Urban American Indian/ Alaska Native Long-Term Care Needs Assessment

Final Report
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Prepared by
The Urban Indian Health Institute
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Acknowledgments

Our sincerest thanks to the American Indian and Alaska Native elders in King County

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Executive Summary

Background and Introduction

The Urban Indian Health Institute (UIHI), a division of the Seattle Indian Health Board (SIHB), serves as a central repository for data gathering and tracking of health information on urban American Indians and Alaska Natives (AIAN) nationally. Although the majority of AIAN now live in urban areas, formal long-term care services for AIAN elders are lacking. This report describes the methods and results from an assessment of long-term care needs of elders residing in Seattle, King County. The primary goals of the project are to provide characterizing data about the elders, assess current utilization of long-term care services and unmet need for long-term care services.

Methods

We used both qualitative and quantitative methods for this needs assessment: focus groups and a survey of elders. Because little is known about the long-term care needs of urban AIAN, a qualitative approach was used to develop an understanding of elder's beliefs, behaviors and experiences. Thirty-two elders participated in the focus group discussions. Once themes and major priorities were identified from the focus groups, we surveyed 198 elders to obtain a representative cross section of the community. The survey allowed collection of detailed information regarding behavior, attitudes, beliefs and attributes. The survey data were used to determine the relationship between demographic and health characteristics of elders and need for long-term care services.

Results

Focus Groups

Services currently using
The top three reported services were pharmacy (20), medical (12) and dental (12), all services that are currently available through the Seattle Indian Health Board. Other commonly used services included skilled nursing (10), housing (9), alcohol, drug and mental health (8) and transportation (6).

Services needed
The top two services needed by AIAN elders were senior drop-in center (13) and housing (12). Other services reported as needed were alcohol, drug and mental health (7), pharmacy (7), dietary (6), social services (6), transportation (6) and financial assistance (5).

Other types of needed services included prevention information, such as diet, illness prevention and an annual exam. Elders also mentioned needing assistance with housekeeping, shopping, cooking, cleaning, vacuuming, yard work and personal care, such as bathing and nail cutting.

Examples of services that AIAN elders mentioned as difficult to obtain and perceived barriers were as follows:

- Alcohol and drug treatment - wait lists
- Hearing aids and pharmacy items - financial barriers
- Social services - knowing how to apply
- Physical therapy and needing referrals
- Housing – unable to access Section 8 housing, poor housing conditions and lack of coverage through Medicaid
- Physician services – difficulty locating physicians who accept Medicare

Needing help accessing services was a common theme mentioned by elders, such as how to find out about services, where to go to obtain services and what makes you eligible to receive services.

Elders mentioned financial barriers in obtaining needed services, both inability to afford some services, but also having too many assets to qualify for programs. They viewed the system as "you have to already be broken" and that "you're not free anymore. You move where they want you to move." This was viewed as "a handicap to a person freedom because then they lose the will to be independent. And they become iller… You become a victim."

Culturally appropriate care

When asked if AIAN elders preferred having services provided by people of their cultural background, the vast majority of respondents thought it would be a great idea. However, elders were clear in stating quality care is most important. One elder mentioned "older folks blend in good with non native and a variety of cultures because they have had to already in their life, whereas it might be more important for younger person to live with their own kind."

Types of care

The overwhelming majority of respondents preferred living in their own home (18). Other types of care they would be willing to use, in order of preference, were as follows: living with family (10), assisted living (9), group home (8) and nursing home (6).

Ideal long term care services

Compiling ideas from all of the focus groups, a sample vision for long term care for AIAN living in urban areas might look as follows:

The ideal long term care facility would be a community center where elders could meet to share ideas and thoughts. A native, co-generational home or being in your own home would be ideal. It would be a place where you would have good company, such as family and friends. There would be transportation provided to get to and from the facility. The facility would be clean, and the workers would be kind, dedicated and provide quality, culturally competent services. There would be a pool, exercise equipment and a big screen TV. They would have three meals a day and have assisted phone services.

Survey

Census Profile

From census data, significant disparities were evident with respect to poverty and disability status likely to put AIAN elders at a disadvantage to better health status. Chronic liver disease and cirrhosis mortality rates were significantly higher than among the general population.

Demographics

Significant disparities that place elders at risk of poorer health outcomes and greater long-term care needs were evident among elders who participated in the survey as well. Elders who participated in the survey were majority (73%) low-income, with annual incomes of less than $15,000. Forty-two percent of elders lived alone. Nearly a quarter of elders were caring for someone, typically grandchildren. About half of respondents had coverage under Medicare, 20% had Medicaid, 9% had Veteran's benefits and 25% had other health insurance. Twenty-three percent of elders were uninsured.

Health Status

Forty-five percent of elders rated their health as fair or poor. Elders were less likely to be physically active compared to elders of all races nationwide and suffered from numerous health conditions. Prevalence of arthritis, diabetes and anxiety was higher among AIAN elders compared to elders age 65+ for all races. Forty percent reported needing assistance with any Instrumental Activity of Daily Living (IADL) and 15% for any Activity of Daily Living (ADL). AIAN elders were more likely to report needing assistance with bathing and showering, housework, shopping, money management and using the telephone compared to elders age 65 and older of all races. Self-rated health status was found to be significantly associated with reported number of ADL and IADL limitations. The poorer the self-rated health status, the greater the number of reported ADL and IADL limitations.

Use of Services

Ninety-seven percent of elders reported use of any AIAN organization serving elders in the community. We found no association between use of AIAN health organizations (Indian Health Service, Tribal Health Program or SIHB) and number of reported health conditions. Among general services available to elders in the community, AIAN elders were most likely to report using physician, pharmacy, dental and vision services. When we examined predictors of service use, we found a significant association with limitations in ADLs, IADLs, presence of health conditions and gender. Elders were more likely to uses services as the number of reported IADL limitations, health conditions and ADL limitations increased and if they were male.

Need for Services

Among elders who reported they were not currently using a service, many reported needing basic, primary health care services: dental, vision and pharmacy. In addition, information and assistance was needed by 28% of elders, such as what services are

available, where to go for help, explanation of eligibility rules, how to sign up for services and where else to go for help when turned down. When we examined predictors of service need, only number of IADL limitations was significantly related. Elders were more likely to report needing services as the number of reported IADL limitations increased.

Ideas for an AIAN Elders Program

The focus groups revealed that elders were very interested in having activities as part of a comprehensive AIAN elders program. The survey results confirmed a strong interest in having activities, with 90% of elders expressing an interest in one or more AIAN cultural activities. Field trips and tours, training and exercise classes were activities many elders (greater than 60%) indicated they would be interested in and could be organized through urban Indian organizations.

Living Preference

A majority of elders preferred living in their own home (84%) as opposed to senior housing. Most elders preferred living by themselves (56%) rather than with family and preferred housing with mixed ages (57%) over living with people their own age.

In terms of long-term care facility preference, elders ranked living with family the highest, followed by assisted living facility, other option, group home and lastly nursing home. Seventy-two percent of elders indicated they did not have a preference for living with other AIAN, however more than half (53%) would prefer an AIAN long-term care facility over a facility not specific for AIAN. Both elders in the focus groups and those who participated in the survey cited "more comfortable" and "beneficial" as reasons for preferring an AIAN long-term care facility.

Conclusions

Several findings suggest an unmet need for long-term care services for AIAN elders in King County:

- Poor self-rated health status
- Lower level of physical activity than elders of all races
- Prevalence of multiple health conditions, often equal to or exceeding prevalence of health conditions among elders age 65 and older in the general population
- Limitations in ADLs and IADLs often equal to or exceeding those reported for elders age 65 and older in the general population
- Number of health conditions, IADL limitations, ADL limitations and gender were found to predict long-term care service use. Elders who participated in the survey reported multiple health conditions and 40% reported any IADL impairment.
- Number of IADL limitations was found to predict need for long-term care services.
- Age requirements for Medicare, Medicaid and state waivers pose barriers for needed services for AIAN elders until they reach age 65. Fifty-eight percent of King County elders (1,378 elders) are in the 55-64 age group according to the 2000 US Census, and would be excluded from receiving benefits.

- Sixty-three percent of elders said they intend to stay in the area rather than returning to the reservation, indicating the need for long-term care services for AIAN elders living in urban areas.

Several priorities emerged based on the results of the needs assessment:

Information and Assistance. Needing information about what services are available in the community and assisting elders through the process was a major theme from the focus groups. This was confirmed by the survey, where information and assistance ranked as the third leading service need requested by elders. Resource advocacy should be pursued to improve access to services for elders. In addition to resource advocacy, outreach and case management might also be worthwhile options to pursue. Further outreach is needed to educate elders about services available in the community. Case managers at the clinic could be assigned to assist elders through the process and follow-up to ensure services are received.

Utilize Urban Indian Organizations as Coordinating Centers for Long-term Care services. Ninety seven percent of elders reported using services at one or more AIAN organizations. This would suggest elders are fairly well connected to urban Indian organizations in the community serving AIAN and indicates an opportunity to serve as coordinating centers to connect elders with long-term care services in the community.

Pursue Home and Community Based Services. The results of this needs assessment supports recommendations from the 2002 AIAN Roundtable on Long-term Care to focus on home and community based services (HCBS). The majority of elders (84%) preferred to live in their own home, supporting the development of home and community based services for urban Indians, which is within the realm of urban Indian organizations to develop. Providing assistance with housework, shopping, transportation and personal care needs will keep elders independent and allow them to remain in their homes. Funding for HCBS could be pursued through Medicaid and 1915c waivers.

Pursue Medicare as Payer for Long-term Care Services. Few elders (20%) had coverage under Medicaid, eliminating one of the major sources of long-term care funding for AIAN. However, 50% of elders had coverage under Medicare, most with Part A and B. Medicare is the 2nd largest payer for long-term care expenditures. Medicare could be a focus for covering long-term care expenses for AIAN elders age 65 and older.

Lower Age Requirements for Programs. Consistent with previous research, elders who participated in the survey appeared to exhibit aging characteristics at an earlier age compared to elders in the general population. This is shown by the greater prevalence of some health conditions and limitations in IADLs even when compared to elders age 65 and older in the general population. The age requirement for long-term care services through Medicaid and Medicare precludes AIAN elders from receiving needed benefits until they turn 65. As suggested in the 2002 AIAN Roundtable on Long-term Care, urban Indian organizations should work with states to establish urban AIAN elders as a targeted group for which lower age eligibility could be set for state waivers.

Integrate Activities into an Elders Program. Elders showed a strong preference for social activities. This was apparent from both the focus group and survey results. Cultural and social activities should be incorporated into any comprehensive urban AIAN elders program, providing benefits for both emotional and physical health. Elders expressed interest in using community resources as well. Field trips could be arranged through urban Indian organizations to use facilities, such as local pools and libraries.

Offering American Indian/Alaska Native Long-Term Care Services in Urban Areas. Depending on the mix of services provided, AIAN elders might utilize AIAN long-term care services. A nursing home would not be well received by AIAN elders. However, the results of the needs assessment indicate that several long-term care services would be very desirable for AIAN elders living in urban areas: offering home based services; an intergenerational group home allowing elders to live with grandchildren; offering long-term care services mixed with social activities.

Introduction

This assessment documents the long-term care needs of AIAN elders living in King County, Washington. Funding for this needs assessment was provided by Indian Health Service (IHS) and was conducted by the Urban Indian Health Institute, a research division of the Seattle Indian Health Board.

Objectives

The primary goals of this needs assessment are to:

- Identify AIAN elders in an urban community who could be served by AIAN administered long-term care services
- Provide characterizing data about the elders (e.g. geographic dispersion, age, and length of time residing in the urban setting, participation in urban Indian organizations (UIO), Indian Health Service (IHS), or tribal health programs)
- Assess current utilization of long-term care services
- Assess unmet need for long-term care services
- Assess eligibility for services under 1915c waiver, Medicaid, or other state long-term care programs
- Identify potential impact of availability of AIAN long-term care services on utilization of those services

Background

Urban Indian Organizations

In 1976 the Indian Health Care Improvement Act (PL94-437) was passed, spelling out the federal government's responsibilities for Indian Health. Title V of the Act specifically provided language "to establish programs in urban centers to make health services more accessible to urban Indians." The language of the Act states the responsibility of the Federal government to Indian people; it does not give priority to location, federal recognition, tribal status, or size of tribe. However, the distribution of resources has demonstrated the priority areas. Urban Indian health receives approximately 1% of the overall Indian Health Service budget.

Despite the disproportionate and inadequate resource distribution, the program for urban Indian health does endure. The Indian Health Service (IHS), the agency responsible for caring out the Indian Health Care Improvement Act, contracts and grants to 34 independent, private, not-for-profit urban health organizations across the country. They serve approximately 151,000 clients annually, with a service area of 84 U.S. counties, in 19 states.

Urban Indian organizations (UIO) will be used in this report to refer to the 34 non-profit organizations situated in urban centers charged with providing healthcare services for AIAN. The Seattle Indian Health Board is one of the 34 urban Indian organizations, providing services for AIAN living in Seattle/King County.

Definition of Elders

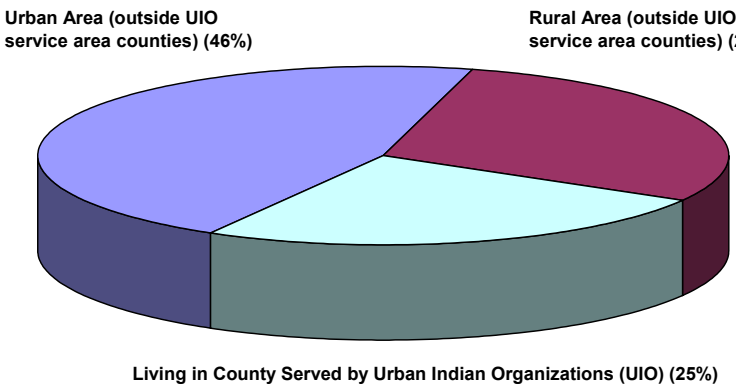
Prior research suggests the onset of old age among AIAN occurs at a chronologically younger age than for the US general population. In some states, AIAN are considered old at age 45 under the Older Americans Act, whereas federally funded nutrition programs use age 55 to qualify AIAN for senior citizens benefits. The National Indian Council on Aging (NICOA) notes most indicators of health and quality of life have declined for elderly AIAN and acknowledge AIAN are often considered elderly at a chronologically younger age than their US general population counterpart (Rousseau P 1995). Locally, the city of Seattle aging office uses age 55 to qualify AIAN for benefits. Therefore, age 55 and older was used to define elders in this needs assessment. For this report "AIAN" and "American Indian/Alaska Native" are used interchangeably, and except where specified, refer to persons who indicated their racial background to be American Indian or Alaska Native alone or in combination with other races.

Demographic Profile

Population

According to the 2000 Census, of the persons who identified themselves as AIAN alone or in combination with some other race, one quarter (25%) lived in counties served by UIO, and another 46% of AIAN lived in census defined urban areas which lay outside UIO counties (**Figure 1**).

Figure 1. American Indian and Alaska Native population living in counties served by Urban Indian Organizations (UIO), 2000.



Source: U.S. Census 2000

In King County as well as in all UIO service areas, AIAN make up 1.2% of the population, similar to the proportion of AIAN nationwide (**Table 1**).

Table 1. Population by Race/Ethnicity, 2000

Race/Ethnicity	King County Number	King County Percent	UIO Number	UIO Percent
White	1,396,099	80.2%	48,905,650	75.9%
Black	109,862	6.3%	9,196,667	14.3%
AI/AN	20,148	1.2%	764,954	1.2%
Asian and Pacific Islander	214,628	12.3%	5,587,667	8.7%
Hispanic as Ethnicity	96,115	5.5%	14,928,729	23.2%

Data Sources: 2000 US Census

Figure 2 shows the distribution of AIAN in King County. AIAN are scattered throughout King County, however AIAN elders appear to cluster in areas closest to city of Seattle.

Figure 2. American Indian/Alaska Native Population in King County, 2000.

