HEALTH AND AGING AMONG AMERICAN INDIANS: ISSUES AND CHALLENGES FOR THE BIOBEHAVIORAL SCIENCES

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In responding to Chapter 11, "Aging and Health," in *Health and Behavior: Frontiers of Research in the Biobehavioral Sciences* (Hamburg, Elliott, & Parron, 1982), we constantly returned to case examples such as the following:

> B.H. is an elderly Navajo man suffering from Parkinson's disease. B.H. lives with his wife of 40 years in a one-room earth-covered hogan without electricity or running water. B.H.'s wife suffers from severe arthritis in her legs and cannot walk even with the aid of a walker. A wheelchair would be of no use to her as the sand and mud (during the rainy season) surrounding her hogan would not support the narrow gauge wheels of a wheelchair. B.H. also has great difficulty getting around. He usually spends most of the day sitting in a very worn easy chair, alert except for short periods following the administration of his medication. Tremors and weakness in his extremities make it very difficult for him to accomplish even the most simple chores, e.g., carrying drinking water inside from barrels stored outside the hogan. B.H. and his wife could not care for themselves were it not for three important factors. A Tribal Home Care Program pays their daughter-in-law minimum wage to spend 4 hours a day with them, helping with cooking, washing, and other chores. The daughter-in-law, even though she lives 2 miles away, would probably provide these services free. However, the income she earns from this program is critical in keeping her family's pickup running. Her husband, B.H.'s son, has worked only 4 months during the last year. His sporadic wage income, his wife's meager salary, and contributions from his parents (whose combined income is about $500/month) help support him, his wife, and their four children. In return, the son's services are critical to the support of his parents. He hauls wood for fuel and water for drinking, cooking, and bathing. He contributes meat from his wife's small herd to his parent's diet (prohibitively expensive otherwise). He also provides critical transportation to a hospital some 45 miles from their residence. At least once a week he takes his parents on an outing to the Trading Post where they socialize and purchase necessities. Both of his parents' degenerative illnesses are monitored by a Community Health Representative (CHR) who takes vital signs, delivers medicine, and tries to anticipate any acute episode.

BEHAVIORAL HEALTH ISSUES AMONG AMERICAN INDIANS AND ALASKA NATIVES
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During the last 3 years due to federal budget cuts, the Navajo Tribe has lost over $100 million dollars in revenue. Further funding for CHRs and Home Health Care is problematic. In addition, the Indian Health Service (IHS) has cut its field health staff in half, doubling the area of responsibility for the remaining staff. The reservation economy is extremely bleak. For example, B.H.'s son must compete for wage employment in an environment of 65% unemployment—although the Census would count him as being employed because he had some employment during the 12-month reference year.

B.H.'s and his wife's diseases will become progressively worse, but it is doubtful whether either of them would accede to being placed in a nursing home. However, if they were placed in such an institution it is clear that outlays paid for their support by the federal government would be 20 to 40 times the amount now being spent to support their portion of the CHR and Home Health Care programs.

As this example and scores like it vividly illustrate, the difficulties which face many older Indians and their families are multifaceted and resist easy solutions. Indeed, as Hamburg, Eliott, and Parron (1982) point out, "the rising numbers and special problems of the elderly present challenges to basic sciences, clinical investigation, service delivery, and social organization" (p. 15). Somehow though, the enormity of the situation for this special population and the unprecedented scope of effort that will be required to effectively address these challenges in the very near future are not captured in the Institute of Medicine volume. This chapter carefully considers the kind, source, and extent of the problems that reside at the interface of aging and health among American Indians and Alaska Natives.

Our deliberations begin with a discussion of the changing demographics of the Indian and Native population, and the delayed, but nevertheless increasing waves of individuals who are living and will live to older age. We then turn to the epidemiologic implications of these trends as the basis for anticipating the nature and scope of the future physical health, mental health, and social service needs of Indian and Native elderly. Lastly, our attention focuses on long-term care services for older Indians and Natives, with a critical look at prevailing attitudes among service providers, the continuum of care as it now exists in Indian communities, and issues that are specific to each service category as well as those that involve the entire system and participants in it.

Demographic Transition

In terms of percentages and proportions, Figure 1 presents age pyramids comparing American Indians versus U.S. All Races, and shows a profile of what has been termed a "demographic transition" for American Indian populations.

Although the American Indian population pyramid has a slightly indented base in the under 10 age group, signalling a decline in fertility for the 1970s, overall, the 19 and under cohort forms a broad pyramidal portrait much in contrast to the sharply indented base of the U.S. All Races, which shows a "steplike" and significant decrease in fertility over the last 2 decades. These contrasting pyramidal bases have important implications for "dependency ratios" which will be discussed in a subsequent section.

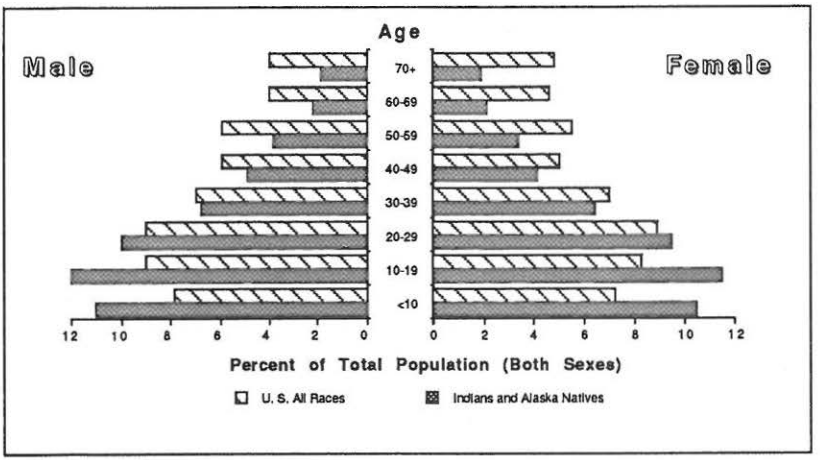

Figure 1. Population by age and sex, 1980 Census.

The model of "demographic transition" postulates three major stages: (a) high fertility and high mortality, (b) high fertility and declining mortality, and (c) declining fertility and declining mortality. Although there has been a decline in fertility of nearly 20% in the last 2 decades for American Indian populations, overall, in comparison to U.S. All Races, their growth rate remains very high: almost twice that of the U.S. All Races, as Table 1 depicts.

Table 1

A Comparison of American Indian and U.S. (All Races) Population Pyramids (In Percentages)

Years of age	American Indian	U.S. All Races
0 - 19	45.0	32.0
20 - 44	36.7	37.2
45 - 54	7.5	10.1
55 - 64	5.5	9.5
65+	5.3	11.3
median age	22.8	30.0

In terms of mortality, there has been a precipitous decline (75%) in American Indian infant mortality in the last 3 decades. The ratio of the Indian maternal death rate, compared to the U.S. All Races, has declined by 50% in the last 2 decades. That is, in the last 2 decades Indian women, who formerly experienced maternal mortality at twice the rate of the U.S. All Races, have drawn almost even (they still experience about a 15% higher mortality). More remarkable, Indian women have experienced an 85% reduction in maternal mortality rates in the last 3 decades.

The great majority of these declines in infant and maternal mortality can be attributed to increased sanitation facilities (which decrease the potential for infection) and the expanding resources and service delivery of the Indian Health Service. It is interesting to note that American Indian infant mortality (with the exception of Alaska Natives) is somewhat higher than the U.S. All Races, but significantly lower (by 30%) than Black infant mortality. Blacks also experience almost twice the maternal mortality of American Indian populations.

Proportionally, the apex (45+) of the American Indian population pyramid is much narrower than the pyramid for U.S. All Races. That is, a much larger segment of the total U.S. population is 45 years of age or older. During the next 15 years, a larger proportion (19.7%) of the U.S. population (versus 13% of the American Indian population) has the potential of entering the 65+ age category. However, because of small initial populations of American Indian individuals over 75, a large number, proportionally, will enter this category in the next 2 decades. Exactly how many is difficult to estimate because the U.S. Census, while making projections for White and Black populations, does not do so for American Indian populations. The Indian Health Service is currently collecting mortality data and plans to make age-specific projections within the next year and a half. Until then, our rough estimates would indicate at least a doubling of the American Indian population over 75 by the year 2000. This population is critical inasmuch as high rates of chronic illness can be extremely expensive to treat at this age. Also given the cloudy issue of the "crossover effect," that is, lower rates of age-specific mortality for American Indian populations over 65, these projections may be severe underestimates. Further analysis in this area is critical for estimating future service demand.

Regional and Urban/Rural Differences

Some regional differences exist in the proportion of American Indians over the age of 65, with the Midwest and West having about 15 to 25% fewer elderly than the Northeast and South. It is interesting to note that the Midwest and West regions have the highest proportion of their population living on reservation or

tribal trust lands (Table 2). Two divisions within these regions—the West North Central (including North and South Dakota and Nebraska) and Mountain West (including Arizona and New Mexico)—account for the majority of this variation.

Table 2

Reservation Population by Region

Region	Total population	Off-reservation population	Reservation population
Northeast	77,430	54,960	22,470
Percentage	100.0	89.7	10.3
Midwest	246,345	130,692	115,653
Percentage	100.0	71.0	29.0
Dakotas		30.0	70.0
South	369,603	186,024	183,579
Percentage	100.0	95.6	4.4
West	670,655	347,371	323,284
Percentage	100.0	59.2	40.8
Mtn. West		33.0	67.0
Pacific		90.0	10.0

One might intuit that reservation populations may be significantly different than off-reservation Indian populations. Those regions heavily influenced by reservation populations do have slightly different population pyramids. The Midwest and West have somewhat broader population pyramids indicating higher fertility in these areas. Broader bases may account for some of the proportional differences between regions, that is, higher fertility "dilutes" the proportion of population over 65.

Table 3

A Regional Demographic Profile of American Indian Populations by Age and Percentage

	<15	16 - 64	65+	Total
Northeast	23,282	60,520	5,619	89,421
Midwest	90,381	157,939	12,918	261,238
South	114,154	266,286	26,834	407,274
West	247,172	485,048	34,183	766,403
Northeast (%)	26	68	6	100%
Midwest (%)	35	60	5	100%
South (%)	28	65	7	100%
West (%)	32	63	5	100%

Because of the way Census information is tabulated, and lacking the often promised special report on American Indians, we will switch our orientation from a strictly off-reservation versus on-reservation perspective to one that also differentiates between urban and rural Indian populations. In general, this provides more contrast to issues concerning poverty; in addition, other forms of

tabulated data, for example, comparisons of Indians living within versus those living outside a Standard Metropolitan Statistical Area (SMSA), reinforce the validity of the urban-rural distinction. There is clear evidence that rural aged Indian populations have fewer economic resources than their urban congeners.

Income and Economic Issues

There is no region of the United States where American Indians over the age of 65 have average per capita incomes equal to Whites. On average, Whites have 40-59% more per capita income (Table 4) regardless of whether the White population lives in an urban or rural environment. Within the American Indian population, with the exception of the Northeast, which has nearly comparable per capita income, urban Indians do far better than rural Indians. Throughout rural America, elderly American Indians have 70% or less of the per capita income of their urban counterparts.

Table 4

A Regional Comparison of American Indian and White Persons 65+ Per Capita Income (In Dollars)

	Whites	American Indian	
		Urban	Rural
Northeast	7,880	5,298	4,902
Midwest	7,704	4,953	3,504
South	7,445	5,675	4,009
West	8,483	5,399	3,393
Whites 65+		8,292	6,599

As a preface to the following discussion one should note that the 1979 income levels used in establishing poverty statistics for persons over 65 are $3,774 for a single-person family, $4,389 for two-person, $5,787 for three-person, and $7,412 for a four-person family. In addition, thresholds for the over 65 category are lower than for the under 65 category (i.e., persons 65+ must have less income to be considered below the poverty line).

Table 5

American Indians 65+ Below Poverty Line by Region and by Urban vs. Rural in 1979 (In Percentages)

	Urban	Rural
Northeast	24.1	27.7
Midwest	25.8	37.0
South	28.8	35.7
West	20.6	43.6

Table 5 indicates that with the exception of the Northeast, all 65+ American Indian rural populations in the U.S. have substantially higher percentages of persons below the poverty line. In the West, rural populations in Arizona and New Mexico have twice the number of persons below the poverty line when compared with urban populations, especially in urban California.

Table 6

A Comparison of American Indian and White Persons 65+ at 125% of Poverty Level by Region and by Urban vs. Rural for Indian Persons (In Percentages)

	Whites	American Indian	
		Urban	Rural
Northeast	19.9	35.5	35.2
Midwest	19.8	39.2	49.4
South	19.6	41.0	47.8
West	13.8	32.0	55.1

Most striking is Table 6 which shows that while White 65+ populations have about 1 in 5 persons below or slightly above the poverty line (25% above), American Indian populations range from 1 in 3 to 1 in 2. In rural areas of the U.S., nearly half the total elderly American Indian population lives at or below the poverty level. This generalization holds despite the fact there is essentially no difference between White and Indian populations 65+ in either urban or rural settings, with respect to labor force participation and employment (see Table 7).

