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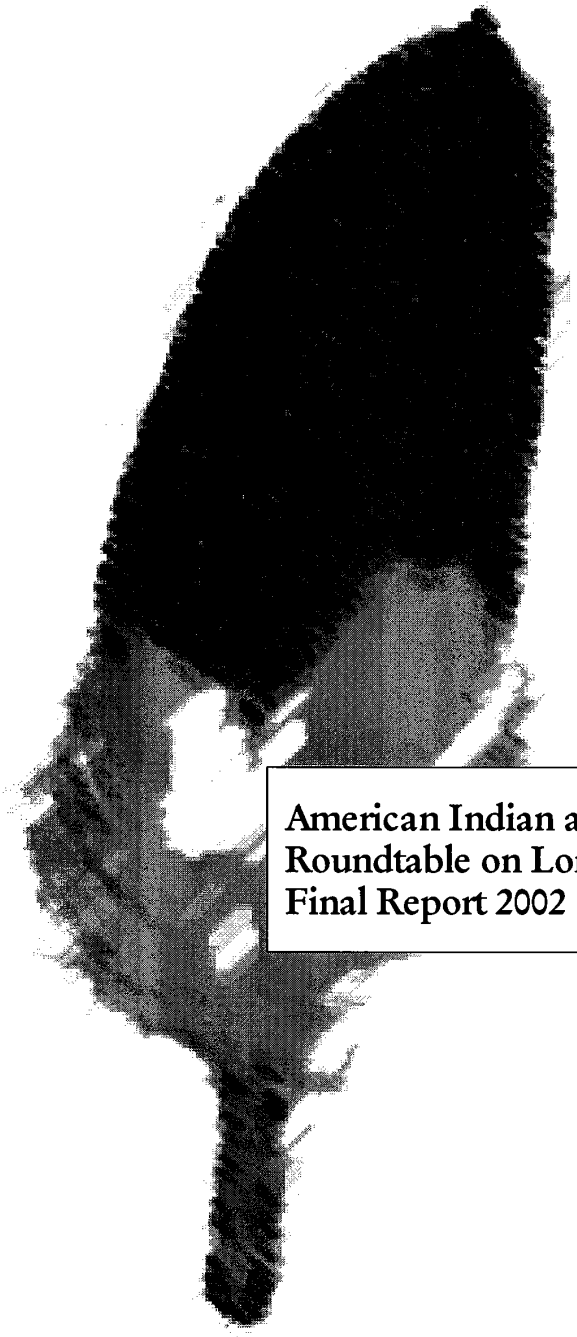

American Indian and Alaska Native Roundtable on Long Term Care: Final Report 2002

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This report was prepared by Kauffman and Associates, Inc. (KAI) under contract with the Indian Health Service (IHS). The views and opinions expressed in this report are those of the participants and authors and do not represent official policy or positions of the Indian Health Service or the Administration on Aging. In addition to the five papers presented herein, this report summarizes the proceedings, implications and recommendations which emerged from the American Indian and Alaska Native Roundtable on Long Term Care held April 11-12, 2002, in Albuquerque, New Mexico.

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American Indian & Alaska Native Roundtable on Long Term Care: Final Report 2002

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INTRODUCTION

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The Indian Health Service (IHS), in partnership with the Administration on Aging (AoA) and the National Indian Council on Aging (NICOA), held a Roundtable Conference on American Indian and Alaska Native Long Term Care on April 11, 12, 2002. The purpose of the Roundtable was to analyze and explore key issues in long term care (LTC) for American Indian and Alaska Native (AI/AN) communities. This report will summarize the discussions and consensus positions developed during the Roundtable Conference. It also provides a forum for the analysis of specific discussion papers prepared by experts in the fields of Indian health and long term care.

Initially, five important topic areas were identified and framed as questions. Individuals with experience in long term care, Indian health, or both were invited to write a draft paper exploring these areas. These papers, presented in draft form, were the starting points for discussion at the Roundtable Conference.