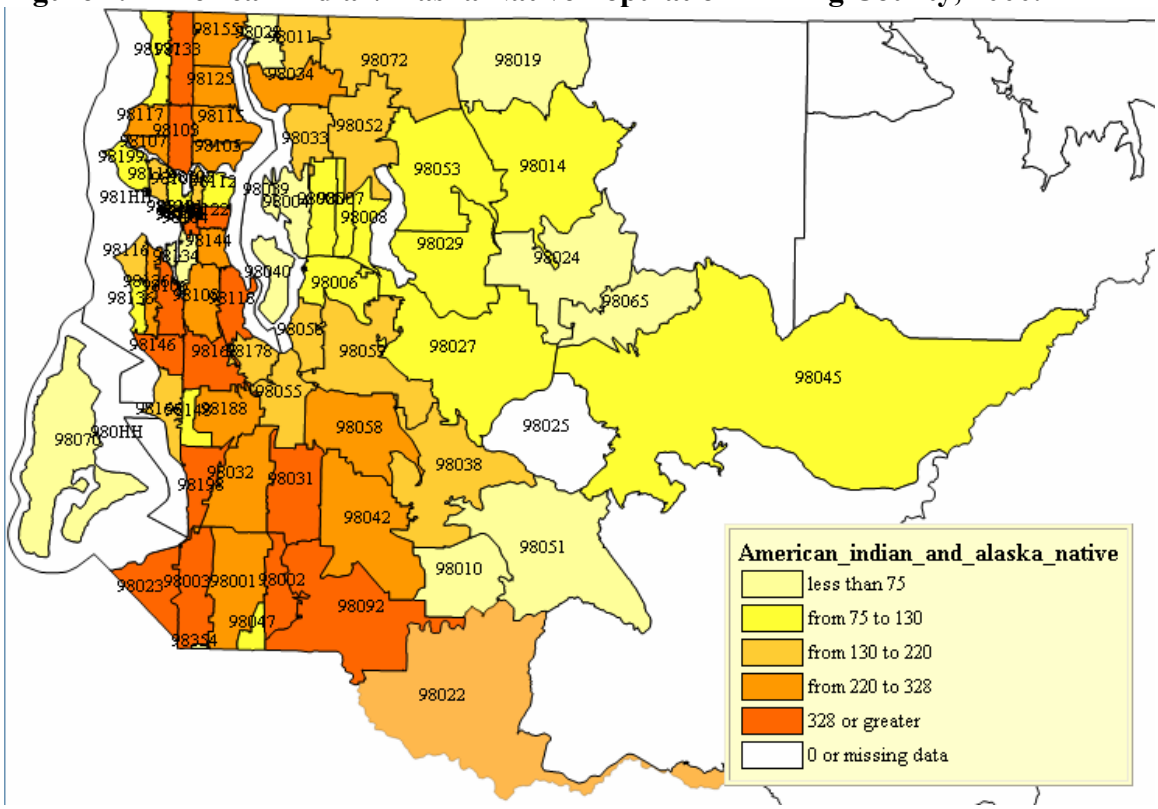


Figure 3 displays population by age group for all races and AIAN in King County and all UIO service areas. Elders age 55 and older make up a smaller proportion of the AIAN population than for all races. In 2000, there were 2,370 elders age 55 and older living in King County representing 11.8% of the AIAN population, and 77,340 elders living in all UIO service areas. For the needs assessment, we surveyed 198 AIAN elders, representing 8.3% of the AIAN population age 55 and older living in King County.

Figure 3. Population by Age Group, King County and All Urban Indian Organization Service Areas, 2000

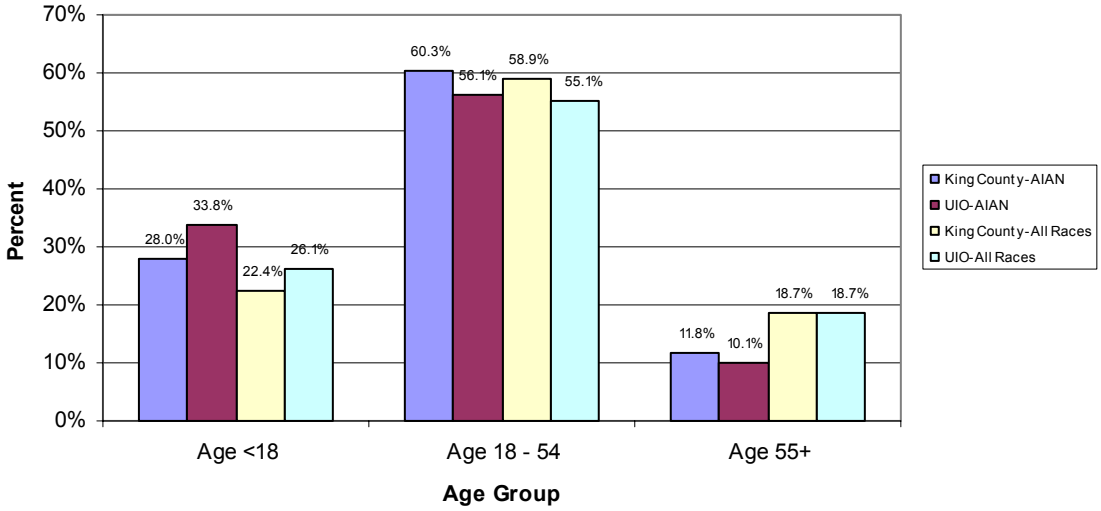


Table 2 compares the 1990 and 2000 AIAN elder population age 55 and older in King County. There was an increase of 13% from 1990 in the population of elders who indicated their racial background to be AIAN alone. The 1990 census only allowed one race selection whereas the 2000 census allowed persons to identify as one or more races, making direct comparison difficult. The U.S. National Center for Health Statistics (NCHS) developed bridged population estimates based on the 2000 census which are in the same single race categories similar to the 1990 census. Using these bridged estimates, there was an increase of 36% in the elder population since 1990.

Table 2. AIAN Population Age 55+, King County, 1990 and 2000.

	1990 AIAN Alone		2000 AIAN Alone			2000 AIAN alone or w/other races		
	Number	Percent	Number	Percent	% Increase	Number*	Percent	% Increase
Males	762	43.7%	942	47.8%	23.6%	1,118	47.2%	46.7%
Females	983	56.3%	1,030	52.2%	4.8%	1,252	52.8%	27.4%
Total	1,745		1,972		13.0%	2,370		35.8%

Data Source: 1990 and 2000 US Census

*Bridged estimates from NCHS

By age group, the majority (58%) of AIAN elders are age 55-64 **(Table 3)**. There were 1,378 elders age 55-64, and an additional 992 elders age 65 and older.

Table 3. Population of American Indians and Alaska Natives, King County, 2000

Age Group	Number	Percent
Age 55-64	1,378	58.1%
Age 65-74	627	26.5%
Age 75-84	288	12.2%
Age 85+	77	3.2%

Population estimates for the AIAN elder population through 2010 are shown in **Table 4**. Nearly 6,000 AIAN elders are estimated to be living in the King County area by 2010.

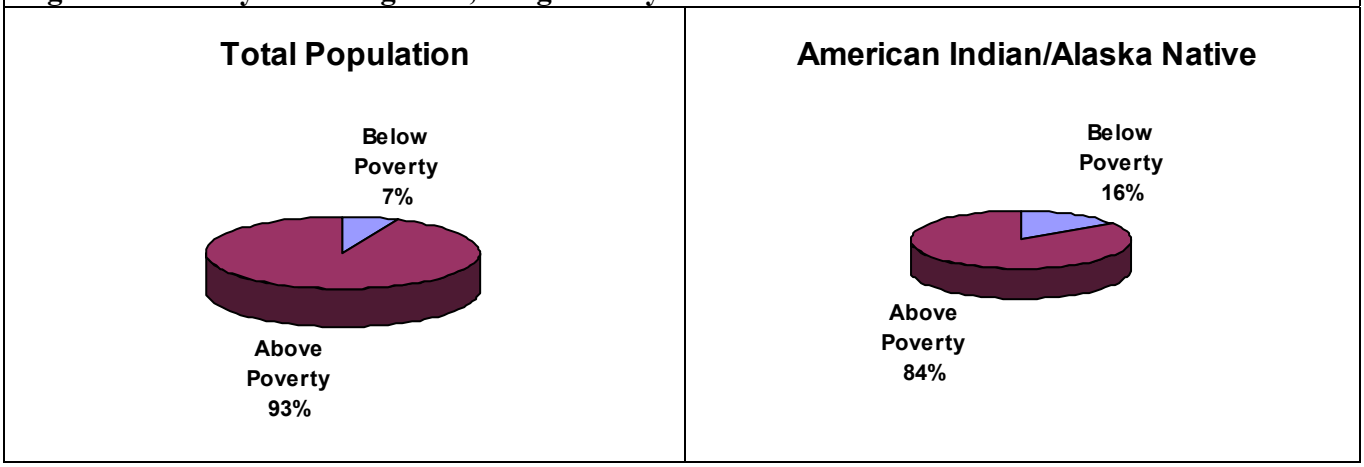
Table 4. Population Estimates AIAN Age 55 and Older, King County, 2002-2010

Year	AIAN alone Number	AIAN alone or w/other race Number
2002	2,535	4,135
2003	2,652	4,325
2004	2,774	4,525
2005	2,902	4,734
2006	3,036	4,952
2007	3,177	5,181
2008	3,323	5,420
2009	3,477	5,670
2010	3,637	5,932

Poverty Status

Figure 4 shows the percent of all elders and AIAN elders age 55 and older living with incomes below poverty in King County. More than twice the number of AIAN elders are living in poverty compared to elders of all races.

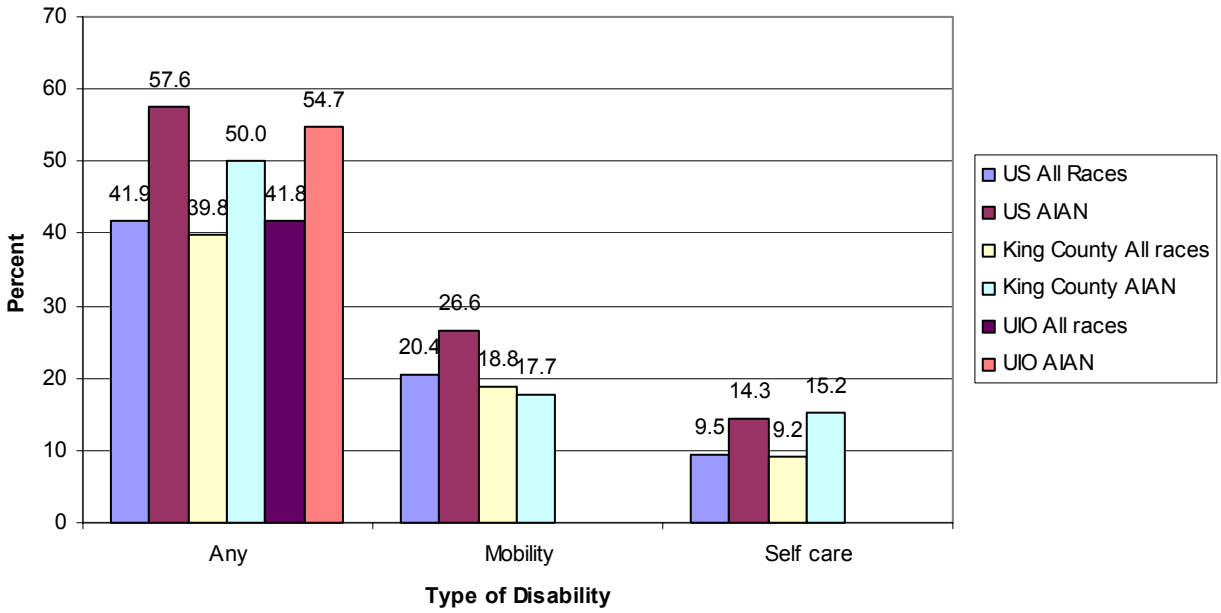
Figure 4. Poverty Status Age 55+, King County 1999



Disability Status

Figure 5 compares disability status among elders age 65 and older for AIAN and all races. AIAN elders were more likely to report having any disability nationally, in all UIO service areas and in King County. AIAN elders nationwide were more likely to report mobility limitations, however rates were similar between AIAN and all races in King County. AIAN elders were more likely to report self care disabilities both nationwide and in King County.

Figure 5. Disability Status Age 65+, 1999



Leading Causes of Death

Leading causes of death from 1990-1999 among elders age 55 and older in King County are shown in **Table 5**. Similar to elders nationally, heart disease, cancer and cerebrovascular disease were the three leading causes of death. However, diabetes was the 4th leading cause of death for AIAN elders, while among elders nationally it was the 6th leading cause of death. Similarly, chronic liver disease and cirrhosis was the 6th leading cause of death for AIAN, while it was the 12th leading cause of death among elders nationally. Chronic liver disease and cirrhosis mortality rate was significantly higher among AIAN compared to elders of all races.

Table 5. Leading Causes of Death Among Elders Age 55+, King County 1990-1999

			AIAN					All races		AIAN
		Total		95% CI				95% CI		compared to
Cause of Death	Rank	Deaths	Rate*	LB	UB	Rank	Rate*	LB	UB	All Races
Diseases of heart	1	142	709.5	597.9	836.1	1	941.9	930.9	953.0	-25%
Malignant neoplasms	2	119	591.8	490.2	708.2	2	810.5	800.3	820.8	-27%
Cerebrovascular disease	3	36	178.6	125.1	247.6	3	300.0	293.8	306.3	-40%
Diabetes mellitus	4	23	114.8	72.9	172.1	6	80.2	77.0	83.5	ns
Chronic lower respiratory disease	5	23	113.3	71.7	170.3	4	184.5	179.6	189.5	-39%
Chronic liver disease and cirrhosis	6	17	86.8	51.0	138.1	12	26.7	24.9	28.6	225%
Influenza and pneumonia	7	14	69.9	38.3	116.9	5	105.7	102.0	109.4	ns
Accidents and external causes	8	12	61.4	32.1	106.2	8	53.2	50.6	55.9	ns
Septicemia	9	11	53.9	26.7	96.5	13	25.5	23.8	27.4	ns
*Rate per 100,000, 95% Confidence Interval										
Data Source: US Centers for Health Statistics										

Overview of Services for American Indian/Alaska Native Elders

American Indian/Alaska Native Organizations

Several organizations in the Seattle/King County area currently provide services to elders in the community. Below is an overview of the main organizations serving elders and the services they provide.

Seattle Indian Health Board (SIHB). The SIHB is a non-profit, multi-service community health center chartered in 1970 to serve the healthcare needs of American Indians and Alaska Natives living in the greater Seattle/King County region of western Washington State. SIHB divisions include: healthcare services, medical, dental, lab, pharmacy, mental health, nutrition programs, a family practice residency program, chemical dependency services, Thunderbird in-patient treatment center and outpatient counseling services, community services and the Urban Indian Health Institute.

United Indians of All Tribes Foundation (UIATF). Formed in 1970 to establish an urban base for AIAN in the Seattle area, today the United Indians of All Tribes Foundation provides vital social and educational services to more than 25,000 AIAN, from early child development and family counseling to housing homeless youth and preparing meals for the elderly. UIATF operates the only existing AIAN elders program in the Seattle

area. The Elders program serves hot nutritious lunches five days a week, excluding holidays. The program is focused primarily to the AIAN community but serves all people equally. In addition, the program helps find transportation to and from the meal site, provides referrals to health service providers, offers stretch and tone classes, arts and crafts activities and assists in coordination of weekend activities. UIATF is based at the Daybreak Star Cultural Center located on 20 acres in Seattle's Discovery Park. It was over 25 years ago that United Indians founder Bernie Whitebear and other AIAN invaded this site, which was originally Indian land, to build a center that would improve the spiritual, social, economic, educational and cultural conditions of AIAN.

Seattle Indian Center (SIC). Located adjacent to the SIHB clinic, SIC is a non-profit organization that provides multiple services to AIAN and the needy in the surrounding communities. Services include: basic computer (including web and email), basic office applications (including word processing, spreadsheet and presentation), drop-in time (open lab), employment training, GED/ABE, Microsoft Office certifications and tutoring/homework help. Their focus is to provide familiarization with computer technology and employment training for adults and to facilitate a youth access program. Although SIC does not operate a formal elders program, they do have a food bank providing meals for low income elders and others in the community.

Chief Seattle Club (CSC). Operating a drop-in center at Lazarus Day Center in Pioneer Square, CSC serves up to 130 men and women a day. CSC provides emergency clothing, meals, nursing services, laundry service and recreation. In addition, they offer referrals to housing, drug & alcohol treatment, federal benefits and general assistance. Again, while not a formal elders program, some elders in the community access services through this organization.

Overview of Long-Term Care Services

In addition to Medicare and Medicaid, Washington State has two home and community based waivers: COPES and Medically Needy Residential Waiver (MNRW). The following information was derived from the UCLA Center for Health Policy Report on Medicaid Home Care and Tribal Health Services for Washington State (Wallace 2003).

The COPES waiver covers personal care services in home and in residential settings (adult family homes and boarding homes). COPES also covers 9 other services if eligible: home delivered meals, PERS (personal emergency response system), skilled nursing, environmental modifications, home health aide, specialized medical equipment, client training, adult day care and transportation. MNRW covers personal care in boarding homes and adult family homes. Other MNRW services include skilled nursing, client training, specialized medical equipment and transportation. Services are provided through the Department of Social and Health Services (DSHS). The State Plan offers personal care services in home, adult family homes or boarding homes.

