of way. Also some way to help our people to be able to leave successfully and become part of the rest of the community and still maintain their Hidatsa, Arikara and Mandan affiliations.

Senator CONRAD. Okay. Mr. Baldridge, if I could ask you the same kind of question, if you had the ability to dictate outcomes here, what would be the things you would point to? What are the things that would leap to your mind as to things that need to be done?

Mr. BALDRIDGE. If this committee, sir, could help us find some creative new solutions to home and community based care in Indian country that would be at the top of my list, along with a single other consideration, that's the empowerment of our title VI program. These directors need help so badly and training so badly, and it's not available for them. They could be a real force in helping us deal with public health issues for our elders. We've got to lift them up and really help them get on their feet and be more viable.

Senator CONRAD. How much of this is related to resources? To put it bluntly, how much is related to money?

Mr. BALDRIDGE. It seems that poverty is the thread that ties everything together in Indian country. Certainly I believe that's the case in this. But there's been no training money available to them since 1995, I believe, through Title IV of the OAA. It's just a stopper right there. That's very resource related. Some of the other, the seeking for demonstration programs to deal with new ways of community home based care is not so directly resource related, but certainly some demonstration projects need to be coordinated.

Senator CONRAD. What would your answer to that question be, Mr. Baker? The question of money, if you were to try to assess, what could be done that would really make a difference, how much of it is related to money being provided to have programs?

Mr. BAKER. Well, I think they're probably of somewhat equal value. I think there certainly needs to be a lot of thought given to innovative ways to deal with the program. Sometimes money is a rather simple solution, or probably a quick fix attempt. So I think they are kind of equal value. We definitely need money to do things. On the other hand, I think it's the ideas or the attempts at programs. One of the things we're trying to do as an elder organization, is to try to talk to the elders, give them a place, have a forum to discuss some of these issues and say, now what can we do.

Senator CONRAD. All right, thank you. Thank you both for not only excellent testimony here today, but I know in the case of Mr. Baker, thank you for a lifetime of involvement in the community.

The CHAIRMAN. Before we adjourn, I would like to make an observation. I believe I have visited more reservations than any other chairman of this. And I have noted one common thread in most of my visits. Most tribes for good reasons want to show their very best. So they guide me through all the developments, the new buildings. I have yet to see one of the dilapidated buildings. They

show me the new houses, the new apartments. In fact, in order to see the worst conditions, I have to ask that I see where the asbestos is leaking from the school building and such.

It is the same with wealthy tribes and poor tribes. They want to show that they have done something. I would suggest that when members of Congress come to reservations to visit, show them the real world. I think they will understand the situation much better.

I have had some of the best meals in poor reservations, and I do not know why they do that. But they want to extend their hospitality and show what friendship is like. But if they are poor, show us that they are poor. If there are buildings that are dilapidated and school buildings are filled with asbestos, we should know about it.

So with that, I thank all of you for your testimony. This hearing is adjourned.

[Whereupon, at 11:57 a.m., the committee was adjourned, to reconvene at the call of the Chair.]

APPENDIX

ADDITIONAL MATERIAL SUBMITTED FOR THE RECORD

PREPARED STATEMENT OF HON. MARIA CANTWELL, U.S. SENATOR FROM WASHINGTON

Mr. Chairman, I thank you for the opportunity to speak concerning Native American Elder Health Issues.

I am especially interested in the findings from this hearing because I represent 29 federally recognized tribes, with 25,000 tribal members.

The committee is well aware that Native Americans experience significant disparities compared to whites for many health indicators, and while the mortality rate for American Indians and Alaska Natives is higher than for all races in the United States, life expectancy is almost 6 years lower.

While life expectancy is certainly an important indicator of population health status—the quality of one's life is also important. This morning's testimony tells us that Native American elders are 78.7 percent more likely to experience congestive heart failure, 17.7 percent more likely to report high blood pressure, 17.5 percent more likely to have experienced a stroke, 44.3 more likely to report asthma, and 173 percent more likely to be afflicted with diabetes.

Diabetes complications, especially end-stage renal disease and lower-extremity amputations are major causes of morbidity and mortality among older Indians. Diet, sedentary lifestyle and obesity are risk factors for the development of diabetes and its complications—factors we can prevent or control.

And we know that heart disease—one condition, at least, which can be somewhat mitigated through prevention and treatment—is the No. 1 cause of death in Native Americans over the age of 45.

1 think it is no great leap to ask if we actually funded the Indian Health Service at more appropriate levels, would the health status of our tribal elders not be better?

While the IHS is tasked with providing full health insurance for the American Indian and Alaska Native population, it is so underfunded that patients are routinely denied care. The budget for clinical services is so inadequate that Indian patients are subjected to a "life or limb" test. Unless their condition is life threatening or they risk losing a limb, their treatment is deferred for higher priority cases; by the time they do become a priority, the treatment required is generally more costly and there are often no funds left to pay for it.

Finally, I also want to add that as Congress continues to consider Medicare reimbursement issues, we need to make Indian-specific policies and procedures to ensure that its billing requirements insure that Indian health program receive fair reimbursement for services provided.

Again, thank you, Mr. Chairman for convening this hearing.

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Statement of

Edwin Walker

Director, Centers for Wellness and Community-Based Services

Administration on Aging

US Department of Health and Human Services

Before the

Committee on Indian Affairs

United States Senate

July 10, 2002

Mr. Chairman and Members of the Committee:

On behalf of the Administration on Aging (AoA), I appreciate this opportunity to discuss the health concerns of Native elders and to provide some information about our programs for American Indian, Alaska Native and Native Hawaiian elders. I commend this Committee's commitment to Native Americans and the support you have shown for aging issues in Indian country.

Josefina Carbonell, the Assistant Secretary for Aging, has identified health promotion and disease prevention, including closing the health disparity gap for minorities, among her priority areas for the Administration on Aging. Our focus is on encouraging Americans of all ages to live healthier lives. Healthy living can prevent diseases and certain disabilities, and it can ensure that today's older persons – as well as future generations – not only live longer, but also better.

The American Indian and Alaska Native population is quite a bit younger than the general U.S. population. According to the 2000 Census, only 12 percent of the Native population is age 55 and older, compared to over 20 percent for the general population. The life expectancy of American Indians and Alaska Natives at birth continues to be lower than that of other ethnic groups. By age 55, American Indian and Alaska Native life expectancy improves to be slightly higher than African-Americans but lower than Caucasians Thus, it is important for us to focus on healthy living throughout the life span.

Great strides have been made in improving the health status of American Indians and Alaska Natives. Advancements in medical science have improved the diagnosis and treatment of many diseases, thus preventing premature disability and death. Chronic diseases now rank among the leading causes of death. Cardiovascular disease is the leading cause of death for all populations in the United States, including American Indians and Alaska Natives. Available data indicate a great deal of variation in the death rates from cardiovascular diseases among the various American Indian Tribes. While the national death rate from cardiovascular disease for

American Indians and Alaska Natives in 1996-1998 was 232 per 100,000 population, the rate varied from highs of 560 in Michigan and 570 in South Dakota to lows of 240 in New Mexico and 153 in California. Researchers suggest that American Indians appear to have increasing rates of cardiovascular diseases, most likely due to the high prevalence of diabetes.

Some American Indian Tribes have the highest rates of diabetes in the world. Nationwide, the prevalence of diagnosed diabetes among American Indians and Alaska Natives age 65 and over, is 21.5 percent. This is nearly double the rate of 11 percent for the non-Hispanic white population, age 65 and over. In some Tribes, notably the Pima Indians of Arizona, half the adults have diabetes.

Diabetes complications, especially end-stage renal disease and lower-extremity amputations are major causes of morbidity and mortality among older Indians. Diet, sedentary lifestyle and obesity are modifiable risk factors for the development of diabetes and its complications. AoA is working both within and outside the Department to help prevent, reduce or control diabetes and its complications. We are working with the Indian Health Service, Tribal health and social service departments, and universities to assist local elders programs in developing programs and services for preventing or controlling diabetes. For example, we are facilitating interactions between staff at Utah State University and Tribes in Utah and the Northwest for gathering native foods. The university is determining the nutrient content of the foods, including the glycemic index which is a measure of how the food raises the blood glucose level. They will then will work with the elders program staff to incorporate these foods into the meals served to the elders.