Table 7

A Comparison of American Indian and White Persons 65+ in Labor Force Characteristics

	Urban		Rural	
	White	Indian	White	Indian
Percentage Employed	12	11	12	10
Percentage Unemployed	1	1	1	1
Percentage not in Labor Force	87	88	88	89

Residential Context

Rural aged populations, both Indian and White, are more likely to be living in a family context (i.e., with close relatives) than are their urban counterparts (Table 8). Similarly, for both populations, the older an individual is the less likely he/she will be living in a family.

Table 8

A Comparison of American Indian and White Persons 65+ Living in a Family Context (In Percentage of Age Specific Total Persons)

	Urban		Rural	
	White	Indian	White	Indian
Percent aged 65-74	70	64	77	77
Percent aged 75+	51	50	58	64
Total persons aged 65+	63	59	70	73

About three fourths of rural American Indian persons between the ages of 65 and 74 live with their families while only about half the urban Indian population over the age of 75 would be living within a family environment. The same dynamics, with only slightly different percentages, occur for White populations. At first glance it would seem that elderly American Indians living in rural areas have a greater potential for family support. However, this realization is tempered with the recognition that rural Indian families with aged members have over twice the proportion of families below the poverty line compared to an average urban Indian family with a member over the age of 65. Thus, while two thirds of rural American Indians over the age of 75 are likely to be living in a family context, more than one third of them can expect to have incomes below the poverty level. On the other hand, while 50% of elderly urban American Indians can be expected (in a statistical sense) to be living with a family, only 16% will be below the poverty line. Again similar dynamics seem to work with White populations, with urban Whites aged 65-74 having the smallest proportion living below the poverty line while individuals 75+ living in rural areas have the highest. Note, however, that there are nearly equal proportions of American Indian elderly living in urban and rural contexts, while urban White elderly outnumber their rural congeners three to one. However, unlike the statistics for family residence which showed very little variation in the proportions between Indian and White populations, that is, age and location (urban versus rural) determines family context regardless of ethnicity, income is determined by "race." Regardless of age or location, Indian families with elderly have 3 times the proportion of their population below the poverty line. At the extremes, rural Native Americans over the age of 75 living in families have 8 times (800%) the number of individuals below the poverty line compared with urban Whites between the ages of 64 and 75.

Table 9

A Comparison of Urban and Rural American Indian and White Persons 65+ Living in Families with Incomes below the Poverty Level (In Percentages of Age-Specific Total Persons)

	Urban		Rural	
	White	Indian	White	Indian
Percentage of persons 65-74	4.3	14.1	10.0	32.2
Percentage of persons 75+	5.7	16.6	13.5	35.0
Total persons 65+	4.9	15.0	11.3	33.0

Generalizations about "family support" must be seen in this context. In fact, poverty may be one of the major determinants of extended families, where elderly Indians live with their children and grandchildren, not only because of cultural norms but to share and reciprocate scarce and irregular resources.

It is important to understand the typology and nested categories of the U.S. Census before attempting further discussion of elderly Indian living situations. We have already analyzed the proportion of elderly living in families, giving special emphasis to age cohort and urban or rural location. The remaining individuals not living in a "family" context can be divided into those individuals who live in households with "nonrelatives" and those who live in "group quarters." Within the "nonrelative" residence category is the subcategory "living alone." Within the category of "group quarters" is the subcategory "inmate of institution." A further subdivision of "inmate of institution" is "home for the aged." It is extremely important to realize that over 95% of the individuals in the "nonrelative" category are individuals who actually live alone. The same holds true for over 90% of individuals classified as "inmates of institution;" they are actually living in "homes for the aged."

Table 10 indicates the distribution of living situations for American Indian and White populations 65+. As might be expected, advancing age in both populations increases the probability of an individual living alone or moving into a home for the aged. Roughly one third of the 75+ population, Indian or White, rural or urban, live alone; however, there are dramatic differences between urban and rural areas in the proportion of 75+ individuals living in homes for the aged. Despite a greater proportion of the total Indian rural population being 65+ (5.8%) as compared to urban populations (4.7%), urban populations have twice the rate of utilization of homes for the aged. This utilization may be an artifact of availability, or perhaps homes for the aged are more profitable in urban areas. However, as more Indian individuals reach the 75+ plateau in rural areas, with the increased probability of degenerative diseases (e.g., organic brain syndrome) and with both these factors being exacerbated by high levels of poverty, many rural Indian families will be facing very unpleasant choices and more than likely will not find the resources they need available.

Table 10

An Age-Specific Comparison of Residence Characteristics For Elderly American Indian and White Persons 65+ by Location (In Percentages)

	Urban				Rural			
	White		Indian		White		Indian	
	65-74	75+	65-74	75+	65-74	75+	65-74	75+
Living in families	70	51	64	50	77	58	77	64
Living alone	28	34	29	35	20	32	19	29
Living in homes for aged	1.7	11.3	2.3	10.5	1.1	7.9	1.2	4.4
Total	99.7	96.3	95.3	95.5	98.1	97.9	97.2	97.4

Note. Rounding errors and residual categories (e.g., "other" group quarters) account for deviations from 100%.

Growing older presents great difficulties for a sizeable segment (perhaps 30%) of America's aged population. Being Indian and being old intensifies these difficulties. But being an Indian over the age of 75 and living in a rural area may mean being a member of the segment most discriminated against in American society. And it is precisely for this segment of our society that IHS will have the responsibility of delivering medical care.

The question of urban/rural differences is further highlighted by Table 11. Higher proportions of persons under 15 years of age in rural Indian populations and 20% more individuals over the age of 65 contribute to higher "dependency ratios." A dependency index or ratio is a proportion of those individuals under 15 plus those over 65, (i.e., those theoretically dependent) divided by the total population of individuals 16 to 64, that is, those engaged in wage labor or "productive pursuits." This ratio of dependents to producers or "supporters" is a simple measure, helpful in calculating a society's "social burden," (that is, determining what personnel resources we have to take care of our young and elderly).

Table 11

An Urban/Rural Age-Specific Demographic Profile of American Indians with Aging Indices and Dependency Ratios

	Urban	Rural	Total
Population 0 - 15	233,598	241,391	474,989
Population 16 - 64	554,684	425,109	979,793
Population 65+	38,793	40,761	79,554
Total population	827,075	707,261	1,534,336
Population pyramid in percent			
Population 0 - 15	28	34	
Population 16 - 64	67	60	
Population 65+	5	6	
Total	100	100	

Table 11 (continued)

	Urban	Rural	Total
Aging index[a]			
American Indian	16.6	16.9	16.8
U.S. White	62.0	45.7	56.9
Dependency Index[b]			
American Indian	49.4	66.4	56.6
U.S. White	48.4	54.9	50.3

[a] Aging index = pop. 65+ / pop. 15 x 100
[b] Dependency index = pop. 65+ + pop. 15 / pop. 15-64 x 100

Dependency ratios for White and Indian urban populations are very similar. In contrast, rural Indian ratios are much higher than their urban counterparts and considerably higher than both urban and rural White populations. As Table 12 shows, some rural Indian populations, such as the Navajo, have dependency ratios in excess of Third World countries such as India, Chad, or Brazil. High fertility and decreasing mortality—the demographic transition—are a major part of the Navajo's dependency index. One might conclude that rural Indian families are going to have an increasingly difficult time supporting their dependent members. Rural families with low incomes simply do not have the resources to support infirm elderly family members. The IHS, with decreasing resources in terms of "constant" dollars, does not have the resources to meet the demand of chronic illness in this age group—especially when 2 months of terminal care can exceed $100,000 in hospital expenses.

Table 12

A Select Sample of Indian and International Age and Dependency Indices

	Age Index[a]	Dependency Index[b]
Southern Ute	7.1	60.1
La Plata County (White)	41.3	43.4
Ute Mountain Ute	12.1	57.6
Montezuma County (White)	40.4	61.6
Northern Ute	8.7	79.1
Uintah and Duchesne Counties (White)	17.4	79.7
Total Ute Population	8.8	67.7
United States	43.7	54.2
Western Navajo	9.2	98.4
Indian	9.2	98.4
Oceania	23.5	63.5
Chad	9.8	81.9
Brazil	7.7	80.8

[a] # individuals 65+/100 x # individuals <15
[b] # individuals 65+ + # individuals <15/100 # individuals 16-64

Note. Source: Report 3:6 (four counties); Social Indicators III:55.

The aging index, a ratio where the population over 65 is divided by the number of individuals under the age of 15, is intended to provide a simple comparative measure of aging between populations. Table 12 clearly shows American White populations with indices 3 times that of Indian populations. Again, Table 12 shows that Indian populations are closer to Third World countries than to the United States. However, we wish to suggest that the aging index is misleading for Indian populations. High fertility, declining mortality, and the possibility of a mortality "crossover effect" indicates that the aging index may be a poor measure for analyzing the outcome of the "epidemiological transition."

Epidemiological Transition

We have previously discussed evidence for the demographic transition among American Indian populations, that is, a declining but still very high fertility rate coupled with steep declines in mortality. This leads to the consideration of an epidemiological transition. In general, such a model postulates a decline in infectious and parasitic diseases (e.g., the precipitous declines in infant and maternal mortality documented earlier) with a marked shift towards degenerative and man-made diseases. Has this shift occurred for the American Indian population (at least for the 28 reservation states covered by IHS statistics)? Certainly there has been a tremendous decline in infectious diseases. However, an unambiguous answer to a shift towards degenerative and man-made diseases cannot be given, although a preponderance of evidence would suggest that such a shift has occurred.

Mortality

Unambiguous evidence for a rise in degenerative and man-made diseases is difficult to assert for a number of reasons. Table 13 illustrates one of the problems. Dramatic shifts in the rates of mortality between two 3-year intervals seemed to have occurred in less than a decade, but not in the direction anticipated! For the 65+ American Indian population, reductions seem to have occurred in some degenerative diseases, for example, diseases of the heart (38% decline), cerebrovascular (33% decline), malignant neoplasms, and diabetes (14% each), while other diseases (with some man-made components) such as cirrhosis of the liver have declined a modest 7%.

Table 13

American Indian Age-Specific Mortality Rates: A Comparison of Two Intervals—1973-1975 and 1980-1982 (Rates per 100,000)

	1973 - 1975		1980 - 1982	
	55-64	65+	55-64	65+
Heart Diseases	451.0	2,064.0	363.0	1,278.0
Cerebrovascular	123.8	492.7	58.1	329.4
Malignant Neoplasms	269.0	683.9	235.7	592.0
Cirrhosis of the Liver	123.8	68.6	177.0	63.2
Diabetes Mellitus	86.4	171.6	83.0	147.3
Accidents—Motor Vehicle	86.4	90.7	57.6	85.6
Other Accidents	101.7	174.0	63.4	85.6
Suicide	12.2	11.0	7.2	6.5
Homicide	21.4	16.6	11.5	6.0

Other declines in man-made vectors (e.g., accidents) seem to have been as dramatic. Actually the cause for these declines (although we can't explain those that remained nearly constant) rests with inaccuracies in the 1970 Census. The population estimates that went into calculating the rates were marked underestimates. Thus, the age-specific denominator for the 1973-75 estimates should have been higher, effectively reducing the rate per 100,000. Using the more accurate 1980 Census information, IHS is currently in the process of interpolating more realistic denominators for these rates. Awaiting these calculations, it is difficult to infer trends from this cross-sectional data, and earlier decades face their own special reporting problems. However, even if these data were available, one would be hard pressed, in the complete absence of longitudinal studies, to explain trends for a number of problems. For example, Figure 2 illustrates the significant proportional differences in mortality among "races" for individuals 65+. Controling for significantly different population profiles (e.g., a much younger, low-risk Indian population) age-specific mortality rates still indicate a seven-tenths lower ratio for Indian populations. If this mortality crossover effect is valid, it can have important implications for IHS planning. For example, is this a "cohort effect," that is, are Indian individuals born around the turn of the century, for whatever reason, more likely to survive in old age whereas individuals born in the 1940s because of introduced factors (e.g., changes in diet and stress) less likely to survive in old age and in effect be similar to White populations? An incorrect prediction could mean a substantial waste of resources (as in the recent incorrect prediction on the demand for pediatric beds, or hospital beds in general). If it is not a cohort (or cross-section) effect will American Indians be more likely to survive into their 80s? When other groups, such as Whites, enter this age category, they are more at risk for certain morbidities, for example, some forms of organic brain syndrome. Does differential mortality mean that Indians will have higher than expected proportions of organic brain syndrome? What will this mean for nursing care

demand? Ultimately, answers to these questions may not be available even with the best of research efforts, but attempts to answer them can only be made through longitudinal research.