Eligibility for personal care services requires one substantial need or three minimal for direct personal care tasks. The Medicaid state plan services for home health requires an MD order.

Waiver services are available to aged, blind and disabled adults 18 and older. Medicaid and both waiver services have an age requirement of 65 and older, and both state plan personal care services (MPC) and waiver services require financial eligibility.

Methods

We used both qualitative and quantitative methods for this needs assessment: focus groups and a survey of elders. Because little is known about the long-term care needs of urban AIAN, a qualitative approach was used to develop an understanding of elder's beliefs, behaviors and experiences. Qualitative methods are useful for gaining depth of knowledge and illuminating the context of a problem (Morgan 1993 and 1998). Focus groups have the potential to yield rich data as participants interact and compare their experiences. The process of interaction helps to elucidate the range of opinions among participants. Focus groups can also be useful for exploring complex social phenomena that may be difficult for an individual to explore in isolation but more easily clarified in group discussions (Morgan 1993 and 1998).

Once themes and major priorities for elders were identified from the focus groups, we surveyed a larger sample of elders to obtain a representative cross section of the community. The survey allowed collection of detailed information regarding behavior, attitudes, beliefs and attributes. The survey data were used to determine the relationship between demographic and health characteristics of elders and need for long-term care services. Methods for the focus groups and survey are described separately below.

Focus Group Methods

Focus Group Participants

Participants were American Indian and Alaska Native elders age 55 and older living in King County with a recent visit (2002 or 2003) to SIHB. We obtained a list of 821 American Indian and Alaska Native patients age 55 and older who had visited the clinic. After excluding those with a visit prior to 2002 (21%), no addresses (7%), homeless (<1%), non-King County residents (20%) and deceased (<1%), we had 421 elders. We used a stratified sampling frame to select participants for the focus groups balanced by year last seen, age group and gender (100 from each year (2002 and 2003), 50 men and 50 women in each of 4 age groups, 55-64, 65-74, 75-84 and 85+). For some cells, there were too few persons to achieve the desired sample number. To make up for deficient numbers, additional names were evenly selected among the remaining cells to achieve 100 in each year last seen. A total of 200 potential participants were randomly sampled on the assumption that approximately 25% of persons would agree to participate to achieve the desired number of 50 participants. Letters of invitation with a self-addressed postage paid return postcard were sent to those individuals selected in the final sample to invite participation in the focus groups. We followed up one week later with a phone call to remind and invite elders to the discussion groups. In addition, elders recommended other elders whom they felt should be present in the discussion groups. Additional letters of invitations were sent to these individuals. Finally, a few additional elders showed up on the day of the focus groups through word of mouth. The actual number of participants was 32 (16% response rate).

Data Collection
The focus group discussions were held on May 15th, 2003 at SIHB. The focus group discussions lasted approximately 90 minutes, with 5-8 elders present in each group. A short, self-administered survey was passed out to each participant prior to the focus group to collect information on demographics, use of healthcare services and insurance information (**Appendix A**). Following the discussions, an Elders Spring Celebration was held with food and traditional Alaskan Native performances for the participants. Besides the valuable information gathered, the elders thoroughly enjoyed spending time with each other.

The focus group moderators and note takers were graduate students from the University of Washington School of Public Health and SIHB staff. A one hour training session was held prior to the focus groups to review the focus group guide and questions. Materials on facilitating focus groups and working with AIAN communities were provided. A follow-up half-day training session was scheduled the day of the focus groups to review focus group procedures. We sought to have at least one AIAN moderator or note taker in each group, however we were not successful. Therefore, two of the focus groups did not have either an AIAN moderator or note taker present in the group.

The focus groups were assigned six questions to answer:

1. What types of services are you or someone you know currently using?

2. What other types of services have you or someone you know needed?

3. In thinking about services, is it important to you to have these services provided by people who are of your cultural background?

4. Would you prefer living in a care facility with other American Indian and Alaska Native elders?

5. If you are unable to meet your own needs, what types of care would you like to use?

6. In thinking about long-term care services for American Indian and Alaska Native elders, what would you want?

The focus group questions are included in **Appendix B**. With permission of participants, all focus groups were audio-taped and then transcribed. Paper copies of transcripts were stored in locked file cabinets in locked offices accessible only by project staff. Electronic transcripts were stored on computers requiring User ID and password. The audiotapes were destroyed at the end of the project period.

Data Analysis
Project staff extensively reviewed transcripts to identify major themes and concepts. Main themes were organized into "codes" that gave structure to analyzing and compiling

data. Refer to **Appendix C** for the codebook. In order to organize and retrieve coded data, transcripts were entered in NUD*IST, a software package for analyzing qualitative data. Designed for handling non-numerical unstructured data by techniques of indexing, searching and theorizing, NUD*IST is the front-line tool for analyzing text-based data. The analysis steps were as follows:

1. Initial codebook developed by the Project Coordinator from the question guide and report outline.
2. Project Coordinator coded all transcripts and edited the codebook as needed.
3. Project members each reviewed several transcripts and final refinements were made to the codebook.

Once the transcripts were coded and the codes were entered into NUD*IST, all the data (across interviews) for a given code were retrieved in a single report. From these reports, emergent themes were explored in depth and the range of views expressed within a theme, as well as the relationship between themes, was considered.

Initial write-up was done by the Project Coordinator. The findings were shared with other project staff who facilitated or took notes at the focus groups as a validity check. Finally, focus group participants were asked to comment on the report through two mechanisms. An Elders Fall Celebration with food and traditional AIAN storytelling was scheduled, and all focus group participants were invited. At the event, the focus group results were presented and participants were asked to give feedback. Secondly, focus group participants who indicated an interest in reviewing the report were mailed a copy of the written report and asked to provide comment.

Limitations

Some members of the community were represented at the focus groups through word of mouth, but primarily recent clinic patients were recruited. Although SIHB serves over 250 tribal affiliations from various socioeconomic backgrounds, the results may not be suitably generalized or representative of all AIAN. Clinic patients may differ from the general population with greater health and long-term care needs, or may represent a healthier population since they are receiving healthcare services.

We were only able to offer limited transportation for participants (bus passes). This may have influenced which elders were able to attend, for instance attracting more elders in better health and with less long-term care needs. This might also explain the low participation rate.

In addition, another concern is two of the focus groups did not have an AIAN moderator or note taker. This might influence the conversation within the focus groups. However, themes were similar among all five focus groups, two without AIAN staff and the three groups with AIAN staff.

Survey Methods

Survey Instrument Development

The survey instrument was designed to address issues most relevant to AIAN living in urban areas to assess which services in the community elders are using and if they would rather use services specific for AIAN. The survey gathered information on general health status, use and need for long-term care services, functional status, physical activity, ideal AIAN elders program, housing and sociodemographic characteristics. Questions were drawn from three sources: an urban Indian elders survey developed by Dr. Josea Kramer conducted in the Los Angeles area, the survey instrument developed by the University of North Dakota National Resource Center on Native American Aging, and a screening instrument developed by Mekinak Consulting and used in the Seattle area. Existing survey questions were used to allow for comparison to previous urban elders needs assessments and needs assessments from tribes. These survey questions were refined and supplemented with additional questions based on feedback from the focus groups. See **Appendix D** for a copy of the survey questions.

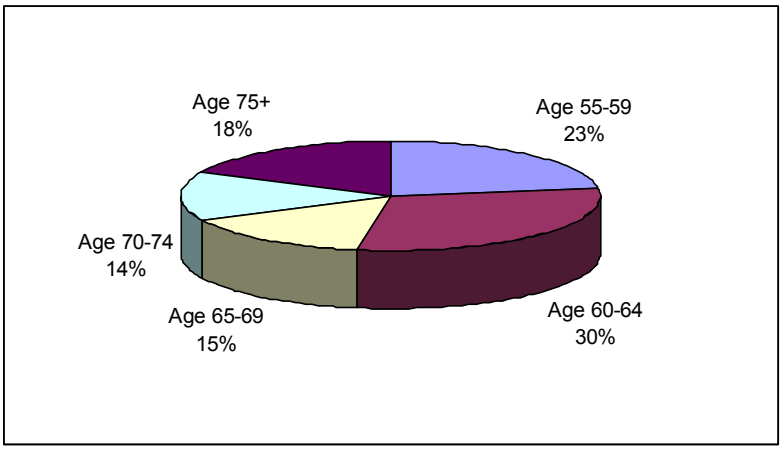
An electronic survey instrument was developed in Microsoft Access, providing a user-friendly interface in which to collect the data while interviewing. Interviewers read the script from the computer and entered responses directly into the computer. Because a computer controlled the questionnaire, skip patterns are executed automatically, there are no out-of-range responses and no missing data. Responses were entered directly into the computer, eliminating data entry and data cleaning steps. Other features of the application included: allowing for stopping and resumption of the interview at any time, backing up to previously answered questions to change a response, automatically advancing to the next question as responses are completed, addition of notes at any time during an interview and saving data as it is entered to ensure protection against any loss.

Sample Selection

All 421 names from the focus group list of AIAN elders age 55 and older living in King County with a recent visit to the clinic were included in the survey sample to obtain 200 completed interviews. An introductory letter was mailed to all persons two weeks prior to calling to describe the project and encourage participation. A telephone contact number was provided in the letter to schedule an interview or to request an in-person interview if the person did not have a telephone. A round of telephone contact attempts were made to invite elders to participate in an interview or to schedule an interview. Calls were made during day, evening and weekend times for up to 5 rounds, or a total of 15 call attempts. In addition, elders were asked to recommend other elders they felt we should speak to or would want to talk to us about long-term care. Other recruitments efforts included attending the elder's lunch program offered through UIATF and having staff refer elders who came into the clinic for an appointment. In all, we had names for 460 elders, including names of new contacts obtained through these various recruitment methods. Forty-three of these had non-working phone numbers, 108 were incorrect phone numbers, 5 were deceased, 6 were ineligible and 24 we were never able to reach after 15 attempts, leaving 274 elders who were successfully contacted. Interviewees were limited to persons who self-identified as AIAN, were 55 years of age or older and living

in King County. If the telephone numbers were incorrect or no telephone number was provided, an attempt to look up phone numbers was made. Interviews were conducted by telephone or in-person, whichever method the elder preferred. A $10 incentive gift certificate was given to all persons. We had 34 elders whom we were never able to reach at a good time and 39 elders who declined to be interviewed (14% refusal rate). Two hundred three elders agreed to participate in an interview; however 5 interviews had to be terminated early on in the survey because the elder had difficulty responding to the questions; these 5 were excluded from the analysis. One additional survey was nearly completed; this survey was used in the analysis for questions for which there were responses. The final number of completed interviews, including the one partial interview was 198. These 198 interviews were included in the analysis. **Figure 6** shows the age distribution of respondents.

Figure 6. Age Distribution of Survey Respondents



Data Collection

The interviews were conducted November 3, 2003 through January 7, 2004. The majority of interviews were conducted by three interviewers who were hired under contract for the project, one AIAN woman and two Caucasian women. However, when elders were at the clinic for other reasons or through word of mouth by clinic staff, elders would drop-in to ask if they could do the interview. If none of the interviewers were scheduled for a shift at the clinic that day, the Project Coordinator or other project staff would conduct the interview. The majority of interviews (67%) were conducted over the telephone, with only 33% of interviews conducted in-person, either at the elders home or at the clinic.

We examined responses to several questions to determine if there were statistically significant differences in the way elders responded to questions depending on the interviewer. The vast majority of questions showed no significant differences in responses based on the interviewer with one important exception. The question pertaining to preference for an American Indian/Alaska Native long-term care facility was more likely to receive an affirmative response for the AIAN interviewer and the Project Coordinator (also a person of color, but non-AIAN) than for the two Caucasian interviewers. However, the second question pertaining to AIAN preference ("Do you

prefer to live with other American Indians and Alaska Natives or it doesn't matter?") showed no significant differences between interviewers.

While conducting the interview, the survey questions would often evoke questions from elders regarding services, and particularly information and assistance with accessing services. All interviewers were given the telephone number of two community resources, Community Information and Assistance and Senior Information and Assistance, which were provided to any elders requesting information. In addition, elders were referred to Resource Advocates at SIHB who could assist elders with accessing services.

Data Analysis

Data were analyzed using Stata 8 and SPSS version 11.5. Descriptive and multivariate statistical analyses were used to provide characterizing information about elders and to examine predictors of use and need for long-term care services. When possible, Chi-squared tests were used to compare survey results with existing data. Simple linear regression was used to examine bivariate relationships for continuous variables, such as health status and number of ADLs. Bivariate logistic regression was used to examine relationship between categorical variables, such as the predictive model of reported use of AIAN health services (Indian Health Services [IHS], Tribal Health Program [THP], and Seattle Indian Health Board [SIHB]) on health condition.

For the multivariate modeling, we first conducted bivariate statistics to examine the associations of individual factors with service use and service need. Next, two multivariate models were constructed, one examining predictors of service use and the second examining predictors of service need. We created a summary variable totaling the number of services used and needed as the dependent variable for the respective models. The independent variables were selected from the literature as predictive of long-term care need (Chapleski 1997, Kim, Pan 1998, Parker, Polivka 2002). These were as follows: age, gender, education, income, presence of health conditions, ADLs and IADLs. ADLs, IADLs and health conditions were summarized into continuous variables summing the total number of ADLs, IADLs and health conditions respectively. Independent variables and selection methods for each model are presented in detail with the results. For the multivariate analysis, persons who responded "don't know" or declined to answer the question were excluded, leaving a sample size of 144 for the multivariate analyses.

Limitations

Some members of the community were surveyed through word of mouth, but we primarily sampled recent clinic patients. As mentioned before, clinic patients may not be representative of the general population. In addition, two of the three main interviewers were non-AIAN. However, as mentioned previously, we found little difference for most questions by interviewer.

Results

Focus Group Results

Demographics

There were 32 elders who attended the focus groups representing 18 different tribes. Women comprised 69% of the participants and the mean age was 72 years. Many of the elders had resided in an urban area for over 50 years, with a mean length of time residing in Seattle or other urban area of 45 years. The majority of participants (88%) had used Seattle Indian Health Board services, 59% had used an IHS healthcare program and 20% had used tribal healthcare programs. Sixty-five percent indicated they were aware of social security, 67% knew of Medicare and 47% knew of Medicaid eligibility rules.

Figure 7. Age Distribution of Focus Group Participants

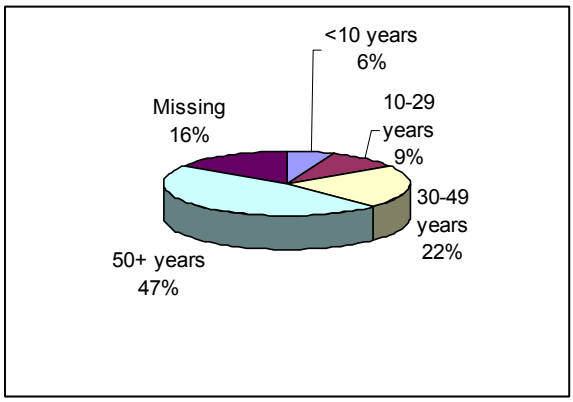
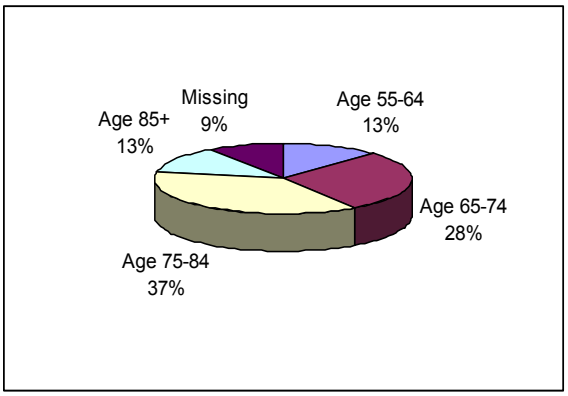


Figure 8. Length of Time Residing in Urban Area



Use and Barriers to Services

Activities

Elders stressed the importance of having activities particularly for socializing purposes and meeting people. Specific activities that elders mentioned were: line dancing, softball, basketball, taichi, cards, contests, computer lessons, and free classes, something that was fun!

Alcohol, Drug and Mental Health Services

Some elders felt there was a very big need for geriatric psychiatry. It was mentioned the service is available at SIHB. A barrier to services mentioned by one elder is the long wait lists for alcohol, drug and mental health treatment. But elders were also very encouraged by success stories they have seen.

Case Management

A few elders mentioned they coordinate getting their health care services "*on my own*". The VA hospice program was mentioned as a place that offers this service. Another elder mentioned there is a need for someone to serve as an advocate for patients, particularly for those who may not have family around to assist.