Now I would like to talk specifically about title VI of the Older Americans Act. AoA annually awards grants to provide supportive and nutrition services for American Indian, Alaska Native and Native Hawaiian elders. The title VI program has been funding services in Indian communities throughout the country for the last 22 years. In 1980, the first grants were provided to 85 Tribes serving a population of just under 20,000 elders. We now fund 236 grants to Indian

Tribes and Alaska Native organizations representing over 300 Tribes, and 2 grants to Native Hawaiian organizations. These programs provide services to nearly 100,000 Native elders.

As the number of elders has increased, their needs have also grown. Today programs provide a wide range of services, including congregate and home-delivered meals, transportation to meal sites, doctor's appointments, wellness programs, home-health services, adult-day care, and family caregiver support, just to name a few. Program performance data from the year 2000 indicate that over 1.7 million home-delivered meals and over 1.3 million congregate meals were provided to elders. Additionally, nearly a million units of individual and family support services, such as homemaker and chore, were provided to elders and their families. More than 700,000 units of information and assistance on issues dealing with Social Security, food stamps, commodity foods and other topics were provided. These services are permitting American Indian, Alaska Native, and Native Hawaiian elders to remain in their homes and communities for as long as possible.

Some elders programs receive substantial Tribal funds and have been able to greatly expand their services. Tribal dollars are complementary and are critical to the expansion of services. For example, the Mississippi Band of Choctaw Indians has just opened a new senior activities center that includes a walking trail and fitness room. The Chickasaw Tribe is building a community swimming pool adjacent to the senior center so their elders will have ready access to it for their wellness program.

Another example is the Rosebud Sioux Tribe's expansion of their nutrition program to include providing breakfast for elders with diabetes. This program began as a pilot program with minimal funding from AoA, but has been so successful in helping the elders maintain good glucose control that the Tribe has continued to fund it.

In addition to our programs that directly assist the elderly, AoA now assists those who care for the elderly and those with disabilities. Our new program, the Native American Family

Caregiver Support Program, was funded for the first time this past year. We are excited about this new program since it provides support to the caregivers of elders who are chronically ill or have disabilities. On April 1, 2002, we awarded Native American Caregiver Support Grants to 177 Tribes. The grants will allow Tribes to provide respite, information and assistance, training, and counseling to family caregivers struggling to care for family members. This is a critical issue for American Indian families. We know that an increasing number of elders need assistance and most prefer to remain in their homes and communities among familiar surroundings.

Another new program for the Tribes is disaster assistance. The 2000 amendments to the Older Americans Act allowed AoA to provide disaster assistance directly to the Tribes. We are currently working with other agencies in the Department to provide some assistance to the White Mountain Apache Tribe in Arizona.

In order to assist the Tribes in developing home and community-based services for their elders, AoA has awarded two cooperative agreement grants to National Resource Centers for Older Indians, Alaska Natives and Native Hawaiians (Resource Centers) -- one at the University of Colorado and one at the University of North Dakota. The Resource Centers are the focal points for developing and sharing technical information and expertise to Tribes and Indian organizations, title VI grantees, Native American communities, educational institutions and professionals and paraprofessionals. AoA and the Resource Centers collaborated on a study to identify the extent to which home and community-based long-term care programs and resources are available in Indian communities. The conclusion drawn from this survey of 108 Federally recognized Tribes nationwide was that there is a wide disparity between the need for home and community-based services by Indian communities and the availability of these services. While emergency and acute primary health care is usually met, the study found that other services such as mental health, home health, homemaker/personal care, home maintenance, transportation and outreach are only moderately met. Services such as adult day care, respite care, assisted living and short-term rehabilitation services are unmet needs.

One of the keys to successful programs is for local planners and program staff to develop flexible programs to meet the needs of their community. While title VI requires nutrition and information and assistance services, other supportive services may be provided, based upon the Tribe's evaluation of the need.

Although a needs assessment may be conducted in a manner deemed best by the Tribe, over the years AoA has been repeatedly requested by our grantees to provide assistance. We asked our National Resource Center on Native American Aging at the University of North Dakota to develop a needs assessment tool for the Tribes to use. They developed a standardized survey instrument and data collection procedures for conducting local needs assessments that provides each Tribe with an accurate picture of the status of the local elders. The survey instrument contains several health and social variables important to elder services, including general health status, indicators of chronic disease, and measures of disability.

Participation in using the needs assessment is voluntary. Those Tribes participating receive the instrument, assistance with sampling, and training on data collection from the Native American Resource Center. Since this is funded through our grant to the center, there is no charge to the Tribe for this service. We are pleased to report that some 83 Tribes chose to use the needs assessment this past year and look forward to the presentation of the data collected.

Although Mr. Allery will discuss the results of the needs assessment in detail, I would like to highlight some of the data that are particularly noteworthy in relation to developing home and community-based services and health promotion programs:

- Nearly 30 percent of Indian elders live alone.
- A greater percentage of Indian elders consider their health to be fair or poor (48%) than elders in the general population (34%).
- Many more Indian elders are overweight or obese (75%) than their non-Indian counterparts (53%). Indian elders may be less aware of their overweight status

since 44% considered their weight to be "about right."

- When asked "if at some point in your life you become unable to meet your own needs," most Indian elders (70%) indicated they would be willing to go to an assisted living facility. Only 18% of the elders indicated they would be willing to use a nursing home.

The feedback we have received from the Tribes using the needs assessment has been very positive. They are happy to have the data but are now requesting additional assistance in interpreting the data and in using the information both in program planning and in writing other grants. We are working with Mr. Allery and his staff in order to provide this additional assistance.

Mr. Chairman, we are very proud that the AoA is able to provide services and assistance to American Indian, Alaska Native and Native Hawaiian elders and their families. We are committed to working with you and your colleagues to improve the quality of life in Indian country in the years ahead.

Thank you and I am happy to respond to any questions you have.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

STATEMENT

OF

KATHLEEN ANNETTE, M.D.,

AREA DIRECTOR, BEMIDJI AREA

INDIAN HEALTH SERVICE

BEFORE THE

SENATE COMMITTEE ON INDIAN AFFAIRS

JULY 10, 2002

STATEMENT OF THE INDIAN HEALTH SERVICE

OVERSIGHT HEARING ON NATIVE AMERICAN ELDER HEALTH ISSUES

July 10, 2002

Mr. Chairman and Members of the Committee: Good morning. I am Dr. Kathleen Annette, Area Director of the Bemidji Area Indian Health Service (IHS). Today I am accompanied by Dr. Bruce Finke, Elder Health Specialist, and Dr. Craig Vanderwagen, Acting Chief Medical Officer, (IHS). We are pleased to have this opportunity to testify on the Native American Elder Health Issues.

The IHS has the responsibility for the delivery of health services to Federally-recognized American Indians and Alaska Natives (AI/AN's) through a system of IHS, tribal, and urban (I/T/U) operated facilities and programs based on treaties, judicial determinations, and Acts of Congress. In carrying out our statutory responsibility to provide health care services to Indian tribes in accordance with Federal statutes or treaties, we have taken it as our mission to raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level, in partnership with the population we serve. The agency goal is to assure that comprehensive, culturally acceptable personal and public health services are available and accessible to the service population. The mission and goal are addressed through four agency strategic objectives, which are to 1) improve health status; 2) provide health services; 3) assure partnerships and consultation with IHS, Tribal, and Urban programs; and 4) perform core functions and advocacy.

The American Indian and Alaska Native (AI/AN) elder population is rapidly growing and the AI/AN population as a whole is aging (increasing 23% between 1990 and 2000 census). With death rates from diabetes five times the national norms and those of kidney disease three times national norms the prevalence of chronic disease among AI/AN elders continues to increase, contributing to a frail, medically complicated elder

population with increasing long-term care needs. You will hear testimony from the National Resource Center on Native American Aging regarding the prevalence rates for functional impairment among AI/AN elders. To our knowledge, this is the best data available on this subject. We know that 1/3 of AI/AN elders 75 years and older have income below the poverty line (over twice that of the national norm). We know that the majority of elders live on or near tribal homelands, while younger family members often move off reservation in search of economic and educational opportunities.

To meet the needs of this rapidly expanding population, the Indian Health Service, through the Directors Initiative on Elder Health, has focused our efforts in three areas. First, is in the area of infrastructure development for long-term care service delivery for AI/AN elders. Second is the development of improved clinical expertise in clinical geriatric care. Third is in the area of improved palliative and end-of-life care.

