Discussion Paper #3

LONG TERM CARE IN INDIAN COUNTRY: IMPORTANT CONSIDERATIONS IN DEVELOPING LONG TERM CARE SERVICES

Summary of Issues

- Between 1990 and 2000, Census estimates of the population of American Indians and Alaska Natives (AI/AN) more than doubled when those who identified themselves in more than one ethnic/racial category were tallied. Such an increase indicates the growing need for long term care services as the AI/AN population ages.

- Service need has been estimated using a number of approaches: census data extrapolation, interviews, focus groups, surveys, and community assessments.

- Collecting quality data is necessary for establishing a baseline level of need within localized communities in order to qualify for program funding and demonstrate appropriateness of the long term care response.

- Cultural and community values and changing family relationships must be integrated into long term care responses in the AI/AN community. Options and choices for long term care should not be limited to nursing home care. Assisted Living as well as home and community-based services need to be explored from a financial and quality perspective.

- The rural character of many tribal groups tends to magnify long term care service challenges, causing the long term care needs of the AI/AN population to remain largely unmet.

- While funding opportunities exist, current care is typically uncoordinated among the funding agencies.

- Barriers to service are complex, including: transportation, housing and amenities, recruitment and training of caregivers, and retention of skilled caregivers.

LONG TERM CARE IN INDIAN COUNTRY: IMPORTANT CONSIDERATIONS IN DEVELOPING LONG TERM CARE SERVICES

Linda J. Redford, R.N., Ph.D.

The need for long term care services in American Indian/Alaska Native communities has been recognized by the federal government and tribal communities for over a decade. In 1990, the Indian Health Service (IHS) convened a roundtable of experts on long term care. This group reported that there existed a lack of focus on geriatric health care in the IHS and concluded there was a need to develop a continuum of care, i.e., a complete range of home, community-based and institutional services, to meet the needs of Indian elders (Indian Health Service, 1993). The consensus statement from the roundtable also emphasized the need for systematic data on American Indian elders' long term care status before the development of services could proceed:

> Long term care in reservation settings…has yet to be defined or quantified, and requires more analysis than has been done so far. Required data is either outdated or nonexistent. Needs assessments, particularly functional assessments, have not been extensively done on a community level. The data from these assessments must form the basis for measurements of demand as well as the planning and design of services (Indian Health Services, 1993, pg.5).

Tribal organizations have reiterated the importance of long term care. At the 1992 National Indian Conference on Aging, 1,400 American Indian elders and service providers ranked the need for long term care as first among health concerns for elders nationwide (National Indian Council on Aging, 1993).

Today, a decade later, there has been little movement by IHS to assume a major role in long term care. Tribes are increasingly recognizing the need to seek other public and private resources and/or develop the resources internally to provide long term care for their elders. This paper highlights factors important for tribes to consider in the planning and development of long term care services.

Assessing Long Term Care Needs

The need for long term care in Indian Country is immediate and growing. According to the 2000 Census, there are approximately 2.5 million people who identify themselves solely as American Indian or Alaska Native. If individuals reporting more than one racial/ethnic category are included, there are 4.1 million American Indians in the United States today.

The numbers of American Indian/Alaska Native elders vary considerably, depending on the source and the definition of elder. Using the definition of elder as persons 55 years of age and older, there are approximately 296,000 American Indian/Alaska Native elders according

to the 2000 Census. If the age 60 years is used, there are over 205,600 elders. All of these numbers represent a significant increase over the numbers reported in the 1990 Census. Part of the increase is the result of an acknowledged undercount of American Indians in the 1990 Census, but rapid growth in the elder segment of the American Indian population accounts for a considerable portion of this change. It is estimated that the American Indian elder population will grow just over 14 percent between 1995 and 2030, more than doubling the number of persons likely to need long term care.

Collecting and Using Data

"We already know the problems. We don't need more data, we need solutions." These are common responses when the need for data on long term care is suggested. They are also understandable given that past efforts at data collection have not always resulted in fast responses. Data have, however, substantiated the need for long term care and are a key element in planning and developing services at the local level.

There are many sources of data and the source may dictate its use. Data on population characteristics, such as U.S. Census data or data from national surveys, help in estimating current and future needs in a large population group. Local surveys will tell the story of current needs in a tribe. The following sections focus on different sources of data, with examples of what has been learned from the different sources about long term care need in Indian Country.

Using Existing Data Sources

Secondary data sources, such as the U.S. Census Data are commonly used to estimate the need for long term care in a population. In the U.S., risk of disability and need for long term care has been shown to increase with age among most ethnic groups. The Census provides information on numbers and percentages of elders, allowing estimates of long term care need.

In addition to advanced age, poverty and low educational levels have been shown to have a strong association with poor health and a greater likelihood of disabling conditions. Rather than directly influencing health, poverty and low educational levels are often a proxy for poorer access to healthcare, less information to inform positive health behaviors, and fewer incentives to promote and protect one's health. The 1990 Census indicated that 36 percent of Indian elders age 65 and older had incomes below the poverty level. Over 60 percent of American Indian elders age 60 and over had not completed high school. This suggests that the need for long term care among Indian elders is likely to be greater than in the general population of the U.S.

The likelihood of disability is generally extrapolated from age and socioeconomic data when using the Census. There is minimal information in the Census pertaining directly to disability, although both the 1990 and 2000 Census do include a few questions about individual health and physical function. In the 1990 Census, 25 percent of American Indian elders age 60 and older reported a mobility limitation, 5 percent a self-care limitation, and 10 percent reported both (Bureau of the Census, 1990). Data on disability from the 2000 Census are not available at this time.

Secondary data, particularly that based on national survey data and Census reports, may not be particularly helpful to individual tribes in planning long term care services. The diversity within the American Indian/Alaska Native population is not adequately captured in national data.

Indian Health Service data provide some insights into long term care needs, although the data focus primarily on medical care issues. Mansion (1989) studied IHS statistics on hospital admission, stay, discharge, and readmittance by disease and age. He found repeated hospitalizations, both for exacerbations of chronic conditions and also for the apparent purpose of providing respite for overburdened families. He interpreted these findings to indicate a lack of adequate long term care resources in tribal communities. Manson also asserted that Indian Health Services, despite their resistance to commit to long term care services, was already deeply involved in long term care by the late 1980's. It might be argued that, rather than truly providing long term care, IHS has become the Band-Aid to cover inadequate long term care.

Surveys of Long Term Care Need

Community surveys are frequently used to identify and quantify long term care needs. The 1991, the National Resource Center on Native American Aging (NRCNAA) at the University of North Dakota, with money provided through a cooperative agreement with the Administration on Aging, began a project to promote needs assessments of tribal elders. Tribes are invited to use a standardized survey instrument (*Identifying Our Needs: A Survey of Elders*) and standard data collection procedures to conduct local needs assessments. The data are analyzed by the University of North Dakota and tribes are provided statistical data for their local areas. The data are then added to the "aggregate" file that represents an overview of Indian elders. Currently there are data from 83 tribal needs assessments, with a total of 8,560 respondents (Ludtke and McDonald, 2002).

Data from these surveys provide useful information to guide tribes in planning long term care and monitoring the impact of that care. Information is provided on specific disease conditions, as well as the limitations resulting from those conditions.
Activities of daily living (ADLs) are a particularly salient indicator of long term care need. For example, the Tribal Elders Survey has shown that 18.5 percent of Indian elders need assistance with bathing as compared with 12 percent of the general population. American Indians displayed a higher prevalence of disability across all ADLs (NRCNAA, 2001).

In 1994, the Elderly Nutrition Program Evaluation (ENPE) assessed the OAA Title VI nutrition program's effectiveness in serving American Indian/Alaska Native elders. Over half of the meal program recipients were overweight, placing them at high risk for heart disease, diabetes and other chronic conditions. American Indians participating in the study reported an average of three diagnosed chronic health conditions. Chronic conditions are likely to affect function in older persons. Among the ENPE participants, 33 percent had difficulty or were unable to shop for food, 26 percent had difficulty or were unable to prepare meals, 24 percent had difficulty with bathing, and 12 percent had difficulty taking medication (Ponza et.al., 1996).

Focus Groups and Talking Circles

Focus groups or talking circles with tribal members and service providers is another approach to developing a general picture of disability and LTC need. While these are not particularly effective approaches to attaining actual measures of need, they are very useful in identifying the overall scope of needs, prioritizing needs and determining community preferences regarding how needs should be addressed.

Hennessy, John and Roy (1998) used a combination of structured survey interviews and focus groups to study long term care needs in the Santa Fe Service Unit. Using surveys, they identified the numbers and percentages of persons suffering from various health conditions and the types of impairments and the levels of impairment among various age groups in the population. Utilizing focus groups, they were able to determine the physical and emotional impact of disabling conditions on those providing care, primarily family members. They found many families were overburdened with care responsibilities for disabled family members and were not prepared to deliver the needed care. They concluded that there is a need for comprehensive geriatric assessment, support services, and caregiver training in American Indian communities

Focus groups and survey interviews are feasible on reservations and in densely populated American Indian communities, but may have limited value in urban and non-reservation rural communities where the target population is more dispersed and cannot be easily identified. Only half of American Indian elders live on reservations, with the remainder spread across urban and rural areas of the U.S. Identifying the needs of Indian elders residing off reservations poses a very different set of challenges and requires different approaches. While this issue is beyond the scope of this paper, it is an area that deserves concerted attention.