Dental Services

Several elders stated they used the dental services at SIHB, several others said they were using dental services elsewhere. The cost of dental care was brought up, in particular, there's no insurance to cover dental, Medicare doesn't cover dental and services are expensive.

One person described how they came to SIHB for dental and was surprised when they were charged for the visit, since nobody had explained at registration that they would have to pay.

Diabetes Management

Diabetes Management appears to be a service that is well provided at SIHB. Participants spoke positively about the diabetes group, which provides nutrition and exercise program. Elders felt this was a good group where they learned to take care of themselves, and even some non-diabetics attend the group just to learn.

Dietary and Nutritional Services

Numerous elders mentioned using dietary and nutritional services, such as meals on wheels, lunch programs, through the diabetes group and senior centers. Elders also said senior centers on the reservation also had meal programs. But it was also discussed that in Seattle, they "only had one place" and they "moved the meal program out". Providing nutrition education as part of preventive services was a suggestion. Elders expressed a sincere interest in youth by suggesting dietary programs start earlier and to connect elders with youth to teach them about nutrition.

> *"have preventable information for older people to understand how they need to watch their diet. Because I know a lot of people who have diabetes."*
>
> *"don't wait till you get older… I didn't know about it earlier. Now I think it's very important."*
>
> *"I was just thinking, you know, for the younger people, and have the older people make the connection, so you know, how they have to watch their dietary thing, you know."*

It was praised that meals on wheels is very accessible, but the meals are not very balanced and they don't provide fresh foods. It was suggested the meals didn't taste especially appealing either. Finally, elders mentioned the need for culturally appropriate nutrition services.

"...you need to be culturally aware of what people eat."

Estate/Will Planning

Elders brought up the difficult subject of estate and will planning. Elders acknowledged the difficulty of planning, but the importance of doing this. The elders had the following suggestions:

"...make your own will now."

"If you have a lot of property, you better get a lawyer."

"Be organized..., get rid of a lot..."

"Have someone plan, help you plan."

"...have your will in order... it can get ugly believe it or not"

"...you have to let your family know whether you want to be cremated or not."

Elders commented on how trying to plan was made even more difficult by other family members who did not like to think about estate and will planning.

"They don't even want to think about it."

"...they just thought I was terrible but I think it's really right"

"...you have to face reality"

Hospital

Elders reported they used the Veterans Administration, University of Washington, Swedish, Virginia Mason, Providence and Harborview hospital. SIHB patients said they go to the hospital for things the clinic can't handle, such as *"broken leg"* or *"new heart"*. It was mentioned that Harborview had excellent emergency room services. One elder mentioned she uses Medicare and ARC (insurance) to go to Providence (hospital).

There were barriers to hospital services expressed as well, particularly for homeless persons: *"I'm dealing with someone right now...can't get dialysis and things..., some special services"*.

Housing

Housing was a need expressed by several elders. Elders described living in public assistance, rent subsidized or senior housing, living in their own homes and living in the street. One elder mentioned their building was a combined independent and assisted living facility. Another elder said senior housing was available on their reservation.

Finding affordable housing was a problem in Seattle. Long wait lists, need for vouchers or minimum income made housing out of reach.

> *"It's like non-existent for Seattle. My girlfriend moved to Port Angeles and got a reply in two weeks. If she was in Seattle, she would have been on the list for anywhere from 2 years plus I don't know whatever."*

> *"They have some affordable housing recently built in Seattle…but you have to have a certain amount of income every month…some people that don't have this income and they call it affordable housing. So yeah, it's still a problem."*

> *"It's hard, some housing you have to get…a voucher and it takes a long time to get a voucher in Seattle. …you have to go there and put your application in and somebody told me…it takes five years. And some of that new housing you have to have a voucher, if you don't have a voucher, you can't move in except for HUD."*

Another elder described poor housing conditions, respiratory problems and pests in their apartment. Another elder wanted Section 8 housing.

Informal Caregivers

Some elders mentioned other family members (son in law, daughter, brother) who provide home-based services, such as taking them shopping, mopping, going to doctor's appointments, bathing and cutting hair. Family members can also serve as an advocate on behalf of the elder. It was suggested by some elders that having informal family caregivers was preferable to having someone from outside coming into the home.

> *"But the boys, my brothers, they don't want them to come in the house. We take care of each other. Maybe 5 years down the road we would probably need help, but right now we don't need it."*

Occupational/Physical Therapy

Elders used occupational and physical therapy services at the University of Washington hospital or at the VA. Elders felt it was a good program to have, but not very accessible. Elders felt you need to be motivated to get the services, and you need to have your doctor give you a referral. One elder said they were able to get their physical therapy services paid for by Medicare.

> *"It's a good program to have. Your range of motion is very important."*

> *"…it depends on your doctor. If he thinks you need it, he'll assign you…or make arrangements so you have it."*

> *"I think the barrier again is a financial one... Unless you have medical coverage to cover that, you're not going to get it.*

> *"…everything takes a referral now. You have to have a referral to say yes, that is needed. Whether you have the coverage or not, if you don't have the referral you're dead in the water."*

"I couldn't go anymore because there was no payment, no medical, for that."

Elders also described the benefits of physical therapy in providing simple exercises not too strenuous but keep you strong. Another elder described someone who used physical therapy to improve balance, which could help to prevent falls.

"I think that after my experience of physical therapy, I think that all elders should have therapy because what it does is keep you flexible and keeps your bones strong and you don't have to go out and jog you know you can just have a little mat and they show you different exercises and its I'm just stronger now."

Pharmacy

Elders in all 5 groups said they used pharmacy services.

"…he takes 17 medicines a day."

"I take a lot of pills. I live off pills."

Elders said financial barriers were the major problem with access to pharmacy services. Insurance may only pay a portion or nothing at all. Other elders said their Medicare did not cover prescription drugs. One elder mentioned she was able to get around the financial problem by getting it free from the pharmaceutical company if you are low income.

"I get a discount with insurance, not very much, it varies and some of my medication every now and then can be costly."

"I think people on Medicaid, they get their medication paid for but I don't have that."

"The cost just keeps skyrocketing."

Physician Services

Elders in all 5 groups used physician services. Elders mentioned using physician services regularly, for checkups or only *"when I get the urge"*. Physicians turning down Medicaid and Medicare were also mentioned as a problem.

Senior Centers

Elders talked about needing senior center services all around town, instead of having services concentrated downtown.

"We need some more services. Most services are downtown…All around. …Your own area."

Elders obtained flu shots from senior centers. Elders requested more activities at senior centers, such as softball, basketball, cards, learning the computer, etc.

> *"I think that would be nice if seniors could go there you know, find out what they can do, learn the computer, or whatever and help with shopping things like that…"*

Another elder commented on having get-togethers at senior centers and how socializing greatly improves your mental health. Some elders mentioned their reservations had nice senior centers.

Elders lamented about the loss of the senior center behind the Indian Center.

> *"They used to have one but don't have it anymore. They took it away. They moved it to way up north."*

> *"We need to have the elders over here like we used to have them. We miss that so much."*

Skilled Nursing

Elders mentioned using skilled nursing services at the VA. Another elder pointed out temporary skilled nursing services should be available for persons just released from the hospital and still recovering.

> *"…they let him out of the hospital before he was ready and he's back in again. I just think it should be easy to get 'cause it's such a need, you're weak and you don't know anybody. …Now he's back in and he's in serious shape. I just feel sorry for him."*

Social Services

Some elders said they used social services at the VA. Social services were perceived by some to be very important, but the barriers to social services were how to apply for services, and where to go if you are turned down.

> *"The barriers are more how do you fill it out? How do you apply for social security? What do you do when you are turned down? Do you just give up?"*

> *"Social services are really necessary. Very much needed"*

Speech and Hearing

Elders reported using or knowing others that use hearing aids. Elders commented that only a hearing test is provided, but not hearing aids. Elders said they were not able to afford a hearing aid.

> *"They don't provide any hearing aids or anything.*

> *"They just provide the test."*

> *"And we haven't been able to afford to get them."*

Transportation
Elders reported using transportation services, such as Metro ACCESS, discounted taxi, and senior fare on the bus, while others indicated they did not need help. Some elders would use transportation assistance when they weren't well, for instance when their arthritis *"flared up"*. Elders said ACCESS was valuable, but difficult to obtain services. Elders described difficulty in contacting ACCESS and having them show up at the wrong time. Elders also talked about having their own van at SIHB in the past, but funds ran out to continue the service.

Veterans Administration
Several elders mentioned using VA services, such as physician, hospital, pharmacy, skilled nursing, hospice, case management, social services, "*everything that you want*". The VA appeared to be a good model for all inclusive care.

Vision
Elders brought up the difficulty in obtaining vision services:

> *"Medicare doesn't help with the eyeglasses and that can get expensive."*
>
> *"We have a lot of people come in, coming to the clinic asking for it & it's not available."*

Service Needs

Home Healthcare
Home healthcare was expressed as a need, even coming once a week to cut fingernails and toenails.

> *"we…have visiting nurse comes once a week to take care of my brother."*
>
> *"the person that I know that used to have that, I think that it's only good for so long and then she, and then they just decide that you don't need it anymore."*

Homemaker Services
A great desire for chore services, such as vacuuming, cutting the grass, shopping, transportation and moving furniture, was expressed by elders, even just twice a month.

> *"That's where I need help with the housework. I can't use a vacuum cleaner and I can't clean at all. My arms got so weak."*
>
> *"It's hard for me to move furniture, like I used to. They're kind of heavy."*
>
> *"I'm not very able to do the chores…"*

Information on Services

Elders were not aware of programs or assistance they could receive or might be eligible for. They didn't know they could get someone to do chore services or get help with transportation. An elder commented that some people still don't know about SIHB and it's been here for 30 years. Likewise, other people did not know what the Seattle Indian Center does. Eligibility for services was another barrier described. Elders had many questions about eligibility for services, such as who can get services, where to go and how to sign up. Elders also sought help beyond getting information about services but actual help accessing services. What can you do if you are turned down for services? Do you give up, or how can you get information on what else you can do? Elders mentioned it is difficult getting downtown to sign up for ACCESS, and finding out how to do this from home would be helpful information.

> *"we gotta know that there is a service that we can go to it, and that they will really help."*
>
> *"What do I need to do?"*
>
> *"pre-entry thing before you get any of these services…?"*
>
> *"…how do they access? Get somebody in here to tell how do you sign up for meals on wheels, how do you sign up for ACCESS. … and it's very difficult to go down there. How do you do it from home? Is there someone you can talk to?"*
>
> *"The barriers are more how do you fill it out? How do you apply for social security. What do you do when you are turned down? Do you just give up?"*

Importance of Native Provider

When asked if AI/AN elders preferred having services provided by people of their cultural background, the majority of respondents thought it would be a great idea. However, elders were clear in stating quality care is most important. Benefits of having a native provider include: feeling more at ease, more comfortable since you can relate to the person, better able to understand them without having to explain, good for native people shy in asking for help and in counseling where many things are solved culturally. Difficulties in dealing with non-Native providers were language barrier with non-English speaking persons, differing values and not able to understand the way others think. More females preferred having a native provider (7 females vs. 1 male) and more males said it didn't matter (5 males vs. 2 females).

Beneficial to Have Native Provider

"I would like to see more natives in the medical field. But, above all, I like to see a competent person, you know, not only in his field but also in understanding the person he is dealing with, or the background of the person."

"if I have someone that's of our background, then that would be more beneficial because then there's a lot of things that we don't have to say so they understand, you know."

"I think it would be beneficial, you know, or helpful. And I think probably most of the people that would come to here would be more at ease."

"I think it would be nice if we had more native people. But once they get that training, they don't ever go back to the reservation."

"I think it's a nice thing in my opinion, it's a nice thing to have but in my I don't think it's required, whoever is qualified, medically qualified you know."

"I think that with a lot of Natives who really don't mind going to the doctor or something like that, that would be good for them, that they would be able to identify, you know because I think that, I think that there's just really a lot of Natives that will even though that they're sick, that unless they're really, really on their death bed they will go, but I think as far as prevention, maybe that might make them, you know…So as long as they're qualified and they're good and they're going to give you excellent care that's the main important thing. But then I'm also thinking of some of those Elders, who you know,…"

"Native people were too shy to ask for help."

"and when it comes to counseling, I think that's important because there's some, there's a lot of things that are solved that are cultural and that is really helpful, so I would say that there's something that the preference, you know because they I'm, I've just worked in Head Start and some of the managers because that they don't really quite understand, they can't relate to the families and you know Native people nothing blows us away because we've seen everything where if you're not a Native, and you don't count the experience, it sometimes just blows them away."

More Comfortable to Have Native Provider

"Would be more comfortable."

"if you could relate to that person, it becomes more comfortable with that person and it's always good to see you know people that are similar feel more comfortable in a way so you have a better report and have that person be knowledgeable…"

Prefer Native Provider

"Of course."

"Course."

"It's very important because the reason I don't associate much with my Caucasian neighbors is that I can't understand the way they think, I just get so flustered."

"Their values are different."

"I had a worker assigned to me from Korea. I think she came yesterday. It was hard to understand, I couldn't understand, had to keep asking her to repeat what she was saying. I finally told her, there's too much to here, and I can't live with that. ' Cuz I'd ask her a chore or something and say don't do this. As soon as I turned my back she'd go right and do just what I asked her not to do. It's just that she didn't understand."

Doesn't Matter

"Is qualified be fine, do a good job. Doesn't make much difference with me."

"I'd rather have a doctor. I don't care…"

"As long as they're qualified."

"to some Indians it would make a difference. But some it would not."

"if you're out here in the urban sprawl, you accept whoever's got the qualifications."

An interesting sentiment was expressed by one elder in it is not very often you see a Native provider, making this a difficult question to answer.

"It always throws us when we get a doctor or nurse that's our own people."

It was also brought up in a couple groups that SIHB had non-Native providers and it wasn't all Native.

"it's not a criticism of the Health Board but merely a statement. That the people that they hire are obviously not always Native American."

"I did not know that Indian Health Board did not mean Indian. …I says, wait a minute, I thought this was Indian Health? Uh, well yeah, everybody can go it's really not "Indian" health. …I am really shocked that why is it called Indian health when it's not. Anybody can go there."

"In Alaska, in ANS in Anchorage, anybody can go there anymore, it's not Native."

"It's not? Oh, for goodness sakes."

Importance of Native Long-term Care Facility

Again, the majority of respondents said they would prefer an all-Native long-term care facility. It was mentioned by several elders this would be nice, but not required, as long as they are medically qualified. It was mentioned by one person that older folks blend in well with non-natives and a variety of cultures because they have had to already in their life, whereas it might be more important for a younger person to live with their own kind. Other elders felt it really depends on the person and how they were treated. Many felt it would be beneficial to have a facility for Native people, many thought it was a great idea. More females preferred having a native home than males (7 females vs 4 males) and more males said it didn't matter than females (6 males vs. 2 females). Some elders spoke of returning to facilities on their reservations to be closer to family. Other elders indicated price is another factor that would influence their choice of a long-term care facility.

<u>Prefer Native LTC Facility</u>

"I believe it would be really beneficial if there was one just for Indians. But I so far haven't seen anything other the one down here that they have. The one I'm staying at, you know, it's all mixed. But, it's pretty nice. I mean, it's not really anything really great, but it's nice and quiet. I would like to see if there was all Indian. I probably would prefer it."

"I think it would be good for myself."

"And that's my wish, to be among other native people, which we have a place on the Blood reserve."

"I believe it's a great idea for Native Americans, Alaskans included. ... And I think for a commune type living that natives together get along better then you have one in the woodpile."

"I think it'd be fun to have natives. Over on our reservation they have separate facility for older people, senior centers. ...I think they're doing fine."

"I think there should be a facility where native and indigenous people can get together."

"Sitting here and talking, maybe we don't realize or understand. But when you're in the nursing home, we're gonna miss our people. I'm gonna wanna see

(name), (name), (name), (name). I can at least talk with them, you know? This is my people. So I really need to be in a nursing home. ... they don't realize it now because we're sitting amongst ourselves. But when we're all by ourselves, there's no more sisters, brothers, friends. You know, we're going to need the other Indian people. We're gonna need them."

"I think the reason why is because the natives are generally polite & kind. They don't want to hurt you. That's an underlying feeling of well, I wouldn't comment about you here, if I thought it didn't look nice, I would just not say anything. But the other groups are not always like that. Sometimes they are very blunt. They're not meaning to be hurtful, but that is the way they behave."

"I think it sounds good. Cuz you know they'll come out and open up. They won't be quiet like they usually are to where they don't talk. They don't have to you know whatever they're holding back out, and that's usually good."

"We're more relaxed with each other."

