Long Term Care Needs of Alaska Native Elders

"Elders need to be near the river where they were raised."
—Rose Jerue, 1989

August 2005

UAA UNIVERSITY of ALASKA ANCHORAGE

National Resource Center for American Indian,
Alaska Native and Native Hawaiian Elders

January 2006

Dear Reader:

The National Resource Center for American Indian, Alaska Native, and Native Hawaiian Elders (NRC) at the University of Alaska Anchorage (UAA) has completed its second year and is pleased to send you its four papers: (1) Alaska Native Elders and Abuse: Creating Harmony by Voicing Traditions of Listening; (2) Achieving Best Practices in Serving Alaska Native and American Indian Elders; (3) Achieving Best Practices in Long Term Care for Alaska Native and American Elders; and (4) Boarding School: Historical Trauma among Alaska's Native People.

These papers are intended to provide information to decision makers on all levels in the Alaska Native community statewide and regionally, to the State of Alaska, to various federal offices in Washington, D.C., to all Title VI programs and to all the federally recognized tribes so that culturally appropriate Elder health care services and programs can be designed and implemented with input from the Elders themselves. By extension, the information provided here would be of interest to the many American Indian tribes and Native Hawaiian Elders. Dr. Josefina Carbonell, the Assistant Secretary on Aging, has directed the NRC to concentrate its efforts in Alaska in the first, second and third contract years. We recently were informed that there is funding for the two resource centers for the 2006 contract year.

This project started with meetings between the Alaska Native Tribal Health Consortium (ANTHC) and the NRC Alaska. A memorandum of agreement was reached to have a joint Alaska Native Elder Health Advisory Committee. This committee has met four times to give direction to both organizations in the first and second year. The ANTHC board has approved the Joint Elder Advisory Committee to meet three times a year. In the second year, individual interviews were held with Elders from the following cultural groups: Inupiaq, Athabascan, Yup'ik, Sugpiaq, Aleut, Tlingit, and Tshimshian. The interviews were transcribed and coded by the Alaska Natives into Psychology students supervised by Dr. Kathy Graves. Cultural consultants from all of the regional areas were also included to review the final comments in the paper entitled, "Alaska Native Elders and Abuse: Creating Harmony by Voicing Traditions of Listening."

This project, also referred to as "Voices of Our Elders," is funded by the Department of Health and Human Service through the Administration on Aging (AoA) in Washington, D.C., Grant No. 90AM2752. The NRC is officially located at the College of Health and Social Welfare (CHSW) at the University of Alaska Anchorage. The NRC started in the fall of 2003. Dean Cheryl Easley of CHSW traveled with the NRC staff to many of our regional meetings. The strategic focus chosen for the College is gerontology.

Listening sessions were held by the AoA through the Title VI programs, and the Title VI representatives (mostly American Indian and Alaska Native Elders) voiced several concerns to be addressed by the two National Resource Center to provide pertinent information to Native American and Alaska Native decisions makers who provide health services to their Elders. The Elders were concerned with Long Term Care issues and preventative health programs that identify best, promising, and emerging programs. The Elders were also concerned with Elder mistreatment and how to address this issue by the communities themselves. The two National Resource Centers have been successful in meeting the directives of the Listening Sessions by the papers drafted by the two NRC staffs. Electronic copies of Alaska NRC reports have also been sent to various pertinent organizations listed above, namely the Title VI programs, and to all the federally recognized tribal organizations. The work of the NRC is designed to provide information to help decision makers meet the expressed culturally relevant needs of their Elders. As such, the Alaska NRC does not conduct research but disseminates health information vital to Elders for culturally appropriate health programs.

The NRC is one of two resource centers in the nation. The other is the National Resource Center for Native American Aging, which has been in existence for over twelve years, located at the University North Dakota in Grand Forks, North Dakota. They conduct surveys on the status of Native American Elder health programs and related issues across the nation. The surveys are in response to the needs expressed by individual tribal organizations. The tribal organizations passed a tribal resolution asking the North Dakota NRC to conduct various surveys.

The NRC is interested in receiving your comments and thoughts on the information presented in the four papers. We invite you to view them on our website: http://elders.uaa.alaska.edu/. We would also welcome your comments or questions at our e-mail address: afjwl@uaa.alaska.edu or call Mr. Jim LaBelle at 907-786-4303.

Sincerely,

Cheryl E. Easley, Ph.D., R.N.
Dean
College of Health &
Social Welfare

Kanaqlak (George P. Charles-Yup'ik), Ph.D.
Director
National Resource Center for American Indian,
Alaska Native and Native Hawaiian Elders

Long Term Care Needs of Alaska Native Elders

Prepared by:

Kay Branch
Alaska Native Tribal Health Consortium
Division of Community Health Services
4000 Ambassador Drive
Anchorage, Alaska 99508

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Contact:

pkbranch@anmc.org
(907) 729-4498

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Long Term Care Needs of Alaska Native Elders

Executive Summary

"Elders need to be near the river where they were raised."

— Rose Jerue, 1989

These and similar words from countless Alaska Native elders and their families guide the work to establish long term care services within the Alaska Tribal Health System (ATHS). Like elders anywhere, Alaska Native elders say they would prefer to be in their own home throughout their lives. In the past elders did stay at home with their families. But in these changing times, that is not always possible and more elders are finding themselves in nursing and assisted living homes in urban areas, far from the river where they were raised.

The Project

The Alaska Native Tribal Health Consortium (ANTHC) received funding from the Indian Health Service to assess the health status and long term care needs of Alaska's Native elders. This project approaches the needs from a systems and service delivery perspective. *The objectives are to determine what services are needed, what services are currently available and where, and how the system can develop services for elders that are culturally appropriate and close to home.*

Quantitative data were gathered from the U.S. Census, Alaska Department of Labor, IHS reports and RPMS data, Medicaid utilization data, the Alaska Trauma Registry, Adult Protective Services and State Troopers, ANTHC Diabetes Program, the Office of Alaska Native Health Research, and ANMC Social Work Department. Qualitative data was collected from elders during regional meetings, telephone interviews with service providers, and the author's twelve years of experience working with elder care service development in rural Alaska.

Long term care is the provision of services, including health care, personal care, social services and economic assistance, delivered over a sustained period of time in a variety of settings, ranging from a person's own home to institutional settings, to ensure quality of life and maximum independence. Most long term care is still provided by families. Medicaid is the pri-

mary funding source for paid long term care services, through both nursing homes or home and community based waivers. The type of long term care services available to Alaska Native elders differs significantly depending on where they live, and on the capacity of local health and social service providers. This report includes a description of long term care services, estimates of current and future numbers of elders needing services, and recommendations for service development in each region of the state.

The ANTHC Board of Directors formed the Alaska Native Elder Health Advisory Committee (ANEHAC) to guide this project and assist with other efforts to provide services to elders. The project includes a partnership with the National Resource Center for American Indian, Alaska Native and Native Hawaiian Elders at the University of Alaska Anchorage.

Alaska Native Elders

According to the most recent estimates by the Alaska Department of Labor, there are 7,135 Alaska Native people over 65, and 8,040 between the ages of 55 and 64. The most rapid increase is seen in the number of elders between 70 and 74, followed by those 85 and older. Health status of Alaska Native people has improved due to increased availability of medical care and improved treatment of infectious diseases and acute illnesses, which lead to longer life expectancies. There is now a higher prevalence of chronic illnesses such as cancer and heart and lung diseases. These illnesses can lead to a higher incidence of functional disability, and a corresponding need for long term care.

The average number of Alaska Native nursing home residents each year is approximately 280. An additional 327 elders and 240 adults with physical disabilities receive long term care services in another setting, either their home or an assisted living home. A total of 635 Alaska Native people received personal care services in 2003.

Model Programs

Rural Alaska presents some particular challenges in delivering services that may be typically available to seniors in more urban areas of the state. However, there are some excellent long term care services provided in rural areas. The personal care programs operated by the Yukon-Kuskokwim Health Corporation and Tanana Chiefs Conference provide services that allow many elders to remain at home, as well as offer employment to local residents. Marrulut Eniit assisted living in Dillingham and Quyanna Care nursing home in Nome are two examples of facility-based care that incorporate the cultural needs of the residents. Although there are ongoing funding, staffing and regulatory challenges for these programs, they are good models for replication.

Key Considerations for Planning Long Term Care Services

Cultural—programs and services need to be based on local culture and tradition.
Regulatory—program regulations should be flexible enough to meet the needs of a culturally diverse population.
Funding—investigate all sources of funding: Medicaid, grants and tribal contributions.
Organizational capacity—develop expertise in operation and funding.
Workforce Development—the availability of a well trained, competent and caring workforce is crucial to the development and success of long term care services.

Priority Health Needs Identified by Alaska Native Elders

Personal care services: PCA services are most important because they are community based and allow elders to remain in their own homes.
Comprehensive care and tracking of chronic illnesses: Comprehensive elder health care based on prevention and maintenance of chronic conditions over time.
Medication issues: Regular review and monitoring of medications for elders.
Elder abuse: Greater understanding of the nature and extent of elder abuse.
Housing: Need for housing that supports people as they age, through modifications of private homes and the development of culturally relevant facility based care.
Alzheimer's Disease and Related Disorders: Understanding the extent of Alzheimer's Disease and other dementias in the Alaska Native population, and information about treatment and family caregiving challenges.
Unintentional injuries: Further investigation into the causes and prevention of falls.
Telemedicine: Expansion of telemedicine to include aspects of home health.
Elder and youth activities: Sharing traditions and participating in intergenerational activities to support youth and community.
Palliative care: Appropriate care in all communities so elders can return when approaching death.
Traditional healing: Ensure the integration of traditional healing methods in long term care services.
Urban/rural differences: Understand why elders are moving to town and the implications this relocation has on service availability in urban and rural areas.

Recommendations: Statewide Service and Facility Needs

1. Work to expand and improve personal care and other home and community-based services statewide. Personal care services are in jeopardy in our tribal communities. The removal of state grants and lack of adequate Medicaid reimbursement; the lack of funding for people not eligible for Medicaid; and inadequate wages for assistants leading to high turnover and shortage of providers in many communities, all contribute to the unavailability of personal care services in many areas of the state.

- *Commitment from the tribal leadership to developing and enhancing personal care and other home and community-based services would fulfill the desire of Alaska Native elders to remain at home.*

2. Develop an ongoing position within the tribal health system for elder care planning. The work of this study provides a baseline of services available and health needs for Alaska Native Elders and offers directions for future planning. This is only the beginning. Ongoing planning and technical assistance is needed for the ATHS to fully address the long term care needs of Alaska Native elders.

- *An elder care position within ANTHC to provide technical assistance and the maintenance of an elder care website, would ensure the continued development of programs that serve Alaska Native elders, and would assist tribal health organizations in achieving their goals for elder care.*

3. Initiate geriatric assessments and preventive programs for elders. Tools for both health assessment and prevention guidelines are available, and models of elder clinics in the Zuni and Ute IHS service areas can be reviewed for replication or modification.

- *Adoption of the Comprehensive Elder Exam tool and Preventive Care Guidelines would enhance health care delivery to Alaska Native Elders and improve data collection on elder health status.*

4. Plan for facility-based care thoughtfully and cautiously. Although elders would prefer to stay in their homes, sometimes this is not possible and their care needs exceed what their family and other supports can provide and they require nursing or assisted living care. Whether to build a regional nursing home, local assisted living home or some other type of supportive housing requires ample discussion and planning.

- *Participate in thoughtful planning for housing and facility-based care. Include both health services and housing agencies in discussions.*

Recommendations: Long Term Care Needs by Region

The recommendations for each region focus primarily on the development or expansion of home and community based services, since elders would prefer to remain in their own homes. Home and community based services are also the most cost effective and will provide employment opportunities to local residents. Long range planning should include the impact of the rising numbers of elders in the region, which will correspond to an increase in those needing services. A continued monitoring of population growth and the functional and long term care needs of elders at the regional level, through comprehensive elder assessments, will be needed to ensure the accuracy of the future planning for services and facility-based care. The most critical regional needs are:

- Elders in the Barrow Service Area and the Aleutians have the highest risk of having to leave the region for care.
- The top priority for facility development is the assisted living home in Bethel.
- Regions needing increased effort in the development of home and community based services are Barrow, Kotzebue, Norton Sound and the Aleutians.
- More in depth research by individual communities or subregions is needed for Mt. Edgecumbe and Annette Island Service Areas, Matanuska-Sustitna Borough, Kenai Peninsula, and Valdez, Cordova and Glennallen.

Conclusion

This report provides a baseline of information formerly lacking in Alaska. The implementation of a mechanism, such as the Comprehensive Geriatric Assessment Tool, for longitudinal tracking of Alaska Native elder health and functional status would allow the ATHS to systematically record data that can be used for planning in the future. Discussions and planning within ATHS are needed, both at the regional and statewide levels, to determine the future direction of elder care in Alaska.

"Our goal should be to help elders live out their lives in comfort, not taking medications they don't need and not living where they don't want to."

—Andrew Jimmie,
chair of the Alaska Native
Elder Health Advisory Committee.

Chapter 1

1.1 Introduction

> *"Elders need to be near the river where they were raised."*
>
> **— Rose Jerue, 1989**

These and similar words from countless Alaska Native elders and their families guide the work to establish long term care services within the Alaska Tribal Health System. Like elders anywhere, Alaska Native elders say they would prefer to be in their own home throughout their lives. In the past elders did stay at home with their families. But in these changing times, that is not always possible and more elders are finding themselves in nursing and assisted living homes in urban areas, far from the river where they were raised.

The lack of services that would allow elders to stay at home is being addressed by tribal organizations around the country. Here, the Alaska Native Tribal Health Consortium (ANTHC) received funding from the Indian Health Service (IHS) to conduct an assessment of the long term care needs and health status of Alaska Native elders. The project began in January 2004 and approaches the process from a systems and service delivery perspective. The primary goal is to ensure that elders who wish to will be able to stay in their own homes throughout their lives, with an appropriate range of services available across the state.

The project objectives are to determine what services are needed, what services are currently available and where, and how the system can develop services for elders that are culturally appropriate and as close to home as possible.

This report is provided to Alaska tribal health organizations for two purposes:

1) To provide information for local health organizations to use for future planning of elder care services within their regions and communities.
2) To address gaps in services from a statewide perspective: to determine what services would be more easily developed at a statewide level and to increase communication within the tribal health system to allow elders with long term care needs a seamless transition between Anchorage, their regional hospital and home.

The Long Term Care Needs of Alaska Native Elders report is organized in the following manner. Chapter 1 includes background information, population data, research partnerships and method-

ology. Chapter 2 outlines the current long term care delivery system, including state, tribal and private services. Chapter 3 provides data on health status. Chapter 4 addresses the current usage of long term care services by Alaska Native elders. Chapter 5 highlights model programs in Alaska and in other IHS areas that are providing elder services. Chapter 6 begins a discussion of estimating the need for services through analyzing the functional limitations of elders. Chapter 7 includes a discussion of the challenges and benefits to providing long term care services and discusses the capacity for providing services around the state. The final chapter outlines the recommendations of the study, both regional and statewide, including suggestions for capacity building and advocacy.

1.2 Alaska Native Elder Health Advisory Committee

To guide this project and future work in elder care, the ANTHC Board of Directors established an Alaska Native Elder Health Advisory Committee (ANEHAC). The committee meets twice yearly and operates as a joint advisory body to the needs assessment project, the National Resource Center for American Indian, Alaska Native and Native Hawaiian Elders at the University of Alaska Anchorage, and the elder care component of ANTHC's Village Health Provider Education and Employment Initiative Program (ViP). The ANEHAC has 12 Alaska Native members nominated by regional health corporations, an ANTHC board member as chairperson, and 8 ad hoc members from various state and community organizations. A list of ANEHAC members is included in Appendix A.

1.3 Definitions

Long term care is care of an elder or individual with a disability who requires on-going assistance with daily activities such as bathing, dressing, eating, shopping and cooking. Long term care is a system that integrates medical and social needs to provide services over time. The system includes nursing and assisted living homes, as well as services brought to the home such as personal care, meal delivery and chore assistance. A full definition of long term care and description of the continuum of services is included in Chapter 2.1.

ANEHAC meetings included discussions on the importance of defining Elders or the elderly, because of the traditional use of Elder in Alaska Native cultures. In traditional cultures Elders are revered for their knowledge and wisdom. The ANEHAC recognizes that everyone who is old is not necessarily an Elder in terms of tradition; and since the work is focused primarily on people who need some type of care in later life, perhaps the term elderly should be used. The ANEHAC will continue these discussions in the coming year. Because the author recognizes the concerns of the advisory group and also wants to offer the respect that is due to the older Alaska Native people under discussion, this report uses the word elder, not capitalized.

1.4 Population Estimates

People over the age of 65 are one of the most rapidly growing segments of the population in Alaska. Alaska Native elders are contributing to this growth. According to the most recent estimates by the Alaska Department of Labor, there are 7,135 Alaska Native people over 65, and 8,040 between the ages of 55 and 64.

Table 1 compares the most current Alaska Department of Labor population estimates of Alaska Native alone or in combination with another ethnicity to the 1990 population. According to this information the population of Alaska Natives older than 55 was 15,175 in 2004. This represents a 75% increase from the 1990 census. The fastest growing age cohort for Alaska Native elders is the 70 – 74 age group, with a doubling of that population in just 14 years. The next highest increase is seen in the "oldest old" group of 85 and over. This is the group that is most likely to need services.

Table 1. 1990 and 2004 AK Native Alone or in Combination with Another Race

	1990 Population			2004 Population			
Age	**Total**	**Male**	**Female**	**Total**	**Male**	**Female**	**% Change**
55-59	2,589	1,289	1,300	4,682	2,251	2,431	81%
60-64	1,949	937	1,012	3,358	1,637	1,721	72%
65-69	1,590	779	811	2,442	1,202	1,240	54%
70-74	977	432	545	2,023	904	1,119	107%
75-79	825	355	470	1,323	593	730	60%
80-84	442	181	261	778	333	445	76%
85+	303	140	163	569	194	375	88%
Total	**8,675**	**4,113**	**4,562**	**15,175**	**7,114**	**8,061**	**75%**

Sources: U.S. Census Bureau 1990 Population Census; State of Alaska, Dept. of Labor Modified Age, Race, Sex Estimates, Alaska July 1, 2004. % change calculated based on Dept. of Labor figures.

The large increase in the number of oldest Native elders is an example of a finding that although the life expectancy at birth for American Indian and Alaska Natives is lower, once they reach age 55, their death rate is lower than the U.S. general population (Jackson 2000). There are several factors contributing to the increase in life expectancy. According to a National Indian Council on Aging (NICOA) report, the life expectancy of American Indian and Alaska Native elders increased dramatically since the IHS was created in 1955. Since that time American Indians and Alaska Natives have seen a reduction in death rates attributable to infectious disease and acute health problems (John and Baldridge 1996). With the advent of these services life expectancy at birth grew from 51 years in 1940 to 71.5 years in 1989 (Benson 2002).

For Alaska Natives specifically, life expectancy is increasing, but life expectancy at birth in the year 2000 is 69.5, not the 71.5 seen in the total American Indian and Alaska Native population (ISER 2004). Alaska Native elders still fall 7.4 years below the expectancy of 76.9 for the U.S. general population (U.S. Census).

Increases in life expectancy can also lead to a higher prevalence of chronic disease and with it increased incidence of disability and functional limitations. American Indians and Alaska Natives reportedly have more disabilities than other ethnic groups (Jackson 2000, John and Baldridge 1996). Higher rates of disability and functional limitations along with the increasing numbers of elders exacerbate the need for long term care planning within the Alaska Tribal Health System.

Projections of the increase of the elder population over the next 15 years are another indicator for service planning. Table 2 presents crude population projections to the year 2020 for Alaska Natives over age 65. These figures are based on the State of Alaska, Department of Labor's previous projections and extrapolate estimates based on regional differences in population increases. Because the figures are based on the total Alaska population, including non-Native, the estimates may be under or overstated for Alaska Native elders depending on the ethnic mix of the region. For example, the Anchorage and Southeast projections may be too high given the larger percentage of non-Native older people in those areas. The Alaska Department of Labor, Research and Analysis Division will be posting updated population projections based on more current population statistics early in 2005. This table does not include the 55 to 64 age group, which is also expected to increase dramatically in the next 15 years.

Table 2. Projected Increase in Alaska Native 65+ Population

Service Area	2004 Population	2010 Population	2015 Population	2020 Population
Barrow	292	341	426	528
Kotzebue	407	476	595	738
Norton Sound	478	559	698	865
Yukon-Kuskokwim Delta	1,257	1,509	1,856	2,431
Bristol Bay	405	512	630	826
Mt. Edgecumbe/Annette Island	1,285	1,631	2,169	2,819
Interior	843	1,087	1,413	1,907
Anchorage-Municipality	1,196	1,567	2,084	2,729
Anchorage-Mat-Su	221	298	411	600
RSU-Aleutians	117	141	173	227
RSU-Kodiak	173	218	290	382
RSU-Kenai	314	402	543	738
RSU-Valdez & Cordova	147	194	263	345
Alaska Total	**7,135**	**8,935**	**11,551**	**15,135**

Extrapolated from State of Alaska Department of Labor, Projected Population 65+ Years of Age July 1, 1998-2018.

The Alaska Department of Labor projects a more rapid increase for the Anchorage and Matanuska Susitna areas. This seems to be true for Alaska Native elders as well. Anecdotal information from Southcentral Foundation's Elder Program indicates a growing need for services and a high number of people moving to Anchorage and the Matanuska Susitna Valley from more rural areas of the state. The Status of Alaska Natives Report 2004 shows a steady increase in the urban Native population due to migration from rural areas (ISER 2004). An analysis of U.S. Census data from 1990 to 2002 indicates a growth in the Alaska Native elder population of 198% in the Matanuska Susitna Borough and 137% in Anchorage (Saylor and Douchette 2004). More research is needed to get an accurate account of the effect of Alaska Native elder migration on services in Anchorage and the Matanuska Valley.

1.5 IHS and Long Term Care

Although it provides health services to more than 1.5 million American Indians and Alaska Natives, the Indian Health Service has not historically funded long term care services. IHS has funded elements of long term care, for example many areas utilize Community Health Representatives to provide services for elders, but there is no comprehensive package designed specifically to address all facets of long term care within IHS. Federal funding for

IHS has not met the increasing need for services in the acute care arena; therefore, providing long term care services has not been an option in most areas. However, the IHS focus on acute care, maternal and child health, and immunizations has played a significant role in shifting the major causes of death and increasing life expectancy for American Indian and Alaska Natives, thereby also increasing the demand for long term care services (Benson 2002).

IHS organized the first Workgroup on Aging in 1991, in response to increasing pressures to develop services for elders (Heath, et.al. 1993). The report generated by the workgroup led to the creation of the Elder Care Initiative office within IHS. Since then IHS has held several other joint roundtable discussions with the U.S. Administration on Aging, assisting with program development and expanding the original research agenda. IHS policy has evolved in recent years to also provide support for local tribal planning. For example, in 2003 IHS provided grants to twenty Tribes to assist in the development of reimbursable long term care services, and funded a technical assistance program to work with tribes. The IHS Elder Care Initiative director, Dr. Bruce Finke, has created a Comprehensive Elder Exam Patient Care Component encounter form (PCC) and Preventive Care Guidelines for the elderly.

Although IHS does not provide funding for elder care, programs have been created within the Indian health system that do address long term care. Partners of the Alaska Tribal Health System (ATHS)[1] currently offer a variety of services to elders and include elder care as one of their top priorities for future development. The Maniilaq Association, the tribal health organization for the Northwest Arctic region, includes in their long-range plan a vision of elders as happy, well provided for and living at home in the service area. The Yukon Kuskokwim Health Corporation in southwest Alaska is moving forward on development of an assisted living home to ensure that elders can remain in the region. ANTHC's strategic plan includes long-range planning for extended care services on the Alaska Native health campus in Anchorage. The Alaska Native Health Board (ANHB)[2] continues to support elder programs throughout the state. The intent of this report is to help all organizations within the Alaska Tribal Health System move forward in their plans for elder care.

1.6 University of Alaska Partnership

For the purposes of this project ANTHC developed a Memorandum of Agreement with the National Resource Center for American Indian, Alaska Native and Native Hawaiian Elders (NRC) within the University of Alaska Anchorage. UAA received a grant from the U.S. Administration on Aging in October 2003 to establish the resource center. The center, renamed "Voices of Our Elders," has the following goals which correlate well with this proj-

[1] ATHS, formalized by a Memoradum of Understanding in March 2004, defines the essential components and interrelationships that will ensure a continuation and enhancement of health services within the tribal health system. The ATHS is composed of 39 tribal health organizations that have agreed to voluntarily participate in the system through signing this inter-tribal agreement.

[2] The Alaska Native Health Board is the statewide Native health advocacy and coordination entity.

ect: 1) assess the current status of Native elders in Alaska, 2) develop an understanding of the cultural values that drive expectations and perceived needs for care, 3) document "best, promising and emerging practices" that are in current use, 4) solicit recommendations for community responses to elder abuse, exploitation and violence that are appropriate to Alaska Native cultures, and 5) provide education to medical providers. The Memorandum of Agreement allows for mutual sharing of existing and newly generated data, and allows the primary researcher for the ANTHC project to participate in regional elder meetings around the state.

The following reports were completed by the resource center during 2004:

- Health Status of Alaska Native Elders
- Cultural Values of Alaska Native Elders
- Best Emerging and Promising Practices
- Elder Abuse Among Alaska Natives

These papers are added as an addendum to this report as the research is complementary to what is provided here. The NRC's work will be ongoing and available in the future to the tribal health system.

1.7 Methods

Because this project takes a systems approach to long term care service delivery instead of the needs of individual Alaska Native elders, no surveys were conducted. Quantitative data were gathered from a variety of secondary sources. The U.S. Census Bureau and State of Alaska, Department of Labor, Research and Analysis Section provide the bulk of the population statistics and projections. IHS reports and Resource and Patient Management System (RPMS) data provided information on ATHS hospitalizations and outpatient visits. Medicaid data on long term care service utilization was obtained from the State of Alaska Division of Health Care Services. The State of Alaska Trauma Registry, Adult Protective Services and the Alaska State Troopers provided information on elder abuse and other trauma. ANTHC Diabetes Program provided information on Type II diabetes and the Office of Alaska Native Health Research at ANTHC provided cancer data. The Social Work Department at Alaska Native Medical Center (ANMC) compiled 4 years of discharge data for analysis

Qualitative data was collected from elders by the NRC during regional meetings with elders around the state. Information about current model programs was obtained through written documents and telephone interviews with providers. The author also relied on twelve years of experience working with elder care service development in rural Alaska. This experience includes observations and discussions with elders, families, tribal organizations and communities throughout the state. The analysis of the data and current and potential service models was presented to the Alaska Native Elder Health Advisory Committee in November 2004 to obtain feedback and direction for report outcomes and recommendations.

Addressing the data from a systems perspective works well in some regions, especially if there is not much variation in geography and service provision. For example, in the Norton Sound region there is a clear regional hub that provides access to most services for specified villages within the region. Obtaining data from the sources available provides a good picture of the services and the gaps in services in that region. On the other hand, Southeast Alaska with its vast geographic separation of communities and numerous non-tribal senior service providers, is much more problematic to analyze from the available data. This report can serve as a starting point for those areas, and more research through collaboration with other local providers will be necessary to accurately plan for future services. Identification of other areas and service gaps is included in the recommendations in Chapter 8.