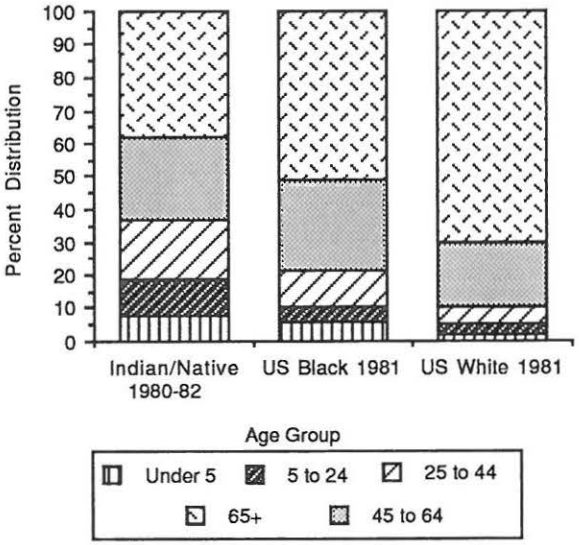

Figure 2. Deaths by age and race.

Similar mortality crossovers occur within age-specific categories of the American Indian population. For example, mortality from alcoholism takes a big drop in the 65+ age group. Is this a process associated with aging or have people who are now old grown up under conditions which make them less at risk for alcoholism?

It is important to disentangle the possible cohort effects. For example, one study asserts that the Indian population aged 45-64 is at risk in a number of areas in proportions similar to the 65+ Indian population. Given what we know about the potential number of individuals about to enter the 65+ age category in the next 2 decades, is IHS facing an expanding higher risk population? One should note that calls for longitudinal health studies of American Indian populations have been strident for at least a decade, however, the possibility for this kind of research seems bleak under present funding conditions.

Whatever the difficulties in analyzing age-specific trends for Indian populations, one can still compare age-specific mortality between different populations (e.g., Indian and White) for a specific point in time. A perusal of Table 14 indicates Indian populations with dramatically lower mortality for

diseases of the heart, cerebrovascular diseases, malignant neoplasms, and suicide. On the other hand, Indian populations face significantly higher mortality from cirrhosis of the liver, diabetes, motor vehicle accidents, and alcoholism. The latter two are man-made and potentially preventable. However, even the results in Table 14 face potential biases. Death certificates lack tribal identification and tribal-specific rates must be inferential. More importantly, with a higher proportion of elderly Native Americans living in rural areas, many probably die unattended by a physician and this coupled with an almost complete absence of autopsies makes diagnosis of death problematic.

Table 14

A Comparison of American Indian and U.S. All Races Age-Specific Mortality (Rates per 100,000)

	U.S. All Races 1978		American Indian 1980 - 1982	
	55-64	65+	55-64	65+
Heart Diseases	521.8	2331.1	363.0	1278.0
Cerebrovascular	74.1	622.0	58.1	329.4
Malignant Neoplasms	441.8	1002.0	235.7	592.0
Cirrhosis of the Liver	43.5	36.3	177.0	63.2
Diabetes Mellitus	26.9	101.3	83.0	147.3
Accidents—Motor Vehicle	18.8	24.5	57.6	52.7
Other Accidents	27.7	75.8	63.4	85.6
Suicide	16.4	17.5	7.2	6.5
Homicide	7.1	5.1	11.5	6.0
Alcoholism	23.3	10.1	75.4	31.2

Morbidity

Unfortunately, the data on age-specific morbidity (by Service Unit) did not arrive in time for inclusion in this chapter. The recent *Chart Book* series contains no information on morbidity. Other summaries completed in the late 1970s suffer from the "denominator" problems alluded to earlier. Even if the data had been available, present tabulation techniques cause important problems. For example, the IHS Ambulatory Patient Care (APC) system (which form the data base for much of this analysis) which records individual visits, is useful for calculating demand but severely limited for epidemiological analysis. A visit may represent an individual's sixth visit that year for the same complaint. If all six visits are counted as independent diagnoses then one has an artificially inflated numerator (i.e., that there are six people with the disease rather than one person who was treated 6 times). Under these conditions, "prevalence" estimates for a specific morbidity are near meaningless. In addition, comparison between several disease categories is difficult. One condition (e.g., diabetes) may require more visits for treatment than another (e.g., hypertension). Therefore, one is uncertain of the rate of specific conditions and, in addition, is unsure of the relative prevalence between disease categories. Finally, differences exist in how

diagnoses are coded (e.g., IHS categories are not isomorphic with the U.S. Bureau of Health Statistics or commensurate with other diagnostic tools, for example, DSM-III). Even APC visits and hospital discharge diagnoses are grouped differently. Despite all these difficulties, the majority of reports suggest that several morbidities—pneumonia, diabetes, alcoholism, arthritis, and dental health—are especially devastating to elderly Indian populations, with diabetes and alcoholism being particularly virulent in middle-aged populations.

One study, *American Indian Elderly: A National Profile* (National Indian Council on Aging, 1981), determined that American Indians suffer from a higher rate of chronic ailments than do White populations. Despite the many drawbacks of this study (e.g., a 40% nonreturn rate on interviewer-conducted protocols), its findings are suggestive. For example, if elderly American Indian populations have lower age-specific mortality, why do one in five Indians 45+ (both rural and urban) acknowledge that poor health interferes with their daily activities? In the same vein, why does the U.S. Census record that American Indian populations 65+ regardless of region or locality (urban or rural), have higher percentages (when compared to Whites) of disabilities that prevent their use of public transportation?

Table 15

A Regional Comparison of American Indian and White Persons 65+ With Physical Disabilities That Prevent Their Use of Public Transportation (In Percentages)

	White	American Indian	
	65+	Urban	Rural
Northeast	14.0	21.1	19.0
Midwest	12.8	19.8	16.7
South	15.8	19.8	24.0
West	13.3	19.5	21.5

Mental Health

In the *1978 Final Conference Report on Aging*, Everett Rhoades noted that:

> The only disease category (in mental health) which those 60 years or older contributed to in a significant way is "organic brain syndrome." A total of 40% of all visits for this disorder could be accounted for by those 60 years or older. Since this disorder is often associated with degenerative diseases such as arteriosclerosis and stroke this is not surprising. (p. 147)

Unfortunately a clear-cut diagnosis of OBS is not easily obtained and differential diagnosis between it and affective disorders is even more difficult. In White elderly populations, variables to consider in the assessment and treatment processes include the interactive effects between physical health, the side effects of medication for physical complaints, the side effects from psychotropic and neuroleptic medications, the impact of the individual's personality on reporting

symptoms or responding to questionnaires, the occurrence of recent traumatic events (e.g., the loss of a loved one), a patient's personal relationships, self-esteem, and family support. Nor is etiology unambiguously ascertained. For example, an abbreviated list of the possible causes of delirium is staggering: congestive heart failure, miocardial infarction, arrhythmias, pneumonia, urinary tract infection, digitalis, sedatives, antidepressants, alcohol, steroids, barbituates, neuroleptics, diuretics, L-Dopa, electrolyte disturbances (manifold in their etiology), kidney disease, liver disease, neoplasms, hypo- and hyperglycemia, and so forth. A differential diagnosis between OBS and depression may take a year. When one adds the refracting prism of a different culture (including a different language and different categories for nosology) to these problems, diagnosis and treatment becomes difficult indeed.

In summing up morbidity, at least two recommendations (that have also been voiced by others for at least 2 decades) become apparent. First, an already overburdened Program Statistics Branch at IHS needs additional resources to analyze the potential for an epidemiological transition and to plan for the consequences of such a possibility. Second, many complications of the most virulent morbidities (e.g., diabetes) are preventable. Regardless of one's cost/benefit philosophy, prevention is cheaper (and more ethical) than treatment.

Long-Term Care

The Indian Health Service, like health agencies in the U.S. generally, is predicated upon an acute care model. This model emphasizes the treatment of short-term, nonrecurring diseases typical of children and young adults. As the foregoing discussion of epidemiologic trends among American Indians suggests, the types of illnesses which beset older Indians are different than those experienced by their younger counterparts. Chronic and degenerative diseases predominate and are the primary causes of death for the elderly in this special population, as is the case for the majority culture. Moreover, mounting evidence indicates that 71% of all Indian persons over age 60 suffer limitations in their ability to perform activities of daily living due to these conditions (National Indian Council on Aging, 1981). Unfortunately, planning for long-term care and support of older Indians is less often discussed and even more uncoordinated than is true presently for elderly members of the general population. Indeed, current Indian Health Service emphasis on youth and family virtually exclude systematic consideration of the health care needs of older American Indians.

This section of our chapter reviews the status and prospects of long-term care services for the Indian elderly. Despite rather bleak circumstances at the level of the parent planning agencies, there are a number of exciting efforts by tribes and within specific service areas to address the emerging problems of care posed by

the needs of older American Indians. These efforts are discussed below in the context of a continuum of care, ranging from the most restrictive to the least restrictive service environments. At various points in the continuum, basic research questions are raised about the differential placement of the impaired elderly, about interventions for assessing, treating, and supporting older Indians, and about the roles of the tribes, IHS, Bureau of Indian Affairs, and local government in planning for long-term care. Answers to these questions will contribute to the integration of existing services and to the identification of missing alternatives which, together, promise to yield a more appropriate system of care than now exists for the elderly in American Indian communities.

Myths About Long-Term Care

Like members of the general population, many tribal, Indian Health Service, and Bureau of Indian Affairs personnel subscribe to a series of myths about long-term care. One of the most persistent of these equates long-term care with a nursing home. This perception stems in part from the high visibility and inordinate cost typically associated with institutionalization. However, long-term care comprises much more than just the nursing home: It encompasses all settings—home, community centers, neighborhoods, and churches—in which older people receive supportive care. Another frequent misperception is that long-term care essentially is a health service, and thus is the sole province of physicians, nurses, and other health professionals. To the contrary, caring for the needs of older people necessarily involves social workers, case managers, homemakers, and other non-health-related personnel. A wide range of assistance may be required to enable older adults to accomplish activities of daily living, including housing arrangements, special transportation, friendly visiting, chore services, and nutrition. Yet a third myth about long-term care is that it constitutes a ready solution to an older person's needs. Quite the opposite, long-term care services are required over a sustained period of time. Certain supportive needs may remain constant for the remainder of one's life; other needs may occur only intermittently or change depending upon one's functional status.

A fourth stereotype characterizes long-term care as primarily rehabilitative and protective, probably as a consequence of the related belief that aging is synonymous with illness and dependency. Indeed, long-term care includes these emphases, but it also is intended to prevent avoidable medical and/or social problems, to insure an optimal degree of independent living, and to promote physical as well as psychological well-being. Lastly, many mistakenly perceive long-term care as a formal service and the responsibility of either the Indian Health Service, the tribe, or more typically, both. Studies of the general population indicate that approximately three quarters of all impaired older adults

are cared for by their families. One suspects that this percentage may be even higher among Indians. For example, a National Indian Council on Aging report (1981) revealed that 46% of the older tribal members surveyed were assisted by extended family in accomplishing one or more activities of daily living. Hence, long-term care depends heavily upon informal support, both family and community-based.

The extent to which the above misconceptions are ingrained in the minds of tribal and IHS providers became apparent during the first author's recent consultation in the Billings Area Office of the Indian Health Service. This consultation focused upon long-term care for older tribal members and included a series of in-service training sessions at several service units as well as the area office. The sessions addressed different models of long-term care, common medical problems among the elderly, caregiver burden, elder abuse and neglect, and ethical issues in caring for older, terminally ill Indians. Prior to the in-service, participants were asked to complete a brief questionnaire about their views on and understanding of long-term care. The results vividly illustrate the currency of such myths among these individuals.

The questionnaire consisted of: (a) an open-ended item that asked the respondent to define long-term care, (b) eight items regarding the respondent's perception of the degree of involvement of various types of providers in long-term care, (c) five items regarding the respondent's perception of the objectives of long-term care, (d) three items regarding the respondent's perception of the types of functioning that long-term care is expected to enhance, and (e) five items regarding the respondent's perception of institutional responsibility for insuring the availability of long-term care services. One hundred and four individuals completed the brief questionnaire. The respondents included 25 administrators (24%), 11 physicians (11%), 19 clinic nurses (18%), 23 community health nurses (22%), 14 other health care professionals, for example, pharmacists, nutritionists, optometrists, physical therapists (13%), 8 community health representatives (8%), and 4 social workers (4%). They constitute a relatively stable and experienced group of professionals, having an average of 4.5 years in their present positions and an average of 13.7 years in their respective fields. However, as those familiar with the Indian Health Service might expect, significant differences are evident in both respects between physicians and all other types of respondents, with the former considerably less stable and reporting much shorter periods of time in practice than the latter.

The definitions of long-term care offered by the respondents almost invariably centered around institutionalization: 81% (n=84) of the definitions provided by the respondents named the nursing home as the only 71% (n=60) or primary 29% (n=24) service setting. Those which mentioned a range of possible settings were

provided exclusively by community health oriented personnel (e.g., community health nurses, community health representatives, and social workers). As is evident throughout the results, provider setting proved to be related consistently to differences in opinion about long-term care.