Over thirty experts in Indian Health and elder care from throughout Indian Country were invited to participate in the Roundtable. These experts were not selected to "represent" Indian Country, but rather to gather a broad array of expertise in the issues attendant to long term care for American Indians and Alaska Natives.

Each topic was presented by the paper author and the content and approach were discussed by the Roundtable experts. Comments were recorded by the Roundtable facilitator and provided to the author for inclusion in the final draft of the paper following the meeting. Participants then divided into small groups to explore implications and recommendations regarding each topic. Topic facilitators presented these to the entire roundtable for further discussion.

What follows is the report of this process. At its core are the five invited papers on key topics (revised with input from the roundtable participants), followed by a summary of the implications and recommendations from the Roundtable experts regarding the issues addressed in each paper. In addition, there are two background papers presented at the Roundtable, one on AI/AN demographics from the 2000 Census, and one with the latest data on the prevalence of functional impairment among AI/AN elders. Finally, there are two additional background papers prepared for the Roundtable; a report on AI/AN nursing homes and a preliminary analysis of the cost of long term care for AI/AN elders using recent IHS user population data.

The first paper entitled "Long Term Care in Indian Country Today: A Snapshot" is presented by William Benson in coordination with the National Council on Indian Aging (NICOA). His paper provides an overview of the issues facing Indian elderly across the United States and a brief profile of some of the federal programs designed to address their needs. His paper also provides preliminary data from a national survey of tribal long term care conducted by NICOA and the National Senior Citizens Law Center.

The second paper entitled "Opportunities for Medicaid Financing of Long Term Care in American Indian and Alaska Native Communities", by Mim Dixon, Ph.D., provides a

thorough and exhaustive review of the existing federal Medicaid programs administered through the states which could potentially provide financial support for tribal and urban Indian LTC services. Her paper identifies areas for tribal, state, and federal collaboration to improve access to long term care services.

The third paper is entitled, "Long Term Care in Indian Country: Important Considerations in Developing LTC Services." It was prepared by Linda Redford, R.N., Ph.D. In her paper, she presents a demographic profile of American Indian and Alaska Native elderly and explores the types of services required by this population. Her paper provides an excellent outline of the key elements to conducting effective planning and development activities for Long Term Care services.

The fourth paper is by J. Neil Henderson, Ph.D., entitled, "How Do We Understand and Incorporate Elders' Teaching and Tribal Values in Planning a Long Term Care System?" This paper provides a structured way to assess and define traditional Native culture and values that can be integrated into LTC systems. Specific and practical examples are provided that offer "rituals of respect" for the culture and values of those served by LTC programs.

The fifth and final paper is written by Ralph Forquera, M.P.H., Executive Director of the Seattle Indian Health Board, entitled "How Do We Address the Long Term Care Needs of Urban Indian Elders?" This paper describes the migration of American Indians and Alaska Natives from rural and reservation settings to America's cities over the last century and provides an important perspective on the issues surrounding access to long term care services for this population.

Those gathered for this Roundtable brought with them more than their expertise in American Indian and Alaska Native health and long term care. They also brought their passion and commitment to the care of elders and those with disabilities. All of us involved in the Roundtable hope that this effort will further the efforts to develop long term care systems and services for American Indians and Alaska Natives.

HIGHLIGHTS OF ROUNDTABLE CONFERENCE IMPLICATIONS AND RECOMMENDATIONS

Following each of the five (5) discussion papers presented in this report is a series of specific implications and recommendations articulated by the Roundtable participants. These Roundtable recommendations should be reviewed in their entirety, as they represent the interaction and analysis of the diverse gathering of experts represented at the Roundtable Conference. Listed below is a brief summary of the larger list of Implications and Recommendations. For a more detailed review, please refer back to each of the five discussion papers in this report.

Over-arching Considerations

Commitment: The commitment by tribal and community leadership is key to developing effective Long Term Care services in tribal communities.

Coordination: Tribes currently provide an array of LTC services, but these are recognized to be inadequate to the need and the lack of coordination of available services may limit the effectiveness of these limited resources.

Culture and Values: Cultural aspects of LTC should be an integral part of all aspects of planning and service delivery. Cultural appropriateness must be deliberately planned into LTC services.