Chapter 2

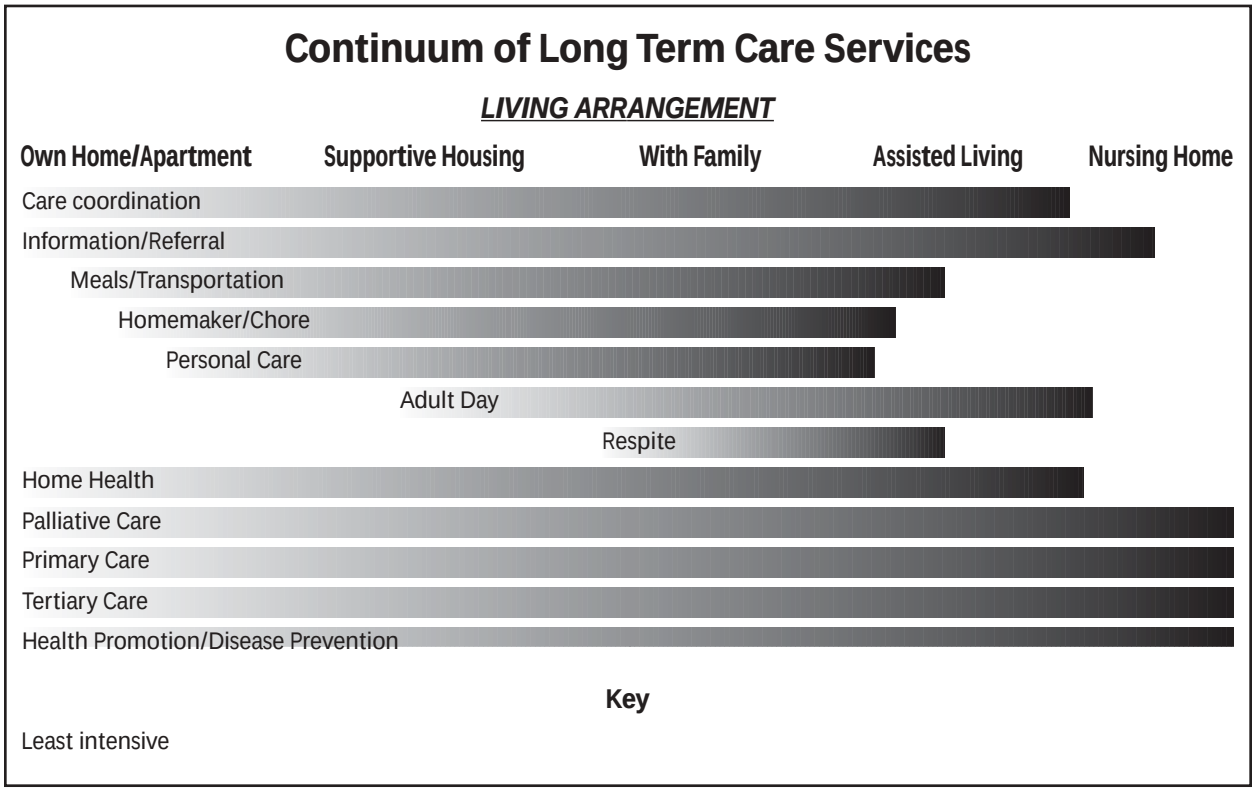
2.1 The LTC Delivery System

> *"People would rather stay in their own homes. They don't want to go and live anywhere else. Coastal ladies want to stay on the coast; the food is different in different parts of the region."*
>
> **— Gladys Jung, Bethel, ANEHAC**

Skilled nursing is only one aspect of long term care. The majority of long term care is provided by family members and is in the form of assistance with the daily activities such as bathing, dressing, grooming, eating, meal preparation, cleaning, toileting and transferring. The following definition will be used for the purpose of this report: long term care is the provision of services, including health care, personal care, social services and economic assistance, delivered over a sustained period of time in a variety of settings, ranging from a person's own home to institutional settings, to ensure quality of life, maximum independence and dignity for all persons. Long term care in Alaska Native and American Indian communities also includes the importance of maintaining cultural values in the delivery system.

This range of long term care services is typically referred to as a continuum of care. The continuum of care describes these services in a linear manner, from least to most complex, but people do not necessarily receive the services in this way. The timing of services needed is specific to each individual, and a person can receive any number of services along the continuum at the same time and or at different stages of their life. Someone may need the most intensive service in a nursing home for rehabilitation following a stroke, and may then move back home and receive services on the lower end of the continuum. Figure 1 depicts the continuum in a linear model with housing options across the top and various home and community based and medical services below. Following the figure is a list of definitions for all services in the long term care continuum. The goal of ATHS should be to strive for a balance of these services statewide.

Figure 1. Continuum of LTC Services



Continuum of Care Definitions from Least Intensive to Most Intensive:

Information and referral—provided on a variety of services and public assistance programs by the state and at many local senior centers and elder programs.
Congregate and home delivered meals—are usually provided with funds from the federal government through the Older Americans Act (OAA).
Transportation—funded by the OAA and municipalities in some areas.
Homemaker/chore—to assist people with the upkeep of their own home.
Home modifications—wheel chair ramps, wider hallways, bathroom modifications, medical equipment
Care coordination—case manager to help coordinate services, assist with paperwork, and monitor service delivery.
Respite care—a service for caregivers, provides time away from the day-to-day responsibilities of caregiving. Respite can be provided hourly in a client's home, daily at an adult day center, or extended at an assisted living home.
Personal care services—personal care assistants are employed in a client's home to help with bathing, dressing, grooming, meal preparation and housekeeping.
Adult day centers—provide structured social and recreational activities in a group setting. Ideal for people with dementia or frail elders who can no longer stay at home alone.
Program for All-Inclusive Care for the Elderly (PACE)—risk-based capitated program providing a range of services in an adult day health center and in clients' homes.

Multi-Use Supportive Housing (MUSH)—a new housing concept developed by North Pacific Rim Housing—a triplex that can provide handicapped accessible living to elders and younger disabled persons as the need arises—flexible to the changing needs of community members.
Assisted living—a congregate residential setting with personal and health care services including 24-hour supervision and assistance.
Home health—visits by professional staff such as a registered nurse, certified nursing assistant, or physical therapist to regain health and functional ability.
Hospice/palliative care—In-home care for very ill or terminally ill clients.
Skilled nursing—the most intensive of the long term care continuum, provides for all the health and personal needs of residents.

2.2 Services Available in Alaska

There are a vast array of home and community based long term care services available in Alaska. The growth of these services in the past ten years has led to more choices for Alaska Native elders in where they receive care as well as the type of care. Most of these services are funded through Medicaid and state grants. Agencies are therefore dependent on adequate appropriation to maintain the availability of these services throughout the state.

At present, the State is actively encouraging tribal health organizations to provide more long-term care and other services paid for by Medicaid. State staff provides technical assistance to agencies to build capacity to provide these services.

Following is a description of the range of services available, accompanied by governing legislation where applicable.[1]

Older Americans Act (OAA): The federal act regulating funding for nutrition, transportation and supportive services to seniors. Funds from Title III of the OAA pass through the state Department of Health and Social Services to non-profit agencies and governments around the state to provide these services. Title VI is grants to Indian Tribes for similar services. Funding for Title VI flows directly from the federal government to Tribes. Services are typically congregate and home delivered meals, transportation and information and referral.[2]

Independent Senior Housing: Apartments for seniors and adults with disabilities. May have a resident manager and common space for activities, but usually other services are not provided.

Personal Care Assistants (PCA): A Medicaid program where PCAs assist clients with the activities of daily living. There are two types of personal care programs in Alaska. The agency

[1] Adapted from "Summary of Long Term Care Services for Seniors in Rural Alaska." Rural Long-Term Care Development Program. State of Alaska, Division of Senior and Disabilities Services. January 2004.
[2] Although recognizing the importance of nutrition and transportation services for elders in rural Alaska, this report did not analyze the client base or extent of the Older Americans Act programs in each region.

based program, in which a registered nurse oversees the services and the personal care assistants; and the consumer directed program, where the consumer takes a more direct role in training and supervising their assistant, and an agency acts as a fiscal agent to bill for services and issue payroll.

Medicaid Waivers: Instituted in Alaska in 1995, Medicaid Waivers (Project CHOICE) provide people who are eligible for nursing home admission to receive services in their home or another, less restrictive, community setting such as an assisted living home. To be eligible a person must meet the financial eligibility guidelines from the State Division of Public Assistance and meet nursing facility level of care.

Home and Community Based Services (HCBS): Services provided in a person's home or in a community facility. Types of services include respite care, environmental modifications, adult day care, transportation, specialized medical equipment, chore services, assisted living, private duty nursing, and congregate or home-delivered meals.

Assisted Living Homes: Licensed residential setting that provides for personal and health care needs. Homes must provide three meals per day plus snacks, 24-hour supervision of residents, and assistance with activities of daily living. Assisted living can be a large multi-unit building or a small, private home.

Pioneers' Homes: Licensed assisted living homes operated by the State, with a focus of caring for Alaska residents with Alzheimer's disease or related disorders. There are Pioneers' homes in Anchorage, Palmer, Sitka, Ketchikan, Juneau and Fairbanks.

Home Health: Home health is a federally mandated Medicare and Medicaid program that provides skilled nursing and therapy services to eligible individuals at home. Home health agencies must be certified by the State Division of Health Care Services. Home health services are intended to be part-time or intermittent, and there are strict criteria for the service to be covered by Medicare and Medicaid.

Hospice and Palliative Care: Palliative care is the active total care of the body, mind and spirit of the patient and family. The purpose of palliative care is to prevent or lessen the severity of pain and other symptoms and to achieve the best quality of life for people dying or suffering from a long-term disease. Comfort is the goal of palliative care. Comfort is also the goal for those patients still receiving potentially curative therapy. Hospice is a program that delivers palliative care to people who are dying and need treatment to prevent or manage pain and other symptoms even when cure is no longer possible. Hospice programs can be certified to bill Medicare, or provide services on a volunteer basis.

Swing Beds: Rural hospitals with less than 100 beds that are more than 50 miles from a skilled nursing home and are Medicare and Medicaid certified may apply to operate swing beds. These beds allow for the provision of nursing home care in empty hospital beds in rural areas.

Nursing Home: Skilled care facilities operated independently or collocated with a hospital. Nursing homes are licensed by the state following national certification and licensing standards. The Certificate of Need process within the Department of Health and Social Services regulates the development of new nursing home beds in Alaska.

2.3 Funding for Long Term Care

Medicaid: The majority of formal long term care services are paid for through Medicaid. Medicaid is a program based on financial need and provides health care coverage for the 65 and older population and those who are disabled. Guidelines for Medicaid consider both income and assets in determining eligibility. Regular Medicaid is the primary payment source for nursing home care in Alaska and the lower-48. Medicaid also pays for in-home personal care services.

Medicaid Waiver: Other long term care services are paid through the Medicaid waiver program, Project CHOICE, which allows people who are nursing level of care to receive services in their own home. The income and asset limits are higher for these community dwelling older people, so it may be easier to meet the financial eligibility criteria. Under a Medicaid waiver the following long term care services are also available: private duty skilled nursing, respite, chore, home modifications, adult day care, meals and transportation. In Alaska, the majority of assisted living home clients are on a Medicaid waiver.

Medicare: Medicare, the other national health program for older persons, pays for very limited long term care services. Eligibility for Medicare is based on an individual's or their spouse's work history and payments to Social Security. Because of the lack of formal employment over their life time, some Alaska Native elders do not qualify for Medicare. Medicare pays for time limited nursing home stays that are transitional and rehabilitative in nature. Medicare will also cover time limited home health services if registered nurse oversight is required and the services are therapeutic in nature.

Individual Assets: Another option to pay for long term care is with private, individual assets, savings or insurance. Most Alaska Native elders have not built up assets, savings or retirement accounts that would allow them to pay for services. Because of the high cost of long term care, even those able to pay may eventually spend down all of their assets and become eligible for Medicaid. Only a small percentage of the U.S. general population has private long term care insurance to pay for services. The high cost of these policies make them unattainable for most American Indian/Alaska Native elders (Baldridge 2001).

Tribal Resources: Since the IHS does not provide funding for comprehensive long term care services, tribes must be creative and develop programs with other tribal funding or assets as well as integrating state programs and funding streams. Some tribal programs in the lower 48 rely on revenue from casinos and other gaming operations to fund elder care services. Other tribal organizations designate a portion of their limited IHS funding for elder services, or utilize their Community Health Representatives to provide these services.

2.4 Service Availability by Service Area

The types of long term care services available to Alaska Native elders differs significantly depending on where the elder lives, and on the capacity of local and regional health and social service providers. Long term care services can be provided by both tribal and non-tribal agencies. Following is a detailed description of services available in each region. Included for each region is a description of current services adapted from the "Summary of Long Term Care Services in Rural Alaska," State of Alaska, Division of Senior and Disabilities Services, January 2004, with additions made from conversations with granting agencies and local providers. A matrix of these services follows the narrative description. This section does necessarily address the level of service in each area, and whether a service is really available at a given point in time. A recommendation for a website that could track current availability is included in Chapter 8.

2.4.1 Barrow Service Area – Arctic Slope Native Association

OAA: The North Slope Borough (NSB) operates a senior center and senior transportation services in Barrow, providing congregate and home delivered meals to Barrow seniors with OAA funding. The tribal government, the Native Village of Barrow, also receives OAA funding and collaborates with the NSB for services. There are limited services available in the surrounding villages. Point Hope receives their own funding from the OAA for services.

Independent Senior Housing: 37 units of independent senior housing in Barrow are operated by the NSB. Tagiugmiullu Nunamiullu Development Corporation received funding from the HUD 202[3] program and the Denali Commission for five units of senior housing in five villages (Point Hope, Anaktuvik Pass, Kaktovik, Wainwright and Nuiqsut). They are looking at ways to integrate other services once the housing is constructed.

PCA: The NSB funded and operated a homemaker program in all villages up until a few years ago. Through this program they provided an array of services to elders that included assistance with the activities of daily living. The NSB and Arctic Slope Native Association have explored ways to provide PCA services in the region, and have worked with Hope Community Resources for them to provide consumer directed personal care services. Hope Community Resources became certified in November 2004 and plan to begin services in early 2005.

Medicaid Waivers/HCBS: There are no care coordinators in the region to provide access to these services.

Assisted Living: The North Slope Borough (NSB) owns and operates an assisted living home currently licensed with seven beds. The home is heavily subsidized by NSB, with residents

[3] U.S. Department of Housing and Urban Development Section 202 Supportive Housing for the Elderly Program includes capital advances for construction or remodel and ongoing rental assistance.

contributing approximately $800/month for their services. NSB does not rely on Medicaid or other state funding for operations. Due to flooding and asbestos in the permanent facility, seven residents are housed in a temporary location, and the original facility will not be renovated. The Borough is planning to close the assisted living home as soon as alternative services such as personal care or a small private assisted living can be established.

Home Health: Home health and palliative care are not available.

Nursing Home: No nursing home beds, no swing beds.

2.4.2 Kotzebue Service Area – Maniilaq Association

OAA: Kotzebue has a senior center with congregate and home delivered meals and transportation services, operated by Maniilaq with OAA funding. Maniilaq also operates a traditional foods program in the region, where hunters are provided with supplies in order to obtain and distribute subsistence foods to the elders.

Independent Senior Housing: There is one 15-unit independent senior apartment complex in Kotzebue, none in the regional villages. Maniilaq recently received a HUD 202 grant for another five unit building in Kotzebue that will be either independent housing or assisted living.

PCA: Maniilaq formerly received funding for agency based personal care services from the state. Service provision has fluctuated over the years in both personal care and waiver services. In FY02 the state removed the personal care component from their grant. They continue to provide some in-home services with other Maniilaq funds in communities where workers are available, and they are looking at the consumer directed PCA option. Access Alaska, a private agency, has also provided some consumer directed personal care services in the region.

Medicaid Waivers/HCBS: Maniilaq has two care coordinators to provide services.

Assisted Living: Maniilaq owns and operates a licensed home with twenty assisted living beds. This home has been subsidized by a yearly Senior Residential Services (SRS) grant of $863,000 from the state.[4] There are currently nine residents who pay approximately $600 per month for their services, which include assistance with personal care, meals, and transportation. In 2004 the state reduced the operating grant to $663,000 and has indicated that the SRS funds may not be available in the future. Maniilaq is working with the housing authority to explore other housing and assisted living options for elders.

[4] SRS grants were issued by legislative action in the mid 1980s, as an initiative by rural legislators to compensate for the lack of Pioneer Homes in rural areas. The funds have been passed through the Alaska Commission on Aging for Kotzebue and Tanana assisted living homes, and have not been available to new applicants. The state is reevaluating these appropriations and may discontinue the grants in the future. Maniilaq has already been advised that their appropriation will decrease further in future fiscal years.

Home Health: Home health and palliative care are not available.

Nursing Home: Currently no nursing home or swing beds. Maniilaq has completed a feasibility study to add a nursing home wing to the hospital in the future. As of December 2004, all paperwork and regulatory compliance issues have been met for Maniilaq to add up to six swing beds.

2.4.3 Norton Sound Service Area – Norton Sound Health Corporation

OAA: With OAA funding Nome Community Services operates a senior center providing congregate and home delivered meals and transportation in Nome and provides meals in White Mountain and Koyuk. The villages of Gambell, Savoonga and Unalakleet also provide congregate meals with OAA funds. Nome Eskimo Community and Norton Sound Health Corporation are submitting an application for OAA funds to provide meals in seven additional villages.

Independent Senior Housing: The Bering Straits Regional Housing Authority operates 19 units of independent senior housing in Nome. Nome Community Center operates the 17-unit Munaqsri senior apartments.

PCA: NSHC has operated a PCA program in Nome and the regional villages for several years. Like Maniilaq, their PCA and waiver services have fluctuated, and they also lost the PCA portion of their grant in June 2002. They are working to increase this program and are currently providing agency based personal care services to 12 clients in Nome and two villages.

Medicaid Waiver/HCBS: NSHC is offering care coordination services for Medicaid waivers and building their client base, identifying eligible elders. Nome Community Center operates an adult day program in Nome with funding from the State Department of Health and Social Services.

Assisted Living: There is currently no assisted living in the Norton Sound Region. Several attempts by different agencies over the last five years to develop assisted living in Nome have not moved forward.

Home Health: Home health and palliative care are not available.

Nursing Home: Norton Sound Health Corporation operates Quyana Care Center, a fifteen-bed nursing home attached to the hospital. The nursing home beds are consistently occupied at 100%. There are no swing beds.

2.4.4 Yukon-Kuskokwim Delta Service Area – Yukon-Kuskokwim Health Corporation

OAA: The City of Bethel operates a senior center with daily congregate and home delivered meals, senior transportation, and an adult day center, with OAA funding. The operations of the senior center will be transferred to Orutsararmiut Native Council in 2005. The Association of Village Council Presidents (AVCP) receives OAA funding to provide meals and supportive services in regional villages. The Kuskokwim Native Association and the community of Mountain Village also receive OAA funding for services.

Independent Senior Housing: The Ayalpik Apartments (23 units) and the Lulu Heron Center (16 units) in Bethel are operated by the AVCP Housing Authority.

PCA: YKHC has a well-developed personal care program offering both consumer directed and agency based services in most regional villages.

Medicaid Waiver/HCB: YKHC provides care coordination and other Medicaid waiver services throughout the region.

Assisted Living: There is no assisted living home in the Yukon-Kuskokwim Delta. YKHC is currently seeking funding for an 18-unit home in Bethel, and will begin construction once funding is in place. Long-range plans call for possible development of smaller homes in the subregional centers of Aniak, St. Mary's, and Emmonak.

Home Health: Home health and palliative care are not available.

Nursing Home: No nursing home beds, three swing beds at the Yukon-Kuskokwim Delta Regional Hospital.

2.4.5. Bristol Bay Service Area – Bristol Bay Area Health Corporation

OAA: With OAA funds, the Bristol Bay Native Association (BBNA) provides meals and supportive services to elders in regional villages. These services are available in Dillingham through the city's senior center. The village of Aleknagik and the Bristol Bay Elders Council receive additional funding for transportation in Aleknagik, Naknek and King Salmon.

Independent Senior Housing: The Bristol Bay Housing Authority (BBHA) maintains 15 apartments in Dillingham and 10 in Naknek. Construction is currently underway for 5 units in New Stuyahok.

PCA: BBNA provided agency based personal care services from 1997–2003. They discontinued this service once the state grants ended and have transferred all clients to three non-tribal consumer directed agencies providing services in the area.

Medicaid Waivers/HCBS: BBNA provides care coordination and other Medicaid waiver services in regional villages.

Assisted Living: Marrulut Eniit Assisted Living (MEAL) in Dillingham is licensed for 15 residents and serves the Bristol Bay Region. It also has residents from the Yukon-Kuskokwim Region. It is owned and operated by a non-profit association, with board members representing all regional entities. Payroll and billing are run through the BBHA. Most residents are on a Medicaid waiver and are therefore require nursing home levels of care.

Home Health: BBAHC provides home health and palliative care to individuals throughout the region through their Helping Hands Program.

Nursing Home: No nursing home beds, four swing beds at Kanakanak Hospital in Dillingham.

2.4.6 Mt. Edgecumbe and Annette Island Service Areas – SouthEast Alaska Regional Health Consortium (SEARHC), Metlakatla Indian Community, Hoonah Indian Association, Yakutat Tlingit Tribe, Ketchikan Indian Corporation

OAA: There are senior centers in Craig, Yakutat, Skagway, Haines, Hoonah, Juneau, Angoon, Sitka, Kake, Wrangell, Hydaburg, Ketchikan, Petersburg, and Metlakatla. Meal services are available in many of these communities with OAA funding, some offered by Southeast Senior Services in coordination with the tribes. Klawock, Central Council of Tlingit and Haida Tribes, Hoonah, Ketchikan Indian Corporation, Sitka Tribe, Craig Community Association and Yakutat Native Association also receive OAA funding for services.

Independent Senior Housing: Tlingit Haida Housing Authority operates independent apartments in Angoon (6 units), Craig (10 units), Hoonah (12 units), Hydaburg (12 units), Kake (11 units), Klawock (12 units), Saxman (12 units), and 12 units in Haines. There are an additional 22 non-tribally owned units in Haines, 40 units in Sitka, 24 units in Wrangell, 128 units in Juneau, 24 units in Petersburg, and 49 units in Ketchikan. Yakutat has 20 units owned by the Central Council of Tlingit and Haida and Metlakatla has 25 units.

PCA: Personal care services are available throughout Southeast primarily by two non-tribal agencies. However, Cornerstone Home Health does have a working agreement with the Central Council of Tlingit and Haida Tribes, and is providing services to tribal elders.

Medicaid Waiver/HCBS: Medicaid waiver services including care coordination are available throughout Southeast. There are adult day centers in Juneau and Ketchikan.

Assisted Living: There are Pioneers Homes in the following communities: Juneau 48 beds, Sitka 102 beds, and Ketchikan 47 beds. There are two private licensed homes in Juneau with

11 units, two in Ketchikan (19 units), one in Wrangell (5 units) and one in Petersburg with 15 units.

Home Health: Home health services are available through the following agencies: Cornerstone (Juneau), Juneau Home Health, Ketchikan Hospital, Petersburg Medical Center, Sitka Community Hospital, and Wrangell Medical Center. Hospice and palliative care services are provided in Haines and through Juneau Home Health.

Nursing Home: Wildflower Court in Juneau with 44 beds, Ketchikan General Hospital with 46 beds, Petersburg Medical Center with 15 beds, Sitka Community Hospital with 15 beds, and Wrangell Medical Center with 14 beds.

2.4.7 Interior Service Area – Tanana Chiefs Conference (TCC), Council of Athabascan Tribal Governments

OAA: Fairbanks North Star Borough receives OAA funds for meal and transportation services in Fairbanks; Fairbanks Native Association receives funds for services to Alaska Native elders. Denakkanaaga receives OAA funding for supportive services throughout the region, and TCC provides meals in many of the regional villages.

Independent Senior Housing: There are 234 independent units in Fairbanks/North Pole, 4 units in Fort Yukon and 15 units in Nenana.

PCA: Personal care services are available through several non-tribal agencies in Fairbanks, and are provided by TCC's Home Care program in the regional villages.

Medicaid Waiver/HCBS: Medicaid waiver services including care coordination are available throughout the Interior region. There is one adult day center in Fairbanks.

Assisted Living: The Fairbanks Pioneers Homes has 101 beds. There are an additional 20 homes in the Fairbanks area with 42 beds, none of which are tribally operated, and a 14-unit home in Tanana operated by the Tribal Council. Louden Tribal Council is pursuing funding for a nine unit assisted living home in Galena for the Yukon-Koyukuk subregion.

Home Health: Fairbanks Memorial Hospital provides home health services in Fairbanks only. Hospice and palliative care services are not available in the region.

Nursing Home: Denali Center in Fairbanks has 90 beds, with a high proportion of Alaska Native residents and a good cultural program. Denali Center has the longest waiting list of any nursing home in the state.

2.5 Anchorage Service Area

2.5.1 Municipality of Anchorage – Southcentral Foundation (SCF), Native Village of Eklutna

Long term care services are widely available in Anchorage and the Matinuska-Sustina valley, provided by a variety of agencies. This section will primarily highlight what is available through tribal health, housing and social service providers, with some information about non-tribal providers.

OAA: Southcentral Foundation receives OAA funding for congregate, home delivered meals and transportation, and provides additional support services through their CHR program. With a current client database of over 700 elders, SCF has instituted a waiting list for services, and is only able to provide intensive services to the clients with the highest needs.

Independent Senior Housing: There are 826 units of independent senior housing in the Municipality of Anchorage, 268 available through the Cook Inlet Housing Authority.

PCA: There are numerous private agencies that provide both agency based and consumer directed personal care services for seniors in the Anchorage area. Southcentral Foundation's plan for expanding services to elders includes adding both agency based and consumer directed personal care services.

Medicaid Waiver/HCBS: There are numerous agencies providing comprehensive HCB services including adult day care, respite, congregate and home delivered meals, care coordination and caregiver support. SCF has started an extensive care coordination program to offer Medicaid waiver services to tribal beneficiaries.

Assisted Living: Approximately 554 assisted living beds in 78 homes in Anchorage, and an additional 228 beds in the Anchorage Pioneer Home, all non-tribal.

Home Health: Home health, palliative care and hospice services are available through an array of non-tribal agencies to anyone that qualifies. SCF has recently taken over the home health services previously offered under contract and are providing these services to tribal beneficiaries in Anchorage.

Nursing Home: 224 nursing home beds at Providence Extended Care and 90 beds at Mary Conrad Center, all non-tribal.

2.5.2 Anchorage Service Unit – Matanuska-Susitna Valley – Southcentral Foundation, Knik Tribe and Chickaloon Native Village

OAA: Congregate and home delivered meals and transportation are available through the Palmer, Wasilla and Houston Senior Centers.

Independent Senior Housing: There are 236 independent senior apartments in the Mat-Su Borough, none operated by tribal housing authorities.

PCA: There are numerous agencies that provide both agency based and consumer directed personal care services, all non-tribal providers. Once fully established, SCF is considering expanding their elder programs into the Mat-Su area.

Medicaid Waiver/HCBS: There are numerous agencies providing comprehensive HCB services including adult day care, respite, care coordination and caregiver support. The Chickaloon Village Traditional Council provides some services to elders through grants and tribal funding.

Assisted Living: There are 104 assisted living beds in 20 Mat-Su area homes, and 82 beds in the Palmer Pioneers Home, all non-tribal.

Home Health: Home health, hospice and palliative care services are available through Valley Hospital and Hospice of Mat-Su.

Nursing Home: No nursing home beds, 4 swing beds at West Valley Medical Campus.

Rural Anchorage Service Unit

2.5.3 Aleutian/Pribilof Islands Association and Eastern Aleutian Tribes, Inc.

OAA: With OAA funding, APIA provides monthly food boxes to elders in the region. The senior center in Unalaska receives OAA funding for meals and transportation.

Independent Senior Housing: There are 14 independent senior apartments on St. Paul Island and 15 units in Unalaska.

PCA: Eastern Aleutian Tribes (EAT) and Aleutian/Pribilof Islands Association (APIA) are working to develop personal care and Medicaid waiver services. Access Alaska is providing some consumer directed personal care services in the region.

Medicaid Waiver/HCBS: APIA received a grant from IHS to assist with the development of reimbursable long-term care services, including those offered under the Medicaid waiver. They are collaborating with EAT on an elder needs assessment and program development. APIA has submitted the necessary paperwork for enrollment to provide Medicaid waiver services.

Assisted Living: There are no assisted living homes in the region. APIA, EAT and the Aleutian Housing Authority have each designated some funding to study the options for residential long term care in the region.

Home Health: Home health and palliative care are not available.

Nursing Home: No nursing home beds, no swing beds.

2.5.4 Kodiak Area Native Association

OAA: The Senior Citizens of Kodiak, Inc. (SCOK) provides congregate and home delivered meals and caregiver support. Kodiak Area Native Association (KANA) receives OAA funding and collaborates with SCOK to provide meals in regional villages.

Independent Senior Housing: Kodiak has 60 units of independent housing, 15 operated by the tribal housing authority.

PCA: Providence Kodiak Island Medical Center provides agency based personal care services to seniors in Kodiak. Kodiak Island Housing Authority (KIHA) contracts with Access Alaska to provide consumer directed personal care services in Kodiak and the surrounding villages.

Medicaid Waiver/HCBS: Care coordination is offered by both SCOK and KIHA. SCOK also provides adult day care, respite and caregiver support.

Assisted Living: 12 units of assisted living are available within Bayview Terrace apartments, a privately owned senior apartment complex.

Home Health: Home health services are provided in Kodiak through Providence Kodiak Island Medical Center. Ongoing palliative care and hospice are not available.