Based on their definitions of long-term care, the respondents were asked to indicate to what extent they believed that various categories of individuals—namely doctors, clinic nurses, community health nurses, other health care professionals, community health representatives, social workers, family, and others—are involved in the provision of such services. The mean ratings are depicted in Table 16 and are summarized by respondent provider category. Considering the aggregate means first, it is clear that the respondents generally perceived doctors, clinic nurses, and community health nurses to have the greatest involvement in providing long-term care services. Families, though thought to play an important role, were rated as significantly less involved than these three types of health care professionals. Others (e.g., neighbors or friends) were believed to be slightly less than moderately involved in the long-term care process. This last perception holds true regardless of respondent provider category. Note, however, that there is a major difference of opinion between the clinic-oriented personnel (administrators, physicians, and clinic nurses) and the community-oriented personnel (community health nurses, community health representatives, and social workers). Specifically, the former rate the involvement of family, community health representatives, and social workers in providing long-term care far lower than do the latter.

Table 16

Mean Ratings of Perceived Involvement of Providers in Long-Term Care (n = 104)

	MD	Clinic Nurse	Community Nurse	Other Prof	CHR	Social Worker	Family	Other
Administrators (n = 25)	7.0	7.0	6.5	4.8	5.1	5.0	4.1	3.9
Physicians (n = 25)	7.0	6.8	6.7	6.0	5.8	4.3	4.0	2.7
Clinic Nurses (n = 19)	7.0	6.8	6.8	6.1	6.0	5.3	5.5	3.8
Community Health Nurses (n = 23)	6.5	6.8	7.0	6.3	6.4	6.1	7.0	3.9
Other Health Care Professionals (n = 14)	7.0	6.5	6.1	4.5	5.1	5.0	4.6	3.3
CHRs (n = 8)	7.0	6.8	6.9	6.0	7.0	6.2	7.0	4.1
Social Workers (n = 4)	6.2	6.1	7.0	6.5	7.0	7.0	7.0	5.0
Aggregate X	6.8	6.7	6.7	5.7	6.1	5.6	5.6	3.8

Note. Respondents were asked: "Given how you have just defined long-term care, to what extent do you believe that [insert provider category] are involved in the provision of such services?" Responses were recorded on a 7-point Likert scale, ranging from (1) not at all, through (4) moderately, to (7) a great deal.

The respondents subsequently were asked to rate the extent to which their understanding of long-term care includes each of five service objectives including: (a) rehabilitation, (b) maintenance, (c) prevention, (d) protection, and (e) prolonged longevity. Unknown to the respondents, these objectives were extracted from the definition of long-term care generated by the Division of Long-Term Care, Health Resources Administration, Department of Health and Human Services. Table 17 summarizes the remarkable consistency among the respondents in their ratings of these objectives. Rehabilitative and protective services were perceived by virtually all of the respondents as being central to long-term care. Maintenance and prolonged longevity were rated by the respondents as moderately included. Perhaps most distressing, and in keeping with the views of the general population, is the near unanimous belief that preventive services fall outside of the realm of long-term care.

Table 17

Mean Ratings of Perceived Objectives of Long-Term Care (n = 104)

	Rehabilitation	Maintenance	Prevention	Protection	Prolonged Longevity
Administrators (n = 25)	6.6	4.5	3.0	6.7	4.1
Physicians (n = 11)	6.8	4.2	3.1	6.3	4.1
Clinic Nurses (n = 19)	6.7	3.9	3.0	6.2	4.4
Community Health Nurses (n = 23)	6.8	4.8	3.6	6.9	4.0
Other Health Care Professionals (n = 14)	6.4	4.0	2.9	6.6	3.5
CHRs (n = 8)	6.5	3.8	3.5	6.8	4.0
Social Workers (n = 4)	6.6	4.1	3.9	6.7	3.8
Aggregate X	6.6	4.2	3.3	6.6	4.0

Note. Respondents were asked: "Thinking now of long-term care, as you have defined it, to what extent does its objectives include [insert objective]?" Respondents were recorded on a 7-point Likert scale, ranging from (1) not at all, through (4) moderately, to (7) a great deal.

The previously mentioned DHHS definition of long-term care also identifies the enhancement of physical, psychological, and social functioning as a major service goal. Respondents were instructed to rate the extent to which their understanding of long-term care is concerned with each type of functioning. The results are reported in Table 18. An overwhelming bias towards physical functioning is evident, with considerably less, but still important, emphasis placed on psychological functioning. However, social functioning generally was not perceived as a primary concern of long-term care as defined by this particular group of providers. Yet respondents again differed markedly in their ratings depending upon the particular setting in which they work. Psychological and social functioning were repeatedly rated as of greater concern by community-oriented personnel than by clinic-oriented personnel.

Table 18

Mean Ratings of Functions Perceived to be Enhanced by Long-Term Care (n = 104)

	Physical Functioning	Psychological Functioning	Social Functioning
Administrators (n = 25)	6.8	4.9	3.2
Physicians (n = 11)	7.0	4.7	3.4
Clinic Nurses (n = 19)	7.0	4.8	3.4
Community Health Nurses (n = 23)	6.8	5.3	4.5
Other Health Care Professionals (n = 14)	6.7	4.6	3.2
CHRs (n = 8)	6.5	6.0	5.7
Social Workers (n = 4)	6.8	6.1	6.5
Aggregate X	6.8	5.2	4.3

Note. Respondents were asked: "Continuing to think of long-term care, as you have defined it, to what extent is it concerned with enhancing [insert type of function]?" Responses were recorded on a 7-point Likert scale, ranging from (1) not at all, through (4) moderately, to (7) a great deal.

The final set of items posed the question of responsibility for insuring the availability of long-term care services for older American Indians. In this instance, the respondents were asked to rate the extent to which they believed this responsibility is that of the tribe, IHS, BIA, state, and family, respectively. As reflected in Table 19, on the whole, the respondents rated both the IHS and state government as principally responsible for insuring the availability of long-term care services. The inclusion of state government may be a consequence of the tendency by the respondents to equate long-term care with the nursing home and their awareness of the role of the state in disbursing Medicare and Medicaid funds which subsidize this level of care. Tribes were rated as having a prominent role in making long-term care services available. The BIA, despite its critical part in delivering social services, was believed to have only a moderate responsibility. This perception may be due in part to the an overidentification of long-term care by the respondents with clinically oriented health providers and with the enhancement of physical functioning. Finally, there was nearly universal agreement that, as the respondents conceptualized long-term care, families have very little responsibility for insuring the availability of such services. This last pattern of results again underscores the limited perspectives on long-term care by the respondents.

Table 19

Mean Ratings of Perceived Responsibility for Insuring Availability of Long-Term Care Services (n = 104)

	Tribe	IHS	BIA	State	Family
Administrators (n = 25)	6.2	6.6	4.1	6.8	2.3
Physicians (n = 11)	6.0	6.9	3.8	6.5	2.0
Clinic Nurses (n = 19)	4.5	6.8	4.0	6.4	2.4
Community Health Nurses (n = 23)	4.2	6.7	4.3	6.6	2.7
Other Health Care Professionals (n = 14)	6.1	6.8	3.6	6.3	2.2
Community Health Reps (n = 8)	4.2	7.0	4.0	6.5	2.1
Social Workers (n = 4)	5.3	6.7	5.5	6.4	2.3
Aggregate X	5.2	6.8	4.2	6.5	2.3

Note. Respondents were asked: "Continuing to think of long-term care, as you have defined it, to what extent is the [insert provider] responsible for insuring the availability of such services?" Responses were recorded on a 7-point Likert scale, ranging from (1) not at all, through (4) moderately, to (7) a great deal.

The brief survey reported above was not conducted among a statistically representative sample of the individuals involved, either formally or informally, in caring for elderly Indians. The respondents were drawn from 4 of 8 service units within 1 of 10 IHS service areas. All of the respondents were IHS employees; thus, providers from tribal programs are not included. Perhaps even more importantly, neither older Indians nor their family members are among those surveyed as to their understanding and views of long-term care. Yet, the results suggest that important, programmatically relevant insights can be gained from the systematic study of the attitudes of people involved in the planning, delivery, or consumption of long-term care for elderly Indians. These beliefs affect every element of the service system.

The Long-Term Care System

Reviews of the long-term care literature abound and need not be recapitulated here (Brody & Mascrocchi, 1980; Vogel & Palmer, 1985). Instead, for the purpose of this discussion, it is sufficient to list the features of the system that are common to the numerous models which others have described at considerable length. Ideally, the long-term care system: (a) has clearly defined goals and objectives, (b) emphasizes care in the least restrictive setting, (c) maximizes the independence of the person seeking services, (d) provides greater incentives for the elderly to remain in their communities and for families to care for them, (e) provides a continuum of services that meets the changing needs of the elderly population, (f) provides coordinated care (case management) and a centralized administrative structure for those seeking services, (g) emphasizes services that are community-based and locally controlled, (h) is less costly or more cost-effective in its financing and service delivery mechanisms, (i) allows the elderly consumer to maintain his/her dignity and respect, and (j) allows the

elderly consumer to actively participate in the decisions affecting his/her treatment and lifestyle (American Health Planning Association, n.d., p. 24). The linchpins in this conceptualization of long-term care are the continuum of care and case management.

The continuum of care refers to a wide range of services and facilities to provide any level of care needed by an older person to maximize his/her ability to function independently in the least restrictive setting. It includes social as well as medical services and ranges from total institutional, care such as nursing homes and hospitals, to less restrictive settings or services such as home health care and meals-on-wheels. Figure 3, taken from Brody and Mascrocchi (1980), depicts the types of services often considered part of the continuum of care and arrays them in terms of degree of restriction, moving from institutionalization, through community-based aid, to in-home care. We will return to this figure in our subsequent discussion of long-term care services within American Indian communities.

Unfortunately, even the best examples of a long-term care system are plagued by discontinuities in service. There often are gaps where the components to address an unmet need are either inadequate or nonexistent. A system may suffer from fragmentation of existing elements resulting from a lack of communication, coordination, or clearly defined responsibilities. Lastly, clients are not easily kept involved; the perceived unacceptability, inaccessibility, and unaffordability of services adversely affect help-seeking behavior as well as utilization. Case management has emerged as one of the mechanisms for minimizing these service discontinuities for clients of the long-term care system (Beatrice, 1981). Its functions typically involve: (a) identifying client strengths, problems, and needs through an ongoing process, utilizing diagnostic, evaluation, and progress information from the involved services; (b) developing client service plans, with provisions for day, evening, and night linkages to the requisite forms of supportive care; (c) referring clients to or transferring them among needed services; (d) insuring quality of care and equity of access to services; and (e) advocating structural or procedural change to better accommodate client needs. These assessment, planning, linking, monitoring, and advocacy functions may be performed by designated personnel within an age-integrated service or by single concept agencies such as a specific provider organization or a local community program.

Despite an abundance of models, the present long-term care system for older members of the general population is, in practice, far from ideal. In many parts of the U.S., the continuum of care is underdeveloped with an overemphasis on institutionalization. Care is expensive and sometimes inappropriate. Families remain heavily burdened, fiscally as well as psychologically, by the demands of elderly parents. Many older adults simply do not receive needed services, even

if available. These problems also characterize the evolution of long-term care services for older American Indian communities. Let us examine the status of some of the key elements of the continuum of care as it has developed in these communities.