Expand Thinking About LTC Beneficiaries: Merging LTC issues for both the elderly and the disabled, in national policy and in local planning is a key consideration for future planning and development.

Inter Agency Collaboration: There is a need for federal agency collaboration and federally funded demonstration projects, LTC planning grants, and education and technical assistance for home and community based care that address the unique issues in Indian Country.

LTC Research Agenda: A formal research agenda on all aspects of LTC in Indian Country is needed and should be developed through a consultative process. This agenda should be established and funded to provide research and information regarding the variety of questions facing tribal and urban Indian communities considering LTC options, such as studying the economic viability of current LTC options, examining best practices and evaluating programs.

The Planning Process

Vision: The process begins with a vision of what LTC should look like in the community and should not be merely driven by funding initiatives. Establishing a vision for LTC services must be a consultative, participatory process. It is important to have a clear understanding of the realm of possibilities for providing LTC. Finding a service model that best meets the needs and most appropriately reflects the values of each community is important.

Involve the Stakeholders: The planning process must provide meaningful involvement from all the stakeholders including elders, Indians with disabilities, family members, advocates, service providers, community leaders and funding sources.

Collaboration: The network of resources potentially available to provide components of a comprehensive LTC system could include not only programs administered by tribes, IHS or urban program, but also county, state, federal and private providers. Collaborating with other providers will open doors to increased services and opportunities.

Education and Understanding of LTC Options: The options for providing LTC services in Indian communities includes many strategies beyond building a nursing home. Education of local leaders and planners is important to ensure that all the various options for home-based, community based services, alternate care facility, assisted living and other options are explored and understood.

Local Capacity and Diversity: Tribes are at very different levels of capacity in LTC planning and program development.

The Structure of Long Term Care

Long Term Care Services: There are a services currently available in tribal and urban Indian communities that provide pieces of the array of services defined as Long Term Care. These services may not be coordinated in an overall LTC system or strategy. LTC services within a community may compete against each other. Anecdotal experience suggests a hierarchy of preferences for LTC services, starting with home care provided by family and ending with nursing home care.

Workforce Development: Workforce development and retention is both critical and problematic when developing LTC systems. LTC service providers are too often not provided the pay or incentive to remain in these positions. Strategies for recruiting, rewarding and retaining individuals to fill these important positions are presented.

Case Management as a Core Element: Case management is a key element in LTC services, and it assumes even greater importance for home and community based LTC services.

Elder Advocacy: There is a need for more effective advocacy for AI/AN elders in nursing homes or in need of other LTC services. The existing state complaint systems do not appear to respond to AI/AN complaints about nursing home quality or practices.

Indians with Disabilities: In addition to meeting the LTC needs of Indian elders, Indian community members with disabilities may require LTC services and should be consulted and involved in the development of services.

Prevention: Effective health promotion and disease prevention for elders will decrease need for LTC services, or at least forestall the need for services.

Financing Long Term Care

Tribal and State Relationship: A meaningful relationship between tribal health programs and the states is key to providing LTC services, since the majority of funding for LTC services comes through the state administered Medicaid programs. States should be held accountable by CMS to ensure meaningful tribal consultation is occurring in the development of state LTC plans and related Medicaid waiver proposals. Tribes need to be more involved in the development of state 1915c waivers.

Medicaid and Medicare Enrollment Barriers: Barriers to enrollment in Medicaid and Medicare limit access to LTC services in Indian communities, since these programs are the primary payors for LTC services. More research is needed to better understand these barriers and to develop strategies to eliminate them.
Demonstration Projects: Federal agencies should collaborate in funding LTC demonstration projects, to begin to develop various models of different sizes and scales through out Indian Country.

Innovative Funding Strategies: Tribes need to be creative in assessing financing opportunities for LTC services to include, Medicaid, Older Americans Act, HUD, USDA, and Veterans Administration in addition to IHS and local tribal support.

Start-Up Funding: Not all tribal or urban Indian communities have the existing infrastructure to begin to provide a LTC service system for their population. Initial start-up funding would assist in moving forward to better coordinate existing resources and to fill gaps in services.