Nursing Home: 19 nursing home beds and 6 swing beds in Kodiak operated by Providence Kodiak Island Medical Center.

2.5.5 Kenai Peninsula – Chugachmiut, Kenaitze Indian Tribe, Ninilchik Traditional Council, Seldovia Village Tribe, Native Village of Tyonek

OAA: There are several senior centers on the Kenai Peninsula where congregate and home delivered meals and transportation are available. The Kenaitze Tribe receives OAA funding for meals and other services for elders in Kenai and Soldotna. Chugachmiut receives OAA funding for food boxes to village elders. Seldovia Village Tribe and Ninilchik Traditional Council receive OAA funding for congregate and home delivered meals.

Independent Senior Housing: There are 131 independent senior apartments in the Kenai Peninsula Borough, in the communities of Kenai, Homer, Sterling, Seward and Soldotna. Cook Inlet Housing Authority has additional apartments in Kenai, Ninilchik and Seldovia. North Pacific Rim Housing is constructing tri-plexes in regional villages to use as multi-use supportive housing for elders and others with disabilities.

PCA: There are numerous non-tribal agencies that provide both agency based and consumer directed personal care services.

Medicaid Waiver/HCBS: There are numerous agencies providing comprehensive HCB services including adult day care, respite, care coordination and caregiver support. Chugachmiut provides some supportive services through their CHR program.

Assisted Living: There are 112 assisted living beds in 17 Kenai Peninsula homes, located in the communities of Kenai, Soldotna, Kasilof, Homer, Sterling, and Seward. None are tribally operated.

Home Health: There are several non-tribal agencies on the Kenai Peninsula offering home health, palliative care and hospice services.

Nursing Home: Heritage Place in Soldotna has 60 beds, South Peninsula Hospital in Homer has 25 beds, and Wesley Rehabilitation Center in Seward has 66 beds.

2.5.6 Valdez-Cordova-Glennallen – Chugachmiut, Copper River Native Association, Mt. Sanford Tribal Consortium, Native Village of Eyak, Valdez Native Tribe

OAA: Valdez senior center receives OAA funding for meals and transportation in Valdez. Cordova Community Medical Center provides meals and transportation in Cordova in coordination with Eyak, who also provides supportive services for elders. Copper River Native Association and Upper Tanana Development Corporation receive OAA funds for services in the Glennallen/Copper Center area.

Medicaid Waiver/HCBS: There are a few agencies providing Medicaid waiver based HCB services in Valdez, Glennallen and Cordova. Services include care coordination, respite, chore and caregiver support.

Independent Senior Housing: There are 57 independent senior apartments in the region. 20 in Glennallen/Copper Center operated by the Copper River Basin Regional Housing Authority, 15 in Valdez and 22 in Cordova that are not tribally owned.

PCA: There are two agencies in Valdez providing consumer directed personal care to the Valdez/Glennallen area, and one in Cordova. None are tribal providers.

Assisted Living: There are no assisted living beds in the region. Copper River Basin Regional Housing Authority is researching the feasibility of assisted living development.

Home Health: Home health and palliative care are not available.

Nursing Home: There are 10 nursing home beds at Cordova Community Medical Center. Valdez Community Health Center just opened a new hospital with 10 nursing home units in 2004.

Community Based Long Term Care Services – Profile by Region

Key: P = Provided by Hospital, L = Provided by Local Community, N = Not Provided

	Transportation/ Meals OAA		Independent Housing		PCA		Waiver		Assisted Living		Home Health/ Palliative Care		Swing Beds		Nursing Home	
	Provided	Comments	Provided	Comments	Provided	Comments	Provided	Comments	Provided	Comments	Provided	Comments	Provided	Comments	Provided	Comments
Barrow Service Area – ASNA	L	Provided in Point Hope, NSB, IVIB	L	Barrow 37 units. Future 5 units in Point Hope, Anaktuv. Pass, Kaktovik, Wainwright, Nuiqsut	L	Provided by Hope Community Resources (new in 2005)	N		L	Barrow (7) units; closing 6/05	N		N		N	
Bristol Bay Service Area – BBAHC	L	Dillingham Senior Center, BBNA Meals in Schools	L	Dlgham 15, Naknek 10, New Stu 5 under constr.	L	Private consumer direct service	L	BBNA: Care coordination provided to all villages	L	Dillingham 15 units	P	BBAHC-home health & palliative care: Helping Hands	P	4 swing beds	N	
Kotzebue Service Area – Maniilaq	P	Kotzebue: Meals and Transportation	L	Kotzebue 15	P	Limtd $/staff. Sporadic svcs. Reg difficulties	N	Will implement waiver services in 2005	P	Maniilaq 20; revising services	N		P	Recently designated 6 swing beds in hospital	N	Plans for nursing home
Norton Sound Service Area – NSHC	L	Nome Community Center: Meals and Transportation	L	Nome 19+17	P	Limtd $/staff. Sporadic svcs. Reg. difficulties	P	Inconsistent: staff turnover	N		N		N		P	15-bed skilled nursing facility in hospital
Anchorage Service Area – SCF/MOA	P	SCF: Meals and Transportation	L	268 CHA	L	Agency Based and Consumer Direct	P	SCF	L	No tribal	P	SCF	NA		L	PEC: 224, MC: 90
Anchorage Service Area – SCF/Mat-Su	L	Palmer, Wasilla and Houston	L	236 Non-tribal	L	Agency-based and consumer direct	L	Available	L	Available	L	Valley Hospital	L	4 Valley Hospital	N	
Mt. Edgecumbe & Annette Island Service Areas – SEARHC/MIC	L	Available in many communities	L	Available	L	Private consumer direct and agency-based services	L	SESS, Cornerstone, Center for Community	L	Juneau, Ketchikan, Sitka, Petersburg, Wrangell	L	Juneau, Ketchikan, Sitka, Petersburg, Wrangell	L	Swing beds in Wrangell, Petersburg, Sitka	L	Juneau 44, Ketchikan 46, Petersburg 14, Sitka 15, Wrangell 14
Yukon-Kuskokwim Delta Service Area – YKHC	L	City/ONC Sr. Center: Meals & Trans. Mt. Village, Aniak: Meals	L	Bethel 23+16	P	Bethel and most villages	P	Bethel and most villages	N	18 units to open 2006	N		P	3 swing beds in hospital	N	Plans for nursing home
Interior Service Area – TCC	L,P	Fairbanks Senior Center FNA, TCC Villages	L	FAI 176, North Pole 24, Fort Yukon 4, Nenana 15	L,P	Fairbanks villages	L,P	Fairbanks villages	L	FAI, N. Pole, Tanana, develop in Galena	L	Fairbanks only	N		L	Denali Center 90 wait list
Rural Anchorage Service Unit																
Kodiak – KANA	L,P	SCDK Kodiak and Villages	L	Kodiak 60	L	KIHA Providence	L	Kodiak: SCDK; other villages: KIHA	L	Kodiak 12	L	Kodiak-Providence	L	6 swing beds	L	79 beds
Kenai Peninsula	L	Non-tribal centers throughout	L	Available	L	Available, non-tribal	L	Available, non-tribal	L	Available, non-tribal	L	Avail: S. Penin., Central Penin.	L	Hom. 4, Sold. 8, Sew. 2	L	Sold. 60, Hom. 25, Sew. 66
Aleutians – APIA/EAT	P	Food boxes 167, no congregate	L	St. Paul 14, Unalaska 15. Feasibility study for more	N	In development: 2005	N	In development: 2005	N	Feasibility study	N		N		N	
Valdez-Cordova-Glennallen	L	Valdez Senior Center, Cordova CR/Glennallen	L	Glennallen 20, Valdez 15, Cordova 22	L	Glennallen, Valdez, Cordova	L	Available	N	CR is planning	N		L	Cordova 13	L	Cordova 10, Valdez 10
Bianna Subregion – Nilavena	L	BBNA	N		L	Private	L	BBNA	N		L	BBAHC	N		N	

Chapter 3

3.1 Health Status

"I worked in the clinic for years and years. If we go to the city, we don't exercise. Life in the village is harder, but it protects the elders. People living in the bush, they have to work, they are physically strong."
— Rose Ambrose, Huslia, ANEHAC

Health status is the collection of measurable data about the overall health of a population that can provide a picture of general health and disability and be compared to similar data collected on other populations. Typical health status measurements include life expectancy, causes of death, the presence of chronic health conditions, and self-reported health status. This study focuses on data that is available through the Indian Health Service data system, RPMS, and includes mortality, chronic illnesses, and disability. Some of the other measures are included in a report by the National Resource Center for American Indian, Alaska Native and Native Hawaiian Elders (Saylor and Douchette 2004). In addition to a discussion on all measures of health status, the NRC report highlights data on self-reported health status by a small sample of Alaska Native elders surveyed by individual tribes and analyzed by the University of North Dakota. Findings indicate that compared to the U.S. general population and other tribal groups, fewer Alaska Native elders report their health as good or excellent and nearly one half the sample indicated their health is poor.

However, health status of Alaska Native people overall has improved over the years, largely due to the increased availability of medical care and advances in medical science. The increase in life expectancy among Alaska Natives to 69.5 years at birth has already been mentioned. This is primarily due to the reduction in infectious diseases and acute illnesses as a major cause of death. The increasing incidence of chronic disease in the Alaska Native population is often associated with an increase in functional limitations and more years of disability. This chapter will discuss that shift and how it relates to the current and future needs of Alaska Native elders.

Table 3 presents the actual number of deaths by leading causes for different age groups of Alaska Native elders. Figures 2 – 4 depict age specific mortality rates per 100,000 for these three age groups and show a comparison to the US White population. Note the change in leading causes with increased age. Although unintentional injuries is the leading cause of

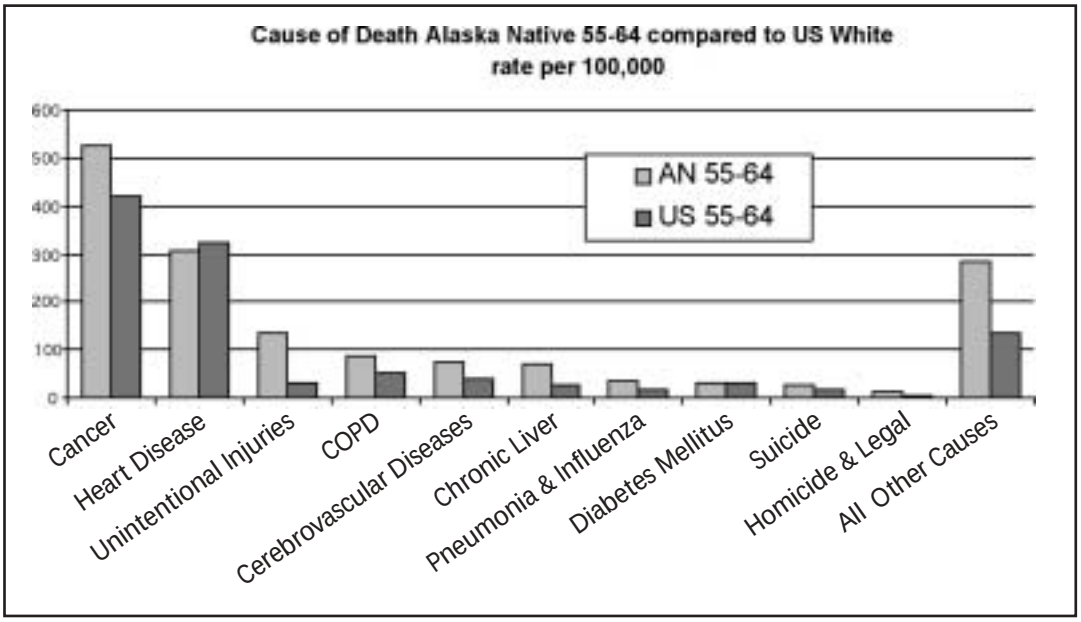
death for the Alaska Area of IHS, this shows a decrease in deaths attributed to unintentional injuries as one ages. The other top four causes of death are comparable to the Caucasian older population in Alaska, and in the lower 48. The major cause of death in the 55-64 age group is cancer followed by heart disease and injury. In the 75+ age group the leading cause shifts to heart disease and injury drops below Chronic Obstructive Pulmonary Disease (COPD), cerebrovascular diseases and pneumonia.

Table 3. Leading Causes of Death by Age 1989-1998, Number of Deaths

Cause	55-64	65-74	75+	Total
Cancer	256	296	293	845
Heart Disease	151	234	423	808
Unintentional Injuries	67	35	39	141
COPD	43	67	111	221
Cerebrovascular Diseases	36	39	147	222
Chronic Liver Disease	34	13	3	50
Pneumonia & Influenza	17	22	89	128
Diabetes Mellitus	15	23	35	73
Suicide	13	5	0	18
Homicide & Legal Intervention	7	4	1	12
All Other Causes	139	180	363	682
Total	778	918	1504	3200

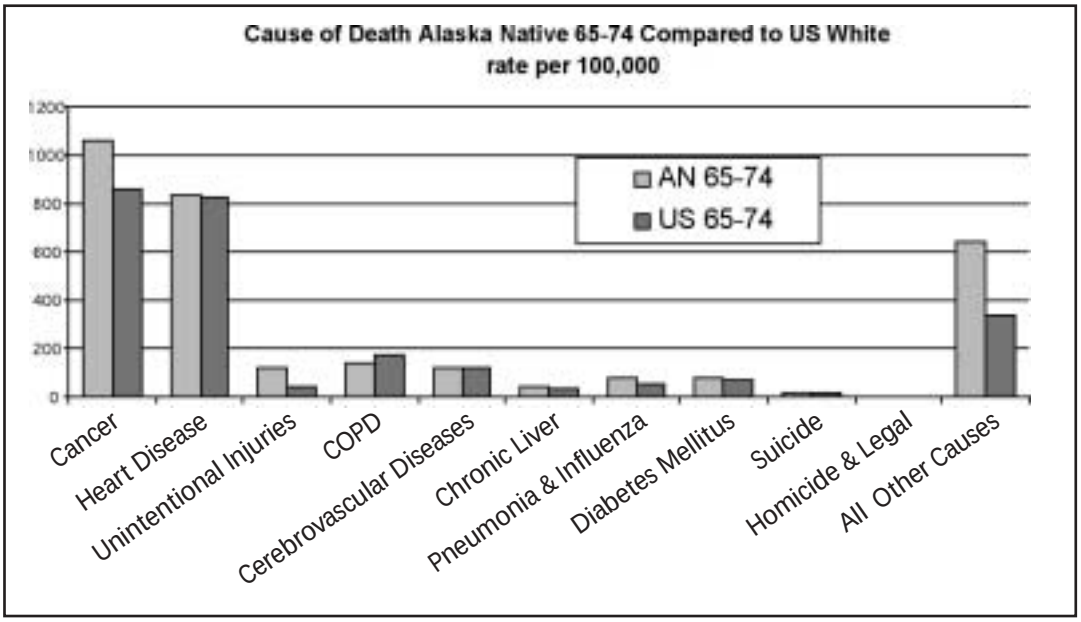
Source: Lanier, et.al. 2002. Alaska Native Mortality 1979-1998.

Figure 2. Age Specific Mortality Rates for Age 55-64



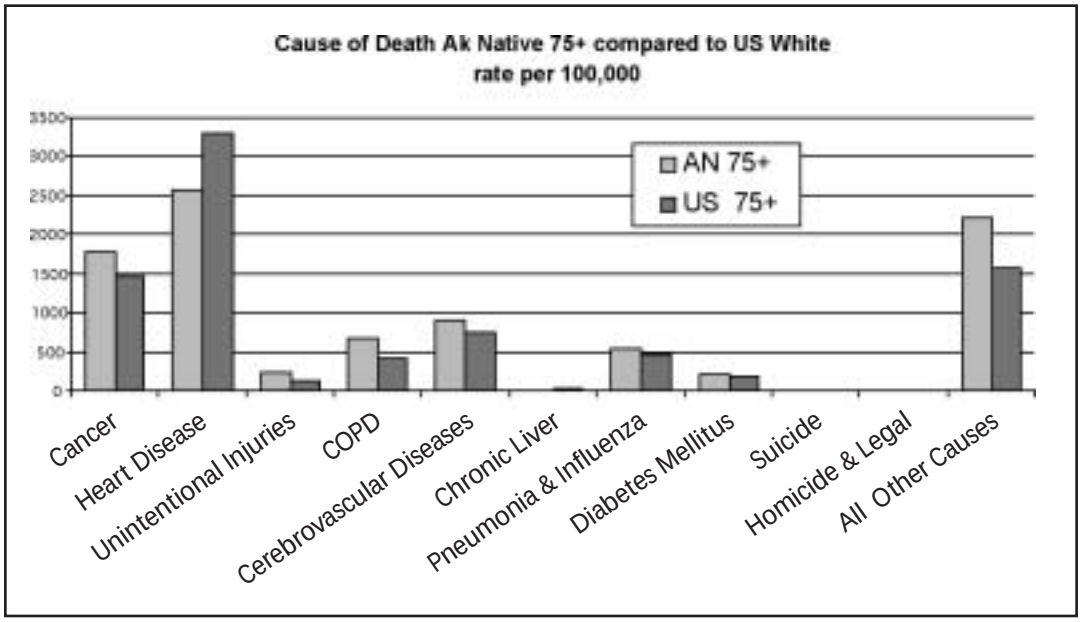
Source: Lanier, et.al. 2002. Alaska Native Mortality 1979-1998.

Figure 3. Age Specific Mortality Rates for Age 65-74



Source: Lanier, et.al. 2002. Alaska Native Mortality 1979-1998.

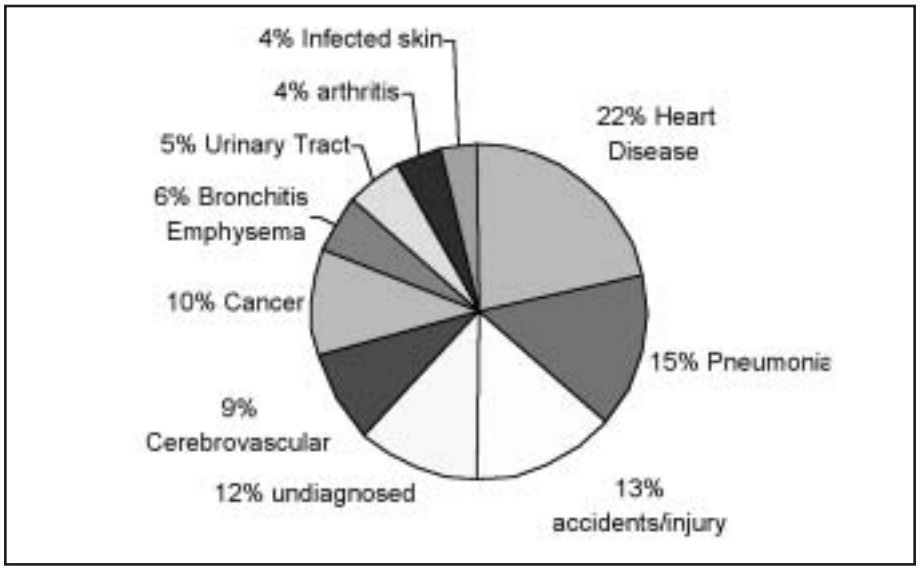
Figure 4. Age Specific Mortality Rates for Age 75+



Source: Lanier, et.al. 2002. Alaska Native Mortality 1979-1998.

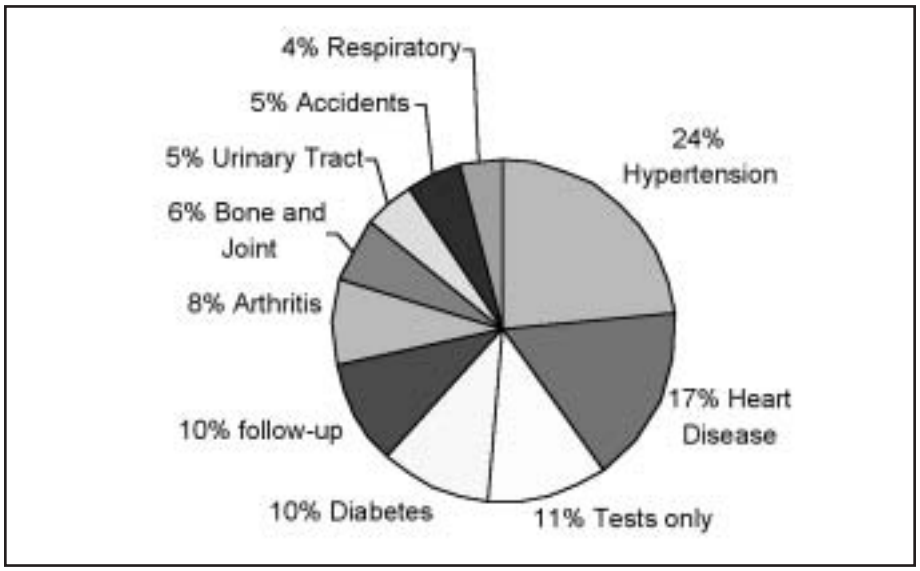
Figures 5 and 6 present the leading causes of hospitalizations and outpatient visits for the elder population. These correlate to the major causes of death and indicate that there is a high incidence of diseases of the heart, circulatory and respiratory systems. Reports indicate that Alaska Native people have a higher prevalence of risk factors for heart disease, such as smoking, high blood pressure and excess weight (DHSS 2001). The COPD death rate in Alaska Natives is almost double the rate for whites. Furthermore, Healthy Alaskans 2010 states that in addition to being one of the 10 leading conditions related to restricted activity, COPD usually results in years of disability before causing death. Increased levels of disability can also be found in individuals experiencing a heart attack or stroke.

Figure 5. Alaska Area Leading Causes of Hospitalization for Ages 65+ FY92-FY97 in Alaska Native Health Care Facilities



Source: IHS Inpatient/Outpatient Reporting System in Albuquerque, Direct Inpatient Report 2C; RPMS.

Figure 6. Alaska Area Leading Causes of Outpatient Visits for Ages 65+ FY92-FY97 in Alaska Native Health Care Facilities



Source: IHS Inpatient/Outpatient Reporting System in Albuquerque, APC Report 1C

Table 4 indicates the top ten conditions accounting for the highest number of hospital days for Alaska Natives 65 and over during a two-year period. Although accidents and injuries are still the second leading cause, this table exemplifies the importance of chronic illnesses in this population.

Table 4. Alaska Area Inpatient Days by ICD9 Recode FY2001-2002

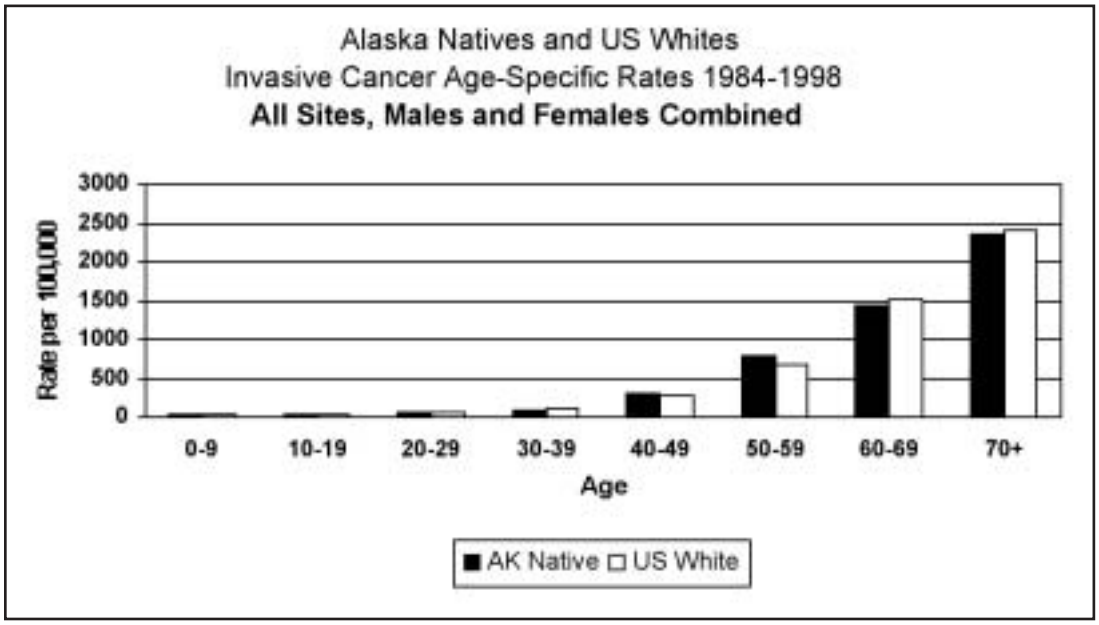
Condition	Hospital Days
Cerebrovascular Disease	3263
Accidents & Injuries	2908
Heart Disease	2304
Malignant Neoplasms	2020
Pneumonia	2015
Psychoses	1919
Bronchitis/Emphysema	1418
Urinary Tract Diseases	890
Bone/Joint Disorders	867
Arthritis	835

Source: NPIRS Report Inpatient 2C.

3.2 Cancer and Alaska Native Elders

Cancer is the leading cause of death for Alaska Native elders. The Office of Alaska Native Health Research (OANHR) at ANTHC has several publications that utilize tracking data from the Alaska Native Tumor Registry, a statewide cancer surveillance in use since 1969. Age specific cancer mortality rates show that Alaska Native elders have a a higher proportion of deaths from all types of cancer than the U.S. white population (Lanier, et. al. 2002). Although cancer mortality is higher in Alaska Native elders than in U.S. whites, the incidence rate of cancer per 100,000 population is very similar (Figure 7) (Lanier, et.al. 2001). Data from the Tumor Registry indicates that between the years of 1969 – 1998 the number of cancer cases has tripled, and more people are surviving cancer. Specific cases of cancer for the years 1984 – 1998 indicate that by far the highest numbers of people with cancer are elders: out of a total of 3097 cases of cancer, 30% are 70 and older, 25% are between 60 and 69, and 21% are 50 to 59 years old. Therefore, as the Alaska Native population continues to age and live longer we can also expect an increase in the incidence of cancer, and will need to factor that into planning for elder services.

Figure 7. Age Specific Rates of Cancer Alaska Natives vs. U.S. Whites



Source: Office of Alaska Native Health Research, ANTHC, Feb. 2005

3.3 Diabetes and Alaska Native Elders

The prevalence of type 2 diabetes increases with age. Data from the diabetes registry of the ANTHC Diabetes Program, which is derived from patient medical records and includes information on all Alaska Natives receiving care from a tribal facility, show an increase of 215% in the presence of diabetes in Alaska Natives from 1990 – 2003. In Alaska Natives over 55 incidence of diabetes increased 185%, and in the age group that will become elders within the next ten years, those 45 - 54, incidence has increased 230%. This data predicts the continuing presence of diabetes in the Alaska Native elder population, and with that a matched increase in disabilities related to diabetes. Figure 8 shows the age distribution of diabetes cases in Alaska.

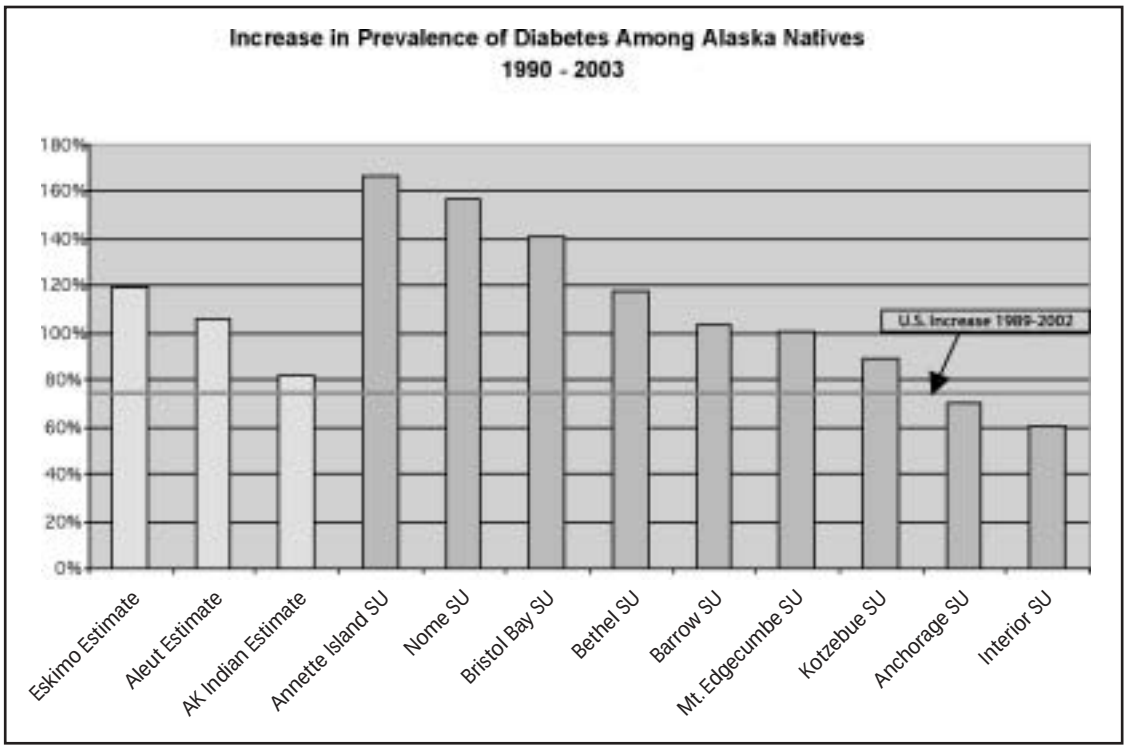
Figure 8. Number of Diabetes Cases by Age in 2003

Source: ANTHC Diabetes Program, Feb. 2005

Studies in the lower 48 indicate that, "Diabetes complications, especially end-stage renal disease and lower extremity amputations, are major causes of morbidity and mortality among older Indians" (Jackson 2000). Although there are still fewer cases of diabetes in Alaska, compared to American Indian populations, the prevalence continues to increase among Alaska Natives and diabetes and its complications, including lower extremity amputations can lead to an increased number of functionally impaired elderly.