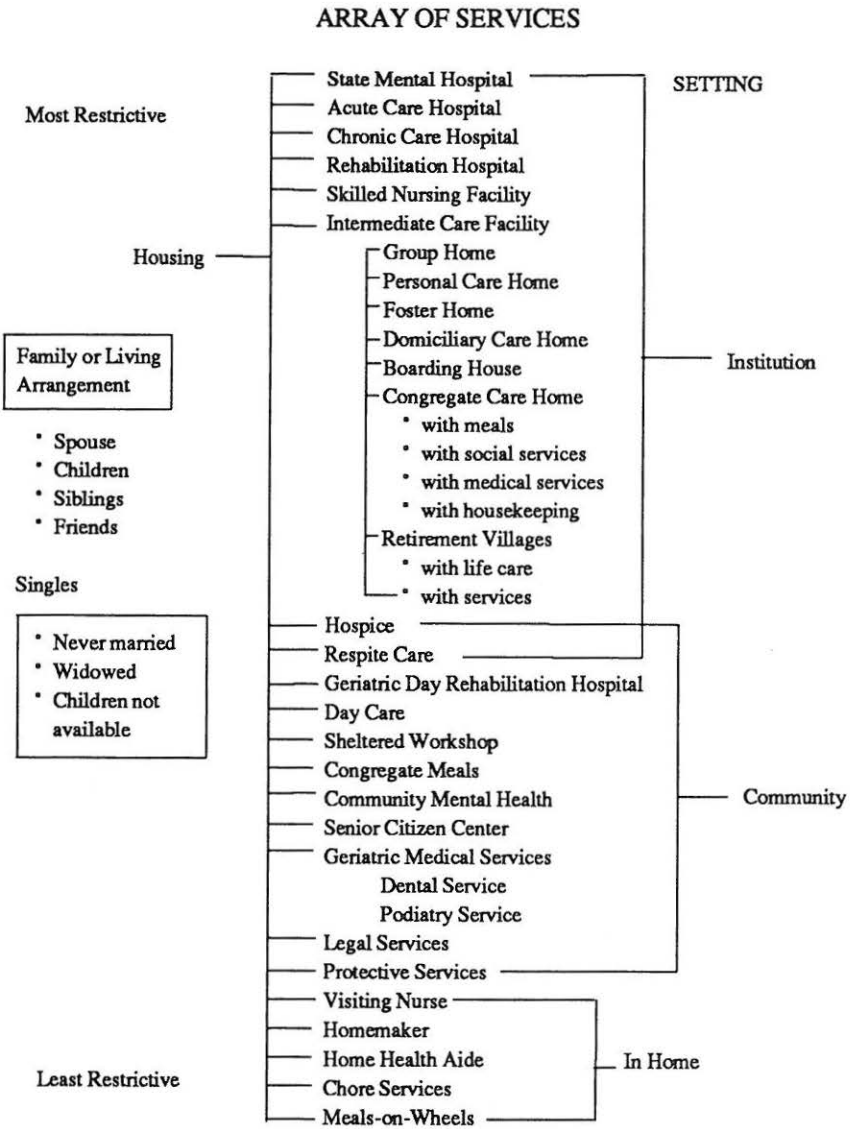

Figure 3. Inventory of recommended available services appropriate to a long-term care support sysem. Adapted from Brody, S. J., and Mascrocchi, C. (1980). Data for long-term care planning by health systems agencies, *American Journal of Public Health*, Vol. 70, No. II, p. 1197.

The Continuum of Care in American Indian Communities

As noted earlier, Figure 3 depicts the array of services commonly referred to as the continuum of care. Examples of these services can be found throughout American Indian communities, though, to our knowledge, never all of them in any one community. This section employs illustrations of services in each major category to surface the salient policy and research questions with respect to aging and health for older members of this special population.

Acute care general hospital. Beginning, then, with the most restrictive settings, the acute care general hospital is the cornerstone of primary medical care and rehabilitative services for American Indians and Alaska Natives. The Indian Health Service, the major provider of these services, presently supports 48 hospitals, most of which are located in Alaska, Arizona, New Mexico, Oklahoma, and South Dakota (see Figure 4). These hospitals range in size from 12 to 170 beds, with a total of 2,148 available beds. They offer medical, surgical, obstetric, tuberculosis, and neuropsychiatric care. Under the authority of Public Law 93-638, tribes operate three hospitals. Numerous Indians and Natives also receive treatment through contracts with several hundred community hospitals in areas where the IHS does not maintain its own facilities. During the 1983 fiscal year, IHS hospitals accounted for nearly 2 million outpatient visits. The leading causes of hospitalization for the same period included injuries and poisonings, digestive system diseases, and respiratory system diseases. Admissions to all hospitals, including those under contract, increased by 110% between 1955 and 1983. Hospital admissions for Indians and Natives 65 years of age and older evidenced the second largest percentage increase of any age group during a 10-year period beginning in 1973.

The prominent role of the acute care general hospital in the IHS health program, the increasing prevalence of chronic, degenerative diseases among Indians and Natives, the growing number of older Indians and Natives admitted for hospitalization, and the relative lack of alternative forms of institutional care in Indian communities are an ominous set of conditions that foreshadow a series of critical problems for the system of care. Several questions demand immediate attention.

In spite of the Indian Health Service's reluctance to commit itself, is it already deeply involved in the provision of long-term care services? One of the simplest ways to begin examining this possibility is to study patterns of hospital admission, stay, discharge, and readmittance by disease group and age. Conversations with IHS hospital staff in three different service areas indicate that a number of beds, though not formally designated for long-term care patients, in fact are often thought of in these terms. Anecdotal reports from IHS physicians suggest at least two different phenomena are becoming common in regard to the hospitalization of elderly Indians. On one hand, physicians describe a vicious

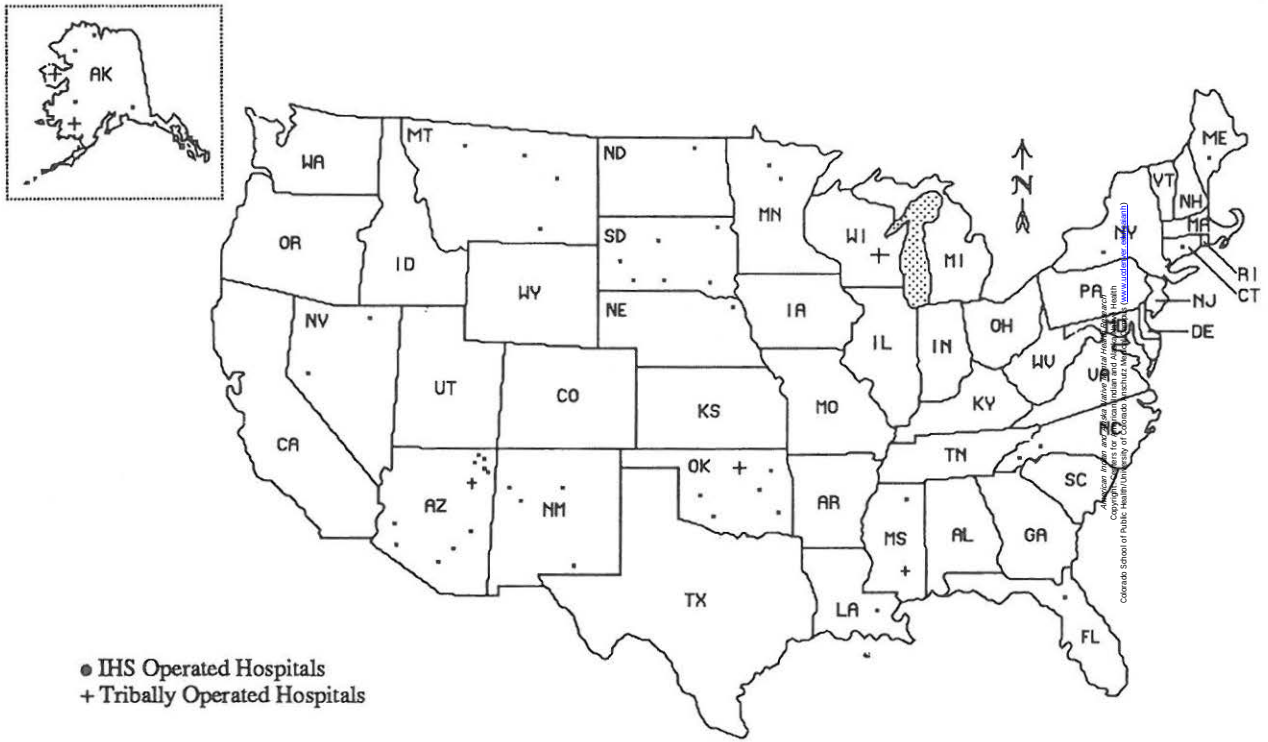

Figure 4. Location of IHS and tribally operated hospitals in the United States.

cycle of frequently recurring acute episodes of an underlying chronic disease. Older patients are discharged to home situations that do not have adequate resources to manage their family members' health problems, only to return in a matter of weeks with yet another exacerbation of a degenerative condition. On the other hand, the same physicians also describe a pattern of repeated short-term hospitalizations that serve an essentially respite function for overburdened families. The older family member is presented at the hospital midday Friday with a succession of complaints that are sufficiently vague to warrant tests and observation. Monday, the family caregiver returns, is told that no new problems were discovered, and is advised to continue the prescribed regimen of care. During a recent visit to a large IHS hospital, one health care provider poignantly recounted her quandary over whether or not to refuse to admit just such a case. She lamented the elimination of "social" admissions.

Has the intersection of these conditions altered thresholds for help-seeking behavior? Has it affected the ways in which Indian and Native people perceive their health problems? Clinical lore among IHS physicians holds that the emphasis on urgent and emergent care has begun to reshape the manner and frequency with which Indian people generally, and the elderly in particular, present for service. Specifically, minor problems such as cuts, abrasions, mild burns, digestive upset, and musculoskeletal strains that seldom occasioned much comment are now believed to precipitate frequent clinic or hospital visits. If true, is it a consequence of the emphasis on acute, institutionalized care? Are Indians and Natives being socialized to accommodate the demands of this particular model of care? Indeed, has the present system and lack of alternatives engendered an unnecessary dependency? Or, are local resources at such a low ebb that families and friends truly cannot manage to cope with even these difficulties among their older adult members? Do they perceive these types of health problems as heralding increased functional dependence of elderly relatives and greater demands on already hard-pressed familial energies? Alternatively, do older Indians, recognizing the immense fiscal and social pressures under which their younger children labor, choose to voice with increasing frequency physical complaints to health care professionals rather than friends or family? Studies akin to those conducted by Brody and her associates (1985) on lay consultation and referral networks among impaired older adults may shed important light on these dynamics.

Skilled and intermediate care facilities. Despite the possibility that IHS hospitals may provide some extended care to older Indians suffering from chronic, degenerative disease, inevitably many of them reach a level of functional dependence that requires long-term institutionalization. Unlike the general population, which boasts tens of thousands of nursing homes, skilled and intermediate care facilities are extremely rare in Indian and Native communities.

A technical report to the 1981 White House Conference on Aging indicates that approximately 4,600 older Indians reside in non-Indian nursing homes. For the most part, such facilities are located far from these communities. Their distance and orientation to non-Indian populations present a number of problems for the elderly Indian resident and his/her family. Visiting by friends and family occurs less often as a consequence of difficulties in transportation. Fellow residents and staff typically are non-Indian. The diet and activity patterns of the elderly Indian resident may be quite different than those of their non-Indian counterparts. As a result, most American Indian tribes and Alaska Native regional corporations prefer to construct nursing homes on their own land and to staff the facilities with members of their own groups.

Beginning in 1971 with the first White House Conference on Aging, and in every National Indian Conference on Aging thereafter from 1975 to the present, the topic of nursing homes—the inadequacy of existing facilities and the need for constructing new ones—has occupied a central place in the discussion of elderly Indian needs. These facilities are gradually appearing, albeit slowly, in Indian communities. The first Indian nursing home was constructed in 1969. Six others were erected in the 1970s; two more have been erected in the early 1980s. To date, there are only 10 reservation nursing homes with 435 residents. American Indian and Alaska Native communities are approximately 10 to 15 years behind the general population which began extensive nursing home construction in the 1960s.

The characteristics of these 10 Indian nursing homes are summarized in Tables 20 through 22 which are adapted from Mick (1983). The American Indian Nursing Home in Laveen, Arizona, is the oldest; Morning Star Manor in Ft. Washakie, Wyoming, on the Wind River Reservation, is the newest.

Table 20

Indian Nursing Homes: Starting Dates, Bed Capacity, Levels of Care, Occupancy Rates, State Location, and Tribes Served

Date and Facility	State	Tribe	Beds	Levels of Care	% Occupancy
1969 American Indian	AZ	Papago Pima	96	Skilled Intermediate Personal Care Board & Care	100%
1971 Chinle	AZ	Navajo	79	Skilled Intermediate	Unknown
1974 Blackfeet	MT	Blackfeet	49	Skilled Intermediate	69-70%

Table 20 (continued)

Date and Facility	State	Tribe	Beds	Levels of Care	% Occupancy
1978 Oneida	WI	Oneida	50	Skilled Intermediate Personal Care Board & Care	90-92%
1978 Toyei	AZ	Navajo	66	Personal Care	90-100%
1978 Carl T. Curtis	NE	Omaha	25	Intermediate	80-85%
1979 White River	AZ	Apache	20	Personal Care	90%
1982 Laguna-Rainbow	NM	Laguna	25	Intermediate	100%
1983 Coleville	WA	Colville	32	Skilled Intermediate	100%
1985 Morning Star	WY	Shoshone Arapahoe	50	undecided	NA

Note. Table 20 adapted from *A Profile of American Indian Nursing Homes* by C. Mick, 1983.