"Nice just to see somebody that looks like you, talks like you or thinks like you."

"Everytime I see somebody I go over and tap them on the shoulder and say, are you native? And they say yeah. It's a great feeling."

Doesn't Matter

"Depends on your environment, how you grew up, and your attitude about being with other people."

"Oh, it doesn't make a difference to me. It doesn't bother me."

"I feel that myself, either one would be fine. Because I like to be with my own people and I don't mind being otherwise."

"No, don't have any trouble that way really. But I can blend in."

"Doesn't matter to me."

"I don't think it'll matter to me as long as I'm getting the care if I need it."

"That's the way I feel too."

Types of Long-term Care

Living in Your Own Home

The most popular choice was living in one's **own home**.

"I think the first choice is you'd rather stay in your own home because you're surrounded by your things."

"If I could able to take care of myself or my son, be home."

"Yeah, just own little trailer house, and not a burden to anybody."

"I myself personally would rather be at home."

Shared Housing/Living with other Natives

Elders brought up **shared housing** and the SHARE program as an option, or even sharing your own **with another native** person or family.

"Well, I had thought that I might look for someone that wanted to live with me in my house, as some kind of part-time care giver."

"They got a program called SHARE, and they have this program that um, to try to suit your interests, your, and um. But they got a lot of data there to share your home. And they take someone into your home that's been prescreened and has a good resume, good references. But they do a screening. Sometime they'll pay half the bills, but if they have to do 15 hours or more, and then they don't pay anything because they'll doing skills for you. There's something you don't have down there. Some people aren't aware of this share program."

"I would prefer helping a native person, native family, because I know when I was a young family, there was no one to help. And so I feel my whole purpose now is to help the native people in my own way too. ...Before my brothers moved in, I had young Indian people stay with me. It worked out OK."

"I'd like to stay in my home. ....I would like to share my home with another Indian person. Because I have two bedrooms. Very small home and easy to take care of. I would rather stay there. Cause if there's some other Indian person that maybe doesn't have a home would like to stay..."

Living with Relatives

Elders also described *"taking care of our own"*.

"One of our elders, if I remember right they're usually living with other relatives."

"I was alone for almost 12 years and now my daughter, she's giving up her 6 bedroom home with 3 trees that she revived, restored, and a creek with fish in it where the kids can catch their own fish. It was absolutely an ideal place. And she gave up all that and she came to live in my home. She lives upstairs in my home. And she brought 4 wonderful

grandchildren, I'm so blessed."

"We take care of each other. Maybe 5 years down the road we would probably need help, but right now we don't need it."

"On our reservation, we have senior housing, and people take care of each other. …We prefer to take care of our own."

Interaction with Youth/Co-generational Home

When talking about housing and long-term care options, a co-generational home was raised. Elders described a strong desire to interact and teach youth.

"So, what I'm doing is taking his children & teaching them and that's one of the reasons why I wanted to be there so they can see how older people carry on. And what the interaction is between his parents and himself, and myself. And so he can see the process of, you know, the aging."

"I'd like to see inter(link?)… I'd like to the seniors to be doing things with the youth you know because our urban youth are not understanding that they should care of their Elders."

"Well the building I'm in we go to the school that's next to us and we go there and they come over to us and that makes it a link"

Don't Want to be a Burden

Several elders mentioned the sentiment of **not wanting to be a burden** to their families.

"I would be on my own prairie… all by myself. Yeah, just own little trailer house, and not a burden to anybody."

"For myself, I told my relatives even my husband, don't let me be a burden. You put me in a place where I can have somebody take care of me. I've lived my life and I don't want them doing things for me because they're my relation, my children , my grandchildren."

Returning to the Reservation

Other elders described returning to the reservation:

"I checked out the senior place in Bellingham… Lummi Island. … It really is a nice place. I may go to when I decide to settle."

"I think some of the Alaska Natives have their nursing homes up in Alaska. Yeah. I feel more comfortable with a Native home that I could stay in."

"And that's my wish, to be among other native people, which we have a place on the Blood reserve."

Group Home

One elder, who had worked in both a group home and nursing home, stated a preference for living in a group home.

> *"Well, I'd prefer group home to nursing home. And that's because I've worked at one. And they're given better care than a nursing home, and I've worked in a nursing home also. And I've got 12-14 patients and you just cannot give sufficient quality care, sometimes a whole floor at night time. But here you cannot give sufficient quality care to 12-14 people. That's why I quit working in a nursing home because you just don't get quality care or care at all. So, I'm preferable. You know, for personal, myself, you know, because I've worked in them, but group home they give you better care because you've only got 6."*

Nursing Home

Nursing home was the least popular option, often expressed as where they'd go if they *"got no choice"*.

> *"Definitely not"*
>
> *"No nursing home"*
>
> *"We don't throw our people away"*
>
> *"But eventually when we get do else we can't do anything more, we got no choice but go to nursing home.*
>
> *"Well, yeah, if I can't take care of myself, anymore, I gotta go to a home."*

Vision for Long-term Care

Compiling ideas from all of the focus groups, here is a sample vision for long-term care:

The ideal long-term care facility would be similar to a community center where elders could meet to share ideas and thoughts. A native, co-generational home or being in your own home would be ideal. It would be a place where you would have good company, such as family and friends. There would be transportation provided to get to and from the facility. The facility would be clean, and the workers would be kind, dedicated and provide quality, culturally competent services. There would be assisted phone services, a pool, exercise equipment and a big screen TV. There would be 3 meals a day, serving traditional foods American Indians and Alaska Natives like to eat.

> *"I would be on my own prairie… all by myself. Yeah, just own little trailer house, and not a burden to anybody."*

"I think I probably…I have land right out on the ocean (back on my reservation). And I think I'd just like to …end it there."

"I might be traveling around the world, I don't know. But if I were constrained to a particular spot, then I'd say I'd rather be with my family."

"I think that there should be something like that for Natives where we can eat the food that we like to eat, be around people that we feel comfortable being around and we want to be around."

"have your own food, have some smoked fish…"

"it would be wonderful to get together to have our, you know and have people around you that know the value of your culture and respect it…"

Survey Results

Sociodemographic Characteristics

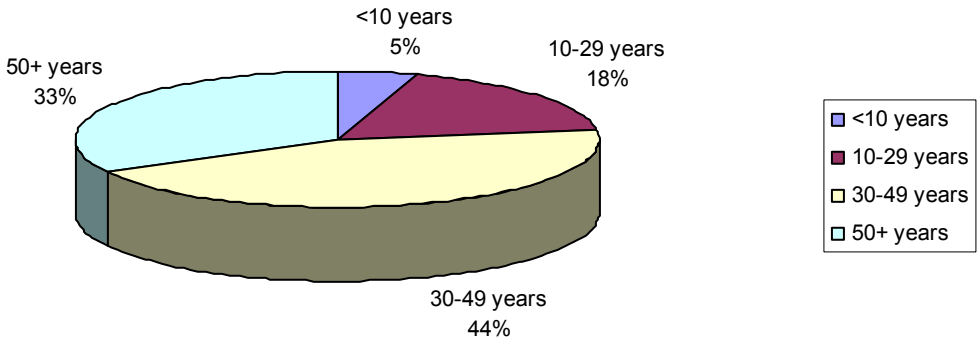
Table 6 summarizes sociodemographic characteristics of the elders who participated in the survey. The mean age was 66 years, with the majority of respondents in the 60-64 age category (30%). Eighteen percent of respondents were age 75 and older, the age group at highest risk of health problems and need for long-term care. The majority of respondents were female (65%) and reported being divorced or separated (39%). Most of the respondents (62%) indicated American Indian and Alaska Native (AIAN) as their only race, and respondents represented 91 different tribes. Most respondents indicated they had completed some college or technical school (37%), followed closely by less than a high school degree (33%). Twenty percent had a high school degree and 9% had additional education beyond high school. Compared to King County AIAN elders age 55 and older, elders who responded to the survey were less likely to be age 55-59, more likely to be female and to report their racial background as AIAN in combination with another race. The vast majority of respondents (98%) indicated English as their primary language. The mean length of time residing in the Seattle area was 39 years (**Figure 9**).

Table 6. Demographics, Survey Respondents and King County AIAN

	Number	Survey Percent	King County Percent*
Age			
Age 55-59	45	22.7	34.0
Age 60-64	59	29.8	24.1
Age 65-69	30	15.2	15.9
Age 70-74	28	14.1	10.5
Age 75+	36	18.2	15.4
Gender			
Male	68	34.5	47.0
Female	129	65.5	43.0
Marital Status			
Now married/living with partner	56	28.4	NA
Widowed	45	22.8	NA
Divorced/separated	77	39.1	NA
Never married	19	9.6	NA
Second Race			
AIAN only	122	61.6	83.0
AIAN + Other race	76	38.4	17.0
Education			
Less than high school	65	33.0	NA
High school graduate	40	20.3	NA
Some college/technical school	72	36.6	NA
College graduate or more	18	9.2	NA
Income			
Under $7,000	56	30.9	NA
$7,000 - $14,999	76	42.0	NA
$15,000 or more	49	27.1	NA

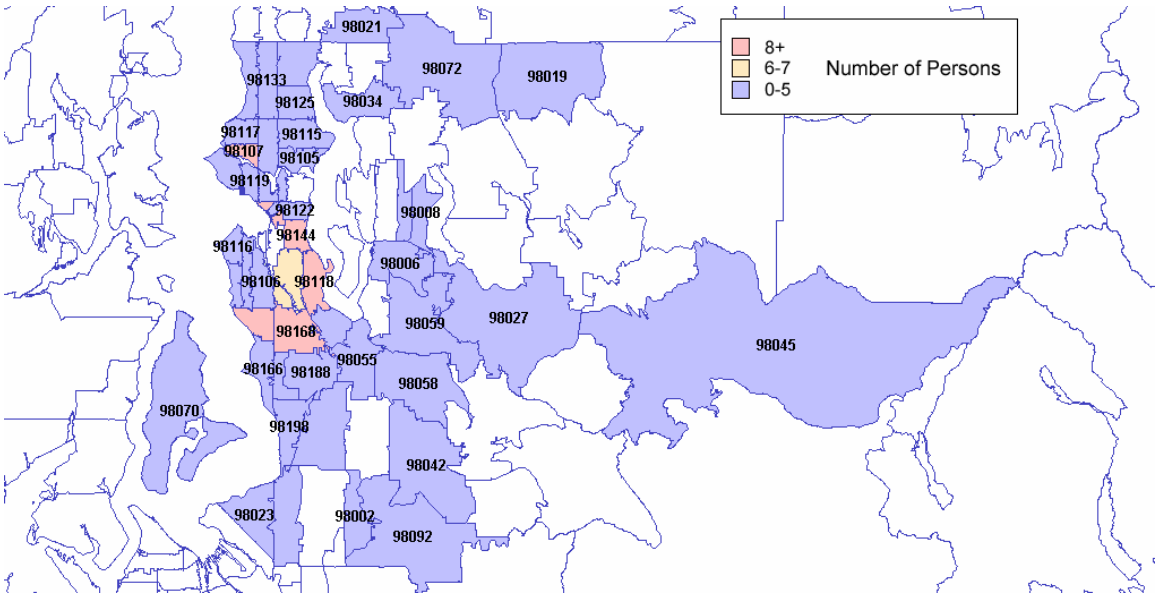
*Data Source: 2000 US Census

Figures 9. Number of Years Residing in Urban Area



Elders resided in regions throughout King County, with a few zip codes in which elders were clustered (**Figure 10**). Similar to where King County AIAN live, elders who participated in the survey clustered around the city of Seattle, particularly the south Seattle area.

Figure 10. Zip Code Distribution of Survey Respondents



Household Composition

Elders who participated in the survey lived with a variety of people. Less than half of respondents (42%) reported living alone (**Table 7**). Among elders who reported living with someone, 49% indicated they lived with their spouse or partner, 42% lived with children, 23% lived with grandchildren, 10% lived with other relatives and 16% lived with non-relatives. Nearly a quarter of elders (24%) indicated they were caring for someone. Among elders caring for an individual, 37% indicated the person they cared for was their grandchild, 36% care for a non-relative, 22% are caring for children and 17% are caring for their spouse or partner.

Table 7. Household Composition

	Number	Percent
Spouse or partner	57	49.1
Child(ren)	47	42.0
Grandchild(ren)	26	23.2
Other relative	11	9.8
Friend(s)	10	8.9
Other non-relative	10	8.9
Person Cared For:		
Grandchild(ren)	17	37.0
Other non-relative	13	27.7
Child(ren)	10	21.7
Spouse/partner	8	17.0
Friend(s)	5	10.6

Health Insurance Coverage

Half of the respondents indicated they had coverage under Medicare, most (90%) with both Part A and B (**Table 8**). Twenty percent of elders had coverage under Medicaid, 9% under Veteran's Administration and 25% had other health insurance, such as private or AARP. Twenty-three percent indicated they had no health insurance. Among elders who had health insurance coverage, 40% did not feel their health plan met their needs, most citing lack of coverage for needed services (84%) as problematic, but also cost (47%).

Table 8. Health Insurance Coverage

	Number	Percent
Insurance		
Medicare - Part A (hospital)	102	51.8
Medicare supplemental – Part B (medical)	97	49.2
Medicaid	40	20.3
Veteran's benefits	18	9.1
Other health insurance	50	25.4
Enough insurance		
Yes	87	60.0
No	58	40.0

Health

Self-rated Health Status

Elders were asked to rate their own health status. Nearly half (45%) rated their health as fair or poor (**Table 9**). Only 22% of respondents rated their health as excellent or very good.

Table 9. Health Status of American Indian and Alaska Native Elders

	Survey Age 55+ (n)	Survey Age 55+ N=194 (%)	Santa Fe Age 55+ (60+ in Taos)* N=429 (%)
Excellent	9	4.6	5.4
Very Good	34	17.5	NA
Good	64	33.0^	50.9
Fair	61	31.4	36.3
Poor	26	13.4^	7.3

*Data Source: Hennessy 1999

^Significantly higher/lower than Santa Fe

In order to compare the health status of our elders with national data, we looked at the health status of elders age 65 and older (**Table 10**). Twenty-two percent of elders who participated in the survey rated their health as excellent or very good, compared to 38% nationally for all races. Forty-five percent of elders age 65 and older who participated in the survey rated their health as fair to poor, compared to only 27% of elders nationwide.

Table 10. Health Status of Elders Age 65+

	Survey AIAN (%)	US All races* (%)
Excellent/very good	22.2	38.1
Good	32.3	35.3
Fair/poor	44.8	26.6

*Data source: 2001 NHIS

Physical Activity

Table 11 reports the physical activity level among elders who participated in the survey compared to elders nationally. Elders who participated in the survey were less likely to report being currently physically active compared to both elders nationally 50 and older and 65 and older.

Table 11. Physical Activity

	Number	Survey AIAN Age 55+ (%)	US All races Age 50+* (%)	US All races Age 65+* (%)
Currently physically active	99	50.3	77.8	76.2
Physically active in the next 6 months	133	67.5	NA	NA
Physically active in the next 30 days	121	61.4	NA	NA
Physically active in the past 6 months	110	55.8	NA	NA

*Data Source: BRFSS 1998-00 age-adjusted

Health Conditions

Documenting chronic illnesses is important because it affects disability and predicts mortality (Chapleski 1997). Elders were asked about 16 health conditions to determine prevalence of specific illnesses (**Table 12)**. Significant morbidity exists among elders who participated in the survey. The most prevalent illnesses among elders in the survey were: arthritis (67%), hypertension (52%), dental problems (49%), trouble hearing and other health condition (each 43%) and anxiety (40%).

Table 12. Health Conditions

Health Condition	Number	Survey AIAN Age 55+ n=198 (%)	Urban AIAN Age 45+* n=283 (%)	Aggregate Data AIAN Age 55+** n=8560 (%)	US All races Age 65+***
Arthritis	133	67.2^ ~	36.4	47.8	36.1
Hypertension	102	51.5^	30.7	50.6	49.2
Dental problems	97	49.0^	33.2	NA	NA
Other health condition	86	43.4	NA	NA	NA
Trouble hearing	86	43.4^	21	NA	NA
Depression	86	43.3^	11	NA	NA
Anxiety	79	39.9	NA	NA	NA
High blood cholesterol	60	30.3	NA	NA	NA
Diabetes	56	28.3^ ~	19.8	38.2	15
Chronic foot trouble	55	27.8	20.4	NA	NA
Cataracts	50	25.3	NA	21	NA
Asthma	39	19.7^ ~	8.1	10.1	8.5
Heart disease	39	19.7~	14.8	11.9	31.1
Osteoporosis	31	15.7^	5.7	NA	NA
Broken hip or fractures	22	11.1	NA	NA	NA
Stroke	13	6.6	4.9	9.4	8.8
Cancer	10	5.1~	2.5	11.2	20

*From Kramer 1991

**Data Source: Natl Res Ctr on Native American Aging, Univ of N Dakota Aggregate Data

***Data Source:NHIS 2000-01 Age-adjusted

^Significantly higher than LA

~Significantly higher/lower than Aggregate Data

The prevalence of arthritis, asthma and heart disease was significantly higher among elders who participated in the survey compared to aggregate data for elders from select tribes participating in a long-term care needs assessment conducted by the National Resource Center on Native American Aging. The prevalence of many conditions were significantly higher than reported by AIAN elders in LA: asthma, hypertension, dental problems, hearing problems, depression, diabetes, asthma and osteoporosis. Age might play a role in this finding, since elders who participated in the L.A. study were age 45 and older, however, we found no relationship between number of reported health conditions and age. Compared to elders of all races age 65 and older, prevalence of arthritis, diabetes and asthma was higher among survey respondents, while heart disease, stroke and cancer were lower.