Long-term care can be understood as an array of social and health care services which support an individual who has needs for assistance in activities of daily living. These needs range from chore services or transportation to full around-the-clock care. While AI/AN communities continue to provide the majority of care through immediate and extended family, this rapidly growing elder population and these demographic shifts have created an urgent need for both services and systems of care to support families as they care for elders.

An example comes from one of our hospitals. A 95 year old elder, mother of 6, lives in the home her now deceased husband built for their family. Her seventy year old daughter provides around the clock care for her, including bathing and feeding, while

still managing the family livestock. Other family members help out. An eighty year old sister stays with the elder while her daughter goes shopping or tends the stock. Grandsons find time between work and home responsibilities to haul wood and water. The elder was recently hospitalized for pneumonia and a small bedsore and on discharge, the family gathered to discuss where she could best be cared for. All of her remaining sisters and many of their children came, and all agreed that she would want to remain in her home. Her daughter was clear that she wanted to continue to care for her. Equipment was arranged for the home, including a manual hospital bed (there is no electricity to the home), a special mattress, a bedside commode (there is no running water in the home), episodic home health nursing (under the Medicare program), and limited personal care services (three hours a day), funded through the state home and community based care program and provided by the tribal home care agency. Referrals were sent to the tribal housing authority for housing modification. At a recent home visit (done after clinic hours) the primary physician found that the elder had gained weight since discharge and healed her bedsore. Her daughter was still providing the care, assisted by some family members. It has been a difficult time for her, but she still feels that she wants her mother to remain in her own home.
This example depicts the challenging setting in which elder AI/AN's receive their health care. It important to note that this Indian elder has family that can assist with her health care. However, for most Indian elders they do not have family members who can assist with their care.

Long-term care services at the community level are funded through a variety of resources, including IHS, Tribal funds, Medicaid, Administration on Aging (AoA), Department of Veterans Affairs (DVA), state home and community-based care

programs, and federally funded housing programs. Each of these resources has unique eligibility requirements and limitations of scope and none of them provides for coordination of services from disparate sources. An efficient and effective system of long-term care would make use of all available resources, integrating and coordinating services to assist families in the care of their elders.

Long-term care is not culture neutral. The way systems are developed and implemented can have significant impact on the cultural and spiritual health of the community. For this reason and others, planning and infrastructure development for long-term care service delivery must be at the tribal level. The IHS is working to enhance capacity for the delivery of long-term care services and to assist tribes to develop long-term care services and systems in several ways. First by refocusing existing IHS resources to meet elders' long-term care needs. An example of this includes enhanced case management, skilled nursing visits, and family support and education through the Community Health Nursing Program. These efforts are dependent both on local health care priorities and on the degree of organization of local systems to care for elders. Second, through technical assistance and capacity building efforts to support the development of tribally based systems of long-term care. Third, through coordination with other federal agencies to improve access to existing resources and to develop new resources for long-term care services.

Recent efforts include the following: In April 2002 the IHS, with the collaboration of the Administration on Aging and the National Indian Council on Aging (NICOA), held a Roundtable on Long-Term Care. Experts in Indian health and long-term care from throughout Indian country were invited to identify and address key issues in long-term

care. The findings of this Roundtable now help to guide our efforts. A copy of the Roundtable Report can be provided to the Committee.

The IHS is co-leading a working group within the Department of Health and Human Services (DHHS) whose goal is to coordinate federal resources to assist tribes as they develop long-term care services and systems. Participating agencies include IHS, Centers for Medicare and Medicaid Services (CMS), Administration for Native Americans (ANA), and AoA. We intend to involve agencies from outside DHHS such as Housing and Urban Development (HUD), and DVA in this effort as well.

The agency is in the planning stages for the development of a technical assistance center for tribes developing long-term care services. This center will make use of existing expertise throughout Indian country, including the National Indian Council on Aging and the National Resource Center on Native American Aging.

Developing clinical expertise in geriatric care involves special challenges in our decentralized, primary care oriented system. Our strategy is to focus on the provision of excellent geriatric care within primary care rather than on development of specialty geriatric services. The focus thus far has been on the development of clinical tools (such as the Comprehensive Elder Exam) and training opportunities for Indian health providers. We have collaborated with the Health Resources and Services Administration (HRSA) funded Geriatric Education Centers, the DVA Greater Los Angeles Healthcare System, and the American Geriatrics Society (AGS) in these efforts.

An effort is also underway to develop improved capacity for quality palliative and end-of-life care. Partners in this process include the Oxford International Centre for Palliative Care, and the Robert Wood Johnson Foundation. We are currently developing funding for a three-year program that will train an interdisciplinary cohort of clinicians from throughout Indian country in palliative care.

The blessing of more elders living longer in our communities brings challenges for the Indian health care system. We are committed to providing comprehensive personal and public health for the elders we serve. This means ensuring access to quality geriatric care and coordinated long-term care services that support the elders and their families in their communities.

Thank you for this opportunity to discuss the Native American Elder Health Issues on behalf of IHS. We are pleased to answer any questions that you may have.

LONG TERM CARE AND HEALTH NEEDS OF AMERICA'S NATIVE AMERICAN ELDERS

PART I

Testimony submitted to the Senate Committee on Indian Affairs

by

Leander McDonald, MA (Presenter)
Richard L. Ludtke, PhD
Alan Allery, MHA

of the

National Resource Center on Native American Aging
located in the Center for Rural Health
University of North Dakota School of Medicine and Health Sciences.

July 10, 2002

TESTIMONY

Mr. Chairman, and Honored Members of the Committee, I am honored for the opportunity to speak on behalf of my elders. My name is Leander McDonald, my mother is an Arikara from the Three Affiliated Tribes, and my father is a Dakota from the Spirit Lake Nation, both reservations are located in North Dakota. I am a research analyst at the National Resource Center on Native American Aging (NRCNAA). The Resource Center is located in the Center for Rural Health at the University of North Dakota School of Medicine and Health Sciences. Established in 1993 with funding from the Administration on Aging, the Resource Center has a mission of providing research, training, and technical assistance to the nation's Native American Elders.

Today we will be presenting new findings about prevalence of chronic disease, their effect on functional limitations, and differences in life expectancy for Native American populations from a nationwide elder's needs assessment project called Conducting Local Assessments: Locating the Needs of Elders. The project entails conducting a survey on reservations that voluntarily participate in this project, and allows for comparison of elders on reservations with their national counterparts. The results from the research not only provide us with new information about Native elders, but also gives each tribe data they can use to help guide them in developing long-term care infrastructure for their communities. The data has been used by a number of tribal communities in their planning efforts, program development, and grant application primarily directed at addressing the need for long-term care services within their communities. To date, we have 83 tribes with 8,560 respondents. Two additional tribes are being processed this week, and will be added to the aggregate file upon completion.

KEY FINDINGS

Life expectancy and Health Status

With that background on the study, let me share with you a picture of elder health and long-term care needs based on our results. Life expectancies for Native Americans and Alaskan

Natives are low relative to the general population. In addition to important differences between Natives and the general population, it is also very important to note that there is substantial variation across Native American and Alaskan Native tribes in life expectancy across the Indian Health Service areas. Average life expectancy ranges from a low of 64.3 years of age in the Aberdeen Area to a high of 76.3 years in the California Area, a difference of 12 years (Table 1). Life expectancy for the general population is 76.9 years (NCHS, 2000).

Table 1

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

Earlier this year, I attended the high school graduation at the Spirit Lake Reservation, and watched as grandparents congratulated their grandchildren in accomplishing a major goal. When I graduated from high school in 1981, I had one grandmother still living at age 77, she died two years later. My other grandmother died during childbirth at age 37, with my two grandfathers

dying both from heart attacks, one at age 62 and the other at age 64. So, while the number of Native elders living to be old is increasing, old age is still rare on the reservation.

Chronic Disease

While quantity of life is an important indicator of health for the general population health, the health status of the aged is also an important focus. As populations including Native Americans age, there is a likelihood of developing chronic illness like arthritis or heart disease, which can impact both life span and quality of life. For example, the Native elders are 19.5% more likely than the general population to experience arthritis (Figure 1). Similarly, Native American elders were 48.7% more likely to experience congestive heart failure, 17.7% more likely to report high blood pressure, 17.5% more likely to have experienced a stroke, 44.3% more likely to report asthma, and 173% more likely to be afflicted with diabetes. Only cataracts were reportedly higher in the general population. So, the Native elder is sicker from chronic disease, but is at least able to see a little better than their U.S. general counterparts.