Table 21

Indian Nursing Homes: Percent Indian Staff, Patient Admission Criteria, Number of Non-Indian Patients, and Proximity of Acute Care Facility

Facility	% Indian Staff	Patient Admit Criteria	# Non-Indian Patients	Proximity of Acute Care Facility
American Indian	83	open	0	IHS, Phoenix 16 miles
Chinle	---	---	---	IHS, 5 miles
Blackfeet	94	open	3	IHS, 4 blocks
Oneida	71	adults only	10	10 miles
Toyei	91	resident Indians	na	IHS in region 65 mi. IHS out of region 26 miles
Carl T. Curtis	80	Omaha Indians other Indians	na	30 miles, small IHS hospital 10 miles
White River	100	resident Indians	na	5 miles
Laguna-Rainbow	95	Laguna Indians	na	IHS hospital, 4 miles
Coleville	89	open (Indians preferred)	9	IHS, 3 blocks
Morning Star	na	undecided	na	IHS, 2 blocks

Note. Information on Chinle was not available; Table 21 adapted from *A Profile of American Indian Nursing Homes* by C. Mick, 1983.

Table 22

Indian Nursing Home Patient Characteristics: Sex Ratio and Average Age

Facility	Male/Female Ratio	Average Age
American Indian Chinle	2:1	66
Blackfeet	1:2	72
Oneida	1:1.3	83
Toyei	1:1	82
Carl T. Curtis	1:1	60-70
White River	1:1.5	75
Laguna-Rainbow	1.3:1	82
Colville	1:1	70
Morning Star	na	na

Note. Information on Chinle was not available; Table 22 adapted from *A Profile of American Indian Nursing Homes* by C. Mick, 1983.

The homes range in size from 20-96 beds with a combined patient capacity of 485. The majority of these facilities offer only one level of care, though at least two admit patients with skilled, intermediate, personal, and board and care needs. Occupancy levels are relatively high, with waiting lists at two facilities. The Blackfeet and Curtis homes attribute their lower occupancy rates to active local home health agencies. Seasonal patterns of admission have been noted by a number of the facilities, specifically, higher occupancy rates during winter months. Eighty to 100% of the staff at six of the facilities are Indian. Patient admission criteria vary markedly, from exclusively Indian with tribal reference to unrestricted admissions. The latter occurred in response to initially low occupancy rates. With some exceptions, these 10 nursing homes are close to acute care facilities. However, despite the cost-effectiveness of regular rounds in such facilities, IHS physicians do not provide even this minimal type of care within these nursing homes. As the different levels of care imply, there is considerable diversity among the 10 facilities in the number and kind of services offered to residents. Most provide occupational, physical, and recreational/ activity therapies, though by a wide range of provider types. The ratio of male to female patients in these facilities does not follow well-established patterns for the general population. Females outnumber males by approximately three to one in the non-Indian nursing home population. However, in two Indian facilities, males outnumber females by more than two to one. Two homes report equal proportions and the remaining three for which there is data indicate that approximately 60% of their residents are female and 40% male. The high prevalence of crippling auto accidents, and alcohol-related functional impairment, both of which involve a disproportionate number of males, may account for this discrepancy. The average age of the institutionalized population

in general is 82 years. The lower average ages of residents at 3 of the 10 nursing homes may be due to the same factors that affect the sex ratios. Lastly, cognitive impairment is the most frequently cited explanation for institutionalization of older adults in the U.S. According to the 1977 National Nursing Home Survey, over 56% of all nursing home residents suffer from moderate to severe cognitive impairment (U.S. DHHS, 1977). Yet, cognitive impairment is reported to be relatively low among Indian nursing home residents. The three most common diagnoses of the residents in these homes are diabetes mellitus, alcohol abuse, and stroke (Mick, 1983).

The recent advent of nursing home construction in Indian communities reflects a long unmet need. The fiscal incentives that fueled the explosion of nursing home construction in the general population during the 1960s are not present in Indian communities today. However, many tribes are rushing forward with plans for "their own home" which seem to be fueled by a number of factors in addition to need. One of these factors involves the physical presence of the facility and, thus, visibility of effort. Eldercare is an emotionally charged issue that speaks to the essence of tribal life and tradition. The nursing home often is portrayed as a tangible expression of community esteem for older members. While true, in some cases it also has become an excuse for disattending to the full spectrum of needs: "...but, they have the nursing home." This selective attention is further reinforced by the previously discussed tendency to equate long-term care with institutionalization.

In light of the gradually increasing number of nursing homes appearing in Indian communities, a series of research questions now deserve close scrutiny. Some of these questions concern past speculation as to the reasons for the underutilization of off-reservation, non-Indian nursing homes.

Does closer proximity of these facilities to residents' friends and family increase the frequency of visits? Distance and difficulty in securing transportation are offered as the rationale for relatively infrequent visiting by Indian families and friends of residents living in off-reservation, non-Indian nursing homes. Is accessibility the major barrier to regular contact or are there other factors at work such as guilt about the inability to care for one's older relatives at home, a wish to avoid being confronted with immediate reminders of the inevitable physical consequences of current lifestyles, and beliefs about death and dying which have become associated with nursing homes in many Indian communities?

Does the predominance of Indian staff in these facilities result in greater resident satisfaction with the care rendered? Staff at non-Indian facilities are presumed to be (and, in some instances, indeed have been) culturally insensitive. This insensitivity is cited as one of the major sources of resident and family dissatisfaction with the skilled and intermediate care provided in off-reservation,

non-Indian nursing homes. Are the staff in these 10 Indian facilities perceived as more culturally sensitive by residents and families? If so, does this make a difference in overall consumer satisfaction? Are there other factors that affect the perceived quality of care which may be problematic in Indian facilities? In her survey of eight reservation nursing homes, Mick (1983) reported that administrators described serious problems in hiring and retaining both professional and nonprofessional staff. The former are difficult to attract because of noncompetitive salaries, benefits, and supportive services. Unexcused absenteeism and alcohol-related problems frequently undermine the effectiveness of the latter.

Are the admission and discharge patterns of residents into Indian nursing homes different from the general population? Seasonality appears to play a major role in the occupancy rates of several of the reservation facilities described above. How are services subsequently affected? Skilled and intermediate care facilities are intended to be rehabilitative: Residents are expected to receive services which will enable them to return ultimately to a less restrictive setting. To what extent do Indian nursing homes function in this capacity? Or, are they, in the words of a tribal council member, "the last stop?"

What is the decision-making process with respect to the institutional placement of an impaired older Indian family member? The extended nature of Indian families is both a blessing and a burden in this regard. The blessings have been well enumerated; consider some of the burdens. Indian families are presumed to be a reservoir of instrumental and affective support. However, one wonders to what extent size may not be confused with function. There is little doubt that tribal values place great emphasis on familial obligations and responsibilities. Endless examples attest to the selflessness of mothers and siblings in putting the needs of others before their own. Therefore, tremendous pressure is felt by all concerned to retain older relatives in the home at almost any cost. Yet, the interminable demands of a frail, impaired older adult strain even this family system. A recent study by Manson (1984) revealed that older urban (n=76) and reservation (n=155) Indians perceived physical illness and limitations stemming from related disabilities to be the most difficult type of situation facing them. Moreover, despite the willingness and availability of a large percentage of their social networks to assist them, the elderly study participants indicated that these same individuals lacked the instrumental resources to provide effective assistance. What circumstances, then, lead to the placement of the impaired older Indian family member? In the absence of community-based or in-home supportive services, it often is the case that the middle-aged children assume the responsibility of care in serial fashion, until each has experienced for herself (or

much less frequently himself) the burden posed by providing for the elderly person's needs. Systematic studies are needed of this process and of appropriate interventions.

Other forms of institutional care. Less restrictive institutional settings for long-term care include a range of housing options for older adults who do not need intense medical care. These options include domiciliary facilities (also known as personal care and boarding homes), congregate care homes, and retirement villages. Domiciliary facilities are intended for individuals who are unable to maintain an independent lifestyle and require personal assistance with activities of daily living, namely bathing, grooming, dressing, and eating. Congregate housing is a group living environment which promotes independent living by supplying supportive medical and social services either directly or through referral to elderly people who are in good health, but may suffer financial or social difficulties. Retirement villages are clusters of single or multi-family housing units designated for occupancy by independently functioning older adults. These housing units usually are linked to community-based services that can assist with homemaker tasks.

Two of the 10 reservation nursing homes described above provide board and personal care services. Two others only provide personal care services. No estimates exist of the number of domiciliary facilities which operate in Indian communities apart from nursing homes, though given the general inadequacy of alternatives, there probably are few of them. Similarly, we are aware of only one congregate housing effort: the Wendell Turkey Shoulderblade Center on the Northern Cheyenne Reservation in Montana. Intended for tribal members who are either handicapped or 55 years of age or older, the Center consists of 35 self-contained apartments, 2 day rooms, a community room, game room, sweat lodge, kitchen, and dining room. It was built by the Northern Cheyenne Housing Authority in 1979 with a loan from the Department of Housing and Urban Development. Residents are expected to maintain a significant degree of self-sufficiency and self-reliance, but are able to rely on staff for certain forms of care. This care includes assistance in accomplishing activities of daily living, mental health counseling, religious activities, adult education, congregate meals, and nutritional counseling with special emphasis on diets for residents suffering from heart disease and diabetes. The Northern Cheyenne Housing Authority describes the objectives of the Center as "...to promote the elderly in every way to encourage the young set to gain respect for them, their lives, their heritage, interest, wisdom, culture, ability, and their devotion to the great spirit. Only then will the young people look forward to good health, long life, and the good things for Indian people."

Special housing for the elderly akin to retirement villages also is rare in Indian communities. Perhaps one of the most advanced complexes of this type is maintained by the Confederated Tribes of the Warm Springs Indian Reservation in north central Oregon. It consists of 28 single family housing units designated for tribal members 55 years of age or older. Housing regulations limit the number and age of children and grandchildren permitted to live with the older residents. The housing complex is adjacent to a Senior Center which provides congregate meals twice weekly and home meals daily if required, two cords of firewood each year, transportation, recreational activities, regular home visits to determine needs and refer as appropriate, in-home services, nutrition education, foot care, and information and referral. This effort is seen as long-term prevention, reducing unnecessary demands on medical and social services, and prolonging independent functioning.

The overreaching questions with respect to these types of long-term care services concern the efficacy of their preventive and promotive activities. Do these types of interventions reduce unnecessary demands on medical and social services? To what extent do they decrease functional dependence: prolong relatively independent living? Do they (can they) positively impact community views on aging and old age, as the Northern Cheyenne hope?

Community-based services. A wide variety of community-based long-term care services can be found in American Indian and Alaska Native communities. Congregate meals and nutrition programs probably are the first and oldest forms of such services. Funded under Title XX of the Social Security Act and Title III-C, or Title VI of the Older Social Security Act and Title III-C, or Title VI of the Older Americans Act, these efforts frequently include group meals, menu planning, nutrition education, recreational activities, employment projects, and even exercise programs. The impetus for the involvement of many Indian communities in other aging-related services can be traced to early successes of nutritional programs for the elderly.

Virtually every Indian community has a noninstitutional focal point for aging-related activities, albeit not all are as elaborate or comprehensive as the Warm Springs example. Such focal points take several forms in addition to the classic senior center model. A multisite system typically has developed where the elderly Indian population is widely dispersed across the reservation. On small reservations which cannot support a separate facility, community centers may sponsor senior activities and set aside space for exclusive use by elders. Some communities have tried mobile approaches: "senior centers on wheels," in which a van or trailer makes scheduled rounds of the reservation. Activities include limited social services, information and referral, and friendly visiting by the well elderly.

Respite care and elderly day care are relatively new concepts in Indian communities. Elderly day care is about to be initiated in the Laguna-Rainbow facility at New Laguna, New Mexico. The Confederated Tribes of Warm Springs have recently embarked on an in-home respite care program in which staff periodically relieve family members who are caring for frail, impaired older relatives.

Community-based programs are one of the largest areas of growth in long-term services for elderly Indians. Both continuity and quality of care issues arise. To what extent are these services linked to the continuum of care? How? By whom? What standards of care prevail? Who is responsible for assuring quality care? In a separate vein, these services are intended to be preventative. Thus, how effective are meal programs, nutritional counseling, and menu planning in affecting diet and health status? Is obesity reduced as well as risk for diabetes and hypertension? Is psychological well-being enhanced by the social engagement stressed in recreational and leisure activities; by the perceived control over some aspects of community life? Do peer networks emerge from these efforts that perform protective and surveillance functions? Are more older Indians or their family members aware of aging-related activities and programs as a consequence of the information and referral element of these services? Is the community better educated with respect to the life experience of older adults and the aging process or does ageism continue unabated? Turning to respite and elderly day care, are there measurable effects? Do these special programs reduce caregiver burden, familial stress, and elder neglect? Do they increase the length of time in which impaired older family members productively remain at home? Are there direct benefits to older participants in terms of decreased isolation and increased socialization with peers?

In-home services. The least restrictive and often most desirable setting for the care of older Indians is in their own or families' homes. An array of services has developed to meet a wide range of needs that threaten the ability of elderly individuals to live independently. Home health care provides medical care for acute or chronic illnesses including cleaning wounds, changing bandages, administering injections, and inserting catheters. Personal care services such as bathing, dressing, and grooming, may also may be performed in-home and often are conducted in conjunction with home health care or chore/homemaker services. Chore/homemaker services entail shopping, laundry, cooking, and household cleaning. Meals-on-wheels is yet another service delivered in-home. In addition to promoting sound nutrition, this particular service also ameliorates the social isolation experienced by the homebound elderly. Nearly every Indian community supports some level of in-home services.