Regional and cultural differences in diabetes prevalence can also be found. The Tsimshian Indians on Annette Island have the highest prevalence and the Eskimo populations of western and northern Alaska have shown the greatest increase in prevalence (Schraer, et.al. 1997). Figure 9 shows the increase in prevalence by service region and major cultural group, compared to the U.S. general population.

Figure 9. Prevalence of Diabetes by Service Region



Source: ANTHC Diabetes Program, Feb. 2005

With the increase in life expectancy for Alaska Natives, the prevalence of diabetes will also rise. Factors influencing the increased incidence are associated with lifestyle changes and the shift from traditional lifestyles with a predominantly subsistence diet and plenty of exercise, to a western lifestyle that includes more processed foods, unhealthy fats, simple sugars, and less physical activity. Studies among the Zuni Indians show that a diabetes program that includes both diet and exercise modifications can reduce the incidence of insulin usage in their older populations (Heath et.al. 1987; 1991). Diabetes prevention activities such as those initiated under the Grants for Special Diabetes Programs for Indians will assist tribal organizations in combating the effects of this illness. All Alaska tribal health organizations participate in this program, which includes educational and activity programs and screening to identify people with diabetes at an early stage. These activities can help mitigate the functional decline in the elder population that has diabetes.

3.4 Pharmaceuticals and Alaska Native Elders

Much has been written about medications and the general population of elderly. The problems include polypharmacy, differing dosages with aging patients, the use of psychotropics and antipsychotics for confusion and dementia, double doses of the same medication under a different brand name, and the consequences of missed or doubled doses by the elderly themselves. In a meeting of the Alaska Native Elder Health Advisory Committee, several

participants recounted stories in their communities and indicated that there needs to be more monitoring of medication for elders. Participants cited instances of over medication, either a mistaken self-overdose or higher than necessary doses prescribed resulting in problems such as dementia and falls. A visit to elders' homes can yield trays or bags of medications accumulated over years of doctor visits and never thrown away. The Pioneers' Homes have instituted a medication review program for all new residents using pharmacists trained in geriatrics, and have offered geriatric pharmacological education to pharmacists in rural communities through a grant from the State DHSS. There is no data on the frequency of self-medication errors in the elderly, and the outcome, which indicates the need for substantive research in this area.

3.5 Trauma and Alaska Native Elders

Trauma data was collected from the State Trauma Registry, the Alaska State Troopers and Adult Protective Services. There are many different types of trauma including fire, vehicular and pedestrian accidents. This report analyzes falls, which constituted the highest number of cases at over 50%, suicide, and assault, especially as it relates to elder abuse.

3.5.1 Falls

During the time period of 1996 – 2000 there were 694 falls reported in Alaska Native people 55 and older. There were falls in all areas of the state with the majority in Southeast, the Yukon-Kuskokwim Delta and Anchorage. Most of the falls, 62%, occurred in the home. In about one-fifth of the cases alcohol consumption was determined to be a factor. These falls resulted in 4,829 days of hospitalization, with an average of seven days per incident and a range of 0 to 113 days. The following table indicates the number of hospital days for the falls. Final disposition of the falls indicate that 16 people died either as a result of the fall or related cause and 44 were discharged to a skilled nursing facility.

Table 5. Fall Related Hospital Days 1996-2000

None	1-3 days	4-7 days	8-14 days	15-21 days	22-28 days	> 4 weeks
84	223	159	139	50	19	20

Source: Alaska Trauma Registry

Falls are the leading cause of injury related emergency room visits for the 65 and older population in all of the U.S. People experiencing falls in their later life show a increasing decline in functional abilities and are at greater risk for institutionalization (Fuller 2000). Because of the high cost of falls, in both public health dollars and personal loss of independence and mobility, there are a lot of studies dealing with fall prevention strategies in public health and medical journals. However, there is little information about falls specifically in Alaska Native or American Indian elders. In one 1983 study on the Hopi Reservation, findings included that

most of the injuries occurred in or near the home. This led authors to the conclusion that an assessment of elders' homes to identify hazards would help prevent falls and the subsequent loss of function (Lindeman 2003).

3.5.2 Suicide

Table 3 above does include suicide as one of the leading causes of death for this population. However, other sources indicate that although Alaska's suicide rate is alarmingly high in younger age groups, the suicide rates in elder Alaska Natives and American Indians are considerably lower than the 55 and over population of U.S. all races or white, especially for males (IHS 1998-99). During the years 1996 – 2000 there were 30 suicide attempts in Alaska Natives 55 and older recorded in the state trauma registry. Of those, the greatest number (22) were female. In the majority of cases (again 22), the method was contributed to a drug overdose, either with prescription or over the counter medications.

3.5.3 Elder Abuse

Elder abuse is a difficult topic to address, but it is present in Alaska Native and American Indian communities. When the types of elder abuse are discussed in community trainings or meetings, following the initial discomfort with the topic, attendees invariably want to talk about instances they have experienced or heard about, and are looking for ways to address the problem in their communities. The U.S. Administration on Aging began to engage groups of American Indian elders in the lower 48 in 2004 in discussions about elder abuse in their communities. UAA's NRC began similar discussions in 17 Alaska communities and will continue to bring awareness to the topic here in Alaska. There are many forms of elder abuse, listed below, that include financial exploitation and psychological abuse that would not necessarily present to a health care facility. Some tribes in the lower 48 are taking an active role in preventing elder abuse; for example, the Navajo Tribe has a program where the tribe mediates with families where abuse has been reported. This mediation allows for both parties to save face, and for the elder to remain in the family environment if desired, while also holding the perpetrator accountable for his/her actions, and keeping an eye on the situation.

Elder abuse data were collected from three sources: Alaska State Trooper encounter database for the years 2001 – 2003; Adult Protective Services (APS) database (excluding Fairbanks and Juneau) for the time period of October 2003 – December 3, 2004; and the Alaska State Trauma Registry for the years 1996 – 2000. The data shows that elder abuse is present in all regions of Alaska.

Of the Alaska State Trooper data, there were 141 cases clearly identified as domestic violence. Some of the other cases could have been, for example 11 forgery calls, but were not identified as such by the responding officer. Twelve additional reports were for welfare checks on an elder, but not recorded as domestic violence. Requests for welfare checks can also be an indi-

cator of abuse, exploitation or self-neglect. In 132 of the 141 cases the perpetrator was identified as male. The victims in these cases were evenly divided 66 females ranging in age from 55 – 83, and 66 male victims in the same age range. In the cases with a female victim the perpetrators' age ranged from 14 – 76 with a median of 38. For the 66 male victims the age range of the perpetrator is 14 – 54, with a median of 34. Alcohol or another substance was identified as a factor in 114 of the 132 encounters. Nine reports indicated a female perpetrator, with an age range of 18 – 50. Three of the victims were female and six were male. Victims range in age from 55 – 76, and alcohol was a factor in seven cases.

Adult Protective Services records 159 cases involving Alaska Native elders from October 1, 2003 to December 3, 2004, not including data from the Fairbanks and Juneau caseworkers. The following table outlines the cases and types of abuse. Some cases were a combination of types so the total exceeds 159.

Table 6. Types of Elder Abuse

Type of Abuse	No. of Cases	Explanation of Abuse
Financial Exploitation	65	The unjust or improper use of another person or their resources
Self-Neglect	44	The act of omission by vulnerable adults that could result in the deprivation of essential services
Neglect	33	The intentional failure of a caregiver to provide essential services
Physical Abuse	26	The intentional or reckless non-accidental infliction of pain or injury
Guardianship	10	Petition for guardianship for any vulnerable adult deemed incompetent who doesn't have family member to petition
Mental Abuse	10	The intentional or reckless non-accidental infliction of mental distress
Sexual Abuse	2	Sexual assault

Source: State of Alaska, Adult Protective Services

Data on assault from the Alaska Trauma Registry is more problematic to determine abuse unless it is indicated in the description that the injury was inflicted by a family member. Nonetheless, the assault reports include 66 incidents in people over the age of 55 for the five-year time period 1996 - 2000. Of those, 62% are male, 38% female. There are two fatalities and 554 total hospital days resulting, and six people sustained permanent disability. The ages of the victims range from 55 – 87, and half of the injuries occurred in the victim's

home. Over 80 % of the cases include alcohol as a factor. 22 of the cases, or one third, clearly indicate a family member as the abuser.

Due to the limitations, it is difficult to portray the extent of abuse among Alaska Native elders with these data. Using the Alaska State Trooper data and comparing that figure to the total 55 and over population of Alaska Natives in all areas except Anchorage, a minimum prevalence rate of 11.6 per 1,000 is determined.[1] Comparing the Anchorage 60 and over population to the total number of cases reported to Adult Protective Services produces a higher number of 43.6 per 1,000.[2] Because elder abuse is underreported the true number is likely higher, but this provides some baseline data to compare at a later date once more data becomes available. It is interesting to note that the data from the trauma registry, which covers a five-year period and is reported to the state by health care providers, is considerably less than the other two sources. It could be that most abuse cases do not present themselves to a health care provider, given that the highest number of cases reported to Adult Protective Services are for financial exploitation; or it could indicate that health care providers are not adequately trained to screen for abuse in the elderly. Members of the ANEHAC commented about the need for more information about the extent and nature of abuse among Alaska Native elders. The NRC will be addressing this issue and the implications for service delivery in the coming years.

[1] This calculation of population data does not include Anchorage, as most Anchorage cases would be covered by the Anchorage Police Department.
[2] Anchorage population estimates include those 60 and over to correlate with the APS data.

Chapter 4

4.1 Statewide Alaska Native Elder Service Utilization

"We have a lot of work ahead. In my own area, we have health aides on force for 29 years, and we need to meet their [the elders] needs. We don't want them to leave the areas; we are going to work to keep them in their areas."

— Dan Karmun, Nome, ANEHAC

This chapter will quantify the number of Alaska Native elders receiving long term care services paid by Medicaid. Since much of long term care for Alaska Native elders is paid by Medicaid, this is a good tracking mechanism for the use of nursing home and home and community based services. Other long term care services may be available through tribal health providers with other funding, but they are not enumerated here. Additional information on long term care placement of Alaska Native elders was compiled by the Social Work Department of the Alaska Native Medical Center (ANMC), and is included in the analysis. These data include the last four years of discharge data and offer a picture of service utilization not available through the Medicaid data.

Comparing state data on Medicaid enrollments in 2003 with population estimates indicates that 74% of Alaska Native elders 65 and over are currently enrolled in Medicaid through the Division of Public Assistance. Additionally, 39% of the Alaska Native population between 55 and 64 are receiving Medicaid due to disability status. Although many elders are eligible for Medicaid because they lack retirement income, this is not true for all. In some areas, especially the Aleutian region, employment by the federal government and subsequent retirement income prohibits elders from being eligible for Medicaid. This does not necessarily mean, however, that they have enough to pay for services themselves. There is no geographic differential on the Medicaid income limits, and no accounting for the high cost of living in rural areas. So, for example, an elder on St. Paul Island, who has a retirement income of $1200 per month is not eligible for Medicaid. But once the elder pays $400 – $500 for utilities and $800 for food, there is nothing left to pay for additional service needs.

4.2 Nursing Homes

There are currently 749 nursing home beds in Alaska. Through interviews with nursing home administrators it is estimated that at any given time approximately 150 – 155 are

Alaska Native residents. The total number of Alaska Native residents increases when looking at the data over a one-year period. Table 7 shows the number of Alaska Native nursing home residents whose payments were through Medicaid during four fiscal years, defining the total residents and the average number of days per year that each resident is in a nursing home. Homes with the highest number of days per year, indicating a longer stay per resident, are Sitka Community Hospital, Providence Kodiak Island Medical Center, and Heritage Place in Soldotna.

Table 7. Alaska Native Medicaid Nursing Home Residents

	FFY 2000	FFY 2001	FFY 2002	FFY2003
Total Alaska Native Residents	296	275	270	277
Average days per year	285	257	251	241

Source: State of Alaska, Department of Health and Social Services, Division of Health Care Services

The homes with the highest proportion of Alaska Native elders are Quyana Care (95-100%), Denali Center (30%), and Providence Extended Care (25%). Data from the State Medicaid records indicate that the percentages are higher during the four-year period reported in Table 8.

Table 8. Alaska Native Residents in State Nursing Homes 2000-2003

Facility	Average Total Number of Residents	Average Number of Alaska Native Residents	% Alaska Native/ American Indian
Ketchikan General Hospital LTC	19	9	47%
Wrangell Medical Center LTC	19	5	26%
Cordova Community Hospital LTC	10	5	50%
Petersburg Medical Center LTC	18	1.5	8%
Providence Kodiak Island Medical Center LTC	22	11	50%
South Peninsula Hospital LTC – Homer	31	5	16%
Quyana Care Center – Nome	21	21	100%
Wildflower Court – Juneau	58	19	33%
Wesley Rehabilitation Care Center – Seward	42	21	50%
Providence Extended Care	296	93	32%
Denali Center – Fairbanks	114	49	43%
Sitka Community Hospital LTC	12	8.5	71%
Heritage Place – Soldotna	66	4	6%
Mary Conrad Center	126	27	21%

Source: State of Alaska, Department of Health and Social Services, Division of Health Care Services

Information from DHSS, Division of Health Care Services on the level of care for Alaska Native nursing home residents in February 2004 indicates that out of 102 residents, 94 are intermediate level of care and 7 are skilled nursing level of care. Intermediate care, as defined in regulation, is for people who do not need skilled nursing or hospitalization, and includes observation, assessment and treatment of people with a long term disability whose condition is relatively stable. Skilled care is defined as people who need skilled nursing or structured rehabilitation provided by licensed personnel. It also includes observation, assessment and treatment, but for patients whose condition is unstable and modifications may be needed.[1] Medicaid waiver clients would typically fall into the intermediate care category and could receive these services at home or an alternative setting.

[1] 7 AAC 43.180

Rural hospitals also have the option to provide swing beds for more long term stays. For FFY2003 and FFY2004 there were seven Alaska Native patients in swing bed status. One individual actually resided in a swing bed for the full two years, because there is no nursing home available in the region. Except one other elder with a stay of over 200 days, the swing bed utilization ranged from 7 to 51 days, with an average of 22 days.

Table 9 displays the number of placements to nursing homes or other facilities by the ANMC Social Work Department for the 55 and over age group in the last four years. This does not reflect total placement in facilities, because some placements are done by families or the regional hospitals. It does, however, provide some information about the types of facility discharges that are occurring. Table 10 provides the same information for those under 55 for comparison. Additionally, the high number of people age 55 and under who were discharged to assisted living may be on Adults with Physical Disabilities waivers, therefore their assisted living care is also reimbursed by Medicaid.

Table 9. ANMC Social Work Discharge Placements for 55+

Facility Type	2001	2002	2003	2004	Total
Nursing Home	33	43	25	19	120
Rehabilitation-Short term placement	16	18	12	20	66
Assisted Living	22	45	31	25	123
Other – family, PCA, VA Domicillary, etc.	2	3	0	1	6
Age range of patients	55 – 103	55 – 95	56 – 97	55 – 92	
Average age of patients	71 years	73 years	74 years	71 years	

Out of the 120 nursing home placements for individuals over 55 during these four years, the majority 72% went to Providence Extended Care, with another 15% at Mary Conrad Center. The remaining 13% went to a variety of homes in Southeast and the small nursing homes attached to rural hospitals. Most of the rehabilitation discharges were to Alaska Regional Hospital Rehab Center. Rehabilitation is typically shorter term placements for skilled therapy to allow the patient to regain function and return to their home. However, some of these placements could later have been referred to nursing homes if improvement in function was not seen. A higher percentage of the under 55 group were sent for rehabilitation.

Table 10. ANMC Social Work Discharge Placements for the Under 55 Age Group

Facility Type	2001	2002	2003	2004	Total
Nursing Home	6	6	7	9	28
Rehabilitation-Short term placement	20	8	15	6	49
Assisted Living	16	27	26	14	83
Other – family, PCA, VA Domicillary, etc.	1	1	0	0	2
Age range of patients	21 – 54	21 – 54	16 – 54	18 – 54	
Average age of patients	44 years	43 years	47 years	39 years	

Table 11 breaks down the number of people who could be identified as placed out of their home region. The social work data does record the service area of origin, so it was possible to determine those placed out of region for areas like Barrow, Kotzebue, Norton Sound, Yukon-Kuskokwim and Bristol Bay. For the Anchorage Service Area, especially the rural regions, and Southeast Alaska determination was not possible in most instances. Therefore, this does not present the complete picture of out of region placements, but gives the readers an idea of the number of elders being displaced. Once again, this information does not include placements made by regional hospitals or families. However, it does exemplify the need for some kind of facility based care in the Yukon-Kuskokwim region, given that the greatest number of people placed out of region were from that area.

Table 11. ANMC Social Work Discharge Placement Data – Identified Out of Region

Service Area	Nursing Home	Assisted Living	Total
Barrow	3	6	9
Kotzebue	6	1	7
Norton Sound	2	2	4
Yukon-Kuskokwim	15	7	22
Bristol Bay	3	1	4
Mt. Edgecumbe & Annette Island	6	3	9
Interior	2	4	6
Anchorage	2	1	3

4.3 Other Medicaid Services

Table 12 describes the number of Alaska Natives receiving personal care services, Older Alaskan (OA) Waivers, and Adults with Physical Disabilities (APD) Waivers. APD waivers include the population ranging in age from 18 – 64, so there may be non-elders depicted. Nevertheless, these are individuals that would benefit from a tribal system approach to long term care services, as they too meet nursing home level of care. The large number of clients in some regions is indicative of the capacity for service delivery in those areas. To protect the privacy of individuals, only the areas with at least nine clients are enumerated independently. Due to the small number of clients on the APD Waiver in Bristol Bay that number is also included in the "all other" category.

Table 12. Medicaid Services FFY 2003

Service Area	PCA	OA Waiver	APD Waiver
Norton Sound	9		
YKHC	152	41	9
BBAHC	49	17	
SEARHC	110	64	53
Interior	79	34	23
SC Anchorage	152	120	104
SC Mat-Su	27	12	15
SC Kenai	35	15	18
RASU	17	17	
All Other*	5	7	18
Alaska Total	635	327	240

** Barrow, Kotzebue for waivers and PCA; Norton Sound for OA waivers; Bristol Bay and RASU for APD waivers. Source: State of Alaska, Department of Health and Social Services, Division of Health Care Services*

ANMC records from November 2001 – May 2004 show a total of 83 elders discharged to home health, personal care or waiver services. The overwhelming majority, 67%, are in the Anchorage services area, not inclusive of the Rural ASU, Kenai or the Matanuska Valley. The region with the next highest percentage (8%) is Yukon-Kuskokwim, one of the regions with a thriving home care program. Growth in these services in other areas of the state would allow for more elders to be discharged back to other regions.

4.4 Assisted Living

The ANMC social work data also includes a large number of assisted living placements. Medicaid is the primary source of funding for assisted living in Alaska. From October 2002 to April 2004 there were 229 Alaska Native people in assisted living homes whose services are paid by Medicaid. The majority (151) were in 66 different Anchorage homes. There were an additional 84 Alaska Natives in assisted living homes receiving payment assistance from the General Relief Program through Adult Protective Services in April 2004. Data on these residents does not include location of service. Three other rural assisted living homes, which serve mostly Native clientele, receive either another form of state funding through a Senior Residential Services grant in Kotzebue and Tanana, or from local funding as the home in Barrow. There were an additional 25 residents at these homes in April 2004. The Pioneers Homes, which are also licensed as assisted living homes, house very few Alaska Native residents. Out of 608 available beds there were only 44 Native residents in April 2004. Conversations with the Director of Longevity Programs indicate that they typically don't have more than 10% Alaska Native elders in residence.

Table 13 shows the number of Alaska Native elders receiving waiver assisted living services by service area for 2000 - 2003. State data about recipient residence is not necessarily accurate, as often the place of residence changes upon admission to a home and the place of origin is no longer recorded. This is why it is important to compare these data with other information available through the tribal system. Barrow does not utilize Medicaid waiver funding, but have had 7 – 9 residents in their facility in the last four years. Medicaid waiver payments to Kotzebue and Tanana have decreased over the years, but they do still operate as assisted living with approximately the same number of residents as in Barrow. In the year 2000 both Tanana and Kotzebue housed two elders from other regions paid by Medicaid. A high number of Medicaid waiver clients reside in Bristol Bay's assisted living home, and the Medicaid payments provide needed operational income. Bristol Bay has consistently had a few residents from the Yukon-Kuskokwim region.

Table 13. Alaska Native Elders in Assisted Living Paid by Medicaid

Recipient Service Area	2000	2001	2002	2003
Barrow	0	0	0	2
Kotzebue	4	2	1	0
Norton Sound	0	1	0	0
Yukon-Kuskokwim	1	3	5	4
Bristol Bay	8	9	12	10
Mt. Edgecumbe and Annette Island	1	1	3	3
Interior Alaska	14	14	20	12
Anchorage and RSU	56	47	65	70
Matanuska Valley	9	6	6	6
Kenai Peninsula	6	5	4	5
Total	99	88	116	112

Source: State of Alaska, Department of Health and Social Services, Division of Health Care Services

Once again we see the largest number of Medicaid waiver clients in the Anchorage area, since there is a greater availability of care coordination and assisted living homes. Elders receiving assisted living services outside of their region in this chart are from the Barrow, Norton Sound, and Yukon-Kuskokwim service areas. Table 11 above provides more information on the out of region residents in assisted living.

4.5 Conclusion

There are some limitations to these data, mentioned above. This analysis does not include discharge data from regional health providers, nor does it depict services that may have been provided but under a different funding mechanism. The data do show an under representation of Medicaid long term care services in some areas, especially in Northwest Alaska and the rural communities outside of Anchorage.

Chapter 5

5.1 Facility and Service Models

"[This] has been a learning experience for me. I appreciate all the thoughts and comments. There is a lot of work to do, but a lot of good things happening. Liz, I'm so impressed with all your work."

— Ethel Lund, Juneau, commenting on the ANEHAC meeting and YKHC's home care program

The majority of long-term care is provided by families, this is especially true in our Native communities. Traditionally, families and extended families cared for elders if they were no longer able to do things for themselves. Alaska Native families have many stories relating to caring for elders. For example, families carrying their elders on makeshift stretchers to fish camp for the summer, and then back to their winter home. There are families pulling together to care for very ill and frail elders at home with little outside help, and times when this is not possible and families are forced to make the difficult decision to place their loved one in a distant nursing or assisted living home. Usually this happens as a result of the changing economy in rural villages, from subsistence to cash-based, and the need for family members to find work outside the home. There is also an increasing out migration of younger Alaska Native people to urban centers, which leaves fewer family members to assist in providing care.

Rural Alaska presents some particular challenges in delivering services that may be typically available to seniors in more urban areas of the state. Distances between villages and the high cost of food and supplies contribute to the challenges. Most elders, like those elsewhere, desire to remain in their own homes, and if they cannot be in their own home, at least as close to home as possible. The alternative is usually a nursing home or assisted living in Anchorage or Fairbanks, far from their family and the place they have lived most of their lives, and home to a culture with significantly different values. Providing the range of long term care services desired by elders and their families is a true challenge for the Alaska Tribal Health System.

The following programs are examples of successful tribally run services for Alaska Native elders. The programs are governed by state regulations, which dictate the types of services that exist. The programs are not without challenges, and staff continually work to maintain and

adapt services to meet the needs of the elders in their regions. They are offered here as models of good programs and potential best practices available within the tribal health system. Also included are some programs offered in other IHS service areas and emerging new models on the national level.

5.2 Home Care

Several tribal health organizations operate home care programs that consist of personal care and Medicaid waiver services such as care coordination, respite, chore, and environmental modifications. Personal care is funded as a regular Medicaid program for people of any age that have a hands-on care need and are eligible for Medicaid. State regulations for personal care services have undergone some changes over the past few years. There are currently two types of programs: agency based and consumer directed. The main difference is that in the agency based model the client receives services from an agency that manages and supervises their care and their personal care assistant (PCA). A registered nurse is required to review care plans and PCAs must have training from a specified curriculum prior to starting work. In the consumer directed model, the client hires and supervises his/her own worker, who is often a family member. There is an agency involved, but their role is to train the consumer to manage their own care, and to bill Medicaid and pay the PCAs. There is no need for a registered nurse or specific training, as the client trains the attendant in how to provide his/her care. Until June 2004 the state awarded grants for personal care services that helped defray administrative costs and allowed for services to individuals not eligible for Medicaid. The discontinuation of these grants has resulted in at least one tribal agency closing their PCA program. There are two highly successful personal care programs operated within the tribal health system by the Tanana Chiefs Conference (TCC) and the Yukon Kuskokwim Health Corporation (YKHC). TCC provides only agency based services, while YKHC has expanded to include both agency based and consumer directed services.

5.2.1 Tanana Chiefs Conference, Home Care Services

The vision of TCC's home care program is to provide compassionate services so elderly and disabled individuals will have the opportunity to live and die with dignity in their own home or community. Services include personal care assistants, respite, care coordination and Medicaid waiver. Elders, adults with disabilities and individuals with Alzheimer's disease or dementia may be eligible for services. Referrals are accepted from the client, family, neighbor, health aide or other health professional. TCC also offers family caregiver service and provides information and assistance, individual counseling, support groups, and training for family and friends that care for an elder or adult with a disability. Medicaid and state grant funds encompass the majority of the program income, and TCC designates a small portion of their IHS funding to supplement the budget.

TCC's home care program employs two registered nurses who travel to the villages twice a year to visit every elder and assess the medical and functional need for home care services.

The nurses also provide preventive education on diet, exercise and socialization during their visit. For individuals eligible for services, the nurses complete a comprehensive assessment: identifying the clients' needs, setting goals for resolving those needs, determining the appropriate services or interventions, and providing on-going monitoring of service delivery and the clients' ability to adapt to services as their medical or functional needs change. The nurses work closely with the village home care staff to implement and monitor the clients' plan of care.

Prior to village travel the nurses review the health summaries and if needed the patients' charts for any new medical diagnosis or changes in the current diagnosis, medications, new hospitalizations and what exams and immunizations are due. TCC uses a family centered approach, including the elder and family members in developing a plan for services. With TCC home care everyone in the village benefits: the elders are able to stay at home, employment and educational opportunities are available for village residents, and collaborative relationships with the health aides and tribal councils improve services for the clientele. TCC home care recognizes that the keys to the success of the services are the local providers and the family caregivers. The primary goals of the home care department are:

- To provide home care services for village residents who qualify.
- To recruit village residents who are caring and willing to work for the elders and adults with disabilities.
- To retain current village staff through appreciative measures.
- To provide education for village staff through continuing education units.

TCC's home care program is not without its challenges: the primary one is recruitment and retention of village providers. TCC has several mechanisms in place to help retain their village staff including a monthly newsletter and calendar, five-year awards, cards, and gifts. The Fairbanks staff always makes the village workers a priority when they are in town. Although these methods have proven helpful, the success of the program will depend on a growing supply of caring individuals to provide services in their villages.