Figure 1. Arthritis

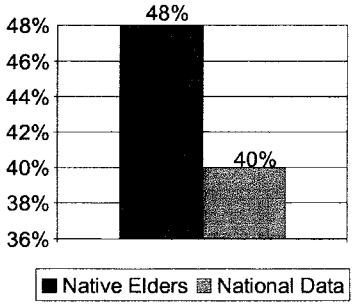


Figure 2. Congestive Heart Failure

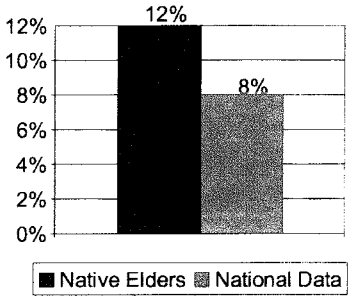


Figure 3. High Blood Pressure

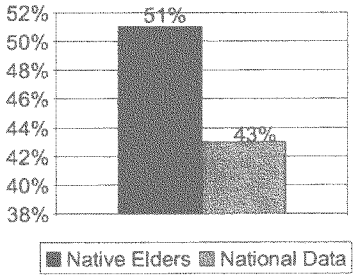


Figure 4. Stroke

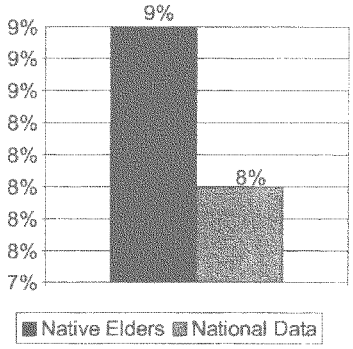


Figure 5. Asthma

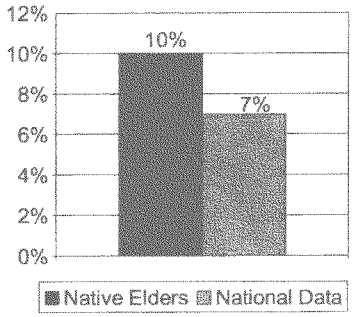
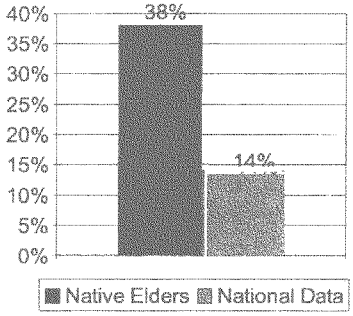


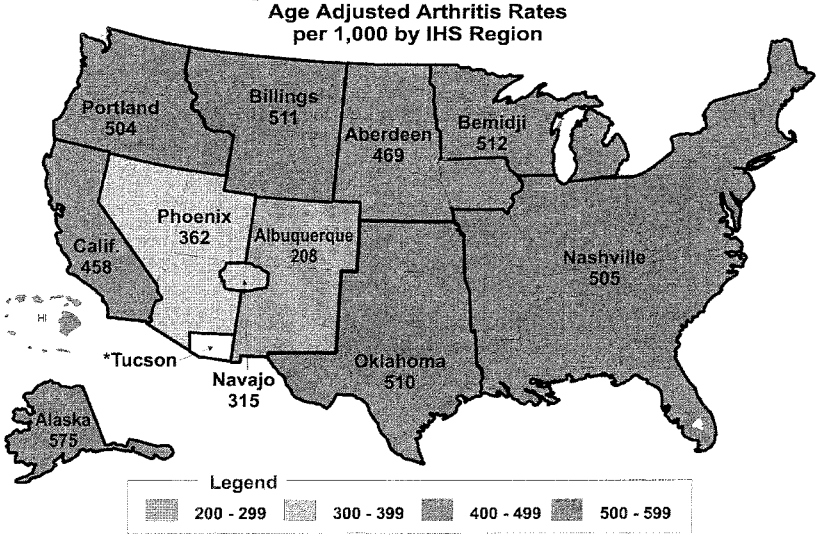
Figure 6. Diabetes



Our data, as seen in Figures 1 through 6, suggest that chronic disease rates are higher among Native American elders in spite of their shorter life expectancy. These findings suggest that the disparate health conditions of the Native elder are the result of other factors such as life style, socio-economic status, and access to timely and adequate care. Furthermore these findings, and the prevalence of chronic disease, like life expectancy, varies across Native American and Alaskan Native tribes.

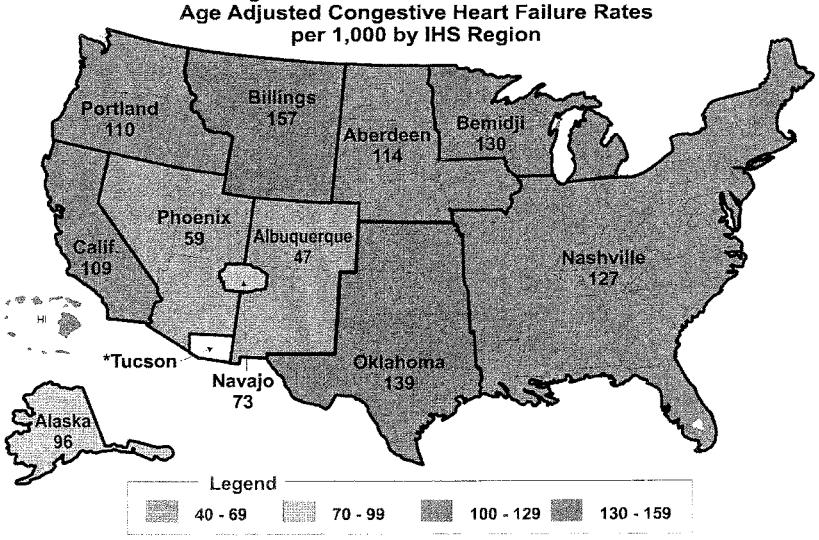
When the chronic disease rates of Native American and Alaskan Native elders in the Midwest or Alaska are compared with their Native counterparts, they are average or below (Figures 7-12). Lower rates of chronic disease appear to be the result of lower life expectancy rather than being indicative of better health status. Chronically ill elders in these regions have shorter life spans, resulting in regional chronic disease rates that are lower. In a sense, only the strong and healthy survive to be elders, which in turn affects the chronic disease rates in the Midwest and Alaskan regions.

Figure 7. Native Elders 55 and Over Age Adjusted Arthritis Rates per 1,000 by IHS Region



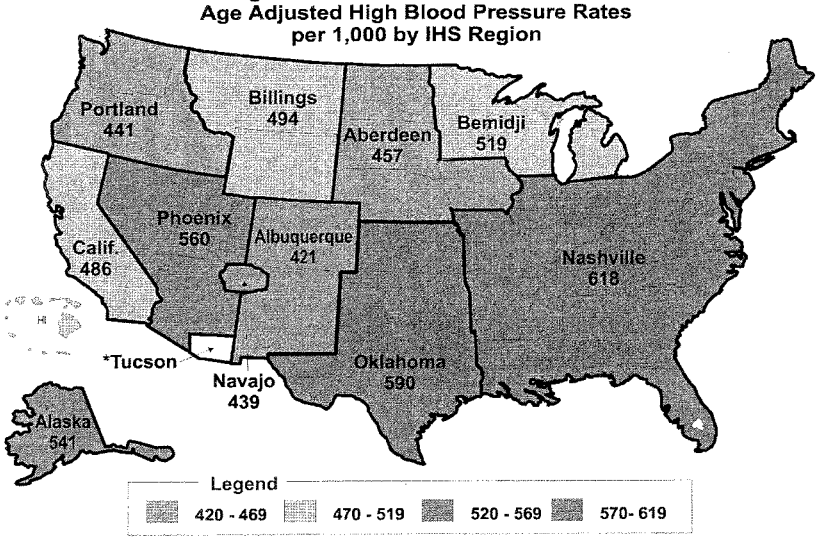
Source: NRCNAA Needs Assessment Data, UND Center for Rural Health.
* No data are available.