One of the exemplary homemaker/home health programs in Indian communities is maintained by the Inter-Tribal Council of Nevada (ITCN). In operation for over 10 years, the ITCN In-Home Services Program (IHSP) has a staff of 15 who serve between 150 and 175 clients each month on 10 reservations in western Nevada. Client eligibility criteria include: (a) being homebound or requiring assistance with activities of daily living; (b) a need for teaching or training related to diet, medications, or self-care; and (c) family caregiver(s) in need of respite. The homemaker services encompass planning and preparing meals, meals-on-wheels, shopping, laundry, mending, ironing, and light housekeeping. In-Home aides also assist with bathing and personal hygiene, dressing, prescribed exercises, supervising the taking of medications, changing wound dressings, conducting weekly physical assessments, nutrition counseling, health education, transportation, and social activities. A number of other Indian communities support similar programs.

IHS community health nurses and community health representatives are the cornerstones of in-home care of elderly Indians. Indeed, the latter are responsible for all of the home health care within the ITCN In-Home Services Program. Community health nurses and community health representatives often are the only link to the acute health care system for older patients. The critical part that community health representatives play in caring for the elderly was recognized by a national task force convened in 1983 to identify areas of program specialization. In its position paper, entitled *Statement and Definition of Indian and Alaska Native Community Health Representative Program Health Care Delivery Areas*, this task force included gerontological services as one of the six subspecialty fields. A study group subsequently enumerated community health representative gerontological specialist functions in three settings (e.g., hospital/clinic, community, and home). These functions included: (a) providing gerontological education and consultation services; (b) providing individual assessment, therapeutic, and follow-up gerontological services; (c) resolving physical, economic, and cross-cultural encumbrances to the attainment of gerontological services; and (d) surveying and controling environmental factors that affect the health status of the aged. Community health representative activity reports recently were revised to reflect the performance of these activities.

As in the other service categories, quality and continuity of care are paramount concerns. In this instance, though, family involvement in direct care enters as a factor. To what extent can family be trained and expected to provide certain homemaker and health care services? Which family members are most appropriate—in terms of time and disposition, as well as role—to perform these functions? Who should conduct the functional assessments of older Indians to determine in-home care needs? How should responsibilities for care be divided among community health nurses, community health representatives, and other

in-home providers? Who can best coordinate this care? How are older Indians in need to be identified? Are tools such as the Older American Resources Survey (OARS) adequate in light of the cultural differences between the original validation populations and elderly American Indians? Finally, how cost-effective are in-home services? What constitutes the break point, at which congregate care becomes less expensive, more efficient, and psychologically desirable?

Conclusion

The changing demographics of the American Indian population, and epidemiologic implications thereof, will force tribes, the Indian Health Service, and other concerned agencies to plan more systematically for the provision of long-term care services for older adults. In addition to the category-specific questions that have been raised, these parties will face, indeed already are confronted by, planning dilemmas which present no easy solutions. These dilemmas cut across client-focused, structural, and strategic concerns.

Client-focused issues can be cast in the form of three questions: (a) Should the elderly be served separately from other age groups, (b) how broadly defined should the target group of elderly be, and (c) what is the preferred service strategy for the elderly? The debate over age-segregated, as opposed to age-integrated, services has raged for nearly 20 years in the field of gerontology. Arguments in favor of the former cite several well-established phenomena. The elderly prefer and benefit from interaction with their peers. The special problems of the elderly require the expertise of gerontological and geriatric specialists. In times of limited resources, the natural inclination is to neglect the needs of older adults in favor of the young. In contrast, those supporting the latter position claim that age-segregated services foster ageism by stigmatizing older adults; whereas, age-integrated services allegedly increase interaction between generations, thereby promoting mutual understanding and acceptance. Sentiments are equally divided on the issue of whether to target services to all elderly individuals or to focus on those who are vulnerable and at highest risk of functional dependence. Proponents for serving all of the elderly reason that a broad spectrum approach will increase the preventive and promotive aspects of such care. They also contend that serving all elderly individuals is both more efficient and enhances the advocacy of the young old. On the other hand, those who endorse a concentration on the frail and vulnerable elderly refer to the urgency and specificity of their needs, as well as the inevitable scarcity of resources and consequent necessity to prioritize services. Lastly, the controversy over preferred service strategies typically pits home-delivered care against congregate services. In-home care is said to be preferable because it is delivered

in natural, nonthreatening environments and is thought to postpone or even eliminate institutionalization. Congregate services are often championed for their positive influence on peer socialization, cost-effectiveness, and the projection of a positive image of the elderly.

The major structural issues also can be characterized in three questions: (a) Should the long-term care effort be comprehensive or limited, (b) should long-term care services and planning be centralized or decentralized, and (c) should these services be coordinated formally or informally? Comprehensiveness of care for older adults generates considerable disagreement. Some advocate that a comprehensive approach is preferable because it is responsive to the total range of service needs, addresses the interrelationships among an older client's usually multiple problems, and accommodates the needs of the client rather than the reverse. Supporters of a limited approach argue that focused services maximize limited resources, are less expensive to operate, offer greater flexibility and encourage innovation, promote the development of expertise in specific areas of care, and are easier to implement. The discussion of the manner in which long-term care services should be organized swings between centralization and decentralization. Individuals favoring centralization emphasize the greater accountability of service provision, the opportunity to enforce uniformity of standards, and increased efficiency of care. Those preferring decentralization describe the increased accessibility of services for clients, greater local autonomy, and closer links to informal helping networks. Coordination of services elicits similar difference of opinion. A formal, planned method is believed to strengthen the capacity of the participating agencies to deliver services, to promote specialization of services, and, if necessary, assure services to a nonfavored group. Conversely, autonomous services are thought to reflect the realities of the difficulty in achieving coordination among agencies which prefer to remain autonomous. Moreover, separate and independent organizational structures are easier to administer and control.

The relevant strategic issues are: Under what auspices should long-term care services be provided, how, and by whom? These are the most widely discussed of all questions in Indian communities and speak to the heart of the relationships among tribes and federal as well as state governments. There are those who contend that the tribes are better positioned than the Indian Health Service to plan services, since they have a sharper focus on the client and may be less likely to be displaced in their pursuit of the service goals. Their antagonists note that the Indian Health Service is more likely to plan equitably, since it is responsible for the well-being of all Indian people and controls the funds necessary for implementing service plans. Turning to the actual delivery of long-term care, arguments in favor of the IHS usually revolve around the greater accountability

of services, uniformity of standards, and greater experience with categorical human services. Proponents of tribal programs assert that the latter's services are more sensitive, more relevant, and more responsive to community needs.

The answers to these questions lie, as is so often the case, somewhere between the extremes, and inevitably involve the integration of possibilities. It is clear, however, that the tribes, the Indian Health Service, and the other agencies concerned with funding long-term care services must acknowledge these large-scale planning and service issues at a level of candor and explicitness not typical of their past working relationships. None of them possess, individually or perhaps even collectively, the resources to meet the geometric increase in service demands that will occur over the next 30 years as a consequence of the demographic and epidemiologic transitions underway in Indian communities.

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Discussion

Dr. Schulz: The topic of aging has been dear to my heart for many years now, and I was both impressed and delighted to see the chapter that Spero and Don have put together. It is a veritable tour-de-force of facts and figures about American Indian and Alaska Native aged individuals, and importantly placed in the context of a broader knowledge base on aging that has been collected for the most part from the majority culture.

Before I address specific issues raised here today, let me begin by giving a little broader context with respect to aging and what's happened in the United States. I'm sure that all of you are aware of the tremendous interest and growth in aging-related research programs and services that have taken place in the last 20 years. There is a general consensus that our interest in these areas has been driven by what has been referred to as a demographic imperative, as the population explosion of individuals who are 65 and older, somewhere around the year 2040, will peak into a population of about 55 million people.

With this interest and the increased study of aging has come some appreciation of several important facts. Among those is an appreciation for the diversity of older persons. For a long time I think we suffered from the myth that as one gets older, one becomes more homogeneous with respect to the population at large that one is a part of, and that in fact you get a condensation of differences. What we have found is that, if anything, on virtually any dimension, the variability among elderly individuals is greater than among younger individuals. We've also learned to appreciate the importance of culture in that context. There has been a great deal of effort in the last 10 to 15 years, looking particularly at Black aging and describing how that is very different from White aging.

Another important contribution that has come out of these efforts is a methodological appreciation and some distinctions that haven't been talked about a great deal, or at least haven't been made explicit. Those distinctions have to do with the difference between cohorts, aging phenomenon or ontologic change, and historical events. We have focused virtually all of our attention on the status of American Indian populations as they exist today to the best of our knowledge, and one of the things aging has taught us is that it is very important to appreciate that historical events, both past and present, affect very much what a given population is like.

The extensive research on aging has also taught us that it is important to appreciate the power of cohorts, that is, the kinds of life experiences an individual has had and how they shape their status at any given point in time, particularly when they are old. If you look at the majority of research done with respect to aging, I would conclude that the fundamental question people have been concerned with is what happens to people as they grow older. It's asked at an ontologic level, that is, at a basic biological level of what happens to

individuals as they grow old, so that when we examine differences between young and older populations, we can say something about the source or the cause of those differences.

One of the things that has struck me in listening to the many papers we have heard here in the last couple of days is that there is an underlying assumption that biological aging for American Indians may in fact be different than biological aging for Whites. Certainly there has been the underlying assumption that the life experiences that Indians have today are very different from the life experiences they had 10, 20, or 30 years ago. That leads me to ask the question, wouldn't it be interesting and isn't it important to get some sense of the normative life cycle of the populations we're talking about, and we certainly don't have that, given the information I have heard today. There may be a variety of good reasons for that, including the fact that the availability of data has been very limited historically.

Let me move to some of the specific issues brought up today. The age-base population comparisons are very important in assessing current and future problems. Examining the age pyramid, as we did a moment ago, can we conclude that we are in a good position to anticipate problems which may occur for American Indians that are being faced by other parts of our society currently; that is, can we learn from things we have done and mistakes we have made in the past?

I would throw in one cautionary note, and that is we have to remember that these cultures are imbedded within a larger context of which they are not ignorant. If we are looking at a particular population or a particular group of Indians who have an age structure which in fact is very different than the age structure for the U.S. as a whole, that doesn't necessarily mean that the kinds of expectations they bring to the situation are going to be very different than those that Americans as a whole brought to the issue of aging 20 years ago. You can't wipe out the knowledge that exists in regard to what's already in place in this country with respect to aging services. This has to influence, in some fundamental way, both the perceptions and the effects of any programs introduced for aging Indian populations.

What also struck me in looking at the demographic data was the similarity between the demographics for Indians and Alaska Natives, and Third World countries. That's an obvious parallel that has been made in several places. I was struck, however, that no one took the next step, which is to look at the modernization hypothesis and apply it to American Indians and Alaska Natives.

The modernization hypothesis has specifically to do with the status of the elderly in a given society as a function of the number of elderly people in that society, as well as the resources they control. As one goes through a demographic transition of the type described here today, one of the consequences

that has been found historically is a reduction in the age status of the elderly. For a variety of reasons, typically including reduced ability to control important resources, the status of older people declines drastically as a particular society moves through that transition.

Again, the cautionary note is that we're looking at groups of individuals imbedded in a culture which they must identify with to some extent. It's very different than a culture which may see itself as an independent, homogeneous entity that doesn't have any relative comparison group that would affect their expectations about what life should be like.

The issue of income and economic status is very nicely discussed in the paper, and I think it has important implications for health care. If you look at the delivery of health care for elderly individuals in the population as a whole, it has been estimated that approximately 80% of all the health care delivered for people 65 and older is delivered by family and friends. The existing professional system, in fact, accounts for only 20%. That's particularly important if we place that in the context of all the health care cost containment problems we have today; one can imagine what might happen if that 80% were drastically reduced and some formal system had to pick up the cost of some of that care. Either there would be a substantial deterioration in the care provided or there would be a tremendous increase in the costs expended for health care. And the aged in the United States, by any measure, account for more of the health care dollar than any other group, far in excess of their percentage of the population.

One of the things we have learned here is (a) the income and economic status of Indians generally is substantially lower than among Whites, and (b) the dependency ratio is worse for Indians than for Whites in the sense that it is close to 1:1 as opposed to 0.5:1 among the White population. This means that the availability of this informal care is likely to be much less than is currently available among the majority culture. At this point, we don't know what the consequences are going to be.