Comprehensive Assessment of the Elderly

Assessing the need for long term care services in a community is far more complex than often realized. Surveys rarely provide all the information necessary to fully identify and quantify long term care need in a population.

Long term care needs are sometimes hidden or go unrecognized. Spouses or other family members may gradually take over the roles of a loved one without consciously recognizing the increasing levels of impairment. Other times family members attempt to hide or deny the failing abilities of a spouse or parent. Among American Indians, the cultural norms and expectations around elder care may also influence the dialogue around care-giving making it more difficult to identify unmet needs.

A serious issue, both for tribal communities and communities in general, are the elders in poor health and with deteriorating physical and/or mental abilities who live alone. Among this group, the more subtle indicators of need for services often go undetected until there are major health consequences. The elderly person who no longer remembers to take medications properly or is too depressed to eat properly may not be apparent to the casual observer or to the trained clinician who is too busy to observe changes or does not understand cultural manifestations of certain conditions.

The failure to recognize long term care needs is less likely in the close-knit context of the reservation community, but only half of Indian elders live on reservations. There is very little information on urban Indian elders.

Comprehensive geriatric assessment programs have been proposed as a strategy for identifying long term care needs in the elder population. A major issue with geriatric assessment in the American Indian population is the dearth of culturally appropriate tools for measuring physical, functional and mental/behavioral impairment in the Indian population. Daily activities necessary to live on many of the reservations in this country are quite different than those of most other populations in the U.S. Activities like chopping wood and hauling water are not asked on the functional assessment tools used most frequently.

Accurate assessment of mental and emotional well-being is also problematic given the vast differences in cultural beliefs about mental illness, the labeling of emotions and their perceived causes, and the variability in manifestations of mental and emotional problems. For example, little is known about Alzheimer's disease in the Indian population because of differences in acceptance, interpretation and tolerance for the symptoms and behaviors. Likewise, the validity of standard depression measures in the American Indian population is questionable. Manson and colleagues (1990) developed the Indian Depression Schedule (IDS) that includes consideration of local customs. The Center for Epidemiological Studies Depression Scale has also been shown to have good internal consistency in Indian populations (Curyto et. al., 1997).

With culturally appropriate tools and well-trained assessors, the individualized approach to geriatric assessment is desirable for obtaining the most objective assessment of long term care needs. Initial geriatric assessments are best conducted in the elder's usual living environment, but this can be cost-prohibitive in rural areas where distances between elders can be enormous.

Medical models of geriatric assessment are particularly time consuming and costly. Generally, the medical geriatric assessment is not required unless the elder has unstable or poorly managed chronic conditions or a diagnostic evaluation is needed.

Informal Caregiving

The development of effective and efficient formal service system hinges on understanding the role of the family and community in long term care. The goal should be to complement and support existing patterns of care, not to supplant them. Once the prevalence of long term care need is established, the issue becomes how needs are currently being met, who is providing the care, what assistance do the current caregivers need, and what needs are not being met.

The bulk of long term care services in this country are provided within the family. It is estimated that 90 percent of long term care for American Indians/Alaska Natives is provided within the family and is unpaid (Baldridge, Pecos, & Dosedo, 2000). National data indicate that 36 percent of long term care service expenditures are out-of-pocket. There are no data on out-of-pocket expenditures for long term care among Indian populations, but such estimates may be of little value. They reflect only the monies spent on formal services

and do not account for caregiver time, the amount of lost wages, nor expenditures on necessary supplies, medications, and private assistance with care.

Family care for elders is consistent with the values and stated preferences of American Indians. Elders are held in high esteem and most families want to care for their elders in ways that preserve and promote their dignity and honor cultural traditions, but the gap between values and the realities of caregiving can be immense.

Lifestyles among American Indians are changing, whether they live on the reservation or in the city. Women, who are the primary caregivers, are increasingly entering the workforce and are not available to provide care. Young often leave the reservation, leaving the old to care for the old. The demands for care have also increased dramatically in the last few decades. Prior to the 1970s, few American Indians lived to advanced ages. Today, life expectancy among American Indians is nearing that of the general U.S. population. With increasing age comes an increasing likelihood of needing long term care. Values around elder care are only now being put to a stringent test in the American Indian population. The growing concerns about elder abuse and neglect in this population may reflect the stresses wrought when values and expectations collide with reality.

In a study of caregivers residing in the IHS Santa Fe Service Unit, New Mexico, Hennessy et.al. (1998) found that 60 percent of caregivers considered their elder care responsibilities to involve substantial physical and emotional demands. The problems experienced by the caregivers included sleep deprivation, concerns about not doing a better job of caregiving, not enough time for themselves, a loss of control of their lives, and feeling angry toward the care recipient. Among those studied, the care recipients were quite impaired with 92 percent exhibiting one or more problem behaviors such as wandering or agitation and close to half were incontinent (John et.al., 2001).

Despite these feelings caregivers expressed about their care responsibilities, less than 10 percent of caregivers indicated they frequently wished they could relinquish caregiving responsibilities. This illustrates the pervasive sense of cultural obligation regarding elder caregiving in the American Indian community. Still, caregivers did actively seek assistance from others and admitted some degree of resentment when help was not forthcoming. This indicates that caregiving is tolerated, but not passively accepted.

A better understanding of the personal and contextual factors influencing perceptions of burden among Indian caregivers will help service providers to better tailor and target services. Not only is this likely to reduce costs by eliminating the provision of unnecessary and unwanted services, but will also bolster and support the family role in caregiving.

Funding Long Term Care

Long term funding care in Indian Country reflects the fragmentation, lack of coordination and gaps found in long term care generally in this country. The problems are magnified, however, by the rural location of many tribal groups and their lack of access to major sources of home and community-based services funding.

In 1995-1996, the Administration on Aging, the Native Elder Health Care Resource Center at the University of Colorado and the National Resource Center on Native American Aging at the University of North Dakota surveyed key tribal program administrators of 108 tribes concerning funding and availability of home and community-based services in Indian country and the barriers encountered in establishing such services. Families were found to be the primary providers of home and community-based long term care services. There remained, however, an extensive need for services that was largely unmet. Although an array of funding sources existed for home and community-based services, the sources were fragmented and insufficient to meet the need (AoA, 2000).

In 2001, the National Indian Council on Aging (NICOA), through a grant from the Retirement Research Foundation, conducted a similar survey of the tribes with Title VI Programs. Of the 109 tribes responding, the results were essentially the same as found in the earlier survey. Even among those tribes who were tapping a number of funding sources for health and long term care services, needs were not being met and fragmentation remained.

It is beyond the scope of this paper to provide detail about all the funding sources available for long term care, but tribes need to understand the role of Medicaid, Medicare, Indian Health Service, Veterans Administration, the Older Americans Act programs, and private insurers in long term care. Other less recognized contributors to long term care include the Department of Housing and Urban Development (HUD) and the U.S. Department of Agriculture. Although these agencies do not directly fund long term care services, they often provide resources to develop and maintain the infrastructure necessary to support long term care.

Community Capacity and Service Infrastructure

Effective and successful long term care services systems are exceedingly difficult to build and maintain. Funding alone does not guarantee success and a wide range of factors must be considered in the development of service systems

Considering Options for Care
It is vital that tribes have a thorough knowledge and understanding of the long term care options available within their own communities, surrounding communities and the state. It is also important for tribal leaders to understand the unique needs and preferences of their people and think creatively about how those needs may best be addressed. It is easy to assume that the most common models or the new "model of the week" is what is needed. For example, in a recent survey conducted by NICOA, a very high percent of tribes indicated their greatest long term care need was nursing home care or assisted living. While this may be an important option for care that is lacking on reservations, it is also the option that appears to be the least acceptable to elders and their families. Studies of American Indian elders and their family caregivers have consistently shown that elders do not want to be cared for in nursing homes and families use nursing homes only as a last resort. Low occupancy rates in some reservation-based nursing facilities support the contention that this is not a particularly acceptable solution, even when available on the reservation.

Assisted living may be a more acceptable option, providing the elder a more home-like environment while providing the needed services to relieve family caregivers. Still, the upfront development costs and maintenance costs of nursing facilities and assisted living are high and the feasibility and acceptability of these options need to be carefully studied before tribes should invest resources in these directions.

The tendency to focus on residential and institutional care options is not surprising, since these options consume a significant amount of long term care dollars and attention in this country. Over the last decade, however, there has been an attempt nationally to move away from the intense focus on institutional care to improvements in home and community-based care that may allow more frail elders to live at home. Reservation communities, with the exception of some of the very large reservations, provide the well-defined and circumscribed type of community where home and community-based services can be provided efficiently and economically. Still, a relatively small amount of available dollars for community-based care goes to reservations and when services are available, there are frequently lengthy waiting lists.