Figure 8. Native Elders 55 and Over Age Adjusted Congestive Heart Failure Rates per 1,000 by IHS Region



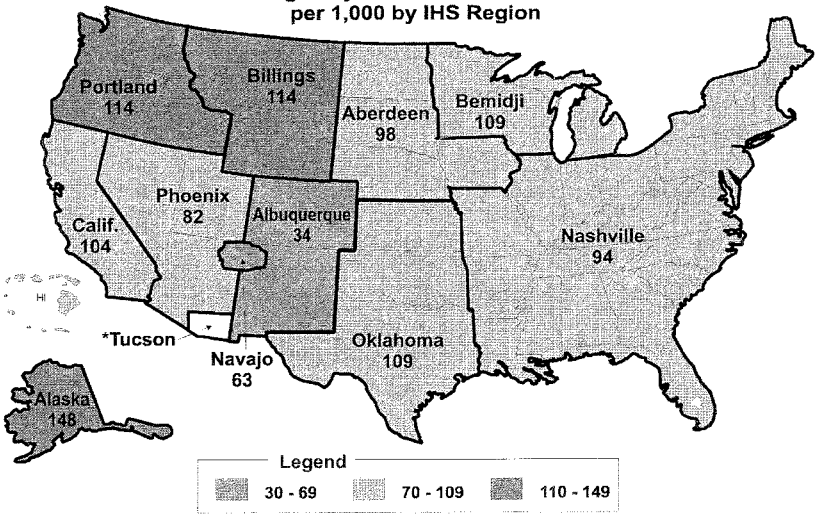
Source: NRCNAA Needs Assessment Data, UND Center for Rural Health.
* No data are available.

Figure 9. Native Elders 55 and Over Age Adjusted High Blood Pressure Rates per 1,000 by IHS Region



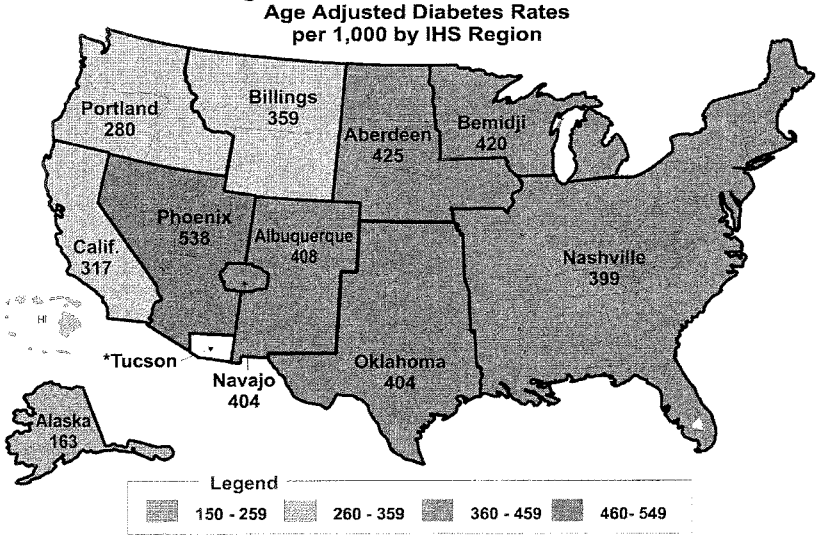
Source: NRCNAA Needs Assessment Data, UND Center for Rural Health.
* No data are available.

Figure 10. Native Elders 55 and Over Age Adjusted Asthma Rates per 1,000 by IHS Region



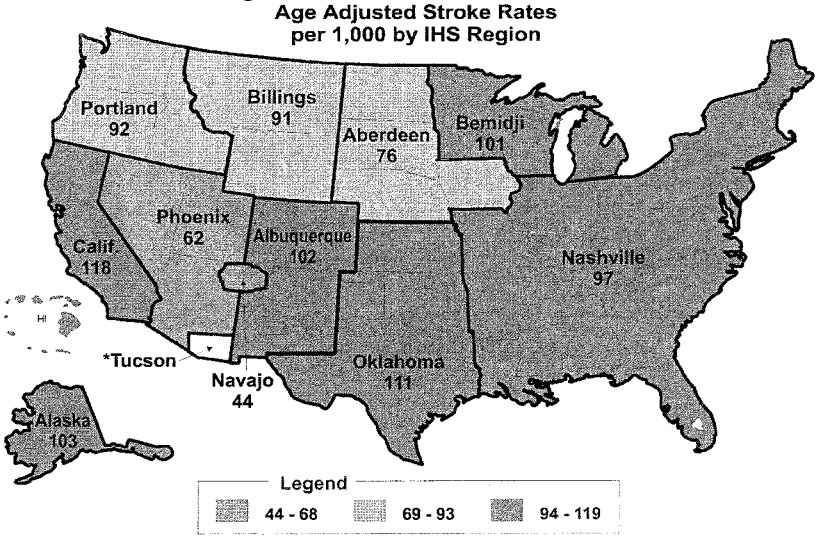
Source: NRCNAA Needs Assessment Data, UND Center for Rural Health.
* No data are available.

Figure 11. 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.

Figure 12. Native Elders 55 and Over Age Adjusted Stroke Rates per 1,000 by IHS Region



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

Additional Information
8-19-2002

Please consider the following information for insertion in response to questions from Chairman Inouye and Senators Conrad and Campbell on pages 47 and 48 of the transcript.

- **Continuation of funding for the National Resource Center at an enhanced level.**
  - The NRCNAA has operated for nine years at a level of $350,000 or less, one year without federal support.
  - Dr. Jackson and the Administration on Aging have been exceptional partners in the process, including assistance with obtaining other resources, but more needs to be done. More tribes and urban communities need to be reached.
  - The NRCNAA can expand services to more tribes with incremental increases in resources, for example:
    - Increase from $350,000 to $1,000,000 would allow the Center to conduct the Native Elder Needs Assessment with an additional 200 or more tribes.
    - A five year cooperative agreement at $1,000,000 per year with the Administration on Aging would strengthen continuity with tribes, create a national data base and allow for resurveys to determine trends, etc.
    - A national data base on American Indian elders would be developed for numerous research applications and most tribes would have their own data for planning purposes.

- **Model Projects**
  - The NRCNAA would like to work with 3-5 tribes throughout the country, at least one or two in North Dakota to explore innovative ideas in the area of long term care. It is clear that the current long term care model does not fit American Indian society and is not cost effective for reservations and for that matter rural America.
  - The NRCNAA proposes to put together a core team to assist tribes with planning, operating, and evaluating the effectiveness of new long term care strategies and infrastructure.
    - A team might consist of a planner, architect/engineer, financial/revenue enhancement person, a cultural expert, and a medical expert.
    - The team could be sort of a "skunk works" for ideas and innovations in the area of long term care and provide assistance to 3-5 tribes a year.
    - Approximate cost (5 fte's @ $75,000 each, travel, materials, etc.) estimated at $500,000 annually.

- **Market Place of Ideas in Long Term Care/Exposure to the best in the field.**
  - The NRCNAA proposes to host a market place of ideas for tribes in North Dakota during 2003. National and international experts and exemplary projects would be encourages to present at a 2-3 national forum.
  - Tribes would be exposed to what is possible and be able to make connection with experts.
  - Approximate cost $125,000 per year, if successful, it would be replicated in other regions of the country.
    - Support would be used to attract experts.
    - Tribal officials would be provided with nominal support to assure attendance.
    - Native elders on fixed budgets would be able to attend to give guidance to the process.

Total Request for Five Years

Enhanced capability to do needs assessments	**$1,000,000 per year**	**$ 5,000,000**
Model Projects Team	**500,000 per year**	**2,500,000**
Market Place of Ideas	**125,000 per year**	**625,000**
Indirect costs	**375,000 per year**	**1,875,000**
Total	**$2,000,000 per year**	**$10,000,000**

LONG TERM CARE AND HEALTH NEEDS OF AMERICA'S NATIVE AMERICAN ELDERS

PART II

Testimony submitted to the Senate Select Committee on Indian Affairs

by

Richard L. Ludtke, PhD (Presenter)
Leander McDonald, MA
Alan Allery, MHA

of the

National Resource Center on Native American Aging
located in the Center for Rural Health
University of North Dakota School of Medicine and Health Sciences.

July 10, 2002

TESTIMONY

Mr. Chairman, and Honored Members of the Committee, I am also honored and grateful for the opportunity this speak. I serve as the Director of Research at the National Resource Center on Native American Aging (NRCNAA) and have worked in close collaboration with Mr. McDonald throughout this project. My comments are an extension of those just presented by Mr. McDonald and will deal with the issue of increasing numbers of Native Americans with functional limitations reflecting a growth in the need for long term care services. I will also comment on strategies for decreasing the number of individuals with functional limitations.