Creating Culturally Appropriate Long Term Care Services

Culture is Integral Component: Cultural appropriateness, or rituals of respect, should be recognized as an essential part of the care and should be included as a component of any quality of care evaluation. Culturally appropriate and sensitive services must be included in any LTC service system in Indian communities, as an integral component of quality services.

Culture is Dynamic: Culture is a dynamic process, and must constantly be assessed and its integration in LTC services evaluated to ensure appropriateness. Indian elders are oftentimes multi-cultural with different experiences and perspectives.

Integrating Culture Must Involve Community: Finding ways to integrate traditional culture and values into LTC must be based on a consultative process with community involvement and the participation of elders, people with disabilities and community leaders.

Urban Indian Elders

Needs Assessment: Little is known about the needs of the urban AI/AN elders with regard to LTC services. More research and assessment is required.

Urban Indian Program Involvement: Federal, State and intertribal efforts to address LTC needs of AI/AN should invite the participation of Urban Indian health programs, as one of the three components of the IHS, tribal and urban system of care. Planning, policy, and funding

should seek to break down distinctions between services provided to elders living in reservation and urban communities.

PRESENTATION OF FIVE PAPERS

Discussion Paper #1

LONG TERM CARE IN INDIAN COUNTRY TODAY: A SNAPSHOT

Summary of Issues

- While demographic data shows a large and increasing need for long term care programming in Indian country, only 6.5% of American Indian and Alaska Native elders receive such services.

- Indian elders' poor health and disability status is mirrored by their equally poor economic health, and is characterized by rural isolation, poverty, limited access to transportation or telephone communication means, and other barriers.

- Long term care services for AI/AN elders are typically uncoordinated in nature. Long term care services provided by the federal government have not been consolidated under one agency and are minimal in nature.

- The Older Americans Act provides $25.729 million in supporting grants to roughly 233 federally recognized tribes, and an array of services including a meals program, case-management, health aid, chore and some transportation services.

- Despite the limits of OAA funding for Indian elders, the services supported under Title VI can be an important part of the foundation for a tribe's long term care services and system.

- Tribal resources are becoming increasingly important to meeting long term care needs. Resources may be raised from tourism, gaming, or other tribal enterprises.

- Preliminary findings from a questionnaire conducted by the National Indian Council on Aging with the National Senior Citizens Law Center are presented and confirm findings about current long term care needs.

LONG TERM CARE IN INDIAN COUNTRY TODAY: A SNAPSHOT

William F. Benson[1]

I also hope you will realize that there are some who have a deep concern for older persons, specifically the older persons in the American Indian community. That we intend to do everything we can to use the authority we have, the resources that are made available to us, in order to get the kind of services through to older persons that will help them look to the future not with despair but with hope. The objective that we should try to keep in mind at all times is to try to make the last days the best days. If we are going to achieve that objective, it's going to require commitment. Not only on the part of those who are in the federal government, the state government, and in community government. Not only on the part of those who are part of private organizations, but on the part of every individual who has a concern for older persons.

Arthur S. Flemming, U.S. Commissioner on Aging
National Indian Conference on Aging
Phoenix, Arizona – June 17, 1976

These words, made more than a quarter century ago, by the venerable Dr. Flemming, who in addition to serving as U.S. Commissioner on Aging had been the first Secretary of HEW under President Eisenhower, remain unrealized today when it comes to services for America's Indian elders. This is especially true with regard to long term care.

For many elders, their last days are spent living with some form of chronic or disabling illness that limits their ability to perform activities of daily living (ADLs). These ADLs include such tasks as bathing, eating, dressing, using the toilet or getting into or out of bed -- in other words the daily activities that allow one to take care of one's basic needs. As noted by the National Resource Center on Native American Aging at the University of North Dakota (NRCNAA), "These activities are fundamental and when people express difficulties with them, they are considered to be in need of help."[2]

Many other elders, while not as severely limited in their independence as those with ADL limitations, have difficulties with other tasks such as cooking, cleaning, lifting, or doing the laundry. The limited ability or inability to perform these tasks, or Instrumental Activities of Daily Living (IADLs), also limits one's ability to take care of oneself and to lead a relatively independent life.