The funding for home and community-based services is generally tied to funding streams controlled at the federal and/or state level. The needs of tribal communities are rarely considered in the allocation of these resources and tribes may have little or no say in the services available to their people. This may be due to a lack of awareness in tribal communities of the options available to support long term care, indifference on the part of some funding agencies toward supporting services on reservations, ignorance within agencies regarding tribal needs and rights to certain funding streams, or some combination of these factors.

Infrastructure Assessment

A complete inventory of the funding streams for home and community-based care in the community and state is an important prerequisite to planning at the tribal level. Tribal leaders must have a thorough knowledge of eligibility criteria for services through specific programs and the particular policies or practices that may affect access of American Indians to the services. In some cases, it may be possible for tribes to negotiate with federal government or states for a portion of monies that can be tribally controlled. In other instances, tribes may at least be given a voice in the design and allocation of services

Before embarking on the development of tribal-based services, tribes must determine their capacity and limitations in providing various forms of care. Capacity includes such factors as financial feasibility, workforce availability and the commitment of tribal leadership. These are all critical to the development and sustainability of services.

The planning process used by the American Indian Disabilities Technical Advisory Council (AIDTAC) at the Research and Training Center on Rural Rehabilitation Services, University of Montana, is one model to assist tribes to clarify their needs and capacities to provide long term care. AIDTAC works with those tribes that have demonstrated a commitment to change and development. They have designed a two-day planning process with tribes that entails a train-the-trainer format.

The National Indian Council on Aging (NICOA) is completing a study of long term care on reservations. The next step in this program is the development of informational materials to assist tribes in understanding the myriad of funding opportunities that can facilitate long term care development on reservations. NICOA is also developing a self-assessment tool for use by tribes in assessing their resources and capacity for developing and delivering long term care services.

There is a significant need for information about the processes for developing and managing long term care models that work well in Indian Country. Even basic information necessary to plan services is often not available to tribes. For example, information about the real costs of providing the services is key to decisions regarding the financial feasibility of a particular service. This information is usually not readily shared by outside community providers. Models from Indian Country may provide the structural, process and fiscal information necessary to bolster the planning process for tribes.

While it is helpful to know about the models that are working well, it is also instructive to know about programs that have not worked and why they failed. Information regarding failures in initiating and sustaining services may help other tribes avert similar fates in their service programs.

Transportation

The direct provision of long term care must be considered within the broader context of the community and the services necessary to support long term care. Transportation is a vital component to ensure availability of long term care services. Availability means that people can get to the service or the service can be brought to them. In rural areas, the necessity of traveling long distances to receive or deliver services makes service delivery expensive and often impractical. Over 60 percent of the American Indian/Alaska Native population lives in tribal areas that are over 50 miles from a city of 50,000 or more population (Kingsley et.al., 1995). Major providers of care tend to be aggregated in the larger and more densely populated urban communities and are often unwilling or unable to bear the cost of delivering services to rural areas.

The likelihood of rural Indian elders getting into the urban area for services is even more remote than the delivery of services to them. Transportation is generally inadequate in tribal communities. In a 1995 Indian Tribal Transit Study, only 13 percent of respondents indicated that their current transit systems met the needs of their respective communities (National Congress of American Indians, 1996).

Availability of vehicles and distance are not the only issues impacting service delivery in rural areas. Inclement weather, unpaved roads and rugged terrain can also pose major barriers to the delivery of services. On many reservations, these factors combine with geographic distance to increase windshield time for providers and escalate the cost of service delivery.

Housing and Amenities

Long term care is generally provided in the home or in a housing facility designated for persons needing long term care. On reservations where care in the home is preferred, it is important that housing be accessible, safe and provide an environment that facilitates caregiving. Regrettably, housing conditions on many reservations are inadequate and

crowded. It is estimated that a fifth (20%) of American Indian/Alaska Native homes do not have safe drinking water or indoor toilets (AOA, 1996). The lack of such basic amenities can pose considerable hardships on elders and their caregivers.

Supportive housing options for persons needing long term care are rare on reservations. Although such options are likely to be found in the outside community, they rarely provide care that is sensitive to the cultural preferences and values of Indian elders. As noted previously, interest in the development of supportive housing on reservations is often directed toward the nursing home model. This is the most restrictive institutional form of long term care and the most difficult to sustain. Before embarking on the development of a nursing home, tribes need to carefully assess the need on the reservation for this level of care and the capacity of the tribe to support such a model financially and with an adequate and appropriate workforce.

Workforce Issues

The recruitment and retention of professional and ancillary workers in long term care is a growing problem nationwide and particularly critical in rural areas. On reservations, workforce issues are compounded by the loss of young to urban areas, low educational levels, and a host of social and behavioral health issues that plague many of the young remaining on the reservations.

The availability of a trained, competent, and committed workforce is vital to the development and survival of long term care services in Indian Country. The development of a workforce to sustain a full spectrum of services may take months or years. It entails the recruitment, training, and retention of a workforce comprised of ancillary and professional providers.

Recruitment and Training

A number of programs have been implemented with the intent of increasing the recruitment of personnel in the health and long term care fields. It has been shown that early introduction to health career options is important to future recruitment efforts. Programs such as "Kids into Health Careers" are aimed at introducing youth to careers in the health and long term care fields. Programs are also available to tutor ethnic minority and disadvantaged youth in math and sciences to better prepare them to enter health professional programs.

Tribes have the authority to structure and administer their own cash assistance and employment and training programs under the Personal Responsibility and Work Opportunity Reconciliation Act of 1996. Known as the Tribal Assistance to Needy Families (TANF) program, this program has been used by tribes for education and job training. To date, most of the monies have gone to support basic education, GED preparation, two and four-year postsecondary degree programs and certificate programs for people who are unable to secure unsubsidized jobs (Brown, 2001). This program offers tribes the ability to provide or pay for training to build a health and long term care workforce.

Other avenues for recruitment were suggested by attendees at the Roundtable on Long term Care held in Albuquerque in April, 2002. One approach is the recruitment of individuals who have been family caregivers and who have the experience, a realistic perspective of the

demands of long term care, and the commitment to providing quality care. Suggestions also included educational talent searches within tribal colleges. It was acknowledged that early identification and mentoring of American Indian students for the health professions is a needed avenue to growing a professional workforce necessary to provide care on reservations and in urban Indian centers.

An expanding number of educational programs provided via the Internet offer new and more accessible opportunities for training without leaving the reservation. This can save tribes considerable money for transportation and lodging of individuals while they are in training and increase the likelihood they will remain on the reservation to work. While the telecommunications infrastructure is still not in place for all tribes to utilize this resource, it is an option for some.

Casinos have proven an economic resource on many reservations and can fuel many educational and service programs. They are, however, a double-edged sword for the long term care industry. Casinos generally offer better pay and better working conditions than available in the health and long term care fields, thereby drawing off potential workers.

Issues in Retention

The field of long term care poses few attractions for workers, even those already in the health and supportive services workforce. The pay is low, benefits are inadequate or nonexistent, working conditions are often difficult, and the work is physically and emotionally exhausting.

In a qualitative study of personal care attendants in Alaska, Johnson and Branch (2001) found a number of factors influenced their attitudes about their jobs and their likelihood of remaining in the job. The major problems personal care attendants faced included low pay, lack of benefits in some agencies, large amounts of paperwork, onerous tasks, unstable work schedules, and lack of respect from health professionals. Those who succeeded and enjoyed their jobs found pleasure and gratification in helping others. As one PCA stated, "PCAs must be 'people-people' (Johnson and Branch, 2001, pg 8)." These are attributes that are difficult to teach, but critical in most helping professions.

This study also provides some very interesting insights into the job-associated factors important to PCAs. Training was viewed as important in making their work easier and helping them to deal with difficult situations. All of them felt that developing training programs that created "career ladders," allowing workers to advance to positions of increasing responsibility and pay in the healthcare field were important in recruitment. There were varying opinions on recruitment bonuses, annual bonuses, and incentive pay for timely paperwork, but in general these were thought to be positive incentives for workers.

Both recruitment and retention of workers needs a multifaceted approach. Wages and benefits for paraprofessional and professional worker are currently inadequate to entice or maintain the best workforce. Tribes need to forge alliances with organizations representing long term care providers and elder advocacy groups to encourage states to consider "wage pass-throughs" in which states designate some portion of a public program long term care reimbursement to increase wages and benefits. Use of tribal resources to bolster wages and benefits should also be considered.

Summary

The development of appropriate, effective and sustainable models of long term care is difficult in any community. Knowledge and thoughtful planning are key elements to success, but are easily overlooked or short-circuited in the rush to implement services. This paper highlights key elements in long term care planning and implementation drawn from the literature, research and information provided by participants in the IHS Roundtable on Long term Care in Albuquerque in April, 2002.