As found among elders from tribes in the Santa Fe Unit (Hennessy 1999), elders who reported health conditions tended to report multiple health conditions. The mean number of health conditions reported was 5.3 (SD=2.6). Only 2% of elders reported no health

conditions. Eight percent of elders reported having two health conditions and an additional 86% of elders reported having three or more conditions.

Activities of Daily Living and Instrumental Activities of Daily Living

Activities of Daily Living

Activities of daily living are considered basic tasks of everyday life. The ability to perform physical activities of daily living provides an indication of the degree to which elders are at-risk of need for long-term care services, whether formal or informal. Measurement of ADLs is critical because they have been found to be significant predictors of admission to nursing home (Branch and Jette, 1982) and use of paid home care (Garber, 1989; Soldo and Manton, 1985). Estimates of the number and characteristics of people with problems performing ADLs are also important because of the increasing number of private long-term care insurance policies and proposed public long-term care insurance programs that rely on ADL measures to determine whether an individual qualifies for benefits (Van Gelder and Johnson, 1989).

The prevalence of ADL limitations among elders who participated in the survey is depicted in **Table 13**. Most elders (85%) did not report any ADL impairment, and among elders who did report needing help, most (73%) required help with only 1-2 ADLs. Elders were most likely to report needing assistance with walking, bathing, dressing and grooming. Fewer than 5 elders reported needing assistance with using the toilet and feeding themselves (data not shown).

Table 13. Activities of Daily Living

	Number	Survey AIAN Age 55+ n=197 (%)	Urban AIAN Age 45+* n=294 (%)	Aggregate Data AIAN Age 55+** n=8560 (%)	US All Races Age 65+*** (%)
Walking	19	9.6 ~	13.1	28.5	NA
Bathing or showering	13	6.6~	7.7	17.2	5.3
Getting dressed or undressed	9	4.6~	5.9	11.9	4.4
Grooming	8	4.1	NA	NA	NA
Changing positions/getting in or out of bed	6	3.1^ ~	8.1	13.5	3.4
Continence	6	3.1	NA	NA	NA

*From Kramer 1991

**Data Source: National Resource Center on Native American Aging, Univ of N Dakota Aggregate Data

***Data Source: NHIS 2001 Age-adjusted

~Significantly lower than Aggregate Data

^Significantly lower than urban

Elders who participated in the survey were more likely to report needing help with bathing and showering compared to elders of all races age 65 and older. Survey respondents experienced fewer limitations in ADLs compared to elders from selected tribes. Elders were significantly less likely to report needing help with changing positions compared to urban AIAN in L.A.

Although limitations in ADLs have been shown to be strongly related to age with more ADL limitations apparent as you age (Kramer 1992, Hennessy CH), this was not found in our population. There was no significant relationship between age and number of ADL limitations. Additionally, there was no difference in number of ADL limitations by gender (refer to correlation matrix in the multivariate modeling section).

Instrumental Activities of Daily Living

The instrumental activities of daily living are activities necessary to live independently in the community and are more complex than the physical domain of ADLs (Guralnik and Lacroix 1992). In contrast to ADLs, 40% of elders reported needing assistance with any IADL (**Table 14**). Among those needing assistance, 60% needed assistance with 1-2 IADLs, 23% needed assistance with 3-4 IADLs and 17% needed assistance with 5 or more IADLs. Elders were most likely to report needing assistance with housework, shopping, getting out and about and doing laundry. These were the same top IADL impairments reported by elders living in the Santa Fe Unit (Hennessy et al, 1999).

Table 14. Instrumental Activities of Daily Living

	Number	Survey AIAN Age 55+ n=197 (%)	Urban AIAN Age 45+ n=294 (%)	Aggregate Data AIAN Age 55+^ n=8560 (%)	NHHCS All Races Age 65+*** (%)
Housework	52	26.4~	19.7	38.1	17.1
Shopping	39	19.8	19.0	17.7	5.4
Getting out and about	33	16.8	19.2	15.6	NA
Laundry	24	12.2	NA	NA	NA
Preparing meals	18	9.1~	15.2	18.5	10.1
Money management	13	6.6	7.2	10.5	0.5
Using the telephone	10	5.1	5.4	8.2	1.6
Taking medications	9	4.6	NA	NA	14.9

*From Kramer 1991

**Data Source: National Resource Center on Native American Aging, Univ of N Dakota Aggregate Data

***National Home & Hospice Care Survey, 2000, data age-adjusted

~Significantly lower than Aggregate Data

Elders who participated in the survey reported higher prevalence of numerous IADL limitations compared to discharged nursing home residents of all races age 65 and older: housework, shopping, money management and using the telephone. Survey respondents were significantly less likely to report limitations with housework and preparing meals compared to elders from selected tribes. Although elders who participated in the survey appeared to have higher prevalence of limitations with shopping and going out compared to urban AIAN in L.A., this was not statistically significant.

Again, we found no relationship between number of IADL impairments and age nor gender. However, self-reported health status was significantly related to number of ADLs and IADLs, showing a stronger relationship with IADLs (data not shown). As

self-rated health status declined, the number of ADL and particularly IADL limitations increased.

Use of Community Services

In order to determine if elders were using services available in the community, both services specific for AIAN as well as general services for seniors, we asked about use of 27 services available in the community.

Use of American Indian and Alaska Native Programs

Table 15 shows use of AIAN programs in the community by survey respondents (refer to the introduction section for a description of the urban Indian organizations).

Table 15. Use of AIAN Programs

	Percent
Indian Health Service	34.3
Tribal Health Program	13.7
Urban Indian Organizations:	
Seattle Indian Health Board	95.5
United Indians of All Tribes Foundation	52.0
Seattle Indian Center	45.0
Chief Seattle Club	14.1
Other AIAN program	7.1

Due to sampling method, we found most of the survey respondents had used services at Seattle Indian Health Board. Thirty-four percent of elders said they had used IHS and 14% had used a tribal health program. Elders also reported frequent use of United Indians of All Tribes Foundation and Seattle Indian Center.

A logistic regression analysis was conducted to determine the relationship between use of native health agencies and presence of health conditions. Three predictive models were run separately with the following dependent variables: reported use of (a) Indian Health Services (IHS), (b) Tribal Health Program (THP) and (c) Seattle Indian Health Board (SIHB). The independent variable was the number of health conditions coded as a continuous variable.

Table 16 displays the results from the Indian Health Services Model, which indicates the number of health conditions does not predict AIAN use of the IHS. The Wald coefficients on the health conditions was non-significant (p=.81 {df=13]. As shown in **Table 16**, the overall model chi-square statistic is non-significant (X^2=7.10, p=.90). The model predicts 64% of the responses correctly.

Table 16. The Predictive Effects of Health Conditions on Indian Health Service Use

Variable	*Wald t-statistic*	*Significance*	*Chi 2 [df]*	*% of Correct Predictions*	*Mc Faddens R^2*
Constant	3.69	.06*			
Health Condition	.06	.81	9.00 [13]	64.0	.03

Note: The Wald statistics are distributed chi-square with 1 degree of freedom.
*Indicated the coefficients are significant to the .10 level

In the second model, the results indicate the number of health conditions does not predict AIAN use of Tribal Health Programs. The Wald coefficient on health conditions equaled .65 which was non-significant (p=.42 [df=1]). As shown in **Table 17**, the overall model chi-square statistic is also non-significant (X^2=.67, p=.41). The model predicts 86% of the responses correctly.

Table 17. The Predictive Effects of Health Conditions on Tribal Health Program Use

Variable	*Wald t-statistic*	*Significance*	*Chi 2 [df]*	*% of Correct Predictions*	*Mc Faddens R^2*
Constant	10.32	.001**			
Health Condition	.65	.42	.67[1]	86.0	..01

Note: The Wald statistics are distributed chi-square with 1 degree of freedom.
*Indicated the coefficients are significant to the .10 level

Finally, the results indicate the number of health problems does also not predict use of the Seattle Indian Health Board. The Wald coefficient on health conditions equaled .06 which was non-significant (p=.42 [df=1]). As shown in **Table 18**, the overall model chi-square statistic is non-significant (X^2=1.29, p=.26). The model predicts 96% of the responses correctly.

Table 18. The Predictive Effects of Health Conditions on Seattle Indian Health Board Use

Variable	*Wald t-statistic*	*Significance*	*Chi 2 [df]*	*% of Correct Predictions*	*Mc Faddens R^2*
Constant	10.17.	.00*			
Health Condition	1.21	.27	1.29 [1]	.96	.02

Note: The Wald statistics are distributed chi-square with 1 degree of freedom.
*Indicated the coefficients are significant to the .10 level

Use of Long-term Care Services

Information was collected on 27 services relevant to long-term care. Refer to **Appendix E** for a definition of services. Among services provided to elders in the community, the top ten services used by elders were: physician, pharmacy, dental, vision, nutrition programs, housing, senior centers, transportation services, medical devices and information assistance (**Table 19**). Fewer than 5% of elders reported using home health care, chemical dependency services, respite care, skilled nursing services, adult day health services or hospice services.

Table 19. Services Use

Services	Percent
Physician/medical services	89.3
Pharmacy/prescription drugs	80.7
Dental	45.2
Vision	37.6
Dietary & nutrition programs	27.9
Housing services	24.9
Senior centers	22.8
Transportation	19.3
Equipment or devices	17.3
Information and Assistance	10.2
Legal services	10.2
Mental health services	9.6
Employment	9.1
Senior adult programs	9.1
Social services	8.6
Estate & will planning	7.1
Home based services	7.1
Speech & hearing	6.1
Other	5.6
Advocacy/Support Services	5.6
Case management	5.6
Occupational/physical therapy	5.1

Predictors of Long-term Care Service Use

To determine predictors of long-term care service use, bivariate and multiple regression analyses were performed.

Bivariate Analysis

Table 1 displays the correlation matrix for the dependent and independent variables used in the multivariate model. In the bivariate analysis, four independent variables were significantly associated with the use of services (**Table 20**), including, (a) number of ADL limitations; (b) number of IADL limitations; (c) income; and (d) number of health conditions. Variables that failed to correlate with use of services were age, gender and education.

Additionally, three independent variables were significantly associated with the need for services (**Table 20**), including, (a) ADL; (b) IADL; and (c) health conditions. Variables that failed to correlate with the need for services were age, gender, income and education. However, a bivariate relationship does not always identify the true association between two variables in a multivariate model. Based on theoretical as well as statistical considerations, the above mentioned independent variables were entered in a stepwise multiple linear regression model.

Table 20. Correlation Matrix Between Service Use/Needs and Coviariates (*N*=144)

Variables	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*
1. DV: Use of Health Care Service	1.00								
2. DV: Health Care Service Need	20**	1.00							
3. IV: Activities of Daily Living (ADL)	.46**	.28**	1.00						
4. IV: Instrumental Activities of Daily Living (IADL)	.46**	.39**	.68**	1.00					
5. IV: Age	.013	-.10	-.09	.01	1.00				
6. IV: Gender	-.07	.12	.08	.10	.01	1.00			
7. IV: Income	-.18**	-.13	-.09	-.09	.13	.00	1.00		
8. IV: Education	.00	.12	-.06	.00	-.06	.06	-.04	1.00	
9. IV: Health Conditions	.38**	.16*	.34**	.42**	.05	.14**	-.06	-.13	1.00

*p<.05 (2-tailed)
**p<.01 (2 tailed)
(DV)=Dependent Variable
(IV)=Independent Variables

Multiple Regression

A multiple regression was conducted to identify a predictive model of service use. Theory supports an Activity of Daily Living (ADL), Instrumental Activities of Daily Living (IADL) and age predictive model (Chapleski 1997, Kim, Pan 1998, Parker, Polivka 2002), therefore stepwise selection methods were utilized. Number of ADL limitations, number of IADL limitations, age, number of health conditions, income, gender, income and education were the independent variables included in the predictive models.

Before the multiple regression analysis was employed, regression diagnostics were performed on the data to examine multivariate outliers. While some cases showed high values of residuals, neither df-betas nor tolerance coefficients were larger than the critical value. Therefore, multicollinearity did not exist, and no outliers were excluded.

The criterion for determining the best-fitting model for both the services used and service needs models were based on the F test, which indicated the statistical significance of the overall models. For the final predictive model of service use (**Table 21**), ADLs, IADLs, gender and health conditions were found to be significantly related. The full predictor set explained 31% (R^2=.31) of the variance in service use. ADLs showed the strongest

relationship to service use ([beta]=.28), followed by health conditions ([beta]=.23), IADLs ([beta]=.21) and gender ([beta]=-.14). Respondents were more likely to use services as the number of reported IADL limitations, health conditions and ADL limitations increased, and if they were male. Bivariate analyses showed no relationship between gender and service use, yet when considered with other independent variables related to service use, a significant relationship existed.

Table 21. Significant Statistical Predictors of Service Use

Predictors	b	SE	β	t value
Intercept	4.44	1.00		4.46**
Instrumental Activities of Daily Living (IADL)	.45	.21	.21	2.10*
Health conditions	.30	.10	.23	3.00**
Activities of Daily Living (ADL)	.70	.27	.25	2.60*
Gender	-1.06	.52	-.14	-2.02*

*p<.05 (2-tailed)
**p<.01 (2 tailed)

Need for Long-Term Care Services

Elders were asked if they were not currently using a service if this was something they needed. **Table 22** shows services needed by elders. Again, elders were in need of basic primary health care needs, such as dental, vision and pharmacy. Information and assistance was another item requested by a third of elders, such as knowing what services are available for elders in the community. Fewer than 5% of elders indicated they were in need of respite care, skilled nursing services, hospice, chemical dependency services, and adult day health services, many of the same services most elders were not currently using.

Table 22. Service Needs

Services	Percent
Dental	38.9
Vision	32.3
Information and Assistance	28.3
Pharmacy/prescription drugs	23.1
Senior adult programs	20.7
Legal services	20.3
Estate & will planning	19.1
Dietary & nutrition programs	18.2
Transportation	17.5
Senior centers	17.1
Home based services	15.7
Housing services	13.5
Advocacy/Support Services	13.4
Occupational/physical therapy	12.8
Speech & hearing	10.8
Employment	9.5
Physician/medical services	9.1
Case management	8.6
Equipment or devices	7.4
Mental health services	7.3
Home healthcare	6.8
Social services	6.7
Other	6.7

Information and Assistance

A major theme that emerged from the focus groups was needing information on what services were available, and getting elders started with accessing services, whether it is filling out the application or explaining eligibility rules. Confirming this finding, more than half of elders (57%) indicated they needed assistance with accessing services. The majority (greater than 90%) of elders requesting information wanted to know what services are available, where to go for help, how to sign up for services and where else to go for help if they are turned down. Among elders who requested information and assistance, 82% wanted an explanation of eligibility rules and 51% requested assistance with filling out applications.

Predictors of Need

In the multivariate regression model used to determine predictors of service need, only IADLs were found to be significantly related (**Table 23**). The full predictor set explained 15% (R2=.15) of the variance in service need. The IADL beta weight ([beta]) for the final model was [beta]=.39. The more IADL limitations reported, the more likely respondents were to report needing services. Forty percent of elders who participated in the survey reported limitations in any IADL, many reporting multiple IADL impairments.

Table 23. Significant Statistical Predictors of Service Needs				
Predictors	b	SE	β	t value
Intercept	2.11	.29		7.23**
Instrumental Activities of Daily Living (IADL)	.77	.15	.39	5.02**

*p<.05 (2-tailed)
**p<.01 (2 tailed)

Ideas for an American Indian/Alaska Native Elders Program

Due to current lack of a comprehensive program for elders in the community, elders were asked to describe their ideal program. Elders had an interest in many AIAN activities (**Table 24)**. Ninety percent of elders had an interest in one or more AIAN activities.