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[1] William F. Benson of The Benson Consulting Group serves as National Policy Advisor to NICOA and president of The Benson Consulting Group and is the former head of the U.S. Administration on Aging (DHHS). The author wishes to acknowledge the contributions to this paper made by Dave Baldridge, executive director of NICOA, Eric Carlson, attorney with the National Senior Citizens Law Center, and Linda Redford, Ph.D., director of the Geriatric Education Center at the Center on Aging of the University of Kansas Medical Center.

[2] *Activity Limitations among Native American Elders*. National Resource Center on Native American Aging, University of North Dakota. Report 01-2. October 2001

When elders can no longer perform their own ADLs or have limits in their IADLs over the long term-- rather than on an episodic basis when recovering from an illness or injury-- they are likely to need some form of assistance from someone else to help perform such tasks. With modest even minimal forms of support, an individual with such limitations may be able to maintain a reasonably independent life in their own home or some other home-like setting, such as living with a relative. Those with severe limits, especially in their ADLs, may require extensive support and interventions or even long term facility care.

According to the NRCNAA, there is a "greater level of need for personal assistance among the Native American elders than in the general population," adding that "only 6.5% of the Native American elders over 55 receive such services."[3] That figure is not surprising given the tremendous dearth of long term care services throughout Indian country, despite the great need and the demand that has grown for long term care especially over the past decade.

Long term care is the single most critical issue facing American Indian elders in the 1990s, according to the *National Indian Aging Agenda for the Future.*[4] Federally funded long term care is virtually nonexistent in Indian country. The need of Indian elders for long term care, including home health and personal care, is growing with the increasing size and longevity of the Indian population. Such services, however, remain undeveloped. Lack of care can weaken older Indians' health, cause premature hospitalization and unnecessary utilization of existing health care services in Indian Country. Chronic illnesses and disabilities also affect Indian elders' quality of life and ability to live independently. Rural isolation, poverty and access barriers further compound the problem for reservation elders.

In 1996, the National Indian Council on Aging (NICOA) published a comprehensive examination of the health status of Indian elders in relation to long term care. T*he NICOA Report: Health and Long term Care for Indian Elders* [5] reveals that "more Indians are living longer. . . There were 108,000 American Indian elders out of a total Indian population of 1,423,043 in 1980 and 165,842 elders out of a total American Indian population of 1,959,234 in 1990, a 52% increase during the decade." According to the Indian Health Service (IHS), Indian elders comprise only 8.3% of the agency's service population but uses 21% of its services.

The report indicates that Indian life expectancy at birth grew from 51 to 71.5 years between 1940 and 1989, and from 61 to 72 years since 1972. As of 1990, the gap between American Indian and White life expectancy had narrowed to less than 3.6 years for American Indian males and 3.0 years for females. Due in part to high birth rates and significant improvements in maternal/infant mortality (reduced by more than 90% since 1955 according to the IHS), American Indians now exhibit the youngest median population of all minorities, averaging less than 22 years compared to the national average of 30 years. This trend portends an "explosion" in the numbers of Indian elders over the next four decades.

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[3] Ibid.
[4] *National Indian Aging Agenda for the Future*. National Indian Council on Aging. 1995. Note Appendix I
[5] *The NICOA Report: Health and Long Term Care for Indian Elders*. Robert John and Dave Baldridge. A report by NICOA for the National Indian Policy Center, 1996.

At the same time, the overall health status of Indian elders continues to be poor. The IHS publication "Regional Differences in Indian Health for 1995" indicates that Indian age-adjusted mortality rates are greater than U.S. All Races rates by the following percentages:

Alcoholism	674%	Diabetes Mellitus	234%
Tuberculosis	480%	Suicide	85%
Accidents	265%	Homicide	62%

Indian elders are also affected disproportionately by disability. According to data from the 1990 Census, "American Indian elders report the highest level of work disability among the five racial groups . . . 44.3% report a work disability compared to only 29.0% of non-Hispanic Whites. Moreover, over one-third of American Indian elders (36.8%) report that their condition prevents them from working compared to only 23.2% of their non-Hispanic White age peers. These high levels of disability among Indian elders offer further evidence of the need for health programs to specifically address the unique needs of this population."