FINDINGS

Functional Limitations

Chronic disease varies widely with some people minimally affected while others have significant levels of disability. The level of disability is related to functional limitations in the population, and is used as criteria for admission to nursing homes, assisted living and to community based long term care programs. Nearly all definitions of functional disability use information about "activities of daily living" (ADLs) and "Instrumental activities of daily living" (IADLs). Examples of ADLs include difficulties such as eating and walking with IADLs focusing on limitations like cooking and shopping.

A Classification of Functional Limitations

When ADLs and IADLs are combined, people can be classified into four levels of need. The associated care requirements can be identified as ranging from no long-term care services needed to home and community based care, to assisted living support and to skilled nursing care (see Table 1). Using these categories, we are able to estimate the numbers of people at these

different levels of need and determine the need for different levels of long term care services.

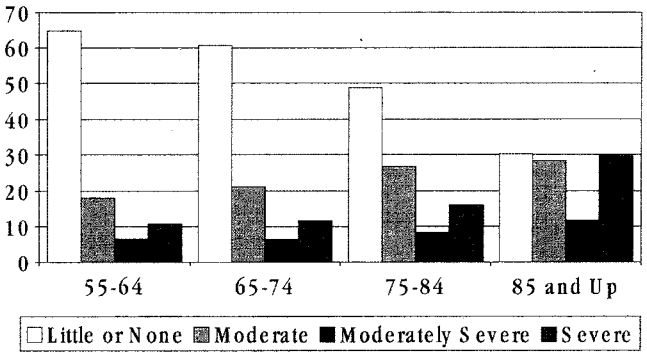
Table 1

Functional Limitation Categories

Categories	Limitations
Little or none	No ADL limitations, up to one IADL limitation
Moderate	One ADL limitation alone or in combination with fewer than 2 IADLS
Moderately Severe	2 ADL limitations
Severe	3 or more ADL limitations

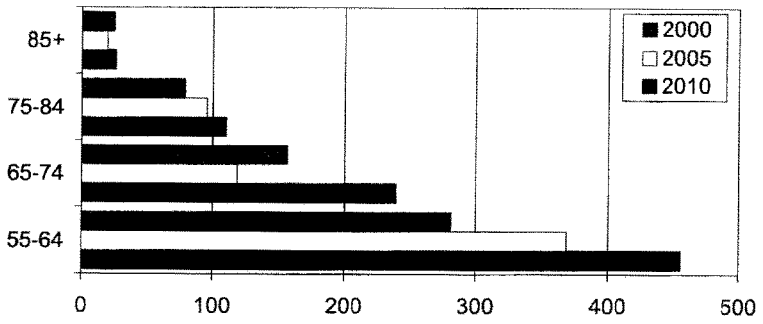
The prevalence of functional limitations increases with age and the severity of limitations also increases with age. Figure 1 contains the data from our surveys regarding functional limitation rates for Native American Elders. It is clear that the rates for all levels from Moderate to Severe increase with age and that they do so most dramatically in the oldest cohorts.

Figure 1. Functional Limitation Rates by Age: Native American Elders 2000



As the population ages, there will be an increased need for long term care services. The numbers of people classified as elders in the Native American population is about to explode with the arrival of those born during the baby boom (Figure 2). When one combines the population data with the measure of functional limitation, a picture of the growth in need for long term care is generated (see Figure 3). The most dramatic growth will occur as a result of the large numbers present in the baby boom cohorts. In the next decade, this growth will expand the population of "young old", and barring any change, will increase the need for moderate levels of care consistent with home and community based services at a rate greater than other cohorts.

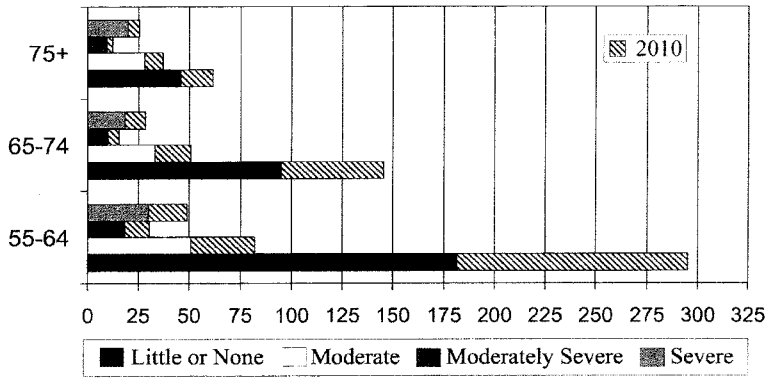
Figure 2. Population Changes by Age: 2000 to 2010



Life expectancy for Native American Elders has been growing rapidly and should be expected to grow in the future. Population projections developed using IHS life tables and Census data show that as of year 2000, the nation has approximately 218,000 Native American

Elders with functional limitations of a moderate or greater level. As the population ages, the number of elders with functional limitations will grow assuming the same rates of disability are continued. By 2010, as shown in Figure 3, we can expect an 51% increase or approximately 329,000 Native elders to have functional limitations of moderate or more severe levels. The large numbers of people becoming elders and early ages of onset for many chronic diseases that produce functional limitations creates a conservative estimate of growth in functional limitations

Figure 3. Population with Functional Limitations by Age: 2000 and 2010

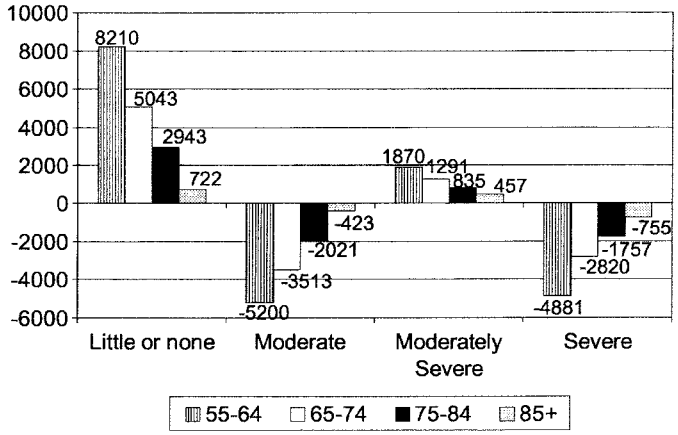


to the end of the decade.

The health and vitality of future elders depends on healthy lifestyles including good diets, regular exercise and refraining from drinking and smoking. If people take care of themselves,

they can reduce the need for long term care services. Access to preventive and other health services is important for delaying onset of illness as well as effectively treating diseases. If we reduce only 10% of Native American and Alaskan Natives limitations, we would see a significant decrease in demand for long term care services. Figure 4 presents the changes in

Figure 4. A Model of Changes in the Population with Functional Limitations by 2010 with a 10% Reduction



numbers of people with each level of limitation that would occur with a 10% across the board reduction in functional limitations that could occur with improved health promotion and access to state of the art health care.

RECOMMENDATIONS

Based on our study findings we have recommendations that we believe merit your consideration. First, given the increase in life expectancy and the increase in the Native elder population, we recommend the following.

1. An initiative to develop intervention and health promotion models that lead to improved outcomes for Native Americans and Alaskan Natives as they enter their elder years. While promoting health behavior is relevant to individuals across the life span, an intense focus on our current cohort of "young elders" can influence health care status and related new demand for more expensive care. These health promotion efforts must incorporate elements of each unique culture.
2. Long term care services, ranging from home care to assisted living to skilled nursing care are largely unavailable in local communities for Native Americans living on reservations. Leaving one's community, family and friends to reside in non-native and occasionally hostile assisted living, or nursing home environment is clearly not adequate. Since there are no nursing homes on the reservation in North Dakota for example, the elders are usually sent to the border towns for skilled nursing home facilities when they need care. In addition to being in a strange environment, unfortunately, we are well aware of cases where Native American elders are met with hostility by non Native Americans in those environments. A locally accessible array of long term care services will be needed for this aging population. Tribes should be allowed and supported to integrate local cultures into their long term care solutions experimenting with models that are tailored in terms of both the types of care that work best, and the means by which local communities can

realistically produce the care required. Also, simplifying the process of creating long term care options and assisting reservation communities in developing local responses acceptable to federal and state agencies would greatly help.

3. Increased support for targeted research on Native American aging and related educational and capacity building programs is essential to help fill gaps in information and help tribes anticipate emerging health care needs. Many questions remain to be addressed. One cannot show a difference in health care problems and then speak to need without developing a way of monitoring change. One also cannot assume that the trends of the nation will be echoed in the Native American population.