Timely and quantifiable information is an important component in the design, development, implementation, and evaluation of long term care services. Data regarding the needs and preferences of the tribal population serves as a foundation for the development of effective and acceptable long term care services. Although tribes vary widely in their expertise relating to designing and collecting data, strategies and tools designed for American Indian communities are available or can be adapted for use. When needed, tribes should seek technical assistance to ensure that their planning efforts are grounded in accurate information.

More importantly, data must be analyzed and used effectively to instruct the planning process, support funding proposals, and demonstrate outcomes of care. It is at this step that the use of data for planning often falls apart and disillusionment with the process of collecting data is engendered. The more proficient tribes become in the use of data from a variety of sources, the more likely they are to compete successfully for funding and subsequently to provide tribal members services that effectively and acceptably meet their needs.

The information needed to develop effective care systems goes beyond knowing the needs of the tribe to having an accurate and realistic assessment of tribal resources and capacities, as well as knowledge of external resources that may be tapped for startup costs, ongoing support, and expansion of services. Long term care service dollars are spread over a complex and fragmented maze of federal, state, and private agencies that may have little knowledge, understanding, or empathy with tribal customs or the realities of service delivery on reservations. Competition for these resources is intense due to limitations in coverage for long term care services. Further complicating access to external resources is the fact that many tribes face a steep learning curve regarding available resources, complex eligibility criteria, and onerous regulatory requirements. Concerted efforts must be made to provide education and technical assistance to tribal organizations interested in developing or contracting for long term care services.

Tribal resources are important for maximum flexibility, but there exists considerable disparity among tribes in regard to available tribal resources and the expertise necessary to develop, sustain and expand resources. Some tribes may require considerable capacity building before embarking on the development of locally controlled services. The needs of other tribes may best be served by collaborating with existing community providers in developing culturally sensitive and appropriate services, as well as training and hiring tribal members to assist in the provision of services.

Some tribes are developing good track records in meshing external services and/or funding streams with tribal resources to implement culturally sensitive service systems. Information on these models and the processes undertaken to accomplish them needs to be broadly disseminated for use by other tribes. Information on models that are working well in Indian Country is currently very sparse.

Finding monetary resources to support long term care services is not easy, but may prove easier than addressing the infrastructure issues that impede service delivery. Vast distances, lack of transportation, inadequate housing and few, if any, supportive housing options pose significant barriers to long term care service delivery. Addressing the long term care needs within tribes will require a comprehensive plan for infrastructure development. This requires a working knowledge of federal, state and private agencies that support community development, housing and transportation programs. Many of these programs have little direct relationship to long term care services, but are critical to an effective long term care services system.

The shortage of professional and paraprofessional long term care workers is currently one of the most serious barriers to service and one that is likely to become more severe as the population ages. Addressing workforce issue requires both short-term initiatives and long term development tasks. Short-term initiatives may include providing higher wages, increased worker benefits, improved working conditions, and creative recruitment strategies within new worker pools.

Meeting the need for more professional workers, particularly more American Indian/Alaska Native workers, will require a much longer-term approach. Strategies need to include encouraging students to consider health care careers early and get the academic preparation necessary for acceptance into health professional programs. Other important initiatives include availability of scholarships and other forms of financial assistance to cover tuition and educational expenses, provision of academic support to increase the likelihood of academic success of students from educationally disadvantaged backgrounds in health professional programs, and provision of career ladders for paraprofessionals wanting to advance into the health professions.

American Indian/Alaskan Native communities will face increasing need for long term care services over the next several decades. Families will continue to be a vital part of a long term care service system, but they are a resource that must not be overburdened as care demands increase. Tribal communities must look internally and externally for resources that will facilitate the development of a comprehensive long term care system to meet the diverse needs of the elderly, the disabled and their families. Some tribes may have the resources to assume full control over the development and management of services. Most tribes will need to combine tribal resources with external funding and forge strategic alliances with some providers external to the tribal community to develop and sustain a comprehensive system of care. Now is the time for tribes to be systematically planning for the future long term care needs of their populations and taking educated risks to experiment with models of care that are culturally sensitive, yet viable within the constraints of the current environment

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Roundtable Discussion of Implications and Recommendations Regarding Planning for LTC Services

1. **Indian Models by Design:** Planning tends to follow dollars rather than be rooted in tribal culture, values and community based input. In the past, nursing homes represented the extent of our understanding of LTC. Today, Assisted Living Facilities and Home/Community Based Services are the preferred approaches. What are the best models for Indian communities? Grassroots planning is needed to determine appropriate service models for Long Term Care. Native culture and values must play a key role in defining the types of LTC services most appropriate for a community and way in which services are delivered.

2. **Involve the Stakeholders:** Identify those who should be involved in the planning process. There needs to be involvement of Tribal government, service providers, Indian elders, Indians with disabilities and their families or advocates, and the informal "shakers and movers" in the community.

3. **Evaluation:** There has to be an evaluation of the current capacity for long term care. This includes an inventory of available services with eligibility criteria and identification of the provider agency. Models should be designed with flexibility to adjust to changing needs and demand.

4. **Collaboration:** Attention in the planning process to improved collaboration between existing service networks and providers will produce more options and expand the array of services potentially available in Indian communities.

5. **Data and Demographics:** Demographic data is important to understanding the level and types of LTC services needed in a community. Planning for future services includes prioritization to determine which services should be developed first and which can be developed later.

6. **Technical Assistance:** Tribes and local Indian communities must be provided quality technical assistance that is adaptable to local culture and demographics. The planning process used by American Indian Disabilities Technical Advisory Council (AIDTAC) at the University of Montana represents an excellent and culturally appropriate approach to providing technical assistance for tribes for long term care planning.

7. **Workforce Development:** Involvement of the tribal colleges and universities is important in recruiting and training local caregivers. Retention of home caregivers remains a difficult issue in some areas. Formal caregivers are low paid and the jobs often have low status and high turn-over. Some suggested solutions are:

- Recruit family/caregivers to formal caregiving. These are individuals who are already caregivers and therefore have shown that they have what it takes to do this.
- Validate caregivers with experience by giving them a mentoring role for others; Tribal recognition of their contributions; treating experienced caregivers as experts and asking for their input; make sure that caregivers are part of the team in the care of the elder and that they have ready access to the professionals involved in the care team; support groups for caregivers.

8. **Policy Issues:** Federal agencies can make a greater contribution to assist tribes and local Indian communities address LTC issues. Various Federal and State agencies supporting LTC services must understand that smaller Indian communities may require more flexibility in meeting requirements for licensure and certification. More clarity is needed for tribes and Indian elders to better understand Medicaid and Medicare restrictions and issues such as estate recovery. State and tribal collaboration to secure Medicaid waivers, which support LTC services in Indian communities, should be encouraged and supported.

9. **Funding Implications:** Funding for LTC services in Indian communities is currently severely inadequate to begin to develop the range of services required. A greater investment in LTC services is necessary at all levels, including Federal, State and local/tribal. Some of the potential ways in which more resources could be targeted at LTC included the following:

- Target IHS Research and Education grants to long term care issues.
- Target Administration for Native Americans (ANA) social and economic development grants to long term care issues.
- Educate policy-makers about needed increased funding for the IHS to cover long term care services as well as basic services.
- Establish third party billing training programs for tribes and local providers for long term care services.

Discussion Paper #4

HOW DO WE UNDERSTAND AND INCORPORATE ELDERS' TEACHING AND TRIBAL VALUES IN PLANNING A LONG TERM CARE SYSTEM?

Summary of Issues

- The elder has an important role in AI/ AN culture as tribal culture keeper that can be compromised by western long term care models which promote an institutional model isolating the elder from family and community.

- In order to preserve AI/AN traditional culture within the long term care framework, Henderson suggests that "Rituals of Respect," or rituals that symbolize important cultural values must be incorporated into daily operations.

- Rituals for including culture in long term care may include rites of 1) passage, 2) renewal, 3) intensification, 4) revitalization.

- Suggestions for keeping culture in long term care include: 1) having a serious intent to do so; 2) using appropriate experts and elders to guide the process; 3) considering the social status of the elder in addition to chronological age; 4) anticipating bureaucratic, policy and legal barriers; 5) organizing elders among ranks to provide guidance; and 6) developing a program of rituals of respect.

HOW DO WE UNDERSTAND AND INCORPORATE ELDERS' TEACHING AND TRIBAL VALUES IN PLANNING A LONG TERM CARE SYSTEM?

J. Neil Henderson, Ph.D.

Introduction

The fact that Indian Country is experiencing increased life span provokes the need to give the utmost consideration to the many-faceted issues of long term care. One of these matters is the crucial importance of carefully crafting types of long term care that respect and preserve elders' roles as treasured holders of tribal culture. This is not a perfunctory, small matter. This is similar to the way that some tribes have special people to guard, preserve, and keep vital sacred ceremonial objects. However, in this case, it is *all* elders who naturally carry, guard, and nourish tribal culture in their minds, spirits, and voices. The problem is the elders' role as tribal culture keeper can be defeated by long term care in two ways: 1) the lack of sufficient, quality long term care, and 2) the use of typical, institutional models of long term care that isolate the elder from family and community.