5.2.2 Yukon-Kuskokwim Health Corporation, Home Care

The goal of YKHC's home care program is to allow elders to age in place by keeping them at home for as long as possible. YKHC home care services began in 1995 and now offers both agency based and consumer directed personal care as well as a variety of Medicaid waiver services such as care coordination, respite, chore and environmental modifications. Elders and adults with disabilities are eligible and referrals are made by health providers and family members. The program income is primarily Medicaid, with additional funding from a designated portion of YKHC's IHS dollars.

Home care is an employment opportunity for local residents. YKHC staff includes nurses, care coordinators, administrative assistants and a range of village based care providers that

can number more than 75 workers at any given time. YKHC offers a career ladder that includes Certified Nursing Assistant training so there are opportunities for a PCA to advance into other health-related fields. All administrative staff are cross-trained and are able to conduct in-home assessments of potential clients. Innovative training ideas include enhanced classes for PCAs and a basic caregiver training for consumer directed PCAs that covers proper lifting, transferring and patient care. YKHC is also looking into an apprenticeship program that will provide on-the-job training and health credit for high school students.

YKHC is the only tribal organization offering services under the consumer directed model. Other tribal agencies have been hesitant to provide consumer directed services due to a question of liability for provision of poor care, and the lack of sufficient oversight of a consumer directed worker. YKHC had the foresight to include these services in their IHS Federal Funding Agreement, which means that they have tort coverage for these services under the Federal Tort Claims Act.

The challenges to the program revolve mainly around funding. The Medicaid reimbursement is not sufficient to meet the basic costs of providing the services and there are several unfunded mandates in the regulations for agency based providers, specifically higher training requirements and registered nurse oversight. The benefits, however, outweigh the challenges from the perspective of the YKHC mission. The benefits include preventing elders' placement in an institutional long-term care setting; ensuring that elders are able to remain at home in the village with family and friends, language, and traditional food; and supporting families to empower them to care for their elders longer.

5.3 Other Services on the LTC Continuum

5.3.1 Southcentral Foundation Elder Program

The Southcentral Foundation Elder Program is a comprehensive approach in providing social and in-home services to address the needs of the Alaska Native and American Indian elder population in Anchorage. The program began in 1985 as a part of the Community Health Representative Program; it has evolved over time to expand services aimed at enhancing the quality of life and promoting independent living to Alaska Native and American Indian elders. It is the intent of the Elder Program to improve the quality of elders' lives through fostering an environment of quality, dignity, and pride.

Services are provided to Alaska Native and American Indian elders, who are at least 55 years of age, and who reside in the Anchorage area. The elder program serves, as a priority, those with the greatest economic and social needs. Individuals with the greatest need include those with low income, are frail and impaired, handicapped, and are geographically and socially isolated as well as those who are non-English speaking. An individual may access services by contacting the program or with the assistance of a health care provider, village health aide, caseworker, or social worker. A preliminary intake and assessment are completed with the individual to identify what types of services are needed.

The Elder Program strives to foster an environment that promotes spiritual, physical and emotional wellness in a culturally appropriate setting. The intention is to empower each individual to share in the responsibility of achieving skills and obtaining assistance necessary to live independently for as long as possible, and to create a continuum of care that supports elders throughout the later years of life. Community and social involvement are not only culturally appropriate to the Elder Program's goals, but are equally as important to the Alaska Native community as a whole. The Elder Program provides opportunities for multigenerational social interaction in the form of monthly potlucks and mentoring opportunities; and through the publication of a monthly newsletter, keeps elders and their families informed of upcoming events.

The Southcentral Foundation Elder Program is designed to provide the majority of our services in the home, including light housekeeping, advocacy, and visiting. The program utilizes a multi-disciplinary approach in proactively planning for services that include advocacy, transportation, congregate meals, promoting health and wellness, social activities, shopping, interpreting/translating, food box delivery, family support, letter reading/writing, and escorting elders.

Elders receive education regarding health in aging, opportunities to socialize and become more involved with the community, participate in traditional activities such as a monthly Potluck with traditional foods and entertainment, venture out during the warmer months to gather berries, sightsee and attend events such as the Alaska State Fair. The Elder Program prides itself on responding to the needs of the elders and will vary the service based on current need. There are times in an Elder's life when the need will fluctuate according present circumstances, such as needing more transportation and medication pick ups after having surgery, or reducing service to visiting when a family member is around to help with caregiving tasks.

5.3.2 Bristol Bay Area Health Corporation, Helping Hands Program

Helping Hands is an end-of-life program that provides an option for terminally ill people in Bristol Bay to return to their home and still receive needed palliative care. The program began in 1999 with a grant from the Robert Wood Johnson Foundation (RWJF) and was designed to combine modern palliative care practices with traditional ways of caring for elders and others nearing the end of life. Clients can be referred by family or friends, but typically the physician makes the referral. The primary staff person is a registered nurse who visits the client in the home to assess their condition, pain management and medical equipment needs, caregiver availability, and determine the plan for services (DeCourtney, et.al. 2003).

End-of-life training is provided to the family, client, health aides and other village residents so everyone is aware of what to expect in providing care and when the end is near. The program was designed to include a volunteer coordinator who would also meet with village residents to offer education and ideas of how to help the family. This aspect of the program has

not continued due to lack of funding. An array of materials was developed with the grant and is still available for use in Bristol Bay communities.

The program, initially funded through the grant, is now funded entirely by BBAHC, with one full-time registered nurse as the only staff. Some of the major obstacles in generating revenue for this type of program revolve around federal regulations requiring nurse visits within a specified time period, and the availability of physical, occupational and recreation therapy, which may be prohibitive in the rural areas of Alaska. The current focus of the program is palliative care and improved quality of life for chronically ill rural elders.

The other primary challenge is staff turnover and the availability of someone to work in a rural area that has a background of palliative or end-of-life care. The lack of a consistent group of village caregivers who know the material is also problematic. The program will be focusing on identifying natural caregivers in communities and training the CHA/Ps in palliative care so they may serve as a resource for village caregivers.

In 2004, ANTHC was awarded a $1.6 million palliative care training grant from the National Cancer Institute. The grant will be used to establish a training curriculum and program to provide palliative care training to all healthcare providers of Alaska Natives including village-based workers. The BBAHC project provided a number of lessons that will result in the development of a training program that is sustainable. For instance, under the RWJF grant, nurses were sent out of state for training at a high cost. When the nurse left BBAHC, someone else had to be trained. By developing a training program in Anchorage, costs of training will be reduced substantially. As part of the grant, a palliative care symposium will be held each year with travel funds available for three providers from each region to attend.

5.3.3 Marrulut Eniit Assisted Living (MEAL), Dillingham

Marrulut Eniit (Grandmother's House) is a ten-unit assisted living home that opened in February 2000. Now housing up to 15 elders the assisted living home is a way to keep regional elders closer to home if they need extended care. MEAL provides the full array of assisted living services in a pleasant environment with staff that are sensitive to the culture and traditions of the residents. A local cook prepares traditional foods, there is a smoke house on site where residents can observe or help with smoking and preparing fish, some staff are bilingual, and there is a maqi or steam bath on the premises. Many local and regional organizations contributed to the development of MEAL and continue to be involved through participation on the board of directors for the separate, private non-profit corporation that was established to own and operate the home.

Funding for the day-to-day operations is primarily from Medicaid, as most residents are on a Medicaid waiver for assisted living services. Each resident also pays a portion of the cost from their Social Security or SSI payment, keeping $100 monthly for personal needs. The total cost per resident per month is between $4,000 and $5,000. People who are not eligible for a

Medicaid waiver generally receive another form of state subsidy through Adult Protective Services. The Bristol Bay Housing Authority continues to support the home by providing accounting services and employee benefits and provides rent subsidies for those who qualify.

The number one benefit of the assisted living home is that elders get to stay in the community nearer to family. Another benefit is full-time jobs that are available for local residents. However, the major challenge to the operations at MEAL is staffing: finding, training and keeping staff requires continued diligence. Another issue is caring for a number of people who meet the Medicaid waiver criteria for nursing home level of care in an assisted living setting. It is advisable in any assisted living setting to have a mix of residents: those who have very high care needs, and those who require minimal supervision and are able to feed and dress themselves. Due to the complex needs of some residents and the need for balancing staff duties, MEAL decided to limit the number of total care individuals to three. Therefore, the need still arises for people to be sent out of the region for care. The other main challenge for MEAL is financial feasibility, and keeping the facility full enough to balance the books. On the average MEAL has housed 9 residents at a time, the highest occupancy was 13. The breakeven point financially is 11. People are referred from all over the Bristol Bay and to some extent the Yukon-Kuskokwim region. Staff have tried a number of advertising schemes within their budget to increase the number of residents. It is the assumption that families in the region still prefer to take care of their loved ones at home rather than send them away, even to Dillingham.

The facility is very much appreciated by many of the families that have utilized it. The care provided is very good and is well received by the residents. One resident when asked how she liked the facility indicated:

> *"When I was living on my own in the independent apartments I was always scared at night. I was going to the hospital at least twice a month. Now that I'm living here I have a night watchman that comes in every night to check on me. When I first moved in I couldn't sleep when they stopped by, but now I'm used to it. Now I only go to the hospital once a month at most."*

5.3.4 Norton Sound Health Corporation, Quyanna Care Center

The Norton Sound Health Corporation operates Quyanna Care Center (QCC), the only tribally managed nursing home in Alaska. The 15-bed home was built in 1988 and is co-located with the regional hospital. Most of the residents are from western Alaska and have strong cultural and family ties to the communities. The occupancy levels at the home are higher than other Alaska nursing homes and there is usually a waiting list for admission. Most of the revenue is from Medicaid, with more than 98% of the residents receiving Medicaid. An approved reimbursement rate of $631 per patient per day allows the facility to sustain successful operations (Mather 2004).

QCC has a strong sense of Native culture with Native food and activity programs and a high level of community involvement. Elders from around the region are able to stay close to family and friends, and still receive the nursing care they need. Although co-location with the hospital allows some economies in staffing and ancillary support services, workforce supply is an ongoing challenge. Also, there are gaps in the lower level long term care continuum of services in the Norton Sound region, which could impact the level of care of residents and indicate that other elders must leave the region because there is no opening at QCC.

5.4 Lower 48 Service Models

Following are a few examples of programs in the Lower 48 that are worth mentioning because of the implications and recommendations for this project. It is not a comprehensive listing of all the long term care innovations existing within tribal organizations throughout Indian Country.

5.4.1 IHS Elder Care Initiative

Two important tools generated by the IHS Elder Care Initiative are the Comprehensive Elder Exam and a preventive care screening tool for the elderly. The Comprehensive Elder Exam is available in the standard Patient Care Component (PCC) encounter form. The inclusion of functional status distinguishes this tool from a more generic PCC (Finke 2000). The Comprehensive Elder Exam tool is designed to guide the clinician through an exam with an emphasis on function, geriatric syndromes and appropriate health screening; document the findings of the exam, the health screening and preventive care measures; and collect data on functional status of the elderly in RPMS. Functional assessment is an essential component of geriatric care. Decreases in function can lead to premature institutionalization and function is an important measure of disability and frailty (Maxted 1998). The reverse side of the PCC includes a guide to assist a provider who is less familiar with a geriatric exam. A copy of the PCC can be found in Appendix B.

The Preventive Care Guidelines for the Elderly were developed by a group of clinicians experienced in geriatric care and Indian health. It includes recommendations based on national standards and some other critical issues identified by the group. This tool can be used in conjunction with the Comprehensive Elder Exam PCC, and is also found in Appendix B.

Dr. Bruce Finke has offered to conduct training on the Comprehensive Elder Exam and preventive care screening tool either by video conferencing or in person to the providers in the Alaska Tribal Health System. A Guide to Geriatric Assessment in Indian Country was published and distributed by the University of New Mexico. The second printing of this guide recently became available, more information is in Appendix B.

5.4.2 Zuni Elders Clinic

The Public Health Services Indian Hospital at Zuni, New Mexico began offering a monthly Elders Clinic in October 1995 (Miller and Finke 1996). The clinic is conducted one afternoon a month with four elders scheduled during each clinic. During the two-hour clinic visit the elder (and their primary caregiver, if possible) is seen by a clinical nurse specialist, physician, pharmacist, psychologist, audiologist, physical therapist, dietician and dentist. Following the clinic this multidisciplinary team of providers discusses each case and formulates recommendations for care and services that are forwarded to the primary care physician and social services for follow-up. The clinic targets elders with complex health problems that have had recent changes in functional abilities, confusion or dementia, multiple hospitalizations, recent falls, multiple medications, or are in social crisis. Referrals to the clinic are usually by public health nurses, primary care physicians or emergency room personnel. Prior to the clinic, a nurse visits the elders to explain the process and conducts a home safety assessment.

Positive outcomes of this program are that staff have increased their expertise in a variety of geriatric topics and a coordinated home improvement program has developed through the tribal senior center and field health nursing. The primary weaknesses of the program are lack of time for follow-up and the resource intensiveness. Other time commitments for the staff continue to limit the program to a maximum of 45 elders in one year. Even with the lack of financial resources, the clinic persists today because of the dedication of the staff and the differences team members have seen in the lives of their older clients. A new fall clinic that is an abbreviated version of the Elders Clinic has been implemented and includes a similar, but smaller interdisciplinary team to evaluate elders after reported falls, and to help prevent future falls.[1]

5.4.3 Southern Ute Geriatric Assessment Teams

The Geriatric Assessment Team at the Southern Colorado Ute Service Unit was initially established in 1991 as part of a pilot project (IHS and UNM). The team consists of a physician, public health nurse, medical social worker, dietician, community health representative, behavioral health representative and others as needed. The criteria for determining if an elder is eligible to receive an assessment are similar to the Zuni Elders Clinic, and include prior or expected need for nursing home placement. In addition to a physical exam, the team identifies nursing needs and assesses the elder's functional and nutritional capacities, as well as conducting an environmental assessment of their home. Unlike Zuni, the Southern Ute program is home based, at the elders' request. Elders only come to the clinic for the physical exam; other providers schedule time in the elders' homes and complete a series of standard tools and protocols.

[1] Personal communication with Kay Redman, Zuni Indian Hospital, December 29, 2004.

The team meets on a quarterly basis to discuss clients. Follow-up and meeting scheduling are the responsibility of the public health nurse. The goal of the program is to decrease morbidity, hospitalizations and the need for nursing home placement, and to increase physical function, quality of life and diagnostic completeness.[2] The elders benefit from the comprehensive geriatric exam and home assessment. The team benefits through increased understanding of geriatric care and the needs of elders. Community Health Representatives receive special training to conduct the home safety assessments.

This program is also labor intensive and requires a lot of time by the public health nurse. Follow-up is difficult to monitor with other duties, so they are revisiting the clients and records every six months to ensure follow-up. This is a small health center, so although the numbers assessed each year seem small, at one elder per month, they are covering those considered to be at the highest risk. The staff feels that the program is beneficial, as they have identified problems through the assessment that they would have missed otherwise, and therefore, their elders receive better care. They plan to continue the program and may bring a pharmacist to the team to conduct medication reviews.[3]

5.5 Federal Models of Long Term Care

5.5.1 Program for All-Inclusive Care for the Elderly (PACE)

PACE is a planned approach to chronic care that serves individuals 55 and over that meet nursing home level of care. The PACE philosophy is based on the premise that providing community-based services to elders and their families will increase their well-being and be more cost efficient. The goal is to manage disability and illness through monitoring and health promotion activities and thereby minimize nursing home and hospital admissions. PACE is a managed care program that includes all needed medical and supportive services, including nursing home, hospital care, case management and personal care in the home. PACE is reimbursable through both Medicaid and Medicare, and requires sponsoring organizations to take full financial risk for all the care needs of the clients.

Two basic components of PACE are an interdisciplinary team and adult day health center. The interdisciplinary team consists of a physician, nurse practitioner, pharmacist, dietician, physical and occupational therapists, social worker, home care attendants, and drivers. This approach is based on the idea that all members of the team have information relevant to the clients' care needs and condition. Therefore, all members have an equal voice in the team meetings. The adult day health center is the location where services are delivered and the clients' condition is monitored. An urban center will typically include a clinic, pharmacy, meals and activities. Another key element to a successful PACE program is geriatric training for all levels of professional and paraprofessional staff.

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[2] Southern Colorado Ute Service Unit Policies and Procedures. Geriatric Evaluation and Management Program.
[3] Personal communication with Susan Turner, Public Health Nurse, Southern Colorado Ute Service Unit. December 15, 2005.

There are only about 35 PACE programs around the country, mostly in urban areas such as San Francisco and Denver. The Centers for Medicare and Medicaid (CMS) and the U.S. Department of Health and Human Services are interested in seeing this program expand to more rural areas and are encouraging development in tribal organizations. CMS is willing to waive some of the regulatory requirements and explore models of client monitoring that would work favorably in rural areas. The Cherokee Nation in Oklahoma is paving the way for tribal PACE and anticipates opening the first day center in the spring of 2006.

5.5.2 Green House

Green House is an innovative concept in long term care that is receiving attention at the national level. The Green House idea was created by William Thomas, M.D., founder of the Eden Alternative, a form of institutional culture change in the nursing home industry adopted by many facilities in Alaska, including Providence, the Pioneers Homes and Quyanna Care in Nome. Green House takes the Eden philosophy of mutual caring, involving residents in decision making, and creating a home-like environment into a smaller setting housing 8 – 10 residents. Care is provided in a home setting with elders and caregivers interacting as a family. Trained caregiving staff provide for all the day-to-day care needs of the residents, including meal preparation and small maintenance tasks. Meals are social times, with residents who are able assisting with the cooking. Staff and residents eat at a large family-style table, instead of using separate tables and individual trays.

The goal of the Green House projects is to eliminate large institutional nursing home settings and create smaller, social settings where elders can receive assistance and still participate in life. To maintain the appropriate level of skilled practitioners such as physicians, nurses and physical therapists for nursing home certification, the staff are employed by a parent organization and make regular visits to each Green House. A large nursing home in Tupelo, Mississippi has been downsized into a series of Green Houses that opened in early 2004. Preliminary analysis and review of the homes are positive, with a more longitudinal study forthcoming. More information is available on the following website: http://thegreenhouseproject.com.

5.6 Conclusion

These are a few of the models for various long term care services in operation around the country. Many are governed by specific state or federal regulations. Some elements might be more useful to Alaska Native communities than others. Tribal organizations may want to advocate for flexibility in regulations in order to create the best continuum of care for our elders. There will be a continued need in the future to examine other innovative program models and improvise or create programs compatible with the needs of Alaska Native elders.

Chapter 6

6.1 Determining the Need for LTC Services

"There is a strong mission being said by these people [the elders] that they want to stay in their community. We have to listen to them."

— Iver Malutin, Kodiak, ANEHAC

The measure of functional status is the most frequently used predictor in determining the need for long term care services. Increased levels of disability affect the functional status of an individual and their ability to continue to perform the activities of daily living (ADL) and the instrumental activities of daily living (IADL). The six primary ADL are bathing, dressing, grooming, eating, moving around and toileting. IADL include more ancillary activities such as housekeeping, meal preparation, shopping, using the telephone, and managing money and medications. Being unable to do these ancillary tasks may also compromise an elder's ability to live independently.

Cognitive impairment is another factor in determining the need for long term care services. However, currently there is no estimate of the number of elders who experience dementia, and in Alaska cognitive impairment alone will not allow access to certain state funded programs. Anecdotal information does indicate that people with dementia may be more likely to be placed away from their region in assisted living homes, but more information is needed on the extent of cognitive impairment, and how families are affected. The relationship of cognitive impairment to independent function cannot be overstated, and speaks to the need for a more comprehensive elder assessment that includes both cognitive and functional measures to get an accurate picture for future planning.

Chapter 3 discussed the increase of chronic conditions that can correlate to increased functional limitations in the elder population. Diseases such as COPD, arthritis, and diabetes contribute to extended disability in later years. Heart and cerebrovascular diseases also contribute to functional decline through disability following a heart attack or the potential for paralysis after a stroke. Increased longevity also increases the likelihood of functional decline, indicating the importance of looking at the 85 and older group, who are most likely to need the most intensive services; and the 75 – 84 age group, which may need more of the lower levels of care.

This chapter will look at methods of determining functional limitations and the need for nursing home beds in the Alaska Native population, and will use those estimates in determining the need for services in each Alaska tribal health region. Estimating functional status and nursing home need is difficult because there is no universally accepted method and there are several different methods that provide very different estimates. The report will highlight the methods most often used nationally and explain the rationale for the methods adopted for the Alaska Native population.

As stated in Chapter 1.4 the population projections are based on previous projection percentages of the total Alaska population by the Department of Labor, which have not been updated for the 2004 population data. Therefore there may be inaccuracies in the estimates. It would be wise for regional health organizations to analyze their specific population projections based on current population information and migration, birth and death calculations for their area. The differing migration, birth and death rates for Alaska Native people in each region will likely generate more accurate projections than those based on the Alaska population as a whole.

6.2 Estimates of Functional Limitations

Tables 14 and 15 describe two methods of estimating functional limitations currently used nationally. From these tables a range of the number of individuals with functional limitations can be extrapolated. Table 14 highlights a model of the expected population at risk of functional limitations by age group, from a low of 8% of those 65 – 74 to a high of 52% in the 85 and older population, and demonstrates the higher limitations associated with an aging population. This method also includes the 55 – 64 age group at a risk rate of 2%, which indicates a lower portion of this age group can be expected to have limitations. Although some studies have shown that the American Indian population demonstrates higher rates of disability at younger age groups, these studies are not current and there is no research to conclude that the same is true for Alaska Native elders.

Table 14. Estimate of Functional Limitations Based on 2004 Population

Statewide Alaska Native Population			
Age	**Total**	**% at risk**	**# with Functional limitations**
55-64	8,040	2%	161
65-74	4,465	8%	357
75-84	2,101	20%	420
85 +	569	52%	296
Total	15,175		1,234

Source: Spector, WD, et.al. (1998)

The estimates in Table 15 are based on the results of a survey developed by the National Resource Center for Native American Aging at the University of North Dakota (UND), and administered by five tribal agencies in Alaska to 401 elders.[1] The survey includes self-reported information about the elders' ability to perform their ADL. Elders in the moderate category have limitations with one ADL and up to two IADL; moderately severe includes two ADL limitations; and severe is three or more ADL limitations. The survey has been more widely used among lower 48 tribes and UND is able to make comparisons to both the U.S. general population, and the total U.S. American Indian and Alaska Native population. Results from Alaska indicate that Alaska Native elders report fewer functional limitations than the U.S. general population or the U.S. American Indian population (Saylor and Douchette 2004). However, because of the small number of tribes using the survey and the diversity of our Native people, these data may not be representative of the total Alaska Native elder population.

Table 15. Estimates of Functional Limitations

Statewide Alaska Native Population				
Age	**Little or None (62.6%)**	**Moderate (24.8%)**	**M/S (5.6%)**	**Severe (7%)**
65+	4,467	1,769	400	499

Source: Data from National Resource Center for Native American Aging, University of North Dakota, calculations presented in Saylor and Douchette 2004.[2]

Table 15 only presents the 65 and older population. The same calculations used with the 55 – 64 age group would skew the data, and add another 563 individuals to the category of severe limitations and an equally high number to the moderately severe category. It is unlikely that such a high number of individuals in the 55 – 64 age group are in need of services. Therefore, according to these methods of determining functional limitations, the number of Alaska Native elders 65 and older potentially needing services ranges from 899 to 1073, more if those with moderate impairment levels are included. Observation of and interviews with Alaska Native elders and family members indicate that elders will remain at home without services for as long as possible. Without the advantage of a clinical functional assessment of each elder, these estimates provide at least an initial starting point for determining the need for long term care services. Due to the lack of a broad enough sample to more accurately predict the number of Alaska Native elders with functional limitations using this method, the model in Table 14 is used throughout the rest of the chapter to calculate functional need.

[1] NRCNAA project, "Identifying Our Needs: A Survey of Elders," a nationwide needs assessment project containing 8,560 respondents in 83 tribes.

[2] Calculated from the total 65+ population and the percentages of Alaska Native elders surveyed who experience functional limitations.

6.3 Need for Nursing Home Beds

The rates of nursing home utilization have decreased nationally in the last ten years, and in Alaska there has been a 20% decline in nursing home usage in the last five years (Mather 2004). Some of this decline can be attributed to the growth of home and community based services and the availability of Medicaid waivers. As noted in Chapter 4.2 most Alaska Native nursing home residents are at the intermediate level of care, which is primarily custodial care for people with stable medical conditions. Some of these residents could receive care in their homes and communities if services were available.

Table 16 highlights two demand estimation methods for nursing home beds currently in use nationally. The demand estimate in column 5 is based on a model stating that 4.9% of the 65 and older population need nursing home services. This broad across-the-board method does not represent Alaska Native elders and provides an estimate that is higher than the current utilization rate. The method used in columns 3 and 4 is comparable to the actual beds occupied for the last four fiscal years, at an average of 280 Alaska Native residents per year. Since it is more similar to actual utilization during the past four years, this model is the method used in Table 17 to estimate the number Alaska Native elders who may need nursing home placement.

Table 16. Current Demand for Nursing Home Beds

1. Age	2. Total Population	3. At Risk	4. Demand	5. 4.9%
55-64	8,040	0.001	8	
65-74	4,465	0.011	49	219
75-84	2,101	0.046	97	103
85+	569	0.192	109	28
Total	**15,175**		**263**	**350**

Columns 3 & 4 based on National Center for Health Statistics demand model, Health and Aging Chartbook. Hyattsville, MD. 1999. Column 5 represents 4.9% of the 65+ population projection cited in an AHRQ Research Report (AHRQ 2001).

In FFY03 there were 277 Alaska Native elders in nursing homes paid by Medicaid and an additional 327 people living in the community on Medicaid waivers. Based on current service utilization in regions where capacity for providing long term care services has been developed, these numbers correlate to the services provided during FFY03. For example, according to these estimates the current demand for nursing home or waiver services in the Yukon-Kuskokwim region is 100 and the estimated number of people with functional limitations is

226. During FFY03 YKHC's home care program had 50 clients on Medicaid waivers and provided personal care services to 152 individuals. Tanana Chiefs Conference and the Bristol Bay Native Association also had service levels comparable to these estimates during FFY03, when BBNA was still providing personal care services. The actual service levels are close, but not equal to the projection of need. Additional factors to consider are the number of elders placed out of the region for facility based care, and waiting lists for services that are not available in a particular community because of the lack of trained PCAs or other workers.

A review of the number of Medicaid waiver clients in these three regions shows a utilization rate of 3.9% of the total 65 and over population in the regions. Because FFY03 was a year when all programs were operating in full capacity, the 3.9% utilization rate will be used to estimate the need for Medicaid waiver services for elders across the state. Be advised that this estimate is based on the assumption that utilization remains constant over the next 15 years and that Medicaid waiver services not only continue to be available in the rural areas of the state, but that they are allowed to develop in the areas that are not currently providing these services. It is more likely, since the number of Alaska Natives 65 and older is increasing, that this percentage will be higher in the future. Nonetheless, this estimate will be used since there is no more accurate estimate available.

Table 17 depicts the aggregate information of estimates of the number of elders age 65 and older with functional limitations and the estimated need for Medicaid waiver services and nursing home beds for the 2003 population estimates and the projected 2020 population. Since Medicaid waiver clients by definition must meet nursing home level of care, those categories are combined in one column, with a caution that since elders prefer to remain in their own homes, regions should first look at providing for elders through an increase in home and community based services available through Medicaid waiver and place less emphasis on adding nursing home beds.

Table 17. Nursing Home and Functional Limitation Estimates and Projections by Region for 2004 and 2020

Service Area	2004 Medicaid Waiver & NH Need	2004 Functional Limitation Estimates	Projected Total >65 population 2020	2020 Projected Medicaid Waiver & NH Need	2020 Projected Functional Limitation Estimates
Barrow	22	49	528	39	80
Kotzebue	29	65	738	55	111
Norton Sound	39	88	865	65	129
Yukon-Kuskokwim Delta**	100	226	2,341	182	365
Bristol Bay	30	68	826	62	124
Mt. Edgecumbe & Annette Island	97	218	2,819	212	423
Interior	65	150	1,907	143	286
Anchorage – Muni	86	200	2,729	204	409
Anchorage – Mat-Su	15	35	600	45	90
RSU – Aleutians	8	19	227	17	34
RSU – Kodiak	15	34	382	28	57
RSU – Kenai	23	54	738	55	110
RSU – Valdez/Cordova	13	27	345	26	52
Total	**542**	**1,223**	**15,135**	**1,133**	**2,270**

Source: Calculations based on current population numbers, projected 2020 population discussed in Chapter 1.4; functional estimate based on Spector, et.al.; a combination of the National Center for Health Statistics demand nursing home model for 65+, and the current waiver utilization rate of 3.9% of the 65+ Alaska Native population is used to calculate waiver and nursing home need. Projections are based only on the 65+ population.