Table 24. American Indian/Alaska Native Activities

Activity	Percent
Powwows	74.6
Native elders lunch program	67.0
Native history	62.9
Native storytelling	59.9
Potlatches	58.4
Give aways	57.4
Arts & craft classes	53.8
Food and herb gathering	53.8
Language classes	47.7
Spiritual training	47.2
Sweatlodge	41.1
Native sports	36.0
Native hand games	35.5
Other native activity	22.2

Other AIAN cultural activities suggested by elders included:

- Dances, including learning dances
- Field trips
- Talking circles
- Social outings, including dances, lunch program, a center for native elders
- Beading
- Sports, such as fishing and canoeing
- Nutrition classes with extended time
- Lunch program with socializing activity, not just eating
- Political discussion groups
- Activities with youth program
- Smokehouse
- Diabetes group

General Senior Activities

We also wanted to find out if AIAN elders were interested in participating in general activities offered at senior centers in the community. **Table 25** shows the results in order of elder's preference of activities they would be interested in participating in.

Table 25. General Senior Activities

Activity	Percent
Newsletter for seniors	73.6
Field trips - tours	70.6
Health screening tests	68.0
Training for elders	62.4
Exercise classes	60.4
Large print library	59.4
Audiovisual library	56.9
Sauna	53.8
Bingo	52.8
Swimming pool	52.8
Emergency clothing	44.7
Gardening/Pea Patch	43.2
Physical rehabilitation	42.6
Income tax assistance	42.1
Personal counseling	41.1
Classes dealing with aging	40.1
Funeral assistance	39.1
Elder abuse counseling	34.5
Family counseling	34.0
Alcoholics anonymous	32.0
Day care or pre-school for children	29.4
Other senior activity	18.6

Living Preference and Long-Term Care Options

Living Preference

Elders were asked various questions about their living preference. Most elders (84%) preferred living in their own home rather than in senior housing (**Table 26**). More elders preferred living by themselves (56%) rather than living with family. Fifty-seven percent indicated they would prefer housing with mixed ages.

Table 26. Living Preference

	Number	Percent
Own home	165	84.2
Senior housing	21	10.7
Don't know	10	5.1
Live by yourself	111	56.4
Live with family	77	39.1
Don't know	9	4.6
Live with people your own age	58	29.4
Live with mixed ages	113	57.4
Don't know	25	12.7
Have other living preference	31	15.7

Long-Term Care Facility Preference

Elders were asked the difficult question about their preference for a long-term facility should they come to a point in their life where they could no longer care for themselves. Nearly 50% of elders ranked living with family as their first choice (**Table 27**). The second most popular choice was assisted living facility, where elders could have their own apartment and are provided with help for personal needs. Nursing home was the least preferred long-term care option. This was the same pattern of preference we found in the focus group discussions. Forty-nine percent indicated they would not be willing to go to a nursing home. As found in previous studies of urban AIAN (Kramer 1992), 63% indicated they intend to stay here as opposed to returning to the reservation to receive services.

Table 27. Long-Term Care Preference

	Percent
Living with family	47.3
Assisted living facility	33.9
Other option	19.1
Group home	14.5
Nursing home	3.3
Receive services here or reservation?	
Receive services here	63.5
Return to the reservation	16.3
Not applicable	12.8
Don't know	7.7

Preference for American Indian/Alaska Native Long-Term Care Facility

Although 73% of elders indicated it did not matter if they lived with other AIAN, when asked if they would choose a long-term care facility specific for AIAN over a facility not

specific for AIAN given same quality of care, more than half (53%) responded affirmatively (**Table 28**). Although the focus groups suggested a difference by gender with AIAN LTC facility preference, we found no relationship among survey respondents (data not shown).

Table 28. American Indian/Alaska Native Preference

	Number	Percent
Living Preference		
Live with AIAN	46	23.6
Doesn't matter	142	72.8
Don't know	7	3.6
Prefer AIAN LTC facility		
Yes	104	52.8
No	78	39.6
Don't know	15	7.6

Reasons cited for preferring an AIAN long-term care facility were:

- Prefer to be around my own kind, nice to be around each other
- Understand each other better
- Have much in common
- Similar thought process, culture, heritage
- Same background, upbringing
- Treated better
- Feel more comfortable, at home
- Cultural aspect, keep Indian culture together, good to get back to your culture
- Easier to get along with
- Spirituality
- Interesting
- Because native
- Can’t identify with non-American Indians
- Know each other, be amongst people I grew up with
- Don’t want people asking questions, want to hear your history

Conclusions

This assessment documents the long-term care needs of AIAN elders living in King County, Washington. For this needs assessment, we interviewed 8.3% of the AIAN elder population living in King County (according to the US Census). Elders interviewed represented 91 different tribes. Several findings suggest an unmet need for long-term care services for AIAN elders in King County:

- Poor self-rated health status
- Lower level of physical activity than elders of all races
- Prevalence of multiple health conditions, often equal to or exceeding prevalence of health conditions among elders age 65 and older in the general population
- Limitations in ADLs and IADLs often equal to or exceeding those reported for elders age 65 and older in the general population
- Number of health conditions, IADL limitations, ADL limitations and gender were found to predict long-term care service use. Elders who participated in the survey reported multiple health conditions and 40% reported any IADL impairment.
- Number of IADL limitations was found to predict need for long-term care services.
- Age requirements for Medicare, Medicaid and state waivers pose barriers for needed services for AIAN elders until they reach age 65. Fifty-eight percent of King County elders (1,378 elders) are in the 55-64 age group according to the 2000 US Census, and would be excluded from receiving benefits.
- Sixty-three percent of elders said they intend to stay in the area rather than returning to the reservation, indicating the need for long-term care services for AIAN elders living in urban areas.

Based on the assessment results, several options for developing long-term care services for AIAN elders living in urban areas could be pursued:

Information and Assistance. Needing information about what services are available in the community and assisting elders through the process was a major theme from the focus groups. This was confirmed by the survey, where information and assistance ranked as the third leading service need requested by elders. Resource advocacy should continue to be pursued to improve access to services for elders. At SIHB, two full-time Resource Advocates are permanent staff at the clinic, providing assistance to seniors, among others, such as: help with paying bills, banking, arranging transportation to appointments, help to arrange home care, chore services and special equipment, deliver medications, and assist families with the decision-making process and search for resources for assisted living, nursing care, convalescent care and other full time care facilities for the elderly. Our experience interviewing the elders for this needs assessment certainly alerted us to the need for resource advocacy for elders. Elders had many questions about various services brought up in the survey questions, and were often referred to the Resource Advocates at the completion of the interview to obtain additional assistance.

In addition to resource advocacy, outreach and case management might also be worthwhile options to pursue, as suggested in other studies (Maricopa County 1994). SIHB has had Resource Advocates for a number of years, yet many of the elders we spoke with were unaware this service was available. This would suggest further outreach is needed to educate elders about this and other services available in the community. Case managers at the clinic could be assigned to assist elders through the process and follow-up to ensure services are received.

Utilize Urban Indian Organizations as Coordinating Centers for Long-Term Care Services. Ninety seven percent of elders reported using services at one or more AIAN organizations. Although we primarily sampled SIHB patients, use of SIHB was not found to be significantly correlated to use of other UIO (UIATF, SIC, CSC) in the Seattle area. Yet, 52% of elders who participated in the survey had used UIATF and 45% had used SIC. This would suggest elders are fairly well connected to the UIO in the community serving AIAN and indicates an opportunity to serve as coordinating centers to connect elders with long-term care services in the community. As mentioned in previous studies, AIAN look to Indian centers to be an obvious place for receiving services, and UIO should be utilized to provide a full range of services, either by direct staff, by contract or providing space for service providers (Maricopa 1994).

Pursue Home and Community Based Services. The results of this needs assessment supports recommendations from the 2002 AIAN Roundtable on Long-Term Care to focus on home and community based services (HCBS). The majority of elders (84%) preferred to live in their own home, supporting the development of home and community based services for urban AIAN, something within the realm of UIO to develop. Providing assistance with housework, shopping, transportation and personal care needs will keep elders independent and allow them to remain in their homes. Funding for HCBS could be pursued through Medicaid and 1915c waivers.

Pursue Medicare as Payer for Long-Term Care Services. Few elders (20%) had coverage under Medicaid, eliminating one of the major sources of long-term care funding for AIAN. However, 50% of elders had coverage under Medicare, most with Part A and B. Medicare is the 2nd largest payer for long-term care expenditures. Medicare should be a focus for covering long-term care expenses for AIAN elders.

Lower Age Requirements for Programs. Consistent with previous research, elders who participated in the survey appeared to exhibit aging characteristics at an earlier age compared to elders in the general population. This is shown by the greater prevalence of some health conditions and limitations in IADLs even when compared to elders age 65 and older in the general population. The age requirement for long-term care services through Medicaid and Medicare precludes AIAN elders from receiving needed benefits until they turn 65, as well as the current age requirement of 65 for waivers in Washington State. As suggested in the 2002 AIAN Roundtable on Long-Term Care, UIO should work with states to establish urban AIAN elders as a targeted group for which lower age eligibility could be set for state waivers.

Integrate Activities into an Elders Program. Elders showed a strong preference for social activities. This was apparent from both the focus group and survey results. Cultural and social activities should be incorporated into any comprehensive urban AIAN elders program, providing benefits for both emotional and physical health. Elders expressed interest in using community resources as well. Field trips could be arranged through UIC to use facilities, such as local pools and libraries.

Offering American Indian/Alaska Native Long-Term Care Services in Urban Areas. Depending on the mix of services provided, AIAN elders might utilize AIAN long-term care services. A nursing home would not be well received by AIAN elders. However, the results of the needs assessment indicate that several long-term care services would be very desirable for AIAN elders living in urban areas: offering home based services; an intergenerational group home allowing elders to live with grandchildren; offering long-term care services mixed with social activities.

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Appendix A

Short Survey

Elders Long Term Care Needs Assessment

1. Have you ever received services through:
   - Urban Indian health care program? ⬭ YES ⬭ NO ⬭ Don't know
   - Seattle Indian Health Board? ⬭ YES ⬭ NO ⬭ Don't know

     If yes, which services?

   - IHS healthcare program? ⬭ YES ⬭ NO ⬭ Don't know
   - Tribal health care program? ⬭ YES ⬭ NO ⬭ Don't know

2. Are you aware of the following program's eligibility rules for long term care services?
   - Social security ⬭ YES ⬭ NO ⬭ Don't know
   - Medicare ⬭ YES ⬭ NO ⬭ Don't know
   - Medicaid ⬭ YES ⬭ NO ⬭ Don't know

3. Any suggestions for areas of improvement at SIHB?

About You (optional):

1. What is your age?

2. What is your tribal affiliation?

3. How long have you lived in an urban area, such as Seattle?

Appendix B

Focus Group Questions

Elders Long-term Care Needs Assessment

SERVICES CURRENTLY USING:

First, I'd like to ask you about services that you or someone you know have actually used, now or in the past.

1. What types of services are you or someone you know currently using?
(prompt the group with the below items if needed)

- **Dietary and nutritional services**
- **Occupational/vocational therapy**
- **Speech/hearing therapy**
- **Meals on wheels**
- **Transportation**
- **Respite care**
- **Personal care**
- **Skilled nursing services**
- **Physician services**
- **Pharmacy**
- **Social services**
- **Physical therapy**
- **Housing**
- **Case management**
- **Alcohol, Drug, mental health**
- **Senior Drop-in center**
- **Other services?**

UNMET NEED:

Next, I'd like to ask you about services that you would like, but haven't been able to use.

2. What other types of services have you or someone you know needed?
(prompt the group with above listed items if needed)

- Were these services available?

- Were you able to access services?

- Which services are difficult for you to obtain?

- What are the barriers to obtaining services?

AWARENESS/PERCEPTIONS

Let's talk more about services:

3. In thinking about services, is it important to you to have these services provided by people who are of your cultural background?

- Would anyone care to say anything more about this?

- Would you prefer living in a care facility with other American Indian and Alaska Native elders?

4. If you are unable to meet your own needs, what types of care would you like to use?
- Nursing home (healthcare facility staffed with providers around the clock)
- Assisted living (an apartment where help with personal needs is provided, such as bathing, grooming, medicine)
- Group home
- Living with family members/relatives
- Living in your own home
- Others?

VISION FOR THE FUTURE:

Now let's talk about your ideal services. They may not currently exist, but that you would like.

5. In thinking about long-term care services for American Indian and Alaska Native elders, what would you want? What else doesn't exist now that you would like? For example, picture your perfect long-term care facility. What would it look like? What would you like to see developed?

Appendix C

Elders Focus Groups Analysis Codebook

(1) Services Used

(1 1) Dietary/nutrition
(1 2) Occupational therapy
(1 3) Dental
(1 4) Skilled nursing services
(1 5) Physician services
(1 6) Pharmacy
(1 7) Physical therapy
(1 8) Social services
(1 9) Housing services
(1 10) Speech/hearing
(1 11) Transportation
(1 12) Home health
(1 13) Hospice
(1 14) Case management
(1 15) Home based services
(1 16) Family help
(1 17) Vision
(1 18) Hospital
(1 19) VA
(1 20) Diabetes management
(1 22) Senior drop-in
(1 23) Alcohol/Drug/Mental health
(1 24) Emergency room services
(1 25) Estate planning/wills

(2) Services Needed

(2 1) Dental
(2 2) Speech/hearing
(2 3) Housing
(2 4) Senior drop-in
(2 5) Vision
(2 6) Culturally appropriate services
(2 7) Dietary/nutrition
(2 8) Occupational therapy
(2 9) Information on services
(2 10) Transportation
(2 11) Physician services
(2 12) Pharmacy
(2 14) Physical therapy

(2 15) Alcohol/Drug/Mental health
(2 16) Smoking cessation
(2 17) Home based services
(2 18) Help with accessing services
(2 19) Respite care
(2 20) Personal care
(2 21) Activities
(2 22) X-rays
(2 23) Preventive services
(2 24) Help elders to be independent
(2 25) Social services
(2 26) Home health
(2 27) Listening to elders
(2 28) Case management
(2 29) Funeral services
(2 30) Estate planning/wills
(2 31) Skilled nursing
(2 32) Hospital
(2 33) Outreach
(2 34) Native programs
(2 35) Exercise program

(3) Importance of native provider

(4) Importance of native LTC facility

(4 1) Depends on the individual
(4 2) Depends on cost
(4 3) Elders blend in

(5) Types of care facilities

(5 1) Nursing home
(5 2) Living with relatives
(5 3) Own home
(5 4) Assisted living
(5 5) Group home
(5 6) Shared housing
(5 7) Nursing home on reservation
(5 8) Not a burden to anyone
(5 9) Soldier home

(7) Ideal LTC situation

(8) Barriers
(8 1) Eligibility for services

(8 2) Financial
(8 3) Insurance
(8 4) Referrals
(8 5) Waiting lists
(8 6) Providers not culturally competent
(8 7) Other reasons

(9) Health conditions

(10) Insurance

(11) Homeless

(12) Miscellaneous

ID#:_____
Start Time:_____

Long-term Care Assessment Questionnaire

Introduction
I AM GOING TO ASK YOU A NUMBER OF QUESTIONS ABOUT YOURSELF AND YOUR PRESENT NEEDS, AND YOUR IDEAS FOR AN ELDERS PROGRAM. EVERYTHING YOU TELL ME IS STRICTLY CONFIDENTIAL. THIS SURVEY SHOULD TAKE NO MORE THAN 60 MINUTES TO COMPLETE. YOU DON'T HAVE TO ANSWER ANY QUESTION YOU DON'T WANT TO. YOU CAN END THE SURVEY AT ANY TIME. IF YOU GET TIRED, WE CAN COME OR CALL BACK ANOTHER TIME TO COMPLETE THE SURVEY.

Screener Questions
1. Which one or more of the following would you say is your race? I'd like to read you the whole list.

READ LIST (mark all that apply):
1. American Indian/Alaska Native
2. Asian
3. African American
4. Hispanic/Latino
5. Native Hawaiian or Other Pacific Islander
6. White
7. Other **(please specify): _____**

If non-American Indian/Alaska Native, say "I'm sorry, but this interview is for American Indians and Alaska Natives. Thank you very much for your time." End call.

2. What is your age (in years) _____

If age less than 55, say "I'm sorry, but this interview is for elders age 55 and older. . Thank you very much for your time." End call.

3. Do you live in King County? _____

If they are not sure which county they live in, you can ask for zipcode and refer to zipcode list to confirm it is in King County.

If non-King County, say "I'm sorry, but this interview is for King County residents. . Thank you very much for your time." End call.

Section A. General Health Status

NOW I AM GOING TO ASK YOU SOME QUESTIONS ABOUT YOUR HEALTH AND USE OF HEALTHCARE SERVICES.