The lack of sufficient, quality long term care can defeat elders' efforts to keep tribal culture alive by allowing elders to sink into physical, mental, and spiritual declines in excess of that which may be expected from chronic ailments alone. Unless elders' health and function are well cared for, their ability to be vital participants in home and community life is lost. When their participation is lost, the tribal culture which they hold is lost to the community. Although some good examples of tribal long term care exist, sporadic availability of appropriate long term care can kill tribal culture by preventing the maximization of elders' socialization with the community and across generations.

The use of typical institutional models of long term care can defeat elders' efforts to keep tribal culture alive by over-reliance on bio-medically derived concepts of LTC. These biomedical concepts serve as a hidden meta-model driving thinking and action. This is why nursing homes, for example, usually look more like hospitals than homes. It is also why psychosocial care suffers while physical care is obsessively given the vast majority of attention. Also, the implicit reliance on today's majority culture way of life has influenced not only nursing home design, but home-based care as well. For example, some issues which are very commonly used across this country include a near devotion to age segmentation as evidenced by the commonness of separating those with the most years into special categories, locations, and economic jeopardy. The loss is the continuous connection with all generations that could naturally occur were it not for the separation of older adults from their extended family.

Initial Conditions for Problem Solving

"Initial conditions" refers to the foundations of thought used to tackle a problem. It is like the starting point for thinking, or the set of unquestioned assumptions that are used as the

first stepping stones leading to problem resolution. These initial conditions *must* be right or all else that follows is flawed. The topic of concern here, "keeping culture in long term care," requires that a specific and correct understanding of "culture" and "long term care" be given. In an effort to best align the problem solving process with correct initial conditions, both "culture" and "long term care" will be examined since both have extreme variance in how they are conceptualized.

Dynamic Culture

It may be surprising that "culture" is the more difficult concept to define and apply. This is due to the very fluid nature of culture along with the fact that it is constantly changing. Common thoughts about culture include the notion that culture is the collection of values, beliefs, and perceptions learned as a member of a social community. While this is basically true, the error is the lack of attention to the dynamic nature of culture. Culture is always moving, changing, and shifting. Too often, culture is wrongly made trivial by simply identifying some traits about a group that seem different from another group. This approach of "trait listing" to understand culture is guaranteed to lead to failed applications in real communities because people are much more complex than a simple list of traits.

Culture and Personality

Moreover, trait listing does not account for the fact that culture is expressed through individuals who each possess certain personalities that "filter" culture as they use it. This can produce observations that some individuals in a community do not behave in accordance with some traits in the list that is supposed to apply to them. The reason is that personality can also "filter" the expression of culture, causing an apparent disconnection with the overall cultural system. But, this is not a problem because all communities have the flexibility to incorporate large amounts of behavioral differences. In fact, such differences are sometimes the sources for new developments in culture that help people adjust to new conditions.

Invisible Culture

Culture is also challenging because it is essentially invisible itself. It is an operating system that is only sometimes made visible by human action. The ways that people produce things from houses, to cars, to clothes all represent culturally based notions of how things should be. Yet, some parts of culture are entirely and always invisible, although very much acting on peoples' thoughts and behaviors.

Culture as a Writhing Knot

A useful definition of culture is that it is a writhing knot of constantly mutating values, beliefs, and perceptions expressed individually by people with different personalities. Consequently, efforts to account for culture in human services are very difficult. However, a correct understanding of culture and its dynamic nature will allow problem solving to be ever closer to an accurate target. The result is a greater opportunity to keep *real* culture alive in all the issues that need attention.

Long Term Care

The subject of the phrase "long term care" is "*care*." "Long term" is a modifier that simply states that the care to be given occurs over a significant period of time. First, "care" is a common fundamental of communities. Communities can't exist unless care is given to nurture children so that they can survive into adults. The problem is that for "older adults," care is not always so vigorously or freely given. How can this be when cultural values have usually been very favorable toward elders? There is no simple answer to this vexing question. Yet, it can be shown that the current national culture, as a political and economic business machine, has developed in a way that causes late life to be a time of greatest risk for financial loss just when the greatest lifetime risk for health and functional limitations to occurs. The combined burden can be huge.

Care and the Social Need of People
Care is best viewed as ways to provide for the spiritual, emotional, and physical well-being of a person. Since people are inherently social, a situation in which a person can experience life with some degree of contact and connection with others fosters a heightened sense of well-being. Isolation is fear-inducing and punishing to human life.

Care and Attitude
Care, as an issue, does not carry with it definitions or directions of what, when, where, or even how to provide care or to be caring. Each of these aspects of care must be discussed. The "what" aspect of care suggests that care can be manifested in many ways. For example, care can be shown by voice tone as well as the delivery of medicines. Also, care can occur simply by one's presence. It may be that the most important aspect of care that will be conveyed to the care-receiver is that of "attitude" on the part of the caregiver. A *sincere* attitude of respect is needed for the optimal connection to be made to an elder.

Of course, care can be the doing of tasks that are needed for promoting health and well-being. These include the tasks of bed and body care as well as psychosocially beneficially tasks like visiting, activities, walking with someone, reading, etc.

When to Care
When care should be given is also an undefined matter. For some elders, care provision is not a full-time necessity. For others it is mandatory. It is possible that some elders would thrive on intermittent care or a type of care balanced by careful preservation of their sense of independence. This means that there is a potential negative to "over-caring" which can lead to learned helplessness. Care should be given at an appropriate time in accordance with the needs and preferences of the care receiver.

Where
Where to provide care is both easy and difficult. In one sense, care can be given regardless of location. On the other hand, a type of care needed may require specialized locations, staff, or technology. However, much of the type of care needed for older adults, in the context of medical stability, is psychosocial and, consequently, not so dependent on technical equipment. Still, psychosocial care can require very specialized knowledge by a caregiver, such as a spiritual leader, social worker, psychologist, etc. No matter what the problem, however, a friendly visitor remains powerful medicine.

Locations for care are many. As is common from the "continuum of care" perspective, care of many types can be delivered at home, day care, meal sites, senior centers, and, of course, outpatient centers, assisted care facilities, and nursing homes. People prefer to stay at home so much of care is delivered to the elder person there. Also, special spiritual nurturing can be done on home land or tribally special land and constitutes an important place of care. In addition, many types of spiritual nurturing can be brought to more institutional settings.

How to Care

How to provide care is an extremely challenging matter. While it may seem strange, care can be given without being in the presence of the care receiver. For example, many types of care are brief ways of "touching base" with a person at home alone, such as phone calls, letters, cards, and gifts. These ways cannot account for all care, of course, but should not be ruled out as important ways to keep people feeling connected, particularly in widely spaced living areas. More commonly, caregiving is a type of personal interaction that can variably be given by lay persons, paraprofessionals, and trained health care professionals. Each of these types of caregivers can have important roles in assisting the elder to maintain optimal function and well-being.

Keeping Culture In Long Term Care: Rituals Of Respect

Creating a system of long term care that keeps culture in it can be done, *but only with real intent and unflagging commitment*. Transforming the intangible values of culture into action is where the commitment and work occurs. The cultural transformation is done by crafting rituals which symbolize the values that are intended to be incorporated into daily operations. *Rituals are simply behaviors that are symbolic of certain cultural values, designed for a specific purpose, are standardized throughout the culture, and consistently repeated.*

There are specific types of rituals. A menu of rituals for keeping tribal culture in long term care includes rites of 1) passage, 2) renewal, 3) intensification, and 4) revitalization. These are the basic tools by which directed, controlled culture change will occur. Rites of passage relate to marking the change from one status to another (e.g., birthdays, retirement, entry into long term care). Rites of renewal are to remind people of a certain status that one or a group of people have (e.g., elder, parent, caregiver). Rites of intensification are to reinforce the status that a certain person or group has (e.g., elder, holders of culture, communicators of tribal culture). Rites of revitalization are to re-capture a former status or even set of roles (e.g., the value of elders, intergenerational communications, tribal cultural values).

Brief Examples of Rituals of Respect in Long Term Care

Rite of Passage

As an elder becomes a user of long term care services, whether at home or in a facility, develop an appropriate *celebration of inclusion* into the new set of services that emphasizes CARING. This can be a gift of food, or smudging, a prayer song, or an actual few steps through a portal or archway that is specially built for such a brief ceremony. These rituals should be accompanied by people and maybe even animals that are important to the person. Note that the specifics of such a rite of passage are HIGHLY variable and are expected to vary greatly from tribe to tribe and person to person.