The table shows that there are currently approximately 1,233 Alaska Native elders who have some sort of functional decline that prohibits them from carrying out their daily living activities. Many of these individuals could receive services from personal care programs, if they

were available statewide. Of those with functional limitations, approximately 542 require higher levels of care that could be provided by enhanced home and community based services like respite, chore, home modifications, or assisted living, if available in the region. Less than one half of these 542 elders would require care in a skilled nursing setting. Mather (2004:17) states that the need for nursing home beds is "dependent on the availability of a continuum of effective alternatives to institutionalization and on the cost of these alternatives to the elderly individual and/or their families." Creating affordable home and community based services and family supports would almost certainly mean fewer elders needing nursing home care.

Some of the other elders with functional limitations, and those with difficulty performing one or more IADL may be in need of less intensive services, for example homemaker/chore services could provide shopping and housekeeping assistance to elders that cannot manage these tasks on their own. Surveys done by tribal agencies around the state in the past ten years indicate a high desire for homemaker and chore services. Unfortunately there is no funding available for these services other than minimally from the Older Americans Act, and regions will need to explore other ways to provide these for elders.

Projecting to the year 2020 calculations indicate that twice the number of elders, 2,270 are predicted to have functional limitations, and 1,133 will require Medicaid waiver or nursing home care. Careful planning by the tribal health system over the next few years will be needed to ensure adequate services for the growing elder population.

Overall, these estimates and projections take a relatively conservative approach so as not to overstate the number of people needing services and provide inflated planning information to regional health organizations. Given the evidence that chronic diseases are increasing there may be a greater number of people needing services in the future. Demand for particular long term care services is impacted by the philosophy of care in the region (Mather 2004), and in the state. If Alaska Native elders had their preference, services would be readily available throughout the state that would allow them to stay at home as long as possible. These estimates provide a base for long term planning of a range of services that can be expanded over time as the need increases.

6.4 Regional Summaries

Regions are summarized according to tribal health service areas. Population data was obtained through the Alaska Department of Labor estimates using U.S. Census areas, which do not exactly correlate to tribal health service areas. For those communities in a different service area, the total population of the community was obtained and the elder population by age group was estimated using the regional proportion for each age group. Because of this, these numbers may not be exact, and will be noted on the table.

Regional health organizations are encouraged to conduct their own analysis of the patterns of long term care service usage. In most regions there is a cadre of individuals that can

work together to provide numbers of elders who have been cared for at home and those that were sent to other regions (usually Anchorage or Fairbanks) for nursing home or assisted living care. Much information can be gained from these interpersonal discussions at the regional level, where people know the elders and their families well.

6.4.1 Barrow Service Area

2003 Elder Population			
55-64	252	**Total 55+**	544
65-74	185	**Total 65+**	292
75-84	82	**M 55+**	266
85+	25	**F 55+**	278

**An estimated 80 elders over 55 years old were subtracted from Barrow, based on 2000 U.S. Census population estimates of Point Hope.*

Based on the population the current estimate of elders with functional limitations is 49, with 22 of those possibly needing more intensive home and community based Medicaid waiver services or nursing home care. This region has a low utilization of LTC services paid by Medicaid with fewer than five individuals receiving either waiver or PCA services in FFY03. The seven residents of the assisted living home have high care needs and may qualify for Medicaid waiver services, if they are income eligible for Medicaid. Elders in the Barrow area are at greater risk of having to leave the region if they need care and have few family supports to help them stay at home. The number of individuals needing services is expected to nearly double by 2020. Expansion of home and community based services in this region in the next few years is crucial to providing care for the expected increase in elders.

6.4.2 Kotzebue Service Area

2003 Elder Population			
55-64	359	**Total 55+**	766
65-74	254	**Total 65+**	407
75-84	131	**M 55+**	354
85+	22	**F 55+**	412

**An estimated 80 elders over 55 years old were added to the Kotzebue region from Barrow, based on 200 U.S. Census population estimates of Point Hope.*

Based on the population the current estimate of elders with functional limitations is 65, with 29 of those possibly needing more intensive home and community based Medicaid waiver

services or nursing home care. There is a low utilization of Medicaid LTC services in the Kotzebue region, with fewer than five clients receiving PCA services under Medicaid in FFY03, and fewer than ten on Medicaid waivers. The number of Medicaid waivers has decreased from 2003 to the present, and the majority of the current residents in the assisted living home do not meet the level of care for Medicaid waiver reimbursement.

The estimates in this region seem high in light of the fact that there has been an active pursuit by the Maniilaq Association recently to identify potential waiver clients, and a study recently completed by Mather (2004) estimates that only 13 individuals are currently eligible for either nursing home or waiver assisted living admission. However, the number of individuals needing services is expected to increase by 70% in 2020. Therefore, expansion of home and community based services in the next few years will be critical to providing care for elders within the region.

6.4.3 Norton Sound Service Area

2003 Elder Population			
55-64	480	**Total 55+**	958
65-74	275	**Total 65+**	478
75-84	154	**M 55+**	486
85+	49	**F 55+**	472

Based on the population the current estimate of elders with functional limitations is 88, with 39 of those possibly needing more intensive home and community based Medicaid waiver services or nursing home care. In FFY03 there were 20 Alaska Native residents who received nursing home care in the region. Nursing home utilization is high in this region due to the presence of Quyanna Care Center in Nome. On the home and community based service side, fewer than 10 elders received PCA and/or Medicaid waiver services.

The number of individuals needing services in the Norton Sound region is expected to increase by 47% in 2020 to a total of 129. Concentration on expanding home and community based services in the next few years will be the key to providing care for the expected increase of elders in the region.

6.4.4 Yukon-Kuskokwim Delta Service Area

2003 Elder Population			
55-64	1,204	**Total 55+**	2,461
65-74	745	**Total 65+**	1,257
75-84	387	**M 55+**	1,212
85+	125	**F 55+**	1,249

**An estimate of 87 elders 55 and older is included from the Holy Cross subregion of Holy Cross, Grayling, Shageluk and Anvik. An estimate of 45 elders are subtracted for the communities of Goodnews Bay and Platinum. Calculations based on 200 U.S. Census population estimates.*

Based on the population the current estimate of elders with functional limitations is 226, with 100 of those possibly needing more intensive home and community based Medicaid waiver services or nursing home care. In FFY03 YKHC provided personal care services to 152 individuals and 50 clients were on Medicaid waivers. Elders needing residential services of any type were displaced to other communities.

The number of individuals needing services is expected to increase by 2020. The addition of facility based care, for example, the assisted living home currently in development, as well as the continued growth of other home and community based services in the next few years is critical to providing care for the expected increase in elders.

6.4.5 Bristol Bay Service Area

2003 Elder Population			
55-64	400	**Total 55+**	805
65-74	247	**Total 65+**	405
75-84	132	**M 55+**	403
85+	26	**F 55+**	402

**An estimate of 45 elders over 55 are added from the communities of Goodnews Bay and Platinum. Calculations based on 200 U.S. Census population estimates.*

Based on the population the current estimate of elders with functional limitations is 68, with 30 of those possibly needing more intensive home and community based Medicaid waiver services or nursing home care. In FFY03, BBNA provided personal care services to 49 clients and there were 22 individuals on Medicaid waivers. There are currently 11 residents in the Dillingham assisted living home, most of whom are on a Medicaid waiver indicating that they have high care needs. BBNA no longer operates a personal care program and all current PCA clients receive services from non-tribal agencies.

The number of individuals needing services is expected to increase by 82% in 2020. The expanding need for services indicates the need for continued commitment to the assisted living home and an increase in home and community based services provided by tribal organizations.

6.4.6 Mt. Edgecumbe and Annette Island Service Units

2003 Elder Population			
55-64	1,363	**Total 55+**	2,648
65-74	807	**Total 65+**	1,285
75-84	381	**M 55+**	1,311
85+	97	**F 55+**	1,337

Based on the population the current estimate of elders with functional limitations is 218, with 97 of those possibly needing more intensive home and community based Medicaid waiver services or nursing home care. In FFY03, 110 Alaska Native clients received PCA services from a variety of agencies, and 117 were receiving services through Medicaid waivers, three of whom were in local assisted living homes. Another 60 individuals received care at one of the five regional nursing homes, and 24 elders resided in one of the three Pioneers' Homes.

The number of individuals needing services is expected to almost double by 2020. Southeast Alaska encompasses a large area with a diverse population scattered through large and small communities. Because of the variety of services and service providers, analysis is more difficult. Data limitations and time constraints prohibited the type of analysis that would be most beneficial to the regional tribal health organizations. Therefore, further analysis of this region is needed to accurately address the needs of the future population of elders.

6.4.7 Interior Service Area

2003 Elder Population			
55-64	990	**Total 55+**	1,833
65-74	518	**Total 65+**	843
75-84	250	**M 55+**	887
85+	75	**F 55+**	946

**An estimated 87 elders over 55 years old were subtracted based on 2000 U.S. Census population estimates of the Holy Cross subregion.*

Based on the population the current estimate of elders with functional limitations is 150, with 65 of those possibly needing more intensive home and community based Medicaid waiver services or nursing home care. In FFY03, 79 Alaska Native clients received PCA services, either through TCC or a non-tribal provider if they reside in Fairbanks, and 57 were receiving services through Medicaid waivers. Twelve of the waiver clients resided in assisted living homes. Another 44 were residents in the Denali Center nursing home and another six elders resided in the Fairbanks Pioneers' Home.

The number of individuals needing services is expected to almost double by 2020. There is a new assisted living home opening in Galena next year, and one currently operating in Tanana. However, there are few options for Native elders needing assisted living in Fairbanks, and none that are tribally operated. A review of the capacity for providing care in Fairbanks, including transitional housing for elders coming to Fairbanks for medical reasons, would provide more insight to the housing and facility based care needs. Continued growth of home and community based services through TCC will be crucial meeting the expected increase in elders needing services.

6.4.8A Anchorage Service Area – Municipality of Anchorage

2003 Elder Population			
55-64	1,705	**Total 55+**	2,901
65-74	816	**Total 65+**	1,196
75-84	303	**M 55+**	1,081
85+	77	**F 55+**	1,820*

** Note the high ratio of the female population to males residing in Anchorage.*

Based on the population the current estimate of elders with functional limitations is 200, with 86 of those possibly needing more intensive home and community based Medicaid waiver services or nursing home care. Information from Southcentral Foundation's Elder Program indicates much higher numbers of elders; both those living in Anchorage and those needing care.

In FFY03 there were 152 clients receiving PCA services from various non-tribal providers and 224 receiving additional services through a Medicaid waiver, 72 residing in area assisted living homes. A total of 117 Alaska Native elders received care in Anchorage nursing homes in FFY03, and 14 were residents of the Anchorage Pioneers' Home. Some of these elders were likely from other regions, but there is no way to differentiate place of origin between Anchorage residents and those from other areas once the elders reside in homes in Anchorage.

The number of individuals needing services is expected to more than double in 2020. In reality the increase may prove to be much higher with the migration of rural elders into

Anchorage, either to receive health care or to be nearer to family members who have relocated for employment opportunities mentioned in a report to AFN (Alaska Native Policy Center, 2004). Southcentral Foundation's future plans for developing tribally operated home and community based services in the next few years will help meet the increasing need. The lack of culturally responsive assisted living homes in Anchorage will also need to be addressed. The need for transitional housing for elders coming to Anchorage for medical care is already being addressed by the tribal health system, and will provide another component of the LTC continuum.

Additional research in the Anchorage area is also needed to adequately analyze the upcoming need for services. For example, the ratio of female to male elders in Anchorage noted on the above table is worth mentioning because it is a stark contrast to other regional population distributions. In all other areas of the state the gender distribution is relatively equal, with the number of males slightly exceeding females in some regions. Whereas, the Anchorage population data indicates there are almost twice as many females as males. There is no significant difference in the data by 10-year age cohorts. An examination of all cohorts shows a similar distribution of approximately 65 – 70% female to 30 – 35% male. This could be related to a longer life span for women or that women will more readily relocate at the encouragement of family members. However, this phenomenon needs more research to determine the reasons behind the gender difference and what service implications it may have for the Anchorage area.

6.4.8B Anchorage Service Area – Matanuska-Susitna Borough

2003 Elder Population			
55-64	362	**Total 55+**	583
65-74	155	**Total 65+**	221
75-84	59	**M 55+**	272
85+	7	**F 55+**	311

Based on the population the current estimate of elders with functional limitations is 35, with 15 of those possibly needing more intensive home and community based Medicaid waiver services or nursing home care. In FFY03 there were 27 Alaska Native clients receiving PCA services and 27 people receiving services through a Medicaid waiver, all these were provided by non-tribal agencies. Eight of these individuals were in assisted living on a Medicaid waiver, and there were no Alaska Native elders in the Palmer Pioneers' Home.

The number of individuals needing services is expected to increase by 157% in 2020, and there is some indication that it may increase more rapidly. The population in the Matanuska Susitna Valley is increasing rapidly, and it appears that Alaska Native elders are part of that increase. U.S. Census data shows that from 1990 to 2002 the Mat-Su Borough saw a greater

increase in Native elders than any other area at 198% (Saylor and Douchette 2004:8-9). An examination of state demographic data from 2002 to 2004 indicates that in just two years the 65 and older population increased by 43%. This rapid growth will have implications for the future need for services by Alaska Native elders in this area. More research is needed to assess the impact of this migration.

6.4.9 Rural Anchorage Service Area

6.4.9A Aleutians

2003 Elder Population			
55-64	140	**Total 55+**	255
65-74	73	**Total 65+**	117
75-84	39	**M 55+**	136
85+	5	**F 55+**	119

Based on the population the current estimate of elders with functional limitations is 19, with 8 of those possibly needing more intensive home and community based Medicaid waiver services or nursing home care. The Aleutian area is the most underserved region of the state in regards to long term care services. In FFY03 there were fewer than five people receiving PCA or Medicaid waiver services. This region has a higher percentage of people who are not eligible for Medicaid due to income and asset limits. Therefore, creative solutions for providing long term care services are needed.

The number of individuals needing services is expected to almost double by 2020. Therefore, expansion of home and community based services in the next few years, and analyzing the need for supportive housing or other facility based care, as is currently underway by a regional Elders Task Force, is critical to providing care today and in the future.

6.4.9B Kodiak

2003 Elder Population			
55-64	214	**Total 55+**	387
65-74	107	**Total 65+**	173
75-84	40	**M 55+**	184
85+	26	**F 55+**	203

Based on the population the current estimate of elders with functional limitations is 34, with 15 of those possibly needing more intensive home and community based Medicaid waiver services or nursing home care. In FFY03 there were less than five Alaska Native elders receiving PCA services and 12 on a Medicaid waiver, one of whom resided in assisted living. Twelve elders were housed in the nursing home that year.

The number of individuals needing services is expected to more than double by 2020. Nursing home care and assisted living are available in Kodiak. There is a need for expansion of home and community based services to the outlying villages in the next few years to allow elders to remain at home.

6.4.9C Kenai Peninsula

2003 Elder Population			
55-64	415	**Total 55+**	729
65-74	199	**Total 65+**	314
75-84	93	**M 55+**	364
85+	22	**F 55+**	365

Based on the population the current estimate of elders with functional limitations is 54, with 23 of those possibly needing more intensive home and community based Medicaid waiver services or nursing home care. In FFY03 there were 35 Alaska Native clients receiving PCA services and 33 on Medicaid waivers, four of whom resided in assisted living. During the same year 29 Alaska Native elders resided in the three area nursing homes.

The number of individuals needing services is expected to double by 2020. Implementation of the new models of multi-use supportive housing developed in the region could help meet the needs of current and future elders in smaller communities. Continued expansion of other home and community based services in the next few years will be critical to providing care for the expected increase in elders.

6.4.9D Valdez-Cordova

2003 Elder Population			
55-64	158	**Total 55+**	305
65-74	84	**Total 65+**	147
75-84	50	**M 55+**	163
85+	13	**F 55+**	142

Also includes Glennallen, Copper Center and Mount Sanford

Based on the population the current estimate of elders with functional limitations is 27, with 13 of those possibly needing more intensive home and community based Medicaid waiver services or nursing home care. In FFY03 there were 11 clients receiving PCA services, 11 were on Medicaid waivers, and 6 residing in either the nursing home in Cordova or swing beds in Valdez. There is no assisted living in this area.

The number of individuals needing services is expected to almost double in 2020. There is a need for more individual analysis of the different communities in this region. Glennallen, Copper Center and Mt. Sanford area on the road system have a different service delivery model than other areas. The small Native population in Valdez differs from the growing population in Cordova, where the Eyak tribe has provided a variety of services for elders over the years. However, discussions with elders in these different communities all indicate the desire to stay in their own homes, therefore, expansion of home and community based services will be a critical component.

Chapter 7

7.1 Discussion

"Our goal should be to help elders live out their lives in comfort, not taking medications they don't need and not living where they don't want to."
— Andrew Jimmie, Chair of the Alaska Native Elder Health Advisory Committee (ANEHAC)

It is clear from the elders that they would prefer to live in their own home throughout their lives. It is also important that they not have to be displaced from their community if they need extended care they cannot receive at home. How does the Alaska Tribal Health System (ATHS) balance the desires of individuals to stay at home with the realities that sometimes prohibit that from occurring and the need to be prepared with facility based care when necessary? How can the ATHS ensure that the focus is not to overbuild facilities, but to plan for facilities that are strategically available throughout the system to ensure quality care in the most culturally appropriate area for all tribal beneficiaries? Through strategic planning as a system to build the services that elders want, and working together to identify the most efficient ways to provide the services that are the least intrusive to the elders, ATHS can help elders retain their dignity throughout their lives. ATHS must not look at the quick solution of capital expenditures and building construction, but instead to more comprehensive and long-range planning for well-developed services provided in the homes and communities of the elders.

Since it is an incremental process to build services, the ATHS can begin this work based on the projections presented in this report, and each region can continue to monitor the growth and changes of their elder population. It is important to characterize the need for services in a way that does not lock the ATHS into existing models, but gives the tribal health system a chance to explore, develop or combine new models. Another challenge is to develop services in a way that does not create a negative change in the culture of caring for and revering elders. Anecdotal examples from providers indicate that once formal services are engaged the family may not remain overly involved in their care, thus allowing more and more of the care to be provided by the formal caregivers. The lack of continued involvement could be for a variety of reasons, including other family or work responsibilities, and is one indicator of the need for more formal services. Some families may still be able to provide support, but need assistance to do so through either the addition of formal services or education and support for their role as primary caregiver. Formal long term care services for Alaska Native elders

should therefore encourage family involvement to the extent possible, and attempt to complement rather than supplant family caregiving.

The National Indian Council on Aging's (NICOA) position on long term care is that "it is time for all concerned parties to work toward a single, accessible, culturally-sensitive continuum of care—one which will allow older Indians and Alaska Natives to live out their lives in their own homes and communities." Furthermore, "the goal of most long term care advocates is the seamless integration of elder services into the Indian health care delivery system and traditional community-based systems" (Baldridge 2001:155). The ATHS can follow the goals of NICOA in the development of home and community based services.

Iver Malutin, the ANEHAC member from Kodiak echoes NICOA's statements when he describes his goals for this project:

- *That all Alaska Native elders receive good health care and the long term care services they need, even those that aren't eligible for Medicaid;*
- *That all regions and tribal councils work together on this common goal, exchanging ideas and continually communicating; and*
- *That we rebuild the traditional respect for the elders in our communities.*

This report thus far has offered descriptions of service models, funding options and estimates of the future need for services. It is important during the planning process to understand what is available within the state and each community, and to understand the preferences of the elders and other tribal members. All these factors contribute to the knowledge needed for future planning. Redford (2002) identifies three key areas of community or tribal capacity needed to develop and sustain long term care services: 1) financial knowledge to ensure feasibility, 2) availability of an adequate workforce, and 3) commitment of the tribal leadership, which includes providing direction for service development and possible designation of other tribal funding resources to ensure sustainability. This chapter will expand on all these concepts in section 7.3 about home care, assisted living and supportive housing. Financial knowledge and tribal commitment of financial resources are specifically addressed 7.4.3. Tribal commitment of time and direction of development are addressed under 7.4.4 organizational capacity, and workforce availability in 7.4.5.

7.2 Themes from ANEHAC

During the November 2004 meeting of the ANEHAC certain themes emerged that highlight the values of the committee and other tribal beneficiaries. These are the themes committee would like to see guide future work for both ANTHC and the National Resource Center (NRC) at UAA. The first is to maintain a focus on the values of the elders, both in research and planning programs. Next the committee would like to gain a better understanding of the factors that contribute to the health and welfare of elders. This includes both risk factors and examples of positive aging. One way to address this issue is to implement the

Comprehensive Geriatric Assessment tool and the preventive care guidelines for the elderly discussed in Chapter 5.4. A recommendation for implementation is included in Chapter 8.2.

The committee was very clear on the direction of service development—that it focuses on services that will allow elders to remain in their home communities. ANEHAC members were very impressed by the services currently available around the state from various tribal organizations, especially the home care programs at YKHC and TCC. They want to continue to identify and develop these "best practices," and discussed some common characteristics of the programs presented, and decided that the values related to these characteristics were important in developing best practice programs for Alaska Native elders. The elders said that programs should be:

- based on local values and owned and operated by local organizations;
- flexible in design to allow for the changing needs of individuals and the local community;
- encouraging family involvement;
- developed with the consumer's interests at the core; and
- based on the culture and traditions of the people they serve.

7.3 Continuum of Long Term Care

Nationally the continuum of long term care services is shifting away from nursing homes toward more home and community based models of care. Public policy has been changed to allow for that shift, especially in the expansion of payments for home and community based services through Medicaid waivers. A brief look at the history of the provision of long term care services provides insight into the financial incentives that preceded the shift in care, and that the development of systems or certain types of services has an impact on the overall demand for services. For example, prior to the creation of Medicaid in the mid 1960s most people were cared for in the home or in small board and care homes. After Medicaid began paying for nursing home care, the nursing home industry grew very rapidly, and nursing homes became the norm for someone requiring long term care. A similar phenomenon happened in Alaska in the mid-1990s, when the new assisted living regulations were promulgated. At that time there was a tremendous increase in the number of assisted living homes opening, especially in the Anchorage area. Most of these assisted living homes were operated by individuals in their own private homes.

Funding plays a very significant role when planning the most appropriate services to develop. Although focus groups and community meetings have demonstrated that elders prefer to be at home in the most independent setting as possible, because of the methodology used to determine reimbursement, it is much easier to create a balanced budget for a nursing home than any other type of long term care service. Mather (2004) demonstrates this in a report to Maniilaq on the financial feasibility of services in the Kotzebue region.

The perception of services by tribal and community members also contributes to the decision of the type of long term care services to develop. Redford (2002:56) explains, "[I]n a recent survey conducted by NICOA, a very high percent of tribes indicated their greatest LTC need was nursing home care or assisted living. While this may be an important option for care that is lacking on reservations, it is also the option that appears to be least acceptable to elders and their families." Redford cautions to develop nursing homes as a last resort, stating that "low occupancy rates in some reservation-based nursing homes may support the contention that this is not a particularly acceptable solution, even when available on the reservation." All of these factors must be considered in planning for long term care service development.

> *In 1993, when I first began working on long term care issues in rural Alaska, everywhere I went, even in the smallest communities, people said they needed a nursing home. Now, instead of a nursing home, folks say they need an assisted living home. While this does indicate a lower service level on the long term care continuum, it is still facility based care. In early 1999 I traveled to a community to talk about assisted living. The meeting was well attended and people were very interested in the possibility of building an assisted living home that could serve their elders and perhaps some in nearby villages. Community members were excited about the state providing technical assistance to them. One person said, "We've wanted to do this for a long time, but didn't know how." The meeting ended on a very positive note, and I looked forward to working with the community toward this goal. A couple of elder women then pulled me aside and said, "You know, what we really want is to be in our own home and have people coming in to help us."*
>
> ***— Kay Branch***

7.3.1 Home Care/Personal Care Services

Descriptions of TCC and YKHC home care programs are included in Chapter 5.2. These programs exemplify how tribal organizations can work to keep elders at home, but they are not without challenges. Tanana Chiefs Conference Home Care program has successfully taken the elements of personal care and Medicaid waiver programs to provide services to 45 villages in their region. Strategies include training local workers; educating elders and family members on health promotion to enable them to take control of their care; and working closely with tribal councils to identify workers and ensure quality service delivery. The Yukon-Kuskokwim Home Care program employs more than 75 workers at any one time to achieve their goal of allowing regional elders to age in place. YKHC is the forerunner in offering two types of PCA services, developing career ladders for workers, and providing training at the high school level. Both of these programs have made several adaptations over the years (within the constraints of state regulations) to enhance service delivery. The missions of both organizations are conducive to providing quality services to all the people in

the regions, and to provide services to all Alaska Native individuals in need, not just those who are Medicaid eligible.

The challenges of operating PCA programs are primarily related to state regulations and funding. Personal care services have undergone some changes in the last two years, which have impacted service delivery, especially in rural areas. The two types of programs, agency based and consumer directed, have distinctively different requirements for staffing but are reimbursed at the same rate. In the agency based model the client receives services from an agency that manages and supervises their care and their personal care assistant. A registered nurse is required to review care plans and attendants have to have specific training prior to working. In the consumer directed model, the client hires and supervises his/her own worker, who is often a family member. There is an agency involved, but their role is to train the consumer to manage their own care and to bill Medicaid and pay the attendant. There is no need for a registered nurse or specific training, as the client trains his/her attendant in how to provide care.

When the consumer directed program began in October 2001, Medicaid payment was set at $21.00 an hour, the same as for the agency based program, except at that time most agency based programs also received a state grant to help pay for the infrastructure needed to provides these services. In July 2004 new agency based regulations went into effect that ended the grant programs, but did not (as was expected) increase the hourly reimbursement for agency based programs. Therefore, these programs are in jeopardy in rural communities where the cost of doing business is higher. The cost of employing a registered nurse and training the attendants far exceeds the hourly reimbursement for services.

Since July 2002, there has been an increase in private consumer directed agencies, extending their services into some of the rural areas, and providing competition for the tribal agencies. Competition can create a positive environment for program quality. However, it can also create confusion for clients as the independent providers do not have the same mission or commitment as a tribal provider and serve only Medicaid eligible clients, which may decrease the client base needed to maintain a tribal program. Tribal programs, on the other hand, have a commitment to provide services to Alaska Native people throughout the region, even those who are not Medicaid eligible, and the grant funding helped them to provide this care. In correspondence to the State Department of Health and Social Services regarding the cost of care, YKHC indicates that they have to subsidize the program at 150% due to “unfunded mandates, onerous requirements and failure to pay for routine costs associated with providing services” and requested a rate increase for rural programs to the total cost of delivering services.[1] As of April 2005, no resolution has been proposed. YKHC and TCC continue their commitment to financially support these programs.

Although the consumer directed model of personal care has fewer overhead costs, most tribal agencies have been reluctant to provide these services because of liability issues. YKHC

[1] Correspondence dated April 28, 2004 from Gene Peltola, YKHC, to DHSS Commissioner Joel Gilbertson.

addressed this by including home care services in their Federal Funding Agreement, which means the service is covered under the Federal Tort Claims Act. Several other tribal health organizations will also be offering consumer directed services in the near future.

Personal care programs require a good deal of administrative support also, especially in rural areas where there is so much distance between the workers and the main office. Since the employees work independently in elder's homes and do not have an opportunity to debrief in person, a lot of time is spent on the telephone supporting workers in their roles. There is a high turnover in most agencies, though there are some employees with longevity. This is a very stressful job, with few monetary benefits. Not all agencies pay health and sick leave, and many employees are non-permanent and part-time. Due to the nature of the service, the agencies can't guarantee hours unless they have a funding source other than Medicaid. Nonetheless, it can be a very rewarding job as is mentioned in the workforce section 7.4.5. It is also the primary service on the long term care continuum that can ensure that elders remain in their own homes.

7.3.2 Assisted Living

Assisted living is one type of housing or facility based long term care. Development of assisted living in rural areas is expensive due to high construction costs, and it is difficult to maintain staff that are capable of caring for residents with high needs, such as those eligible for a Medicaid waiver. Homes in rural areas must be small in order to not overbuild for the need, but this means that they cannot obtain the economies of scale found in more urban settings.