SUMMARY

In closing, I would like to leave with three points of importance to the Native American and Alaskan Native people. The first point is the need to reduce chronic diseases and functional limitations, so our Nation's Native American elders might have a better quality of life, thus increasing access to care, and reducing the demand for health services. The second is to eliminate disparities across tribes, and between Native American elders and the general population, increase life expectancy, which can be partly remedied if the first point is resolved. The last point goes back to the tribes who have completed the needs assessment. In a huge majority of these tribes, we see the data being used for planning and the building of long term care infrastructure where there is none. Therefore, the last point is to address the shortages or lack of long-term care options in Indian Country.

Thank you for allowing us to come and testify about the needs of the Nation's Native elders, we would be happy to answer any questions.

The Needs of Indian Elders
A Hearing by the Senate Committee on Indian Affairs

July 10, 2002

Statement by the National Indian Council on Aging

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Despite our nation's prosperity, times are still very hard for Indian elders. Their health status ranks among the poorest of any minority in the nation. They are disabled at rates 50% higher than other American elderly. Nearly three out of five of them live below 200% of poverty. Only 66 percent of eligible Indians are accessing Social Security, a rate far lower than the national average of 88 percent. As the diabetes epidemic continues in Indian Country, elders are affected by the disease and its complications more severely than any other age group. More than two of every five Native elders have diabetes and in some communities, more than half of our elders are afflicted. As they live longer, elders are also living with the complications and disabilities caused by the disease. We need more help from you in educating them about how to prevent the disease . . . or how to live with it. Nowhere are the disparities in minority health care so great . . . nowhere is the mandate to the federal government so compelling as with the well-being of Indian elders. Today, we bring to your attention several of the issues most critical to their well-being.

ELDER ABUSE: TITLE VII

Title VII of the Older Americans Act, "Vulnerable Elder Rights Protection," was created in 1992. It includes Subtitle B, which authorizes a program for tribes, public agencies, or nonprofit organizations serving Indian elders to assist in prioritizing issues relating to elder rights and to carry out activities in support of these priorities. Funds have never been appropriated for this purpose. While funds have been appropriated to states for similar purposes, these programs seldom reach Indian elders due to cultural and geographic barriers. Indian tribes have little or no access to the agencies, departments, ombudsman, or other programs that are available to states. Further, tribes have no additional source of mandated federal funding for elder protection activities. Anecdotal evidence provided by those involved with elder services in Indian country suggests a high incidence of elder abuse in Indian country. It is commonly acknowledged that "abusers" are often family members such that elders often do not know they are being abused and if they do know, they are reluctant to disclose this information. Outreach and demonstration programs are needed to increase awareness of elder abuse and to help tribes devise ways to minimize abusive behavior.

As the Indian criminal justice system attempts to cope with increasing rates of violent crime IN OUR COMMUNITIES, it is ill- prepared to deal with the more subtle, less visible crimes of elder neglect, financial and physical abuse that take a toll on reservation elders. Rurally and culturally isolated from mainstream programs offering respite, counseling, and other state services, Indian families often find themselves under exceptional stress. State services do not reach them.

Because very few established long-term care services exist in Indian communities (only 12 known tribal nursing homes in the entire nation), the burden of long-term care falls heavily on Indian families. Studies show that up to

90 percent of reservation long-term care is provided by families. Many of these family members report extraordinary levels of stress. THIS STRESS UNDOUBTEDLY CONTRIBUTES TO ABUSE.

Future in-home care burdens--perhaps leading to increased abuse--will be dramatically complicated by the epidemic of diabetes that now pervades Indian country. Indian elders are living longer, but they are also CREATing huge burdens for their FAMILY caregivers. Indian caregivers now must deal with daily diabetes management--the shots and dietary restrictions--as well as the Amputations, blindness and kidney dialysis that diabetes brings.

Nationally, more than two of every five elders has the disease and many Indian communities report that more than half their seniors are afflicted. We perceive that diabetes means greater caregiver burden, and that this burden will increase elder abuse.

We are grateful for ongoing federal initiatives designed to reduce the disparities in Indian health care, such as the IHS National Diabetes program. They are providing us with opportunities to improve our elders' lives. At the same time, we request that you not overlook some basic protections, such as the one afforded by Part B of Title VII, that are available to most of the nation but still haven't reached Indian elders. A demonstration grant program directed to Indian country in the amount of $1,000,000 would begin to address this very serious issue.

TITLE VI: Nutrition and Other Programs

The 238 programs funded through Title VI of the Older Americans Act are the primary source for many nutrition and other supportive services provided to rural

Native elders.

Since its inception in 1980, Title VI (Older Americans Act) funding has been so inadequate that reservation services have never been "comparable to those provided under Title III" [Title III is State formula grant program that funds a wide range of social services for the elderly; whereas, Title VI is a comparable program dedicated to American Indians, Alaska Natives, and Native Hawaiians]. Nevertheless, this program remains the cornerstone of Older American Act services to Indian elders. While funding per project ranges from $71,400 to $174,400, approximately half of the nation's projects are at the $71,400 level. This amount is intended to provide meals and other supportive services for a minimum of 50 elders for an entire year! Projects funded at the highest levels need to serve 1,500 or more elders! Further, with the aging of the population in Indian country, more tribes now qualify but cannot be served due to fund limitations. Concurrently, funded projects are struggling with relentless increases in the cost of providing nutrition and other supportive services to their clientele group. These conditions reiterate that current funding of $25.7 million is grossly inadequate and an incremental increase in funding to $30 million is in order.

Title V: SENIOR COMMUNITY SERVICE EMPLOYMENT PROGRAM

In Title V, the Senior Community Employment Service Program (SCSEP), regulations were again tightened this year. The SCSEP's nine national sponsors are now required to consult with the governors of each state where they operate. NICOA, AS ONE OF THESE SPONSORS, refused to accept this regulation, arguing that states should not have any control over Indian job placements. Because of the Federal Trust Responsibility, Indian elders should not be subject

to regulation by individual states.

Because of NICOA's stand, Title V now provides this exemption, which we interpret to mean that an entirely separate Equitable Distribution Plan should be applied to the 847 SCSEP positions that NICOA operates. We will be able to serve Indians in states (such as Montana and the Dakotas) that were previously off limits because of their small population.

Title IV: Research and Demonstration Grants

TITLE IV, "RESEARCH AND DEMONSTRATION GRANTS" HAVE TRADITIONALLY FUNDED OTHER CRITICAL-PROGRAMS IMPORTANT TO INDIAN ELDERS. TITLE IV PROJECTS HAVE HISTORICALLY PROVIDED ANNUAL TRAINING TO TITLE VI PROGRAMS. HOWEVER, SINCE 1995 THESE TRAINING ACTIVITIES HAVE NOT BEEN FUNDED. TITLE VI DIRECTORS HAVE HIGH TURNOVER RATES DUE TO LOW PAY AND JOB STRESS. TYPICALLY, DIRECTORS HAVE A HIGH SCHOOL EDUCATION AND A FEW YEARS OF EXPERIENCE. THEY OFTEN WORK UNDER GREAT PRESSURE AND OFTEN LACK A BASIC UNDERSTANDING OF THE PROGRAM'S RULES AND REGULATIONS. UNDERSTAFFED AND UNDERPAID, TITLE VI DIRECTORS RECEIVE LITTLE OR NO TRAINING IN BASIC NUTRITION, BUDGETING, FOOD PREPARATION AND PROGRAM REPORTING. YET TITLE VI DIRECTORS ARE SOME OF THE MOST IMPORTANT PEOPLE IN THE LIVES OF OUR INDIAN ELDERS. THE ELDERS GROW TO TRUST THEM, LOOK FORWARD TO THEIR COMPANY, AND RELY UPON THEM FOR INFORMATION AND CARE, ESPECIALLY IN RURAL RESERVATION COMMUNITIES. CONSEQUENTLY, THE NEED FOR FUNDING TO PROVIDE TRAINING FOR TITLE VI DIRECTORS IS ONE OF

NICOA'S FOREMOST CONCERNS.

TITLE IV ALSO PROVIDES CRITICAL FUNDING FOR NICOA'S ONGOING WORK IN INDIAN COUNTRY, INCLUDING A PROJECT TO EDUCATE INDIAN ELDERS ABOUT DIABETES PREVENTION AND MANAGEMENT. WE HA VE ALREADY MENTIONED THE TYPE 2 DIABETES EPIDEMIC THAT CONTINUES TO RAVAGE INDIAN COUNTRY, HITTING OUR ELDERS THE HARDEST. CLEARLY, PROGRAMS AVAILABLE TO INDIAN ELDERS THROUGH THE OAA MUST PLAY AN INCREASING ROLE IN HELPING COMBAT THIS DISEASE. NOT ONLY DOES THE ACT—THROUGH TITLES IV AND VI—CREATE OPPORTUNITIES FOR EDUCATING ELDERS ON HEALTH ISSUES, IT PROVIDES THEM WITH NUTRITIOUS FOOD, HEALTHY DIETS AND EXERCISE—CRITICAL ELEMENTS OF DISEASE PREVENTION AND MANAGEMENT.