> **EXAMPLE:** In an elder's home---The elder who is new to the service system is at home in his or her familiar and comfortable surroundings. By preplanning and permission of the elder, long term care workers come to the house with an appropriate person (who may also be an elder) who is considered worthy of offering a blessing to the service recipient. This person may be a spiritual leader independent of the long term care service group, or may happen to be a staff member of the service group. These people will greet the elder and explain that they are there to get to know the elder and the family as well as for the elder to get to know the people of the service agency. It may be that some of these occasions will be marked by people who have known each other for years. But, this doesn't cause a problem. The service people and the spiritual leader will welcome and honor the elder as a person they will provide special care for. The spiritual leader may offer a prayer, smudge the elder by using a feather fan or eagle feather to move the smoke of sage and/or cedar over the elder, or sing a prayer song. After this blessing, an appropriate gift can be given to the elder. Gifts may be of a kind that are important to the tribal culture, such as tribally valued foods, art, or books that are considered appropriate. This Ritual of Respect should convey a definite sense of caring and honor for the elder. It should convey a future in which the elder thrives in the emotional and spiritual sense in the midst of caring others.

Please keep in mind that the specifics of this example will change according to the tribal cultures involved.

Rite of Renewal
At regular intervals of long term care service, a rite of renewal can be developed which reminds the person that they are specially cared for in ways that keep them connected to the tribe. This may be an elder or elders who have been using services for a season or two. The interval can be by all seasons or selected ones. The specifics could include a party atmosphere with more serious elements as well, such as smudging, songs, or gifting. Someone may want to say a few words that emphasize that the elder is special to their community, family, and the caregiving staff (again, whether at home or in a facility).

> **EXAMPLE:** Like birthdays, it feels affirming to be regularly reminded that one matters to others and that a person's "specialness" has not "worn off." Service providers, an important person in the tribal community, and family may be involved in the renewal and reminder of caring and importance extended to the elder. These people can meet with the elder at their own home or even at a facility for ways to show the elder respect, honor, and that they are cared for. The elder may be placed in a special seat or location. The others can gather around them. Each person may say aloud a variety of things that reflects the elder's value to them and the community. Sometimes these things are very humorous and other times, they may be quite solemn in tone. The group may sing a tribal song or a prayer song. They may show pictures that involve the elder taken over the last season or year. Then, to mark the end of this Ritual of Respect, someone may make reference to looking forward to the next season or year of helping to provide care for the elder. Making note of the elder's value to the community is fully appropriate.

Rite of Intensification
At regular intervals, a ritual of intensification can be developed to bring attention to fact of elders' unique and valuable role as holders of tribal culture. This may be for one or a group of elders. The specifics may include the elder(s) telling stories, singing, or dancing. Also, old pictures of the elders can be enlarged as used as a device for the elder to tell of the old ways, since parts of the picture my stimulate memories of how life was (clothing, technology, housing, etc.). Perhaps this could be done in the presence of youth of the tribe and/or family. Again, the specifics will vary in accordance with tribal culture.

> **EXAMPLE:** Service providers can preplan a picture or slide show that contains examples of the older life ways of the tribe. The more specific to the early days of the elder, the better. It may be that most of the other participants will not be of the same generation. The elder becomes the unique and special holder of the actual lived experience that relates to the pictures. In this way, the elder's life is seen as unique, a living lens into the past that may be otherwise lost. In this ritual, the elder is the single teacher in the group. All others are the elder's students. This Ritual of Respect can end with prayer, songs, or gifts, and the promise of another time of this special honor.

Rites of Revitalization
At regular intervals, that may be seasonal or related to tribal histories, a rite of revitalization may be developed for elders to be re-established as cultural leaders and guardians of tribal culture. This may include an elder or elders who may be asked to speak in the way of authority for the tribe, open-ended, without time limits. The elders should be honored in culturally appropriate ways, such as gifting, smudging, or showing how their advice and guidance has been helpful to the tribe.

> **EXAMPLE:** The timing of this Ritual of Respect may be attached to important tribal culture events that come from history or tribal religion. Perhaps it is also seasonal. By preplanning, service providers can assist the elder, if necessary, in organizing their preparation for offering some words of wisdom that they have learned over their life or to reinforce some of the tribal values that have always existed. The listeners must be the long term care service providers, and may also include others, such as family and friends. It may be that the elder can be helped to get their tribal regalia in place, if that is appropriate, for conducting this Ritual of Respect. The telling of a story or giving admonitions (without time limits) may be promoted by prior help in recollecting such matters, but only if this is necessary due to some impairment. Otherwise, the elder will speak on their own. This Ritual of Respect should further cement the importance of the elder to the community.

Keeping Culture In Long Term Care: Tribal Values

The discussion of culture, care, and ritual establishes the initial conditions for solving the problem of how to keep culture vital while delivering long term care in multiple settings, governed by external policies. The task now is to apply a reality-based concept of culture into a reality-based notion of long term care for elders. The task here is to identify ways to elicit tribal culture from elders about what their life experience has taught them that tribal culture and care should be like. In this way, the elders can have the primary voice in the

development of types of long term care that fit with their expectations. Also, those non-elders who are involved in the policy and fiscal aspects of long term care will be mandated to listen to the elders and then act on their behalf to the ultimate degree possible.

Culture: Seen, Thought, and Hidden

There are some ways to think about culture that provide a framework for developing a plan for how culture can be integrated with long term care. First, culture can be very explicit and easily seen, like in pictures, designs, and styles of structure. Second, culture can be more invisible by being expressed in thinking and behavior, like in knowing about spiritual matters or how family behavior should be in different situations. Last, culture can be out of the user's awareness, yet still powerfully operating. For example, all cultures have rules about how close people stand to each other when talking. Some cultural rules are further apart and others closer together. But, no one even thinks about them, unless someone violates the hidden rule. Then, a distinct sense of discomfort occurs so powerful as to make the person begin to move around to find the spacing that makes the proper feeling of culturally correct distance.

The "talking distance" case is a mundane example, but other aspects of "hidden culture" are more important and can dictate how people think when problem solving. For example, when people think of typical long term care in a nursing home, the caregiving staff is thought of as those that do nursing, activities, and those who work in the kitchen to provide nutritious food, and maybe some others like those in social services. However, research has shown that the housekeeping/janitor staff can be some of the most important people to provide psychosocial care. We don't even think of them being care providers because they don't wear white, deal with charts, provide body care, and don't have any specific training about giving direct care. Yet, actual behavior shows that they may very well be some of the best providers of psychosocial support. The lesson is that trying to conceive of what long term care is like by using our usual problem solving tools may not give the best results. What can be done to get beyond this thinking block? How can tribes find what is traditional culture and long term care is, or should be? There is no easy answer to this. However, there are means usable to elicit the ways that people think about real culture. This may include structured interviews, research-style focus group, open-ended interviews, and specific elicitation interviews. Both quantitative and qualitative analysis would follow to produce valid results. After getting such information, *collaborative communications with elders* can lead to better long term care design and operation.

Techniques to Tap Elderhood Cultural Values

There are a variety of ways to tap into the cultural values of our elders. The following are provided as examples for consideration and to perhaps trigger additional ideas based upon the unique cultures in your own community.

- Have current elders identify and talk about their memories of how elders used to be treated; Give examples of behaviors of elders; Native Language use to show elder respect; Stories that had themes which valued elders; Rituals/ceremonies that showed respect for elders

- Collect pictures from the old days and ask elders to look at them and talk about the old days, particularly the ways that elders were treated.

- Talk about the favorite foods of each tribe.

- Talk about the favorite ceremonies or most important ones.

- Talk about what fears are present about typical nursing home stays.

- Ask what an elder is?

- Make the senior center the actual "center" of the community.

- Just like a language course, have an "elder respect" course for all staff that provide care. Culture is learned both "automatically" and by specific teaching.

- Integrate the senior care with child care.

- Have senior day in all of the schools or an hour per week of elder day in which the respect for elders is talked about by elders and youth.

- Have a lunch day in which the kids provide a lunch for the elders.

Examples of rituals for keeping culture in long term care could also include the following.

- Reminiscence Therapy in cultural context.
- Pet Therapy in cultural context that include local animals common to the tribal area or important to tribe's in symbolic ways. In some situations, some clan animals may be important to be included, if appropriate, for the clans.
- Native Talking Circles.

Summary

In order to keep culture in long term care:

- Have a serious intent to do so.

- Use appropriate experts (e.g., anthropologists, sociologists, historians, etc.), PLUS tribally based experts, PLUS elders as those who will guide the process.

- Consider that elders in the tribe may vary in chronological age from "young elders" to "older elders" and that the social status of "elder" may be different from those people who are elders due to a long life.

- Anticipate that in keeping long term care in culture there may be confrontations with bureaucratic, policy, and legal barriers. Be "creative" to avoid defeat by such intrusions.

- Elders may benefit from some organization among their ranks to help provide guidance about keeping culture in long term care.

- Develop a program of Rituals of Respect for Elders as a means to ensure that culture and long term care go together.