The rural assisted living model presented in Chapter 5.3.3, Marrulut Eniit Assisted Living (MEAL) in Dillingham, has won two national best practice awards. Following are the key elements that have contributed to its success:

- There were several local "champions" committed to the project, who were able to devote substantial time to the development process.
- MEAL was developed with advice from a task force comprised of people from all regional service agencies. This allowed the initial champions to build community support.
- Ongoing meetings with regional elders were a part of the development process in order to seek their guidance and keep them informed of the progress.
- A separate private non-profit board composed of members of each of the local service entities was established.
- The staff includes local people, many who speak the language, cook traditional foods, and have known the elders all their lives.
- The commitment of local agencies to provide financial support when necessary.

Although considered a successful model, MEAL also experiences some continuing challenges:

- Staffing is the number one ongoing challenge. There have been difficulties with some staff being prepared to come to work on a regular basis. The need for time off for activities such as family matters and subsistence gathering can be problematic when providing 24-hour care to numerous residents. Behavioral health issues and background checks have also factored into staff recruitment and retention.
- The high costs of building and operating MEAL make it prohibitive for people who do not receive some sort of state assistance, such as Medicaid waiver funding. The negotiated Medicaid reimbursement rate is about $4160/month and there is an additional $800/month from each elder's income for room and board.
- Since most residents are Medicaid waiver eligible, and are therefore nursing home level of care, their high care needs can place an extra burden on staff.
- The design is not optimal, with long hallways and residents out of sight of the central work area. The elders had requested a circular building design, but builders said that would be too costly.
- The cultural elements were included in the planning and initially there was a lot of community involvement. However, it takes effort to maintain this community support over time, which can be difficult when balancing the duties of the day-to-day care needs of the residents.
- Financial support, primarily from BBHA, continues to be necessary for sustainability.

Other models of rural assisted living include Kotzebue, Tanana and Barrow, all of which receive either state or local funding to operate. Maniilaq has operated the 20-bed home in Kotzebue since the mid-1980s funded by a state grant. The old building is expensive to maintain and the state has advised Maniilaq that the subsidy will end in the next few years. Maniilaq will be closing the home and transitioning residents to either independent housing or a smaller version of the current assisted living model because of lack of funding. Most of the current residents are a low level of care, needing primarily supervision and meal support, and therefore do not qualify for Medicaid waiver reimbursement for services, which would bring in additional revenue.

The Village of Tanana also receives state funding to operate a 16-bed assisted living home in a building previously used to house nurses when there was a hospital located there. Occupancy has fluctuated over the years, with some residents returning to their villages during the summer months when the weather is better. Like Kotzebue, the residents in Tanana do not have high care needs, but just need a safe place to live with the added services of meals. They have had only a few Medicaid waiver clients over the years so cannot count on that revenue.

The North Slope Borough operates an assisted living home in Barrow with 7 residents. The home is fully subsidized by the Borough. Difficulties with flooding and asbestos in the original facility have forced the NSB to relocate residents twice in the last few years, and to re-examine the feasibility of the home. NSB is working to close the assisted living in 2005 or 2006 by either transitioning people to personal care services, residential housing, or assisted living operated by another organization if developed.

There are two other assisted living homes are under development: a 9-unit home in Galena, which is using the MEAL model; and a 18-unit home in Bethel, which will be operated by YKHC. There is discussion in the Interior region that the opening of the Galena home will have a detrimental effect on Tanana, and may force Tanana to close. The Galena home is supported by the villages in the Yukon-Koyukuk subregion and will rely heavily on Medicaid waiver clients. Ultimately a fine balance must be achieved in regional placement and development of assisted living homes in rural areas.

7.3.3 Supportive Housing

Because of the challenges of assisted living development and operations, there is a need to include other types of supportive housing that are less intensive than assisted living. Assisted living has taken the forefront in development because there is a funding mechanism in Medicaid waivers. But what about the people who just need a safe place to live and perhaps some supervision, meal preparation and social support, like those in Kotzebue? Tribal health organizations can form partnerships with tribal housing authorities to develop solutions that would support these individuals.

For example, the Tagiugmiullu Nunamiullu Development Corporation (TNDC) in Barrow recently received funding for five unit apartments in five of the regional villages. TNDC will be looking for ways to incorporate housing with services in these units. Grant funding may be available through national housing agencies for resident services coordinators in some locations. A coordinated effort between housing and health organizations could produce some creative position sharing to ensure that elders receive the care they need.

In another example, the North Pacific Rim Housing Authority (NPRHA) developed Multi-Use Supportive Housing or MUSH in four communities. This housing concept could be a viable option for housing elders or people with disabilities in small communities where assisted living might not be feasible. The building is a triplex consisting of one, two and three-bedroom fully handicapped accessible units, and could accommodate any number of alternative living arrangements from independent housing to licensed assisted living. The MUSH unit in Port Graham houses the offices of the Community Health Representative and behavioral health counselor. In the future they could employ a live-in caregiver or personal care attendants to provide for elders in residence. NPRHA has committed funding for the ongoing maintenance and upkeep of the building, and is working with the tribe and health organization on a plan for staffing when needed.

7.3.4 Nursing Homes

Nursing home care is the most intensive long term care service, and one that most people indicate is the least desirable. However, nursing home care does have its place on the continuum, and a discussion of any additional nursing home services needs to take place within the ATHS. The only tribally operated nursing home in Alaska is Quyanna Care Center, attached

to the Norton Sound Health Corporation's acute care hospital. Other small nursing homes are co-located with hospitals in Cordova, Kodiak, Petersburg, Sitka and Wrangell. These small rural nursing homes are expensive to operate, and co-location with hospitals is necessary to maximize cost efficiency in staffing, dietary support, maintenance, laundry and administration (Mather 2004).

As mentioned previously, one of the problems with building for highest level of care, nursing homes, is that once constructed the beds must be kept filled in order to achieve financial solvency. This can create a disincentive for developing home and community based services in a particular area, especially if the population base is not sufficient to maintain all types of services. By addressing the continuum as a whole and identifying each service needed the ATHS can minimize the possibility of overbuilding nursing homes.

Regions desiring to add nursing home beds in their hub communities are advised to conduct a thorough assessment of the need for the service and financial feasibility prior to moving forward. There are also issues related to co-location of nursing homes, which is not an IHS service, to federally owned properties. Mather (1997) suggests, that the impact of federal ownership and the Medicaid rate, for both residential and medical services be clearly defined and investigated prior to developing a rural nursing home.

7.3.5 Other Services

There are models of service delivery from other parts of the country that may be adapted for use in the ATHS. Two of these, PACE and Green House, are mentioned in Chapter 5.5. It may not be these models specifically, but elements of them that might work well with Alaska Native elders, and should be examined. For example, PACE's focus on health promotion, disease prevention and well living in the community promote the mission of tribal health organizations. Providing the type of services required in a PACE program across the spectrum of ATHS providers would ensure more comprehensive treatment of Alaska Native elders.

The Green House is a new model for a nursing home, which combines technology with personal elements of care provision and sharing. It is a small model utilizing technology to reduce overhead costs. These smaller homes emphasize the creation of pseudo family relationships and the sharing of chores based on the capabilities of the residents. This complements the traditional values of Alaska Native elders and could be a model that would work in small communities.

Telemedicine has already entered the realm of home health and long term care in some areas of the country.[2] As telemedicine in Alaska expands and capacity for an interactive connection increases, disease management, remote monitoring of chronic conditions and physi-

[2] See http://tie.telemed.org/homehealth/ for more information.

cal therapy in an elders home could become a reality. With an actively growing telemedicine system, the ATHS is in a particularly good position for future development of a service that could ensure elders receive the best possible care at home.

7.4 Considerations in Developing LTC Services

7.4.1 Cultural

Tribal health organizations strive to be culturally sensitive in delivering services and interacting with customers. This can be challenging when attempting to merge cultural traditions and values with the dominant culture of health care delivery and state and federal program regulations. One of the reasons it is so important for tribal organizations to either develop or play a significant role in the development of services is their understanding of the need to retain the cultural values and traditions of Alaska Native people.

> *Marrulut Eniit Assisted Living home was developed by tribal organizations with advice from elders. Some cultural elements, such as a circular design, were not used because of costs. Other cultural elements, such as family and community involvement, especially with intergenerational visiting and the donation of subsistence food continue to thrive. However, the degree to which the family members assist with the care of their loved ones has not met the initial expectation. Is it because MEAL is still primarily a western model, or is there a more complex cultural reason?*

In a recent study in Alaska, elders expressed the desire to live independently or with family members, as was traditional in the past. Elders said that in the past the entire community, as well as family members took responsibility for elders. They took care of household chores, provided, cooked subsistence foods, and attended to the elders' physical needs (Graves 2004). However, lifestyle changes in the last 10 - 15 years, such as integration into the cash economy and out migration of younger family members, have increased the need for formal services. Family caregiving is still very evident in Alaska Native homes, but the realities of caregiving are very complex and with the added pressures of modern life, families may need some assistance providing for an elders' care. Since the family is such a large part of the Alaska Native culture, in addition to developing formal services it is important to find ways to support the natural informal caregiving that takes place: to learn how to support the family in continuing to care for their loved ones, and to complement those efforts.

The ANEHAC discussed intergenerational sharing and how much elders enjoy conveying long-standing traditions to young people. Graves (2004) describes elders' distress about how the youth today seem to have lost interest in learning traditions. Both elders in the study and

ANEHAC are excited about the community wellness programs that are beginning around the state and talked about the possibilities of reengaging the youth in traditional activities. Dan Karmun of Nome related a story of helping a few high school boys see the value of traditional activities, such as seal hunting, and a formal education to help them get along in today's world. This is one way the elders feel they could give back to their community and continue to pass on the lessons they learned as children and adults. Iver Malutin of Kodiak indicated that one of the major goals of working together is to "rebuild the traditional respect for the elders in our communities." Community wellness programs can help foster traditional values and revive the traditional respect for elders.

7.4.2 Regulatory

Another consideration is the regulatory environment and how ATHS could work with state and federal agencies to ensure that program regulations include enough flexibility to build culturally relevant programs. Regulations will also change over time depending on the priorities of government; any changes should be made with adequate and timely input by the ATHS. Recent regulatory changes to the personal care program were mentioned in 7.3.1. Additionally, changes in the Medicaid waiver regulations include a decrease in the number of respite hours per client, and a change in the client assessment process. The regulations now require the client assessment be completed by an independent agency contracted by the state for that purpose, instead of allowing local people, trained as care coordinators, to conduct the assessment. This change has affected the timeliness of the waiver process in all areas of the state, and is particularly detrimental in rural areas.

7.4.3 Funding

Adequate funding for long term care services is the primary concern of provider organizations. With a limited amount of government funding to provide the realm of services to tribal beneficiaries, ATHS members need a revenue source for any new programs or they must divert funding from other services. The main funding source for long term care is Medicaid.

All over the country older people are choosing to live in their own homes and receive care there, either through Medicaid services or paying privately. This is important for the elder and their family, as well as costing considerably less than facility based care. For example, in Alaska the cost to Medicaid of an elder residing for one year in one of the rural nursing homes is around $237,250. Whereas, the Medicaid cost for an elder in a rural assisted living home might reach $49,275 and the cost for someone receiving the maximum number of hours for PCA services per week (35) is currently $38,220. With state and federal Medicaid expenditures expanding and the number of people over 65 increasing, it is easy to see which services are most cost effective.

However, as with the personal care program, the Medicaid reimbursement is not always sufficient to cover the cost of providing services, especially in rural areas. The Rural Tribal

PCA work group is addressing the lack of adequate reimbursement through education and advocacy. This effort should be supported at the highest level of the ATHS order to keep current PCA programs viable and allow other tribal agencies to provide this service.

Making sure that eligible people are enrolled in Medicaid is another ongoing task for the ATHS. Due to the history of the economy, some regions have fewer people eligible although they may not have income adequate to privately pay for services. There is also resistance to enrolling in Medicaid by some elders, so even if they are eligible the tribe cannot count on the reimbursement. Some regional health organizations have been very aggressive at signing people up for Medicaid in the last several years, and have increased their capacity for third party billing. YKHC has what they call the "M&M ladies" whose job is to assist elders and others with the paperwork necessary to apply for Medicaid and Medicare.

Many ATHS organizations are already contributing some of their own funding for long term care services. For example, TCC's home care program utilizes a variety of state, federal and private grants, Medicaid and tribal IHS dollars to pay for the array of services offered to regional elders. It is important to recognize this tribal commitment. Benson (2002:18) states "With regard to long term care, the commitment of resources by an individual tribe becomes critical to its ability to assess its own capacities, to start funding a long term care program, and to meet gaps in covered services. Successful adaptations of diverse resources, therefore, can create a foundation for a long term care program."

Redford (2002) also suggests that tribes must look externally and internally for resources to fund long term care services. Tribal resources that are typically used in the lower 48 are casinos and other gaming. For example, a recent study completed for NICOA surveyed 109 tribes that operated Older Americans Act programs. 92% of the tribes reported that long term care is included in the top ten most important issues for the tribal leadership. A high percentage of respondents provided tribal funding for both supportive and health-related services. The majority of tribes had either full casinos (53%) other gaming (21%), or another significant business operation. A portion of the gaming revenue is used to supplement services for elders (Redford, et. al. 2004). Since there are no casinos in Alaska, the ATHS must look for other sources of tribal resources. Regional and village for-profit corporations established under ANCSA could be one resource. Many of these corporations have a method of redistributing some of the profits to shareholders. The ATHS could work with these corporations to establish endowments or special set aside allowances to contribute to the funding of needed elder services.

7.4.4 Organizational Capacity

Creating the organizational capacity to develop and operate long term care services is another important consideration. The vast array of services and funding sources can be overwhelming and confusing. Many communities have expressed the desire to provide long term care services, but have been unable to build the capacity, either because they lacked the staff

to commit to the project or the internal organizational structure and operating procedures are not conducive to elder service development. One role for ANTHC could be to assist with the development of organizational capacity.

ATHS partners need to identify the services that they would like to develop and provide as well as those services that might be provided through collaboration with other agencies. Redford (2004) indicates that although some tribes can do it alone, most may need to create alliances with non-tribal providers to systematically plan for the future.

Regional housing authorities are an untapped resource for many tribal health organizations. The need for collaboration between health care, social services and housing is being recognized all over the country. Managers at elder apartment buildings often have an intimate relationship with their residents and can provide useful information about their needs. Since elders prefer to remain at home or close to home it will be increasingly important that "housing be accessible and safe and that it provides an environment that facilitates caregiving." (Redford 2002). ANTHC will be working with the State Department of Health and Social Services and the Denali Commission during 2005 on a study of elder housing in the state, including a survey of property managers.

7.4.5 Workforce Development

The availability of a well trained, competent, and caring workforce is crucial to the development and success of long term care services. In most programs mentioned in Chapter 5, recruitment and retention of qualified staff is a major challenge. This is nothing new to health care providers; the workforce shortages in this field are well documented in Alaska and nationally. Focus groups with rural personal care assistants revealed some of the issues they face in their day-to-day work (Johnson and Branch 2001). PCAs indicated that low pay, unstable work hours and lack of benefits, including career ladders and continuing education were some of the things that contributed to the high turnover in the PCA field. There is also an emotional drain on workers related to the closeness of the relationship that develops with a client and grief issues when a client dies. Recommendations from focus group study include the need for:

- respect from employers, the community and the medical field;
- pay and benefits commensurable to the position and the value of keeping Alaska Native elders at home;
- support for the emotional aspects of their job; and
- continuing education and career ladders.

It is essential to identify employment resources at the beginning of the planning process and ensure that adequate training, pay and benefits are built into the development of services. It is important for the top levels of the tribal health system to recognize and support the providers of long term care services. One goal of the Rural Tribal PCA work group is to

increase visibility, respect and awareness of personal care attendants in tribal communities. This group is part of the Village Health Provider Training/Education and Employment (ViP) Initiative; membership includes the directors of tribal PCA programs. Other group goals are to improve staff development and retention, develop public relations activities, and increase recruitment. They will also be taking on the task of assisting each other in enhancing tribally run personal care programs and developing program standards for tribal agencies. Members of the group have also worked to provide dual credit personal care assistant training for high school students and adults.

There are other initiatives throughout the state to specifically support workers like personal care attendants. The Alaska Alliance for Direct Service Careers (AADSC) hosts an annual conference for direct service workers and solicits nominations for outstanding professionals to be awarded a trip to a national conference. AADSC also sponsors a leadership institute to train supervisors of direct service workers and has established a committee to advocate for increased wages and benefits at the state level.[3]

With all of these workforce challenges, it must also be noted that people who work in this field feel incredibly rewarded by the clients they serve, the elders. When asked about why they did this work, focus group participants overwhelmingly talked about the elders—hearing their stories and learning from them. They were proud of their role in helping elders to stay at home (Johnson and Branch 2001).

7.5 Conclusion – Creating Good Programs

Mary Schaeffer, the Maniilaq representative on ANEHAC said programs must be based on the traditional values of sharing and respect. In light of the many considerations and challenges in developing long term care services, it is still the tribal health providers who are in the best position to create programs to serve Alaska Native elders. When asked to recommend the essential components of value-driven programs, ANEHAC members indicated that programs should incorporate local people, be flexible in design, include family involvement, be consumer driven and based in the culture. These are the characteristics that should direct the ATHS as it develops programs for Alaska Native Elders.

After twelve years of experience working with elders and the development of long term care services in rural Alaska, the author has identified several other critical elements to successful development and service delivery. Following is the accumulation of lessons learned that can assist in service development:

1. It is important to have a committed person or group of persons, a "champion," to advocate for, develop and provide services.
2. It is equally important for the leadership to commit fully to the development of long

[3] For more information see http://www.partners.hss.state.ak.us/aadsc/.

term care services, in case the "champion" leaves. This will ensure program continuity and continuation despite the absence of the individual that originally guided the process.

3. Cultural components, such as traditional foods and activities, are crucial in the development of services for Alaska Native elders.

4. Elders must be brought in as decision-makers and advisors.

5. Cooperation between local and community service agencies is a significant factor in ensuring that the needs of the elders are met.

6. Continuing outreach and education to the community about service development activities is necessary to keep up the momentum of community involvement.

7. Staff of the same cultural background or those who have developed a good understanding of the culture of the people they are serving and are dedicated to see that culture endure are best suited to provide long term care services to elders.

8. Above all remember that, *"Elders need to be near the river where they were raised."*

Chapter 8

8. Recommendations

"It's time we put our money where our mouth is in regards to our elders."

— Robin Samuelson, Dillingham, 1997

Mr. Samuelson spoke these words as Chief of Curyung Tribal Council in Dillingham when announcing tribal monetary support for the development of Marrulut Eniit Assisted Living. Funding remains one of the biggest challenges for providing long term care services, and one the ATHS will continually address while moving forward with elder care planning. That elders want to be at home was emphasized again and again through discussions statewide. It will take creative program development and identification of funding options to ensure that elders can remain in their communities.

Following are the recommendations for addressing the long term care needs of Alaska Native elders. The recommendations are separated into three sections.

8.1. Priority health needs or topics of concern for continued research and development.
8.2. Recommended strategies for statewide planning and development.
8.3. Recommendations for each region based on current services and population estimates.

8.1 Priority Health Needs Identified by Alaska Native Elders

There were several health-related topics that recurred in discussions with elders during the past year. ANEHAC members discussed the topics at the November 2004 meeting and decided to present them as the priority health needs of Alaska Native elders.

Personal care services: PCA services were overwhelmingly the most important need since they are community based and allow elders to remain in their own homes. ANEHAC members expressed the need to investigate the two types of personal care services and work with the state to ensure the program guidelines and regulations are flexible for the rural areas of Alaska.

Comprehensive care and tracking of chronic illnesses: ANEHAC recommended more comprehensive elder health care based on prevention and maintenance of chronic conditions over time. They felt the current system is based more on acute incidences that are treated independently, and it does not always provide the comprehensive care that would benefit elders.

Medication issues: Elders shared stories about prescription medication problems among themselves or friends, and the need for review and monitoring of medications for elders. ANEHAC members cited situations of self-medication errors, and higher than needed doses that resulted in dementia, falls or other difficulties.

Elder abuse: Elders are very concerned about elder abuse in their communities and would like to better understand the nature and extent of this issue. They would like to see more education and collaborative work among different community and state agencies to address the various kinds of abuse.

Housing: Elders discussed the need for housing that supports people as they age, through modifications of private homes and the development of culturally relevant assisted living or other facility based care.

Alzheimer's Disease and Related Disorders: Elders would like to know more about the extent of Alzheimer's Disease and other dementias in the Alaska Native population. They would like more information on the treatment of the dementia patient, how dementia affects family caregiving, and how dementia is viewed in the cultural context of Alaska Native elders.

Unintentional injuries: ANEHAC members were particularly concerned with the information presented about falls in the elderly population. They would like further investigation into the causes and ways elders can prevent future falls.

Telemedicine: ANEHAC was interested in the possible expansion of telemedicine in the future to include aspects of home health.

Elder and youth activities: Sharing traditions and participating in intergenerational activities to support youth and community wellness is a top priority for ANEHAC members and elders throughout Alaska.

Palliative care: Elders around the state indicate the desire to return to their communities when approaching death. Tribal health providers support this, but are often lacking the training that would help make this possible.

Traditional healing: Elders want to be sure that the future of elder health and long term care within the ATHS integrates traditional healing methods.

Urban/rural differences: A top concern of ANEHAC is the rapid growth of the Alaska Native elder population into the urban areas, especially Anchorage. Members related stories about being in town instead of the village and indicated that village life is healthier in many ways. They would like more investigation into the reasons elders are moving to town, how they handle the difference in culture, and how to meet the health and service needs of elders in urban settings.

8.2 Statewide Service and Facility Needs

1. Work to expand and improve personal care and other home and community-based services statewide. *Personal care services are in jeopardy in our tribal communities. The removal of the state grants and lack of adequate Medicaid reimbursement; the lack of funding for people not eligible for Medicaid; and inadequate wages for assistants leading to high turnover and shortage of providers in many communities, all contribute to the unavailability of personal care services in many areas of the state.*

There are two outstanding models of personal care programs within the ATHS at the Tanana Chiefs Conference and the Yukon-Kuskokwim Health Corporation. Both of these programs include PCA and an array of other home and community based services designed to support Alaska Native elders. The Rural Tribal PCA Work Group, part of ANTHC's Village Health Provider Training/Education and Employment (ViP) Initiative, is working to promote the programs and the value of PCAs. They are also assisting other ATHS partners in developing PCA programs, advocating for adequate Medicaid reimbursement, and seeking additional funding sources.

- ***Commitment from the tribal leadership to developing and enhancing personal care and other home and community-based services would fulfill the desire of Alaska Native elders to remain at home.***

2. Develop an ongoing position within the tribal health system for elder care planning. *The work of this study provides a baseline of services available and health needs for Alaska Native Elders and offers directions for future planning. This is only the beginning. Ongoing planning and technical assistance is needed for the ATHS to fully address the long term care needs of Alaska Native Elders.*

The Alaska Native Elder Health Advisory Committee, established by the board of ANTHC, could expand duties to include exploring other models of care, ensuring the integration of cultural and traditional practices and beliefs into service development, working to improve the coordination of services statewide to allow elders in need of services a seamless transition between care setting, and offering suggestions for integrating elder care into family wellness centers and other wellness activities.

This position would also be responsible for maintaining a website that would provide information and technical assistance. Ideally the website would be updated frequently with current service capacity in each region, which would provide helpful information to ANMC physicians and social workers working to discharge clients.

- ***An elder care position within ANTHC to provide technical assistance and the maintenance of an elder care website, would ensure the continued development of programs that serve Alaska Native elders, and would assist tribal health organizations in achieving their goals for elder care.***

3. Initiate geriatric assessments and preventive programs for elders. *This was identified as a need by the ANEHAC. Tools for both health assessment and prevention guidelines are available, and the models of elder clinics in the Zuni and Ute IHS service areas can be reviewed for replication or modification.*

The need for a comprehensive geriatric assessment is not unique to Alaska. Tribes in other IHS service areas are also seeking ways to provide better services to their elders. Dr. Bruce Finke, with the IHS Elder Care Initiative has developed a geriatric assessment tool and preventive guidelines for elder health.

The PCC Comprehensive Elder Exam tool is included in Appendix B, and there is a discussion of the periodic elder health exam in the December 1999 and May 2000 issues of the IHS Primary Care Provider. This instrument allows for screening and recording functional and cognitive limitations and would provide ATHS with better data in order to assess the changing needs of Alaska Native elders and continue to plan for future services. RPMS currently has the capacity to include functional status data, and guidelines for entering the data into RPMS are available. With this tool the ATHS could obtain functional status data on the active user population of elders during the next two to three year period, and be well positioned for future planning.

Dr. Finke recently revised the preventive guidelines, (also in Appendix B). Discussions on the use of preventive care guidelines are found in the January 1999 and May 2003 issues of the Provider. IHS, in collaboration with the University of New Mexico, developed a Guide to comprehensive Geriatric Assessment in Indian Country, which is available through UNM. The contact information and table of contents is also included in Appendix B.

- ***Adoption of the Comprehensive Elder Exam tool and Preventive Care Guidelines would enhance health care delivery to Alaska Native Elders and improve data collection on elder health status.***

4. Plan for facility-based care thoughtfully and cautiously. *Although elders would prefer to stay in their homes, sometimes this is not possible and their care needs exceed what their family and other supports can provide and they require nursing or assisted living care. Whether to build a regional nursing home, local assisted living home or some other type of supportive housing requires ample discussion and planning.*

Services provided by tribal organizations, with a focus on cultural needs including Alaska Native caregivers are important, and there are few facilities offering this focus. Nursing homes can only be financially feasible if attached to rural hospitals; there are a few areas where additional facilities might be appropriate. Assisted living requires intensive staffing and knowledge of complex care needs in order to accept Medicaid waiver clients, who make up the majority of residents in Alaska. There are a variety of independent housing types that may work better in small communities.

There are inherent problems with building for the most intensive service and level of care: the need to keep the beds filled can be a disincentive for developing home and community based services. The nursing home model is what most people associate with the highest levels of long term care, but perhaps there is a better, more economical model for providing high level care that can be created within the tribal health system. Therefore approaching facility development from a tribal health system perspective ***and*** including housing authorities in the discussion, will allow for a more complete perspective of the facility and housing needs of each region. The need for affordable housing for elders who need to remain in Anchorage, but do not need to be in the hospital is a system-wide need being addressed by ANTHC.

- ***Participate in thoughtful planning for housing and facility-based care. Include both health services and housing agencies in discussions.***

8.3 Long Term Care Needs by Region

The recommendations for each region focus primarily on the development or expansion of home and community based services, since elders would prefer to remain in their own homes. Home and community based services are also the most cost effective and will provide employment opportunities to regional residents. Long range planning should include the impact of the rising numbers of elders in the region, which will correspond to an increase in those needing services. A continued monitoring of population growth and the functional and long term care needs of elders at the regional level, through comprehensive elder assessments, will be needed to ensure the accuracy of the future planning for services and facility-based care.

8.3.1 Barrow Service Area

Elders on the North Slope are at high risk of placement outside of the region if their families cannot provide for their care. There are few formal home and community based services available and the assisted living home will likely close in the near future. The current estimate of elders with functional limitations is 49, with 22 needing higher levels of care in either nursing homes or on Medicaid waivers, if services were available locally. Current and future service and facility needs include:

- A concentrated, coordinated effort to develop personal care and other home and community based services.
- Increased efforts to enroll eligible residents in Medicaid as a revenue source for services.
- A permanent assisted living home in Barrow for 8 – 12 residents.
- The addition of swing beds as a service of the hospital and incorporation of swing beds and other long term care needs into the design of the new hospital.
- The need for collaboration between housing and health services for the independent living units soon to be constructed in five small North Slope Borough communities.

8.3.2 Kotzebue Service Area

Elders in Kotzebue and the surrounding villages have some options for long term care services through Maniilaq Association, paid for with Maniilaq funds. The assisted living home will likely close in the near future, with residents transitioning to independent housing. There are currently 65 elders in the region estimated to have functional limitations, 29 of whom who may be nursing home level of care. If Medicaid waiver services are not available in the community, people are referred out for nursing home care. Current and future service and facility needs include:

- Continued development of home and community based services, including personal care and Medicaid waiver services.
- Diversify funding for in-home services by increasing Medicaid enrollment and expanding billing capabilities.
- Add swing beds to hospital services (this is currently underway).
- Develop a less operationally expensive model for assisted living or supportive housing for 8 – 12 residents.
- Continue planning for the continuum of care for the future, including the possible addition of nursing home beds.