4. Would you say your health in general is, and I'd like to read you the whole list:

READ LIST:

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

Don't read:

7. Don't know/not sure

5. Do you have any of the following chronic illnesses or health problems? I am going to read you a list, and you can tell me "yes" or "no" to each health conditions.

Health Condition	Yes	No	Don't Know
Arthritis			
Diabetes			
Osteoporosis			
High blood pressure (Hypertension)			
High blood cholesterol			
Asthma			
Cataracts			
Trouble hearing, or trouble hearing even with hearing aid			
Dental problems			
Chronic foot trouble (bunions, ingrown toenails, toe nail fungus)			
Heart disease			
Cancer			
Stroke			
Broken hip or fractures			
Anxiety			
Depression			
Is there any other health condition?			

Section B. Use and Need for Services

6. I am going to read a list of agencies and programs that are run by natives for natives. Have you ever used services from or visited the following agencies? Please answer "yes" or "no" to each of the following programs.

	Yes	No	Don't Know
Indian Health Service			
Tribal health program			
Seattle Indian Health Board			
United Indians of All Tribes Foundation/Daybreak Star Cultural Center			
Seattle Indian Center			
Chief Seattle Club			
Any others?			

7. I am going to read a list of general services offered to seniors in the community. Please tell me which services you are currently using by answering "yes" or "no" to each service.

READ THROUGH ENTIRE LIST AND MARK "YES" OR "NO" FOR EACH SERVICE. FOR ANY SERVICE MARKED "NO" FOR QUESTION 7, ASK THE FOLLOWING:

7a. What I'd like to do is go back to those services you are not using and find out if this is something you need or could use.

	Currently using		Need this service	
Services	**Yes**	**No**	**Yes**	**No**
Adult day health services(Providence Elderplace, Elderhealth Northwest)				
Advocacy/Support Services				
Case management				
Chemical dependency services				
Dental				
Dietary & nutrition programs (meals on wheels, foodbanks, hot meal programs, congregate & emergency meals, etc)				
Employment				
Equipment or devices (prosthetics, durable medical equipment)				
Estate & will planning				
Home based services (chore services, home repairs)				
Home healthcare (personal care-bathing, feeding yourself)				
Hospice				
Housing services (rent subsidy, low income housing, Seattle Housing Authority housing)				
Information and Assistance (Community Information Line, Senior I & A)				
Legal services				
Mental health services				
Occupational/physical therapy				
Pharmacy/prescription drugs				
Physician/medical services				
Respite care (give caregiver a break)				
Senior adult programs (Seattle Parks & Recreation)				
Senior centers				
Skilled nursing services				
Social services				
Speech & hearing				
Transportation (Metro ACCESS, Senior services)				
Vision				
Anything else you would like to add?				

8. Could you use some information or assistance with accessing services?
READ LIST:
1. Yes
2. No (**skip to Question 9)**

Don't read:
7. Don't know/not sure (**skip to Question 9)**

IF YES TO QUESTION 8, ASK THE FOLLOWING:

8a. What type of assistance would be helpful to you? I will read you a list. Let me know which items would be helpful to you. It can be more than one.

READ LIST (check all that apply):

1. Information on what services are available
2. Where to go for help
3. How to sign up for services
4. Help filling out applications
5. Explanation of eligibility rules
6. Where else to go for help if you are turned down
7. Any other type of assistance that would be helpful to you that I haven't mentioned?_____

9. Could you use some help from time to time with any of the following activities? I am going to read you a list, and you can tell me "yes" or "no" to each activity.

	Yes	**No**
Using the telephone		
Shopping		
Preparing meals		
Housework (doing dishes, straightening up, mopping)		
Laundry		
Getting out and about		
Taking medications		
Money management (keeping track of expenses, paying bills)		
Bathing or showering		
Getting dressed or undressed		
Using the toilet, including getting to the toilet		
Changing positions/getting in or out of bed		
Personal hygiene, which is continence, going to the bathroom		
Feeding yourself		
Walking		
Grooming/taking care of your appearance		
Please tell me any other activity you need help with that I may have missed:		

Section C. Current Physical Activity

NOW I AM GOING TO ASK YOU SOME QUESTIONS ABOUT YOUR CURRENT REGULAR PHYSICAL ACTIVITY. FOR PHYSICAL ACTIVITY TO BE CONSIDERED "REGULAR" IT MUST BE DONE FOR 20 MINUTES AT A TIME (OR MORE) PER DAY, AND BE DONE AT LEAST 4 DAYS PER WEEK. THE INTENSITY OF ACTIVITY DOES NOT HAVE TO BE VIGOROUS BUT SHOULD BE ENOUGH TO INCREASE YOUR HEART RATE AND/OR BREATHING LEVEL SOMEWHAT. EXAMPLES OF ACTIVITIES COULD INCLUDE BRISK WALKING, LEISURE BIKING, SWIMMING, DANCING, AEROBICS CLASSES AND OTHER ACTIVITIES WITH A SIMILAR INTENSITY LEVEL.

10. According to this definition:

10a. Do you currently engage in regular physical activity, yes or no?
1. Yes
2. No

10b. Do you intend to engage in regular physical activity in the next 6 months, yes or no?
1. Yes
2. No

10c. Do you intend to engage in regular physical activity in the next 30 days, yes or no?
1. Yes
2. No

10d. Have you been regularly physically active for the past six months, yes or no?
1. Yes
2. No

Section D. Traditional Native Activities

NOW I'M GOING TO ASK YOU ABOUT VARIOUS ACTIVITIES THAT MIGHT BE OFFERED BY A NATIVE ELDERS PROGRAM

11. I am going to read you a list of possible traditional native activities that might be offered by a native elders program. Please indicate those activities you enjoy and would come to the program to take part in, or think other older natives in Seattle would be interested in getting involved in. Please answer "yes" or "no" to each activity, or "don't know" if you don't know what the activity is.

Activity	Would participate in or other older Natives would go to		
	Yes	No	Don't Know
Powwows			
Potlatches			
Give aways			
Arts & craft classes			
Language classes (both Tribal and English as a second language)			
Native hand games			
Native history			
Native storytelling			
Native sports			
Spiritual training			
Food and herb gathering			
Sweatlodge			
Native elders lunch program			
Any activities I missed?			

Section D. General Senior Center Activities

12. I am now going to read you a list of activities that other senior centers around the city offer. Please tell me what activities you would come to the center to get involved in, or you think other older natives in Seattle would be interested in. Please answer "yes" or "no" to each activity, or "don't know" if you don't know what the activity is.

	Would use or other older natives would use		
Activity	**Yes**	**No**	**Don't Know**
Bingo			
Day care or pre-school for children			
Funeral assistance			
Family counseling			
Personal counseling			
Classes dealing with aging			
Physical rehabilitation			
Swimming pool			
Sauna			
Exercise classes			
Training for elders (computer, resume, parenting classes)			
Gardening/Pea Patch			
Newsletter for seniors			
Large print library			
Audiovisual library			
Health screening tests (hearing, vision, diabetes, blood pressure, flu shots)			
Income tax assistance			
Alcoholics anonymous			
Elder abuse counseling			
Emergency clothing			
Field trips - tours			
Please list any activities we may have missed:			

Section E. Housing Conditions

NOW I AM GOING TO ASK SOME QUESTIONS ABOUT HOUSING

13. Do you currently live alone?

1. Yes **(skip to Question 14)**
2. No

13a. Who else besides yourself lives with you?

READ LIST IF NEEDED (mark all that apply):
1. Spouse/partner
2. Child/children
3. Grandchild/grandchildren
4. Other relatives
5. Friend
6. Other (please describe):_____

14. Do you take care of anyone?
    1. Yes
    2. No **(skip to Question 15)**

14a. What is the person(s) relationship to you?
READ LIST IF NEEDED (mark all that apply):
1. Son or daughter
2. Grandchild
3. Friend
4. Spouse or partner
5. Other (please specify):_____

Section F. Housing Preference

15. Would you prefer to live in your own home, apartment or motor home and get financial assistance for the rent and utilities OR live in a building just for senior citizens?

1. Own home
2. Building just for senior citizens
7. Don't know/not sure

16. I'm going to ask your living situation preference.

16a. Do you prefer to:
1. Live by yourself OR
2. Live with family

16b. Do you prefer to:
1. Live with other American Indians and Alaska Natives OR
2. It doesn't matter

16c. If living in a non-family setting, do you prefer to:
1. Live with people your own age OR
2. Live in co-generational home/housing with mixed ages

16d. Is there another living situation you would prefer that I haven't mentioned? If so, could you describe that? _____

17. If at some point in your life you became unable to meet your own needs, would you be willing to use any of the following options? Please **rank** your order of preference (1 is your first choice, 2 is your second choice, etc).

_____Go to a Nursing Home (state-licensed healthcare facility staffed with nurses around the clock and a physician on call)

_____Go to a Group Home (residence which offers housing and personal care services for a small number of residents)

_____Go to an Assisted Living facility (an apartment where help with personal needs is provided, such as bathing, grooming, medicine)

_____Have family members take care of you

_____Other (please describe):_____

18. If unable to meet your own needs, would you prefer to receive services here or return to reservation for services?

1. Receive services here
2. Return to reservation
3. Don't know/not sure
4. Not applicable

19. If quality of care is the same, would you choose a long-term care facility specific for American Indians and Alaska Natives over a long-term care facility not specific for American Indians and Alaska Natives?

1. Yes

2. No **(skip to question 20)**

7. Don't know/not sure **(skip to question 20)**

19a. What are the reasons you would prefer an American Indian/Alaska Native long-term care facility?

Reason #1:_____ _____
Reason #2:_____ _____
Reason #3:_____ _____

Section G. Health Insurance

NOW I'M GOING TO ASK ABOUT YOUR HEALTH INSURANCE.

20. Can you please tell me whether you have coverage under any of the following health plans? I will read you a list, and please answer "yes" or "no" to each health plan.

IF "NO" TO ALL OF THE BELOW, SKIP TO QUESTION 22

Program	**Yes**	**No**	**Don't Know**
Medicare - Part A (hospital)			
Medicare supplemental – Part B (medical)			
Railroad board benefits			
Medicaid			
Veteran's benefits			
Any other health insurance? Describe:			

21. Have you felt that the health plans you are covered by meet your needs?

1. Yes **(skip to question 22)**

2. No
3. Don't know/not sure **(skip to question 22)**

21a. What is the reason? I have a list. Let me know which reasons apply. It can be more than one.

READ LIST (mark all that apply):

1. High cost
2. Eligibility rules
3. Doesn't cover enough services
4. Can't find a provider who will accept my health plan
5. Any other reason that I haven't mentioned? If so, please describe:

_____

Section H. Demographics

THE LAST SET OF QUESTIONS ARE GENERAL QUESTIONS ABOUT YOUR BACKGROUND

22. What is your gender? **(ask only if you can't tell)**
    1. Male
    2. Female

23. What is your current marital status? I will read you a list.
    1. Now married/living with partner
    2. Widowed
    3. Divorced
    4. Separated
    5. Never married

24. What is your personal annual income? Include income from all sources, including social security. I will read you a list, and you can stop me when I get to your income range.
    1. Under $5,000
    2. $5,000 – $6,999
    3. $7,000 – $9,999
    4. $10,000 – $14,999
    5. $15,000 – $19,999
    6. $20,000 – $24,999
    7. $25,000 – $34,999
    8. $35,000 – $49,999
    9. $50,000 or more

25. What is the highest grade or year of school you have completed?
    1. Grades 1-11
    2. High school graduate
    3. Some college/vocational school
    4. Bachelor's degree
    5. Graduate school work

26. In which language is it easier for you to talk about things?
    1. English
    2. Native Language

27. How long have you lived in this area? _____ **(Year or number of years)**

28. What is your zipcode in the area where you live? _____

29. What are your tribal affiliations? **(can be more than one).**
Tribal affiliation #1:_____
Tribal affiliation #2:_____

30. Do you have any unmet health needs that haven't been addressed or anything additional you would like to tell us?
Unmet need #1:_____
Unmet need #2:_____
Unmet need #3:_____
Unmet need #4:_____
Unmet need #5:_____

Section I. Other Native Elders

WE WOULD LIKE TO ASK YOUR HELP IN FINDING OTHER NATIVE ELDERS.

31. Do you know any other American Indians or Alaska Natives age of 55 or older living in Seattle or King County that might be interested in talking to us about long-term care? If so, I can write down their information, and I will be sure to contact them.
(write down the names, addresses and phone numbers of all the people he/she knows)

Name #1:	Address #1:	Phone #1:
Name #2:	Address #2:	Phone #2:
Name #3:	Address #3:	Phone #3:
Name #4:	Address #4:	Phone #4:
Name #5:	Address #5:	Phone #5:

Section J. Close
Thank you very much for your time and ideas. They will certainly be an important addition to our basic information about the health and welfare of the older natives living in the Seattle area. As a thank you, we will send you a $10 gift certificate at Safeway. Can I confirm your address?

Read address from log.

If incorrect:
What is your correct address?
Street:_____
City, State, Zip:_____

□ Gave gift certificate

End time:_____

Appendix E

Elders Survey

Definition of Services

Adult day health services. Provides comprehensive, professional support in a protected environment including on-site nurses, physical therapists, social workers, and/or other professionals for adults who are experiencing a decrease in physical, mental, and social functioning and require tailored medical and/or psychiatric supervision. Such centers normally offer a wide range of therapeutic and rehabilitative activities as well as social activities, meals, and transportation.

Advocacy/Support services. Services to advance consumer healthcare education and to empower older adults and their family members to make informed long-term care decisions.

Case Management. Assessment and coordination of the overall care needs of a person, including both medical and social needs. A service in which a professional, typically a nurse or social worker, assists in planning, arranging, monitoring, or coordinating long-term care services. Services may include making an assessment, creating a care plan, and arranging for services in multiple locations from numerous people and organizations.

Chemical dependency services. Prevention, treatment, and rehabilitative services for substance abuse.

Dental. Oral surgery, teeth cleaning, extraction.

Dietary and nutritional services. Meals on wheels, food banks, hot meal programs, congregate & emergency meals, nutrition counseling.

Employment. Services to help connect seniors with meaningful employment, including job listings, training, employer outreach, Internet access and computer training, individual coaching, 24-hour job hotline.

Equipment or devices. Prosthetics, durable medical equipment

Estate/Will planning. Estate planning transfers your assets to your beneficiaries quickly and usually with minimal tax consequences. The process of estate planning includes inventorying your assets and making a will and/or establishing a trust, often with an emphasis on minimizing taxes.

Home based services. Non-medical services provided to older people still living in their own homes. These services may include case management, meals, companions, housekeeping, home repairs, adult day care, senior center, and other services designed to keep people as independent as possible. Many states are experimenting with the development of Medicaid-funded HCBS programs in an effort to keep people in their residences and out of expensive nursing homes, in order to reduce the drain on the state's Medicaid budget.

Home healthcare. A licensed provider which delivers medical services in patients' homes. Personal care-bathing, feeding yourself.

Hospice. A special concept of care designed to provide comfort and support to patients and their families when a life-limiting illness no longer responds to cure-oriented treatments.

Housing services. Senior housing, rent subsidy, low income housing, Seattle Housing Authority housing.

Information and Assistance. Community Information Line, Senior Information & Assistance.

Legal services. Legal advocacy, guidance, and services to enhance the lives of people as they age.

Mental health services. Crisis intervention, counseling, psychological services, psychiatry.

Occupational/physical therapy. Use of physical agents and methods in rehabilitation and restoration of normal bodily function after illness or injury, acute rehabilitation (e.g., post-operatively, following stroke, after stroke or hip fracture).

Pharmacy. Prescription drugs.

Physician services. Primary medical care, medical specialists.

Respite care. Temporary short term care to provide temporary relief from caregiving duties to an unpaid, primary Caregiver.

Senior adult programs. Seattle Parks & Recreation.

Senior center. Place where elders come together for services and activities, responds to their diverse needs and interests, enhances their dignity, supports their independence, and encourages their involvement in and with the center and the community.

Skilled nursing services. Level of care which requires the training and skills and 24 hour-a-day supervision of a Registered Nurse, is prescribed by a doctor, and which may not be provided by less skilled or less intensive care.

Social services. An organized activity to improve the condition of disadvantaged people in society. Examples: Welfare, case work, social workers that address psycho-social issues, resolve family problems.

Speech/hearing therapy. Correction of speech and language disorders/ evaluation and measurement of impaired hearing and the rehabilitation of those with impaired hearing, eg hearing aids.

Transportation. Senior Transportation Services, Metro ACCESS, Escort Services Curb-to-Curb Service, Demand-Response Service (Dial-a-ride), Door-to-Door Service, Fixed-Route, Paratransit, Ridesharing.

Vision. Eyeglasses.