Roundtable Discussion of Implications and Recommendations Regarding Culture and Traditional Values in LTC

1. **Must Be a Serious Intent:** We cannot make it to the priority list, unless it is taken seriously. Culture needs to be seen as just as important in our health systems as the protection of life and limb.

2. **It Can Be Done Cheaply:** You don't need to build new structures with multi-million dollars. Modest investment to ensure cultural components can make a huge difference.

3. **Best Practices:** Look for models and best practices of how culture has been kept within LTC settings.

4. **Support of Policy-Makers:** Demand that there be a policy to support a program of including culture in the care. This should be a requirement of a planning process..

5. **Culture as an Integral Component:** Cultural appropriateness, or rituals of respect should be recognized as an essential part the care and should be included as a component of the quality of care in any evaluation.

6. **Anticipate Changing Traditions and Multi-Culture:** Culture is a dynamic process and each cohort of elders may see things differently. Elders are multi-cultural. There are multi-cultural experiences through geographical location, marriage, education, media, life experience. There is no "one size fits all" cultural component. This is not a problem, but is inherent to understanding the dynamic nature of culture.

7. **Physical Access to Elements:** Ensure access to culturally important things to the elder, such as access to horses, foods, sacred places, practices.

8. **Make Human Needs Priority Over the System Needs at all Times.** While realizing you cannot ignore regulations and law, human needs must always be considered first.

9. **Planning for LTC Involves Community and Elders:** LTC which is planned and developed within tribal culture and communities will more likely meet the needs of elders. Elders must be involved from the start and continuously in "real and meaningful" ways.

10. **Government Encouragement of Cultural Models:** Tribal, federal, and state governments must include the considerations of culture in the development of LTC policies and programs.

Discussion Paper #5

HOW DO WE ADDRESS THE LONG TERM CARE NEEDS OF URBAN INDIAN ELDERS?

Summary of Issues

- With an estimated 60-70% of the American Indian and Alaska Native population living in urban centers and no long term care infrastructure under Indian control to serve the growing population, long term care needs may represent an impending health crisis.

- Urban health care spending is poorly funded, resources are stretched to cover diverse health needs, and service eligibility is broadened to include AI/AN tribal members with or without federally-recognized status.

- Urban, long term care program planning is further challenged by the low rate of AI/AN health insurance coverage.

- The traditional cultural practice of caring for family members in a multi-generational setting also leads to the need for alternative long term care choices if the needs of the aging urban AI/AN population are to be truly honored.

HOW DO WE ADDRESS THE LONG TERM CARE NEEDS OF URBAN INDIAN ELDERS?

Ralph Forquera, M.P.H.

Introduction

Like other Americans, American Indians and Alaska Natives are an aging population. Findings from the 1990 and 2000 census indicates that as many as 60 to 70 percent of Indian people are now living in American cities.[1] A growing number of these Indian people are living into their 70s, 80s and beyond. The life expectancy of Indian people has increased dramatically in the past several decades. Improvements in health care and state-of-the-art medications are helping to prolong the life of many Indians including those who live in urban areas.

With this knowledge in hand, the future need for long term health care for urban Indian elders appears on a collision course with the realities of Indian health service development and financing. For urban Indians, the problem could be even more pronounced although the availability of information to assess the extent of this problem is not currently collected. So, how are the long term health care needs of urban Indians going to be address.

This paper will describe the current status of health care for urban Indians, the implications of this system on long term health care for urban Indians, the problem that long term care financing will have for urban Indians, and the probable need for special services in the future. Lastly, some speculation on the cultural and historic biases that must be addressed if we are to plan for this impending crisis will be presented.

The Urban Indian Landscape

Urban American Indians and Alaska Natives (AI/AN) represent the largest segment of Indian people in the United States. The 2000 census indicates that over 60% of the 2.5 million Americans who marked "Indian only" on their census form live in American cities.[2] When the figure for Indian plus another race is considered, the percentage is even higher (estimated at over 70%).[3]

The movement of Indian people to American cities has been an on-going process since the turn of the century. Today, urban Indians are multi-generational. Third generation urban Indians co-exist with Indians just arriving in cities. Those who have only known urban life cannot be easily distinguished from those who only recently have arrived from reservation lifestyles as we consider planning for long term care needs. The service demands of these apparently disperate groups are actually separated only by the cultural demands of the groups, biases established in cultural norms that may enhance or interfere with service access.

When Indian people leave reservations for American cities, they generally lose eligibility for benefits granted to them when living in these areas.[4] This includes access to health care services offered through the Indian Health Service. Except for a small contracting program authorized under Title V of the Indian Health Care Improvement Act (P.L. 94-437)[5], few resources are made available to address the health care needs of off-reservation Indians. As a result, there is a lack of continuity in the availability of health care for urban Indians and little national data available to describe the needs of those affected. However, as the population ages, and as the demands of chronic health care necessitating coordinated disease management and medications grows, the lack of a uniform system to care for the needs of this rapidly growing population is likely to mean poorer health outcomes for urban Indians as they age.

The current Congressional policy regarding Indian health is heavily influenced by a set of principles established in 1970 aimed at encouraging tribal self-governance and local management of federally-sponsored Indian benefits, on Indian reservations, that are controlled by local federally-recognized Indian tribes themselves.[6] This being the case, little attention has been given to Indians that live away from federal reservations, in part a result of insufficient funding for the Indian Health Service itself and other Indian programs by the U. S. Congress.[7]

In the case of Indian health, urban Indians have, since 1979, received just over 1% of the annual funds Congress appropriates to support the health of Indian people. During this same period, the Indian population has shifted toward urbanization in large numbers. Inadequate support to reservations and the need for jobs or schooling have lured increasing numbers of Indians to urban areas.

In FY-2001, Congress appropriated just under $30 million for urban Indian health assistance.[8] These funds support 34 contracts and a series of small categorical service grants to community-based, non-profit agencies that are governed by Indian people. These independent agencies are located in a limited number of urban communities in 17 states.[9] Because they do not have the protections of tribal trust lands, urban service providers are subject to local and state rules, regulations, and laws including all state and federal non-discrimination laws.

In FY-2000, over 90,000 Indians received assistance through this incomplete network of urban Indian health providers.[10] None of the current contractors provide services that would meet the definition of long term care.[11]

With few exceptions, there are no clearly defined urban Indian communities. In most cities, urban Indians are geographically dispersed throughout a metropolitan area. The urban Indian community is tribally mixed. It is not uncommon to find Indian people from more than 200 different federally-recognized Indian tribes in some urban cities.[12] Those of mixed racial backgrounds may or may not identify as Indian on census reports or other official documents. Racial misclassification on official documents such as birth and death certificates has been well documented for both reservation and urban Indian populations.[13] Thus, determining the exact size of an urban Indian population in a given area is proving to be a considerable challenge.

The Urban Indian Health Program

The 34 agencies that contract with the Indian Health Service to provide assistance to urban Indians make up the Urban Indian Health Program for the nation. The contractors are themselves highly diverse in their size and services offered. Eleven contractors provide what is considered "comprehensive medical services," i.e., direct, full-time, outpatient, primary medical care, as well as other direct and supportive health care services to their communities. Unlike services through the IHS and tribes that are often offered at no cost to the Indian beneficiary, direct health care at urban programs is provided using a sliding-fee. To further afford to provide direct health care, urban programs frequently rely on additional funding from local, state, private, and non-Indian federal sources that are generally allocated to care for those Americans in poverty or in the lower socio-economic strata in the society.[14]

An additional eleven contractors provide limited medical care, i.e., services offered on a more limited basis in time or types of direct care that can be offered. Often, these programs may have a part-time physician or a nurse or mid-level health provider, often without the direct support of a laboratory or on-site pharmacy assistance.[15]

The remaining 12 contractors do not provide any or very limited direct health care services. These programs offer as their main service: information, referral, and outreach/education to assist urban Indians in gaining access to non-Indian health care, be it from private health providers or non-Indian community health centers. In some areas, urban programs may also assist urban Indians who might be eligible for direct care at a tribal or IHS facilities to reach these facilities with transportation assistance or other facilitative activities.

Another dimension of the urban Indian health program is the more flexible eligibility standards for assistance than is required of urban Indian programs. IHS and tribal services are often restricted to Indians who are members of federally-recognized Indian tribes. For urban Indian health programs, eligibility is broadened to include those Indians who are no longer affiliated with a federally-recognized tribe. This includes Indians who were displaced as a result of the relocation and termination policies of Congress during the 1940s and 1950s, as well as those Indians who reluctantly chose to leave their reservation homes for jobs, education, or to escape reservation poverty. Additionally, there are countless urban Indians who were adopted by non-Indian families over the years, a practice that continues today, and thus were raised outside of an Indian community where cultural beliefs and practices could be learned. Most lost touch with their Indian roots. A number do not even know the tribe from which they were adopted.

Finally, urban Indian health programs are situated in cities. As such, programs and services are subject to federal and state non-discrimination laws requiring that services are to be offered to anyone who seeks aid. These distinctions are important to consider when planning for services as these different standards may affect approaches to the problem both on and off reservation.