8.3.3 Norton Sound Service Area

The local nursing home attached to the hospital operates at a full capacity year round, so usually elders needing high levels of care are able to continue to live in the region. There is a need for the full array of home and community based services for elders in Nome and the surrounding villages, to serve elders not requiring nursing home care. There are currently 88 elders estimated to have functional limitations, 39 of whom may require either nursing home or Medicaid waiver services. Current and future service and facility need include:

- The expansion of home and community based services, including personal care and Medicaid waiver services, and coordination between health and social service providers to maximize delivery of these services in Nome and the surrounding villages.
- Diversify funding for in-home services and increase Medicaid billing capacity.
- Collaboration between health, social service and housing agencies on plans to develop an assisted living home in Nome.
- Once the immediate needs of elders are met, long-range planning for the growth of elders in the region is needed.

8.3.4 Yukon-Kuskokwim Delta Service Area

There is no facility-based long term care in the Yukon-Kuskokwim region. This is a large region with the high number of elder residents, and elders here are at the highest risk for

placement outside the region if their care needs cannot be met in the home. Fortunately, much of the need is being met in the home by families and through the services of the YKHC Home Care Department. With a current estimate of 226 elders with functional limitations, including 100 who are nursing home or waiver level of care, the need for facility-based care cannot be overstated. Current and future service and facility needs include:

- Developing the planned 18-unit assisted living home in Bethel. This should be a top priority for the region and the state.
- YKHC Home Care Program should be recognized by the ATHS for being a leader in the development of elder services.
- YKHC Home Care should continue to refine and enhance their services with the support of the ATHS.
- Investigating the financial feasibility and sustainability of smaller, 4 to 7-unit assisted living homes or supportive housing in subregional communities, such as Aniak and Emmonak.
- Consideration of a nursing home addition to the hospital as part of a long-range plan to keep elders in the region.

8.3.5 Bristol Bay Service Area

With the development of the assisted living home in Dillingham, area residents who need nursing home level of care no longer have to leave the region. However, MEAL does have limitations on the number of total care residents that can live there at any one time, so there may be a need to more fully utilize swing beds in the regional hospital. Additionally, there is the potential of elders having to leave the region when they need assisted living or supportive housing, but do not meet the criteria for Medicaid waiver. Currently an estimated 68 elders have functional limitations and 30 of these may require nursing home or waiver services. Current and future service and facility needs include:

- Ensuring the continued presence of personal care services in the region either through collaboration with private agencies or the development of another tribally based program.
- BBAHC should be recognized by the ATHS for their continued commitment to the Helping Hands palliative care program, after the initial grant funding ended.
- ATHS should consider ideas for expansion of the Helping Hands model statewide, with the help of BBAHC.
- Collaboration between health, social services agencies and the housing authority to ensure the need for other supportive housing is met in Dillingham and other regional villages.
- The utilization of swing beds when people can no longer reside at MEAL. In rural areas swing beds can be used indefinitely if there is not an alternative setting within the region to meet the care needs of an individual.

8.3.6 Mt. Edgecumbe and Annette Island Service Areas

There is an array of long term care services available to elders throughout Southeast Alaska. This report gives a general overview of the region, and due to data constraints is unable to make conclusions about specific locations where additional services may be needed. SEARHC, the Central Council of Tlingit and Haida Tribes, the Tlingit-Haida Regional Housing Authority, and Southeast Senior Services have all conducted assessments of the needs of regional elders. Further analysis of these reports and separation of Southeast communities is needed to get a full understanding of the facility and service needs of the elders in the region. Estimates of functional limitations indicate there are approximately 218 elders needing some type of assistance with daily activities, and 97 who may require nursing home of Medicaid waiver levels of care. General current and future service and facility needs include:

- Collaboration among agencies to review the outcomes of the various needs assessment reports and to determine the future of long term care services in Southeast Alaska, including the need for tribally operated services such as assisted living.
- Continued collaboration between tribal and non-tribal service providers to ensure quality personal care and other home and community based services continue to be available.
- Long-range planning to ensure a range of long term care services are available throughout Southeast Alaska that are culturally sensitive and reflect the values of the regional elders.

8.3.7 Interior Service Area

Home and community based services in Fairbanks are offered to Alaska Native elders by a variety of agencies, including Fairbanks Native Association for meals and social support. Elders in the regional villages receive services from TCC's home care and elders nutrition programs. There are independent residential options in some communities; assisted living in Tanana and under development in Galena. There are currently 150 elders in the region estimated to have functional limitations, 65 of whom may require nursing home of Medicaid waiver services. Current and future service and facility needs include:

- The TCC Home Care Program should be recognized by the ATHS for being a leader in the development of elder services.
- TCC Home Care should continue to refine and enhance their services with the support of the ATHS.
- Conduct further analysis region-wide of the need for assisted living and supportive housing. Collaborative analysis will generate thoughtful planning that can eliminate competition for a limited number of residents within the region.
- Further analysis is needed along the road system area from Delta Junction to the Canadian border.
- Collaboration between TCC and other tribal provider agencies including FNA,

Denakkanaaga and regional housing authorities to develop a long range plan for elder services in the region.

8.4 Anchorage Service Area

8.4.1 Municipality of Anchorage

The entire continuum of long term care services is available to Alaska Native elders residing in Anchorage, although primarily through non-tribal providers. Southcentral Foundation is actively engaged in expanding the services they provide to elders to include care coordination, personal care and home health. The elders program recently moved to a new location closer to the ANMC medical campus. There are numerous small and large assisted living facilities in Anchorage, but none that are tribally operated and provide culturally relevant care. A major challenge for ANMC social workers is helping elders who have chronic care needs and must remain in Anchorage find affordable housing.

There is concern by SCF and ANMC about being able to meet the growing need of the many elders moving to Anchorage from outlying areas. Based on the Department of Labor (DOL) estimates there are 2,901 Alaska Natives 55 or over living in Anchorage, figures are most likely higher, and the vast majority are women. Functional limitation estimates based on the DOL figures indicate that 200 of the elders residing in Anchorage have limitations, and approximately 86 of those need more intensive nursing home or Medicaid waiver services. Current and future service and facility needs include:

- Transitional housing for individuals not needing hospitalization, but unable to live alone or return to their community.
- ATHS should support the efforts of SCF to increase services to Anchorage elders through developing tribally-based in-home services, case management, home health and personal care.
- Addition of a tribally sponsored adult day health center for social activities and health monitoring of Anchorage elders. This would ideally include adult day services for elders with dementia and to provide support for family caregivers.
- Up to 50 assisted living beds in Alaska Native owned and operated homes or larger facilities, including special units or homes to serve elders with dementia.
- Additional long-range planning by the ATHS to address the needs of elders relocating to Anchorage. Elders move here from all around the state, away from their regional health provider and into the Anchorage system. Thoughtful planning is needed to address this in-migration and the implications for the tribal health system.

8.4.2 Matanuska-Susitna Borough

Like Anchorage, the continuum of long term care services is readily available in most communities of the Matanuska-Susitna Valley. SCF has recently opened a primary care center in

the area and plans to expand elder services in the future. The impact of the rapid growth of the population in this area, including in-migration of Alaska Native elders has not been determined. Based on the available population figures, an estimated 35 Alaska Native elders with functional limitations reside in the Valley, 15 of whom may require nursing home or Medicaid waiver services. The current needs in the Matansuka-Sustina Valley are:

- Further analysis of the population increase and how Alaska Natives factor into the increase is needed in order to plan for services that may be needed in the future.
- Collaboration with non-tribal senior and health service providers to ensure Alaska Native elders are accessing available services.

Rural Anchorage Service Unit

8.4.3 Aleutians

Elders in the Aleutian and Pribilof Island region are most at risk for out of region placement when they need more care than the family can provide. This region is the most underserved in the state in regards to long term care services. Contributing to the lack of services are the remoteness of the region due to location and weather conditions, and the lack of elders who are eligible for Medicaid due to higher retirement incomes and other factors. The Eastern Aleutian Tribes, Inc. and Aleutian/Pribilof Island Association are collaborating to address these service gaps. They were recently joined by the Aleutian Housing Authority to review the supportive housing needs in the region. Currently there are an estimated 19 elders with functional limitations, 8 who could receive nursing home or Medicaid waiver services. Current and future service and facility needs include:

- Continuing collaboration among regional entities to ensure the development of home and community based services, including personal care and Medicaid waiver services.
- ATHS support for any efforts to incorporate hospice and palliative care services, which is a particular interest in this region.
- ATHS should support any facility development proposed as a result of the current housing needs assessment in the region.

8.4.4 Kodiak

Most long term care services are available to Alaska Native elder living in Kodiak, primarily from the hospital or the local Senior Center. There is effort to provide personal care services in the surrounding villages through contact with a private statewide agency. There are approximately 34 Alaska Native elders estimated to have functional limitations and 15 that may need higher levels of care provided through a nursing home or Medicaid waiver. Current and future service needs include:

- Support for any local tribal agency or collaborative effort that chooses to provide personal care and other home and community based services for elders in Kodiak and especially the surrounding villages.

8.4.5 Kenai Peninsula

Long term care services are generally available to Alaska Native elders residing on the Kenai Peninsula. Difficulty with service provision arises in the smaller communities, such as Port Graham, Nanwalek and Tatitlek, where services may not be as uniformly available due to lack of travel funds, lack of local workers or other reasons. Based on the Alaska Native elder population on the Kenai Peninsula approximately 54 elders have functional limitations and 23 may require higher levels of care. What these numbers do not say is where on the Peninsula these elders reside. Due to the diversity of the area and the large number of non-native residents, further investigation by tribal health providers would provide more detailed and accurate information. Current and future service needs include:

- Continued collaboration between tribal and non-tribal service providers to ensure quality personal care and other home and community based services.
- Further analysis and discussion of North Pacific Rim Housing's model for multi-use supported housing (MUSH) will identify the usefulness of this model for replication in other small communities.
- Further analysis of the individual communities from a tribal health perspective is necessary.

8.4.6 Valdez-Cordova-Glennallen

The problem with analyzing long term care services in this region is that there are in fact three distinct areas: Valdez, Cordova, and Copper Center/Glennallen, including the communities of Chistochina, Slana, and Gakona. While the catchment area for the Valdez nursing home may well include other communities on the road system between Valdez and Tok or Anchorage, home and community based services may need to be provided more locally. The services available to Alaska Native elders vary depending on the elders' location. Further analysis of these areas individually, would better describe the needs of the elders. What can be estimated from the data is that approximately 27 Alaska Native elders in these areas has some type of functional limitation, and 13 may require higher levels of care. Current and future service needs include:

- Continued development of home and community based services to expand personal care and waiver services
- Collaboration with the Copper River Basin Regional Housing Authority to ensure the availability of supportive housing in this area along the road system. There may be a need for 5 – 8 assisted living units.
- Separate analysis of the three main population centers and surrounding areas is needed to fully understand the service and facility need.

8.5 Continued Research and Collaboration

This report provides a baseline of information formerly lacking in Alaska. The implementation of a mechanism, such as the Comprehensive Geriatric Assessment Tool, for longitudinal tracking of Alaska Native elder health and functional status would allow the ATHS to systematically record data that can be used for planning in the future. Discussions and planning within ATHS are needed, both at the regional and statewide levels, to determine the future direction of elder care in Alaska. Gaps in the research still exist as noted in the regional sections. It is particularly important for ATHS to determine the impact on services due to the growth of the Alaska Native elder population in Anchorage and the Matanuska-Susitna Valley.

ANTHC will continue to collaborate with UAA's National Resource Center for American Indian, Alaska Native and Native Hawaiian Elders, housed in Dean's office of the College of Health and Social Welfare. Gerontology is the strategic planning focus for the college, which also houses a new Geriatric Education Center. This partnership will allow further coordination of research and resource development that will benefit the ATHS. During the coming year, the NRC will continue to focus on elder abuse and defining best practices from the perspective of Alaska Native Elders. The NRC is creating a website resource for elders and service providers, available at http://elders.uaa.alaska.edu.

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Appendix A

Alaska Native Elder Health Advisory Committee

Alaska Native Tribal Health Consortium
And UAA, National Resource Center for American Indian, Alaska Native and Native Hawaiian Elders (Elder's Voices)

Alaska Native Elder Health Advisory Committee

Members

Andrew Jimmie, Minto, ANTHC Chair
Rose Ambrose, Huslia
Mary Schaeffer, Kotzebue
Janet Guthrie, Metlakatla
Sophia Chase, Anchorage
Isaac Akootchook, Kaktovik
Gladys Jung, Bethel
Mike Zacharof, St. Paul Island
Rose Heyano, Dillingham
Ethel Lund, Juneau
Lothe Wolf, Gakona
Iver Malutin, Kodiak
Dan Karmun, Nome

Ad Hoc Members

Ella Craig, UAA Geriatric Education Center
Jaylene Peterson, SCF Elder Program
Nancy Burke, Alaska Mental Health Trust Authority
Karen Purdue, UAA
Greta Ghoto, First Alaskans Institute
Steve Ashman, Division of Senior and Disability Services
Michelle Anderson, HUD & Denali Commission
Jim McCall, Alaska Housing Finance Corporation

Staff

ANTHC
Kay Branch, Elder/Rural Health Program Coordinator
Charles Fagerstrom, Extended Care Manager
Charmaine Ramos, ViP Coordinator

UAA/NRC
George Charles, Director
Janell Smith, Research Associate

Appendix B

PCC Comprehensive Elder Exam

IHS Preventive Care Guidelines for the Elderly

Comprehensive Geriatric Assessment in Indian Country

HS-065 (1/00)

PCC
COMPREHENSIVE ELDER EXAM

Date _____

Arrival Time _____ : _____ AM PM

Clinic _____

Appt _____ Walk-in _____

PROBLEM LIST UPDATE
(Enter Problem Numbers From Health Summary)

Remove	Move to Inactive	Move to Active

	APPT.	DIS.	INITIALS / CODE
PROVIDERS			
PRIMARY PROVIDER			

Functional Status

	Independent	Needs Help	Totally Dependent
ADL			
Toileting	☐	☐	☐
Bathing	☐	☐	☐
Dressing	☐	☐	☐
Transfers	☐	☐	☐
Feeding	☐	☐	☐
Continence	☐	☐	☐
IADL			
Finances	☐	☐	☐
Cooking	☐	☐	☐
Shopping	☐	☐	☐
Housework/Chores	☐	☐	☐
Medications	☐	☐	☐
Transportation	☐	☐	☐

Change in Data Entry Software

Same	Improvement	Decline
☐	☐	☐

Tobacco: ☐NO ☐YES
Alcohol: ☐NO ☐YES
Exercise: ☐NO ☐YES
Work:

Is the patient a Caregiver: ☐NO ☐YES

Key Family and Support:

Community Services:

Home Equipment:

Assistive Devices:

Review of Systems

Problems with:	NO	YES
Hearing	☐	☐
Vision	☐	☐
Dentition	☐	☐
Nutrition	☐	☐
Sleep	☐	☐
Continence	☐	☐
Prostatism	☐	☐
Digestion	☐	☐
Mobility	☐	☐
Falls	☐	☐
Pain	☐	☐
Affect	☐	☐
Cognition	☐	☐
Substance Abuse	☐	☐
Abuse/Neglect	☐	☐
Skin	☐	☐
Sexual Function/Dys	☐	☐

PMH/Surgeries/Hospitalizations

Allergies:

Temp
Pulse RR
BP
Wt.
Wt. 1 yr ago
Ht.
Vision corrected R L
Uncorrected R L
Eye Exam Date:
Audiology Date:
Dental Date:
Nutrition Screen Date:
Foot Eval Date:
Mammogram Date:
Pap Date:
Date:
Date:
Colorectal Screen Date:

Chief Complaint/Review of System/Physical Exam

Exam	NL	ABN
HEENT	☐	☐
Neck	☐	☐
Lungs	☐	☐
Heart	☐	☐
Abdomen	☐	☐
Extremities	☐	☐
Feet	☐	☐
Pulses	☐	☐
Genitalia	☐	☐
Skin	☐	☐
Nodes	☐	☐
Neuro	☐	☐
Breast	☐	☐
Pelvic	☐	☐
Rectal	☐	☐
Mobility	☐	☐
Cognition	☐	☐

Td:
Pneumovax:
Revaccination:
Influenza:
PPD *
Status:
Treated:
Advance Directive
Reviewed:
CBC
SMAC
UA
TSH
B12
Lipid Profile

Other Test/Procedures Ordered

A-A1-C	#	Purpose of Visit, Problem List Update

List all Medications: Est. Creatinine Clearance:

Medications/Patient Education

HR #
SSN #
NAME
B DATE SEX TRIBE
RESIDENCE
FACILITY DATE

REVISIT/REFERRAL TO: DATE TIME
PURPOSE:
INSTRUCTIONS TO PATIENT: ☐ SIGN RELEASE RECORDS
PROV. SIGNATURE

Functional Status

ADL = Activities of Daily Living (Katz)
Toileting: getting to the toilet
Bathing: maintaining basic hygiene
Dressing
Transfers: in and out of bed or chair
Feeding: getting food from plate to mouth
Continence: independence includes management of one's own continence care.

IADLs = Instrumental Activities of Daily Living
Finances: paying bills, balancing checkbook, cashing checks
Cooking: meal preparation
Shopping
Housework/Chores: as appropriate to roles
Medications: Manages own medications
Transportation: Able to get about independently

Community Services might include:
Senior Center
Meals on Wheels
Commodities programs
Senior Daycare
Home Health Nursing
Public Health Nursing
CHR visits
Community based long term care

Advance Directives
sample questions

Many people have an idea of what they want done if they should get sick and not be able to give us instructions. Have you thought about this? Do you have any instructions for us?
Have you talked this over with family members? Is there someone we should talk to about this?

Assistive Devices might include:
Cane
Walker (regular or rolling)
Wheelchair
Crutches
Splints
Reacher

Home Equipment might include:
Bedrails
Bath Chair (single or total transfer)
Raised Toilet Seat
Bedside Commode
Incontinence briefs

Signs of Changing Mental Status

- Decreasing functional status without obvious cause
- Difficulty managing finances (forgets bills, overdrafts checking account)
- Diminished attention to hygiene or appearance
- Gets disoriented or lost in previously familiar places
- Asks about people who have died
- Accuses family or others of doing harm or stealing things
- Sudden mood changes
- Forgets who people are
- Loses things
- Restricts activities to home
- Spends more time sitting or in apparently purposeless activity
- Wanders
- Loses track of mealtimes
- Nighttime disorientation
- Bowel or bladder incontinence

Review of Systems sample questions

Hearing: Do you have difficulty hearing conversation one on one or in a group? Do you have difficulty hearing with background noise? Can you listen to radio or television?

Vision: Do you have difficulty seeing well enough to do what you want to do? Is night time difficult? Does glare bother you? Do you have eye discomfort or dryness?

Dentition/Nutrition: Do you have any trouble chewing? Are there foods you can't eat? Who prepares your meals? What is a typical breakfast, lunch, dinner? Do you have trouble getting food in the house?

Sleep: Do you sleep well? Do you have difficulty falling asleep? Do you wake up during the night? Do you feel rested in the morning? Are you sleepy during the day? Do you take naps? Are you ever short of breath at night?

Continence: Do you lose control of your urine or bowels?

Prostatism: Do you have difficulty starting to void? Do you have dribbling at the end? Do you awaken at night to void? How many times?

Digestion: Do you have trouble with constipation or diarrhea? Any problems with swallowing? Does it seem to take you a long time to eat? Do you have indigestion, or a sour taste in your mouth?

Mobility: Are you having any difficulty or pain with walking? How far can you walk? Does pain or weakness limit your ability to do the things you want to do?
Do you have shortness of breath, chest pain or leg pain when you walk?

Falls: Have you fallen in the last several months? In the last year? What happened?

Pain: Do you have pain? Does it interfere with sleep or activities?

Affect: Do you feel sad or lonely? Do you enjoy things? Do you feel anxious, irritable? (Be alert for somatic symptoms related to depression).

Cognition: (Best assessed with observation and collateral information. See Signs of Changing Mental Status)

Substance Abuse: Do you use alcohol, marijuana, other drugs? Have you ever drank 5 or more alcoholic drinks on one occasion? Is there alcohol or drug use in the family? How does it affect you?

Abuse/Neglect: Are there times that you don't get the help you need from your family? Have you been yelled at or hit? Does anyone use your money in ways you don't approve of?

Skin: Do you have dry skin, itching, rash, or bruising?

Sexual function/Gyn: Are you satisfied with your sex life? Do you have dryness, discomfort or discharge in the vaginal area? Have you any vaginal bleeding? Do you have difficulty with getting or keeping an erection?

Office Based Mobility Assessment
(Tinetti)

- Patient gets up from chair without use of hands, walks forward, turns around, walks back to provider.
- Examiner nudges the patient gently on sternum three times, observes the patient with patient's eyes closed
- Patient turns head, reaches up, bends over.
- Patient sits without use of hands.

Observe:

- Initiation of movement
- Gait pattern (initiation, step height, step continuity, step symmetry, path deviation, turning)
- Positional vertigo
- Ability to follow verbal command
- Dynamic and static balance
- Functional range of motion
- Fear of falling

Estimated Creatinine Clearance
(Cockroft and Gault)

$$\frac{(140 - \text{age, yr})(\text{lean body weight, kg})}{72 \times (\text{serum creatinine, mg/dl})}$$

for women multiply by .85

References

Tinetti ME, Ginter SF: Identifying mobility dysfunctions in elderly patients, JAMA 259:1190, 1988.
Katz S et al: The index of activities of daily living: a standardized measure of biological and psychosocial function, JAMA 185: 914, 1963.
Cockroft DW, Gault MH: Prediction of creatinine clearance from serum creatinine, Nephron 1976, 16:3

IHS-865 (12/00)

PCC Comprehensive Elder Exam (IHS-865)
PCC+ Elder Exam

The PCC Comprehensive Elder Exam (also available in PCC+) provides a guide to comprehensive geriatric assessment for the individual provider. The goal of the form is to allow the provider to approximate the interdisciplinary team evaluation. In doing so it should make comprehensive geriatric assessment accessible to all elders.

In the upper left corner is the assessment of basic and instrumental activities of daily living or the Functional Status Assessment. This is an essential element in geriatric assessment. A decline in functional status should trigger an investigation into causes and possible interventions. The Functional Status data can also be entered into RPMS, providing valuable information to understand long term care needs of elders. There are also questions that address health habits, work status, social supports and assistive devices.

The Geriatric Review of Systems differs from the traditional review of systems in two ways. While traditional ROS is organ and disease focused, the geriatric ROS highlights the high prevalence, multifactorial geriatric syndromes (i.e. falls, incontinence, pain) and emphasizes function as well as disease finding. The last section across the top gives room for relevant medical history and allergies.

Along the right side of the form are three distinct areas. Above the top bold line are the vitals, including a current weight and weight one year ago. Unexplained weight loss is another key indicator for further investigation. Below the bottom bold line, are commonly ordered lab tests. These are not indicated routinely, but should be considered as part of a comprehensive exam. Between the bold lines are health care maintenance items. Included with those items is space to note the date at which advance directives were addressed, with the expectation that this discussion, if held, will be documented in adequate detail elsewhere.

The central portion of the form allows for a targeted physical exam and the space to document details of issues addressed above. At the bottom is an area for medication review with the estimation of creatinine clearance to facilitate proper medication dosing. On the back of the PCC are a variety of tips and sample questions to help the provider with less experience at geriatric assessment.

Experience with the PCC Comprehensive Elder Exam in Zuni indicates that the complete assessment with targeted physical exam can be done in about 45 minutes. With a well elder, the exam can be completed in 30 minutes; with a very sick or frail elder, the exam will take longer. Prescreening the chart and noting the dates of completion of the health care maintenance items between the bold lines on the right border improves efficiency. The Comprehensive Elder Exam can also be used by Community Health Nurses, Community Health Aides and Community Health Representatives as part of a community-based assessment.

The PCC Comprehensive Elder Exam guides the practitioner through a high quality geriatric assessment and makes this process available to all elders.

— Bruce Finke, M.D.

IHS Preventive Care Guidelines for the Elderly

Revised January 2005

Elements which are specific to an Elder Exam (age 65 and older)

1. Assess functional status (Actvities of Daily Living)
2. Note weight gain or loss over preceding year.
3. Medication review
4. Vision Screen (optometry exam or screening questions)
5. Screen for Hearing Impairment (questions or audiology)
6. Screen for increased fall risk (fall w/in past year?)
7. Screen for cognitive impairment
8. Screen for urinary incontinence
9. Screen for elder abuse, neglect, or exploitation, including domestic violence

Elements common to all adult health maintenance strategies

10. Blood pressure
11. Height and weight (BMI)
12. Oral health examination
13. PPD (High risk only, as defined by the CDC).
14. Screen for depression
15. Screen for chronic pain
16. Screen for diabetes
17. Screen for problem drinking

Elements with age or gender specific indications for screening

18. Colorectal Cancer Screen
19. Mammogram +/- annual Clinical Breast Exam
20. Cervical Cancer Screen
21. Osteoporosis Screen
22. Discuss the risks/benefits of PSA for prostate cancer screening
23. Lipid Screening

Immunizations

24. Influenza (annually)
25. Pneumovax (with booster after 5 years)
26. Tetanus (every 10 years)

Preventive Medications

27. Aspirin (for CAD risk > 3% in 5 years)
28. Ensure adequate Calcium and Vitamin D
    - i. 1000 mg / day Calcium
    - ii. 400-800 miu / day Vitamin D

Guide to

COMPREHENSIVE GERIATRIC ASSESSMENT IN INDIAN COUNTRY

Co-Produced By

NEW MEXICO GERIATRIC EDUCATION CENTER
UNIVERSITY OF NEW MEXICO HEALTH SCIENCES CENTER
MSC 09 5040 1 University of New Mexico, Albuquerque, NM 87131-0001
505/272-4934 FAX 505/272-4962 Email: dfranklin@salud.unm.edu
http://hsc.unm.edu/som/fcm/gec

INDIAN HEALTH SERVICE ELDER CARE INITIATIVE
45 Vernon Street, Northampton, MA 01060
413-584-0790 Email: bruce.finke@mail.ihs.gov
http://www.ihs.gov/MedicalPrograms/ElderCare/index.asp

Table of Contents

Appendix C

List of Acronyms

List of Acronyms

AADSC – Alaska Alliance for Direct Service Careers
ADL – Activities of Daily Living
AHRQ – Agency for Health Care Research and Quality
ANCSA – Alaska Native Claims Settlement Act
ANEHAC – Alaska Native Elder Health Advisory Committee
ANHB – Alaska Native Health Board
ANMC – Alaska Native Medical Center
ANTHC – Alaska Native Tribal Health Consortium
APD – Adults with Physical Disabilities Waivers
APIA – Aleutian/Pribilof Islands Association
APS – Adult Protective Services
ASNA – Arctic Slope Native Association
ATHS – Alaska Tribal Health System
AVCP – Association of Village Council Presidents
BBAHC – Bristol Bay Area Health Corporation
BBHA – Bristol Bay Housing Authority
BBNA – Bristol Bay Native Association
CHA/P – Community Health Aide/Practitioner Program
CHR – Community Health Representative
DHSS – State of Alaska, Department of Health and Social Services
DOL – State of Alaska, Department of Labor
DSDS – State of Alaska, Division of Senior and Disability Services
EAT – Eastern Aleutian Tribes, Inc.
HCBS – Home and Community Based Services
HUD – U.S. Department of Housing and Urban Development
IADL – Instrumental Activities of Daily Living
IHS – Indian Health Service
ISER – Institute for Social and Economic Research
KANA – Kodiak Area Native Association
KIHA – Kodiak Island Housing Authority
Lower 48 – the contiguous 48 states
LTC – Long Term Care
MEAL – Marrulut Eniit Assisted Living
MUSH – Multi-Use Supportive Housing
NICOA – National Indian Council on Aging
NPRHA – North Pacific Rim Housing Authority

NRC – National Resource Center for American Indian, Alaska Native and Native Hawaiian Elders, University of Alaska Anchorage
NSB – North Slope Borough
NSHC – Norton Sound Health Corporation
OA – Older Alaskans Waiver
OAA – Older Americans Act
OANHR – Office of Alaska Native Health Research, ANTHC
PACE – Program for All-inclusive Care for the Elderly
PCA – Personal Care Assistant
RASU – Rural Anchorage Service Unit
RPMS – Resource and Patient Management System
RWJF – Robert Wood Johnson Foundation
SCF – Southcentral Foundation
SEARHC – SouthEast Alaska Regional Health Consortium
TCC – Tanana Chiefs Conference
TNDC – Tagiugmiullu Nunamiullu Development Corporation
UND – University of North Dakota, National Resource Center on American Indian Aging
ViP – Village Provider Employment Initiative Program
YKHC – Yukon-Kuskokwim Health Corporation

Appendix D

List of Tables and Figures

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