One of the things Spero and I have talked about is obtaining a much better sense of the family structures of Indian populations in order to get a handle on how much care-giving actually takes place within those populations, and the extent to which the appearance of a relatively disabled elderly individual, who begins to place heavy demands on the family system with respect to care, affects the whole family structure. One of the interesting and exciting areas of research in general right now has to do with the provision of care to disabled elderly individuals. These are individuals for the most part who are suffering from one chronic disease or another. Our interest has been in looking not only at the victim, but also the primary caregiver and the family, and how those two interactive systems change over time as a function of the care magnitude of the disability that has to be dealt with. One of our primary interests is in looking at

the psychological and physical health costs incurred by the individual who provides that care, and those costs are, in many cases, tremendous. There are many individuals who have become seriously physically and psychologically disabled because of this incredibly altruistic giving of themselves to another individual.

Turning to long-term care, the distinction between long-term care and acute care is becoming more fuzzy as time goes on. We have recently been involved in looking at several acute care community hospitals and collecting data on whom they take care of, what segment of the population is coming in, and what is done for them. It becomes clear very quickly that over 50% of all of the patient care days in a given community acute care hospital are accounted for by older people with chronic disabilities who are coming in and out of the health care system.

That raises some interesting questions about the acute care system's ability to take care of these individuals, and particularly the expertise they possess to accomplish that. I'd like to inject that idea into the questionnaire that Spero described regarding the definition and understanding of long-term care by the professionals he interviewed in Billings, Montana. Although those data are interesting, I think it's more important to find out the extent to which individuals who are involved in the care of the elderly have knowledge and appreciation of the elderly as a distinct care entity, as an individual who is very different in many ways, both at the biologic level and at the social level, with respect to how one delivers care.

It's important also to find out the extent to which the behavior of individuals toward the care recipient is affected by the age of the individual receiving the care. In our own work, we found that to the extent to which people interact with older persons, their attitude towards them as clients becomes more positive, yet, even under those circumstances, if you give doctors the option of specifying whether they would rather work with an older person or younger person, they still more often say they prefer working with or taking care of a younger person. Fortunately, I think economics is making them shift with respect to both attitudes and behaviors. The community care physicians are very sensitive to the potential of the elderly as a client and the importance of being good at what they do with respect to serving those clients.

Spero raised a series of questions at the end of the paper. Let me speak briefly about a couple.

The first concerns whether the elderly should be served separately from younger clients. I don't think that's a good idea. What is more important is to get people to appreciate or become sensitive to the fact that elderly people are a unique treatment entity, and not necessarily that they have to be treated separately, in contexts that are exclusively devoted to their care.

Issues having to do with the provision of in-house versus congregate care are mixed at the moment. One of the great hopes within the majority population was, and perhaps still is, that in-house care will not only save a lot of money, but will provide better care. Interestingly, and somewhat disappointingly, we have discovered that in-house care is actually more expensive than providing care in an institutional setting.

I'll close with a comment on provision of comprehensive or limited services. It's important particularly in this context, because the health problems of Indians are uniquely different from the health problems observable among institutionalized White populations in general. Because of the very different prior history that has led them to a long-term care institution or to seek care in general at an elderly age, one might prefer in that case more limited or focused kinds of care provision, because we don't get the variability and the general kind of disability observed in other populations.

Let me stop there for general discussion.

Dr. May: I think that your point about learning from other populations is extremely important at this time and age, because of the demographic information you presented. As part of that, we might consider models not just from the United States, but European and particularly British and some other systems, as novel tiered aging care programs.

The question I have is that of the 10 Indian programs that you presented, is there any one or two in particular you could highlight for us that have real efficiency and/or real promise for other tribes?

Dr. Manson: I have not visited with the Rainbow Corporation. However, what I have read and heard about the things going on there are intriguing to me, not the least of which is that they seem to be moving most rapidly to a broader spectrum of services in that facility. Not only are they skilled in intermediate and boarding care, they're also now looking at respite care, as well as child day care within the context of the facility itself. Larry Curley, of course, is the executive director of that program. Formerly with the National Indian Council on Aging, he has a very keen interest in conducting sound evaluation research on these kinds of issues.

The other example was the Morning Star Manor in Northern Cheyenne, a $1.3 million, 50-bed facility, recently completed. Unfortunately, the planning of the physical facility was paramount and outstripped any planning of types of services to be incorporated. In fact, they simply don't know. They're wrestling now with their population projection of older adults suffering from the kinds of problems that they had imagined managing with a skilled or intermediate care facility. There are not going to be sufficient patients to make that a profit-making venture. They have another interesting issue in that the Shoshone and the Arapahoe are the two tribes that populate that particular reservation. As

you know, there are intertribal differences and they will have to look minimally to both tribes to begin to fill those beds to make it a profit-making venture. Moreover, it's really very clear they're going to have to go off-reservation and attract, as several others have, non-Indian residents into that facility in order to make it break even. In fact, what you see in the three Indian nursing homes that have begun to admit non-Indian patients is that they couldn't make it with an all-Indian patient admission criteria.

Dr. Kunitz: Why is that? If the problems of the elderly are looming so large, and the number of nursing homes or extended-care facilities are so small, why are they having to go outside? And are they culturally sensitive to the needs of the Anglos?

Dr. Manson: I'm not sure they're culturally sensitive to the needs of the Indian residents, much less the Anglo residents. I have been impressed—and this is totally anecdotal—by the attempts, for example, to include a natural fieldstone altar for burning of cedar bark and related rituals in the context of the Morning Star Manor on Wind River. I know of other examples in which there have been attempts to include these kinds of culturally relevant activities. However, it strikes me that we have a different set of issues raised with respect to these nursing homes. Many problems face the administrators in these facilities, not the least of which is a high prevalence of alcoholism and absenteeism among the Indian staff, which present a different set of problems to quality of care.

There are some intriguing issues with respect to caregiver burden. We need to look at the decision-making process that goes on with respect to placement of family members in these facilities. I tried to relate a few anecdotes about the serial placement that occurs with older adults among different children's homes in an attempt to keep the older adult out of the long-term care setting.

Just as in the general population, the first 2 weeks of placement in these facilities looks to be fairly critical in terms of whether or not the individual is going to remain there for a long period of time. What you're frequently getting is family members coming in who have not been involved in the primary caregiving process and saying, "You don't belong in here, let me take you." Then after a few months, the burden of that responsibility becomes so great they go back into the facility, and cycle like this a fair amount. I think it's worth looking at that process to see how physicians and other providers can begin to educate them with respect to what to expect, both in terms of the health status of their family members, the implications of increasing functional dependency, and subsequent placement in the nursing home.

Dr. Bloom: Are they attracting chronically mentally ill?

Dr. Manson: No. In fact, the rough data suggested the degree of mental impairment among these residents was remarkably less.

Dr. Callaway: I'd like to make two additional points not mentioned in the paper. I think some investigation about elderly American Indians' attitudes towards nursing homes is critical. My research on Jerry and Steve's project seems to indicate to me—and this is anecdotal—that there are some things worse than death, and a nursing home is one of them.

Secondly, it may be that the cohort now in nursing homes among American Indian populations will be dramatically different in any number of ways than the cohort that will enter in the next 20 years.

Dr. Dinges: I'd like to ask another question about some of your tables. If I understand the way they are constructed, you're showing a decrease, for example, on Table 13 between the 1973/75 time frame and 1982/83 time frame. I always thought diseases of the heart and cerebral vascular disease were age correlated, and with progressive age, the incidence went up.

Dr. Callaway: The 1973 to 1975 rates are crazy, and they are based upon completely inaccurate census information. The denominators are much too low. The rates for that period once they are smoothed, will go down considerably. But what I can't explain is, if they are going to be smoothed for diseases of the heart and cerebral vascular system and so forth, how come the rates in some other categories are fairly comparable in that 10-year interval? My resounding conclusion is that I'm extremely skeptical of rates of mortality. We haven't talked morbidity here, but that's even worse. And so I'm really skeptical, and I'm curious to see what 1990 brings in terms of the next census.

Dr. Kunitz: You have only mentioned your skepticism in terms of the denominator.

Dr. Callaway: Well, my skepticism of the numerator in terms of morbidity is as wide as all outdoors, and for mortality, slightly less, but it's dramatic.

Dr. Kunitz: The fact of death is probably fairly accurately recorded for American Indians. I don't know about Alaska Natives, but the cause of death is accurately recorded at some levels and not at others. We are doing a study of elderly people on the Navajo reservation and following mortality experience. One of the people working with us reviewed death certificates of people we knew had died and, in fact, the death certificate was signed accurately with regard to race. The people who died were written on the death certificate as Navajo, but when that was punched onto the tape that goes to the National Center for Health Statistics and then gets sent to IHS, one of the people, a Navajo interpreter who had worked with us until shortly before his death, was listed as an Anglo. And another person—

Dr. Callaway: He was listed Black.

Dr. Kunitz: Right, he was listed as Black. Another person was listed as Anglo—a lady who died at a nursing home. So the IHS in Washington that is producing a lot of mortality statistics is probably getting some very funny data.

Similarly with fertility data. If you look at the number of births to Navajo women in Navajo area hospitals as reported from the hospital reporting system, it is significantly higher than the number of births as reported by vital statistics through the Washington office based upon birth certificates. So, depending on your source of data, you may be having all kinds of problems with the numerator, as well as with the denominator.

Dr. Trimble: You can have problems with the base, too. You're going on the basis of the Bureau of Census definition of what is American Indian, which means self-declaration. There are two other criteria defining who is an American Indian and these are used to collect census-related data.

The United States Department of Education and the Office of Indian Education use a much more liberalized definition than the Bureau of Indian Affairs. In 1983, the Department of Education conducted an Indian definition study because they found huge population distributions from age 6 to 18 among "Indian youth." If we were to project that data base into the future, we're going to have a much more sizable and substantive elderly population 40 to 50 years from now, following the DOE definition. Congress is placing pressure on the three relevant entities to decide on one definition.

Dr. Neligh: It will be the most restrictive.

Dr. Trimble: No, it will be the most liberal.

Dr. Levy: I doubt it.

Dr. Callaway: Let me make two points. Most of the data in those tables vary between the U.S. Census, which enumerates everyone in the U.S., and IHS, which enumerates everyone in reservation states. That's real tough to control for, because there's about a 15% or more difference, and that is very skewed. If you start going down to the tribal level, you get into the kind of arguments that go on between tribal councils and the BIA and the tribal membership as to what constitutes an enrolled tribal member.

It's even worse than that in terms of mortality. One of the things I'm interested in is that there are very few autopsies done. American Indians do not die in the presence of a physician. If organic brain syndrome is not mentioned as a morbidity because we don't see it, it sure isn't mentioned as a mortality statistic because there is no autopsy done.

With a small amount of additional resources by IHS, we could refine our margin of error and decrease our confidence interval with mortality/morbidity statistics and population projections, which would be critical in planning, but that doesn't seem to be the case.

Dr. Kunitz: In the study that we are doing, which is a random sample of one area, the western end of the Navajo reservation, I tried to figure out from the census what the population was of the elderly: 65 and above. Then Don and

another person actually constructed our sample based upon a number of other data sources, and it appears that the census underenumerated the population there by over 40%.

Dr. Manson: Before we get drowned in pessimism about the population data, there are some bright notes we didn't get to bring up. We tried to highlight the community-oriented services to some extent. This is a really bright spot. The interest in specialization among CHRs, though motivated for political and fiscal reasons, is an interesting tack. I was particularly pleased to see that one of the six areas of specialization included gerontology.

Moreover, I think there are some really lovely examples of comprehensive programs, at least in terms of community-based as well as in-home services, being done around the country. One of the best examples of case management that I have come across is being done in the Northern Cheyenne reservation by an individual who is currently performing all of the basic case management functions you would think of in the ideal sense with respect to older tribal members. Now, admittedly, that's a smaller reservation, but he's coordinating the provision of care and the relationship of older adults placed in nursing homes as far away as 60 to 70 miles from the various services, both medical and social, on this particular reservation.

We face the continuity of care issue, and I think there are some debates about whether or not we ought to have service-specific entities or whether we ought to have case management functions across varying forms of care. I think these are very serious issues beginning to surface independently across different service areas.

Dr. Walker: One of the things that I enjoy about this is the optimism in working with the elderly. I met with the elders' group at Colville, and the thing that impresses me as a clinician is the cognitive function among elderly Indian people. It's an area that has not been examined, but I was surprised to see the clear-thinking, problem-solving abilities of lots and lots of elderly people in the homes. Bob Kraus feels that the same experience is true for him up in Alaska, and I think that it would be an interesting area to look at in the aging process. It might be an interesting thing we can learn something about, and especially in relationship to chronic illnesses as the elderly move into the larger homes.

Dr. Callaway: It was my impression, also, in the couple of hundred Navajo elderly I talked to, that there was almost a complete absence of a cognitive deficit. If this is true, then if you want to tie into national interests about a genetic component to dementia, American Indian populations ought to be high on the agenda for research.

Dr. Levy: Senile dementia was not underrepresented in our sample. It's not a very high prevalence phenomenon, but we have cases that fit in with other studies in the general population.