Long Term Care Facilities

Currently, there are no nursing homes or other long term care facilities in the United States that are owned and operated exclusively for urban Indian people. The 34 agencies that

contract with the federal Indian Health Service to serve urban Indians provide primary health care and/or referral assistance only. There are no urban Indian hospitals and only fragmented access to specialty care in urban Indian facilities, i.e. a consulting obstetrician, podiatrist, optometrist, etc. may offer some in-facility assistance either as a volunteer or under contract.

A few physicians working for urban Indian health programs have reported attending to a very few Indian patients in nursing homes or consulted on Indian patients in non-Indian long term care facilities.[16] But this practice is seen as an extension of their regular patient/physician relationship with a given patient and not a specifically defined part of their medical practice.

In an informal e-mail survey of the urban Indian health programs, only two reported that their primary care physicians had visited a nursing home or convalescent hospital to assist with care for an Indian client. We speculate that there are Indian people in long term care facilities across the nation, but because of the limited scope of urban program activity, it is not possible to assess the extent of Indian people using long term care facilities.

Financing and Long Term Care

American Indians and Alaska Natives are one of the least insured of all Americans. A report by the Henry J. Kaiser Family Foundation on enrollment of Indian people into Medicaid, Medicare, and SCHIP found that few Indians, although eligible for these publicly sponsored programs, actually enroll.[17] Even fewer Indians appear to buy private health insurance although data on the percentage of Indians with private health coverage from their employment is unavailable.

According to the Urban Institute, financing for long term health care comes primarily from Medicaid and Medicare respectively.[18] Private insurance made up only about 5% of the $54 billion spent on long term care in 1995. Medicaid, which is a state administered program, is the major source of non-hospital financial assistance to the elderly, especially those with a disability.[19]

Medicare eligibility is not universally guaranteed for Indian people. In the past several years, a few reservation elders and Alaska Native people usually from remote villages who never paid into Social Security have been found. Since these individuals never worked in a job where payment into Social Security was required, we found that they did not qualify for Medicare coverage when they reached age 65. While the number of Indian people who find themselves in this situation is small, the group represents a unique challenge for securing health care financing for both long term and general primary care assistance.

Lastly, the fact that Indians eligible for Medicare and Medicaid fail to enroll in these government-sponsored programs may support the notion that similar practices would exist for long term care. As such, the manner in which long term care is financed in the country would appear to offer limited options for Indian people including those living in American cities. This assessment can also be reached with regard to private health insurance. Already, few Americans in general, familiar with the importance of health insurance, are known to

buy private long term care coverage. It is probable that Indians, both on and off reservation, do not purchase private long term health care insurance.

Home Health and Other Outpatient Assistance

Many Indian families in urban areas continue the traditional cultural practice of caring for family members in a multi-generational way. This notion that family loyalty and support is an obligation would reinforce creating more home health care options for long term health assistance. Unfortunately, there is no existing data to clearly show how extensive home health aid is currently being handled by Indian people. Most urban Indian programs that provide direct care only refer patients for long term care from non-Indian providers. Seeking licensure as a home health care agency may be an option for future consideration.

In Seattle, the majority of Indian elders served by the Seattle Indian Health Board live alone or with family or friends. We have a number of clients who must use wheel chairs or have other disabilities. We find that most continue to live either alone or with relatives maintaining quite nicely.

Indian elders that we care for seem quite self-reliant and independent. Those requiring assistance rely on family and friends who appear to accept this responsibility with few complaints. This finding further reinforces the potential of developing home health options through urban Indian health programs, an approach that deserves greater exploration and planning.

Perceptions of Long Term Care

In most parts of the country, perceptions of long term care, both facilities and access to home and other assistance, is not always favorable. Countless headlines report physical abuses and neglect in long term care facilities. Funding for these organizations is often deficient leading to staffing shortages, facility maintenance problems, inadequate program management, and an atmosphere that many people would consider inadequate for their loved ones. Most of the Indian elders that I spoke with in Seattle said they would refuse to go to a long term care facility. Those receiving home health care complained about their workers. Many felt they were not receiving the help they deserved, and when they complained, they felt they were labeled as "troublemakers" by officials.[20]

The attitude and treatment by staff responsible for helping individuals receive and maintain public assistance for their long term care was also cited as a barrier. In some cases, elders felt they were treated in an abusive and insulting fashion. The attitudes of these public servants contributes to the lack of follow through on the part of clients referred for assistance. A few of those I spoke to felt that the workers sent to their homes were not adequately trained. At least one mentioned that their health care worker had robbed them. Such incidents are quickly communicated to the broader Indian community reinforcing the already skeptical perceptions about outside, mostly non-Indian, helpers.

Staffing

The issue of staffing is a frequent complaint by Indian clients in urban areas. While most urban programs try to hire well-trained Indian professionals and support staff, they are difficult to find and expensive to employ. The insufficiency of funding for urban Indian health programs limits the salaries that can be paid for skilled Indian employees. In addition, the overall number of Indian people in training for health professions has declined in the past decade. There is an overall nursing shortage in the nation, and the number of Indians choosing health professions is down from the mid-1990s.

Urban Indian Programs and Long Term Care

The current health care commitment for urban Indians in the nation does not adequately address the primary care needs of this population let alone the need for long term care for the elderly or disabled. Congress has chosen to restrict its commitment to urban Indians to just over 1% of its annual appropriation while the population of Indians living in urban areas is growing. With little political strength in most metropolitan areas, urban Indian health programs, while a logical choice for the planning of long term care options, are themselves mired in maintaining current services. Most do not possess the necessary planning capacity to effectively study long term care needs.

The urban Indian health programs I spoke to are aware of the need for additional elder care and the crisis in long term health care that looms on the very near horizon. Several programs are instituting elder programs designed to keep Indian elders healthier. Many operate or support hot meals programs, social and cultural programs, and special programs to address diabetes, heart disease, and other chronic conditions which may help to reduce or postpone the need for long term care. But we know that the Indian population, like all other Americans, is aging. Indian people already experience higher rates of chronic diseases and at younger ages than the general population. In addition, the demands of contemporary city life combined with changes in family dynamics will likely interfere with the historic patterns of caring for sick or elderly family members. Unlike their reservation counterparts, urban elders may not live with or close to their direct families. Therefore, urban Indian elders cannot completely "count on" family for their care as they age.

Summary

It is clear that urban Indians will have need for long term health care as they age. The ability to incorporate long term care services into urban Indian health programs is not defined. Since the urban Indian health network has not even established a uniform national primary care health system, it is unlikely that this group will be in a position to accept the challenge of creating a long term health care capacity in the near future.

Existing financing methods for long term care, already inadequate for the general public, will also pose a challenge for urban Indians. The current economic downturn is decreasing Medicaid budgets as they become prime targets by state officials for cost reductions in the aftermath of severe state budget shortfalls. Since a majority of the cost for long term care comes from Medicaid, the budget crisis will have a direct effect on eligibility and future funding.

The lack of sufficient funding has already affected the quality and quantity of long term care beds around the country. Further reductions in reimbursement will likely force current long term care facilities to restrict access or even close. The shortage of well trained and appropriately-skilled professional and support staff to work in long term care facilities or to offer home health services is likely to continue.

While the picture presented above would appear bleak, one bright spot may be the historic manner in which Indian people have cared for their elders and those with long term disabilities. Indian Country continues to show greater acceptance of persons with disabilities or elders needing personal assistance. Indian families continue to accept their historic obligation to care for their elders and those who need help. So while the mainstream long term care picture may not appear pleasant, creativity, devotion, and a sense of community may be a strength to be exploited in finding solutions to the long term health needs of urban Indians.

Roundtable Discussion of Implications and Recommendations Regarding Urban Indian LTC Issues

1. **Urban Indian Needs Assessment:** We don't know the numbers of individuals with disabilities or the numbers of elders in need of LTC in urban settings. Indians tend to move back home toward their later years to retire. Needs assessments are needed to better understand elderly and disability in urban Indian communities.

2. **Training and Orientation on LTC:** Urban Indian health programs serving the 34 cities under the IHS Urban Program should receive more in depth training and orientation about LTC for elders and Indians with disabilities.

3. **Urban Indian Involvement:** Federal and State LTC programs should encourage urban Indian community involvement in LTC systems in the urban environment and begin a dialogue with urban Indian service providers.

4. **Focus on Home and Community Based Services:** Nursing homes and skilled nursing facilities are likely beyond the scope of urban Indian health centers, but Home and Community Based Services (HCBS) and training of Personal Care Attendants (PCA), or home health aids, are areas that we can focus on and also create opportunities to work in collaboration with tribes to provide those services.

5. **Dissolve Artificial Barriers Between Urban and Tribal Communities:** We need to get away from the tribal and urban distinction when we talk about services for Indian people. Indian people travel back and forth between urban and reservation communities. We need to look at each other as collaborators and not competitors. This message needs to get to the leaders, so that this collaboration is not just words but can become reality.