NICOA WILL CONTINUE TO request your sponsorship of a $600,000 appropriation request FOR TRAINING TITLE SIX (vi) DIRECTORS AND DEVELOPING THEIR CAPABILITIES TO BETTER SERVE INDIAN ELDERS.

TITLE IV: RESEARCH AND DEMONSTRATION GRANTS

Title IV of the Older Americans Act, "Research and Demonstration Grants,"

continues to provide important resources for most of the National Aging Network and for many of the nation's seniors. These ongoing benefits, however, do not accrue to Indian Country. Title VI programs, serving the nation's most rurally isolated and socio-economically deprived seniors, have not directly benefited from Title IV funding since a small grant was awarded in the early 90s. Even badly-needed training initiatives, authorized for these program directors under Title IV, have generally not received appropriations.

Despite of Congressional intent that Title VI programs provide services "comparable to those under Title III," the reality is that Title VI remains without a national infrastructure (no paid staff), without a national training program at any level, without the capacity for regional or national meetings, and without even the capacity for its estimated 238 tribal programs to communicate with each other.

Often, the only assistance available for Title VI strategic needs comes from the National Indian Council on Aging (NICOA), which provides forums for Title VI directors at its biennial national conferences, or from N4A, which counts Title VI directors among its membership.

NICOA urges Congress to create a capacity-building initiative, directed by NICOA, to engender skill-building, communication, and greater economic self-sufficiency for Title VI programs. Necessary components of the initiative include:

- Annual training
- Development of an organizational infrastructure
- Capacity building, to include:
- Hiring and training a national Title VI COALITION director;
- the creation of a fiscal management infrastructure;

- the creation of an operational infrastructure;
- creation of grant application and management protocols.

WE REQUEST A project, FUNDED UNDER TITLE IV OF THE OLDER AMERICANS ACT, to integrate nutrition services into a health promotion and disease prevention strategy. THIS INITIATIVE cOULD OPERATE IN collaboration with THE Nih, Cdc, usda, ihs, nicoa, and OTHER tribal organizations..

LONG-TERM CARE

As American Indians and Alaska Natives grow older and have more disabilities, one of their greatest fears is being placed in a nursing home far from their families and friends, where no one speaks their language, where the food is unfamiliar and where they are left alone to die.

The need for long-term care services in Indian Country is great and continues to grow. The Indian Health Service has never included long term care as part of its mission and it does not operate or fund any long term care facilities. We need to think creatively about enhancing existing resources to meet the needs for home and community based long term care.

While it is recognized that there is no national overall policy regarding long-term care for the nation's elderly and disabled, it is also true that billions of dollars in

federal and state funds are spent on long-term care, particularly for nursing home and home and community-based services under Medicaid.

It is important to understand that there are virtually no funds available to Indian Country for long-term care. The IHS, as i mentioned, has no responsibility for providing long-term care services. HHS can and should play a major role in helping tribes to begin to address this important and growing need in Indian Country.

in south dakota, tribes are extremely anxious to develop nursing home care on their reservations, but are prevented from doing so due to a state imposed moratorium on the construction or acquisition of additional medicaid beds. this impasse has gone on for nearly a decade. without medicaid funding tribes would have no choice but to use tribal resources to subsidize care in such facilities. few tribes would be able to do that and certainly not south dakota's tribes.

The state government has said they agree tribes need their own nursing homes but that their hands are tied due to their own self-imposed medicaid moratorium. south dakota argues that elders and advocates should take their concern to the federal government; that the federal government has the responsibility for providing long-term care to indian elders. south dakota's tribes are in a catch-22: the state, which is the locus of long-term care under medicaid, refuses to do what they can by law. the federal government doesn't presently have programs or dedicated funding sources that suppport long-term care services. it seems highly unlikely that the ihs would receive additional funding sufficient to address long-term care coverage for indian country.

TESTIMONY

Mr. Chairman, and honored members of the Committee, thank you for allowing me to speak before this distinguished group regarding the concerns of the Indian Elders of North Dakota and in particular the elders of the Mandan, Hidatsa, and Arickara Tribes. My name is Frederick Baker. I am chairman of the Mandan, Hidatsa, and Arickara Elder's Organization, an organization that was officially chartered and sanctioned by the Three Affiliated Tribes Business Council, to represent the concerns of our elder population. I have been appointed to the Governor's Committee on Aging for the State of North Dakota.

The elders of the Ft. Berthold Reservation are those folks who are 60 years and older. We were born between the years 1905 and 1942. Our oldest member is 97 years old. There are approximately 573 of us that are in this age range. 307 of us live on the Ft. Berthold Reservation, 74 live outside the Reservation but in North Dakota, and 192 of us are sharing the virtues of North Dakota with other states.

As an age group, we have endured and survived great change. Most of us were born in dire poverty; most of us saw family members die from causes of the frustrations of poverty such as alcohol, despair, poor to none existent health care; most of us are products of off-reservation boarding schools; many of us were given a one way ticket to urban communities such as Los Angeles, Chicago, Dallas, with virtually no preparation of urban survival skills and very limited financial resources (many of us still bear the scars of that experience).

Our age group also went to war in defense of our country. Many of us walked the jungles of the South Pacific, landed at Normandy, defended the frozen ridges of Korea, and saw the monsoons of the Mekong Delta. Many of us returned maimed in body and sometimes in spirit, many of us were returned for burial.

Without question, the most devastating event for us was the Garrison Dam. It was almost as devastating as the smallpox epidemics (1781 and 1837). Prior to the Garrison Dam, we were settled in communities such as Independence, Lucky Mound, Nishu, Shell Creek, Elbowoods, Beaver Creek. We were raising our own food, just like we had been for centuries. Beef replaced the buffalo as our major protein supply, and we proved to be excellent cowboys. The River (Missouri) and its bottomlands provided us good soil for our gardens and crops, shelter for ourselves and our livestock, timber to build our homes, but especially it allowed us to practice our cultural traditions. These traditions helped us to be independent and develop our own systems of caring for ourselves and one another. We didn't need "social" programs. We took care of our children, our elders, our ill. We had our own system of "law and order".

The Garrison Dam changed all of that. We were forced to move from the bottomlands up into the "hills", where the quality of the land was such that it was very difficult to raise gardens. It took many more acres to raise livestock. Our homogeneous communities were broken up, and replaced by isolation. We did not have access to capital, except the meager amounts of credit that was offered through the Bureau of Indian Affairs. Most of this credit was just enough to get one into serious difficulty

Unfortunately, many of our people died in the process of relocating and readjusting from the Garrison Dam. Many of us turned to alcohol, and ourselves and our families suffered as a result. Terms like unemployment, welfare, foster care, spouse abuse, child abuse, elder abuse, alcoholics/alcoholism, juvenile delinquency, "low rent" housing became part of our vocabulary. Our languages are in danger of being lost, and we get confused between poverty culture and Indian Culture.

Despite these difficulties, some members of our age group were the first in their families to earn a college degree; to enter professions such as education, nursing, social work, medicine.

We face many of the same problems today. Among these are inadequate medical care; poor/substandard housing; lack of home health care; elderly abuse issues; inadequate transportation; inadequate meal service. Our written testimony will more clearly document these problems

Let me just highlight a few things:

- Average health care expenditure in the USA is approximately $3500, while at Ft. Berthold, it

is $1300.

- All of North Dakota is seeing a return of elders who are seriously or terminally ill, hence the drain on the already limited Medicaide resources is critical. We need more Medicaide dollars.
- Set aside for Indian Reservations for meal sites under Title 6 of the Aging Act only is enough to meet a part of the needs of elders.
- Housing is badly needed for elders, and especially assistance is needed in repairing homes. Many elders live in very crowded conditions because their children or grandchildren have no housing and therefore move in with them.
- Elderly abuse is rampant and needs to be addressed by Congress. Please support the pending legislation that will probably be introduced this year.

Thank you for your time, I will be glad to answer any questions that you may have.

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