Indian elders' poor health and disability status is mirrored by their equally poor economic health. "The 1990 Census shows that 30% of Indians aged 65 and older who reside in rural areas have no vehicle available, 31% have no telephone in their living quarters, and 24% speak English poorly." Because of their rural isolation, poverty, and other barriers, reservation elders have little access to existing long term care delivery mechanisms that may serve mainstream or urban elderly populations. The NICOA report also examined the lack of nursing homes in Indian Country, stating:

> Unlike the general population (which has many nursing home facilities available), nursing home facilities are extremely rare in Indian communities. The development of long term care institutions in Indian communities is well behind the general population, which began extensive nursing home construction in the 1960s (Manson, 1989).
>
> The first Indian nursing home was constructed in 1969, and only 13 tribally-operated nursing homes existed as of 1993. With the exception of these tribally operated facilities, other institutions tend to be located long distances from where Indian elders live. Consequently, many elders are placed in non-Indian facilities and may become isolated from their families and friends. Lack of cultural diversity and isolation…are major sources of resident and family dissatisfaction with the care provided in off-reservation homes.
>
> Because of these problems, many tribes are considering the feasibility of establishing their own nursing homes to meet the need for institutional care within a tribal setting. However, the solution to the long term care needs of American Indian elders presents obvious economic difficulties (of construction, maintenance, and staffing) and may not represent the wishes of American Indian elders.

For a variety of reasons, many Indian tribes and health care providers are ill-prepared to deal with the pending "explosion" in the numbers of elders whose health, economic, and demographic characteristics all point to the urgent need for a full array of long term care services. Both public and tribal resources fall far short of necessary levels. A recent report by the National Indian Health Board describes the dearth of long term care, both home-based and in nursing homes, in Indian communities in the nine states in its study:

> Only three states in this study have tribally operated nursing homes: Arizona (3), Minnesota (1) and Washington (1). Of the three states, Arizona is the only one with managed care for long term care. [The other six states in the study are California, Michigan, New Mexico, New York, Oklahoma and Oregon.]
>
> Home health care is covered more often under Medicare than Medicaid. However, Medicaid does pay for some home health services . . . The major barrier consists of state requirements to become a certified home health agency under state laws. Some states require that home health agencies offer a range of services that are beyond the tribe's capability, such as occupational therapy or physical therapy.[6]

The development of long term care in Indian Country will require the effective use of all available funding resources. Such resources arise primarily through Medicare, Medicaid, the Indian Health Service (IHS) and tribal resources. Each offers unique but limited support, making a composite of resources a key to future planning.

Medicare

Medicare is a principal existing source of health care coverage and payment for Indian elders. Because it covers hospitalization and other forms of acute care and treatment, Medicare is not available to meet extended needs in chronic care. In limited ways, such as for those who are homebound following a hospital stay, Medicare is useful in supplying short-term home health in an individual's transition to chronic care. Medicare also pays for skilled nursing facility stays but the conditions under which eligibility for the service is established and maintained is stringent and thus covers only a limited amount of nursing home care.

Medicaid

Medicaid is the principal source of public long term care financing in the United States. It is the largest public payer of nursing home care and is providing increasing amounts of home-based care, usually through a state's use of Medicaid waivers or through the provision of personal care services as an optional Medicaid service. Unlike other Medicaid services, health services provided by either tribal or IHS providers to enrolled tribal members are fully financed by the Federal government. Health care under Medicaid remains primarily a state responsibility. State home care coverage varies, particularly in state definitions of homemaker services. The federal Centers for Medicare and Medicaid Services (CMS, formerly the Health Care Financing Administration) define basic rules for Medicaid participation. It can set liberal policies on state waivers for direct funding to tribes, although this flexibility appears to remain unrealized.

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[6] *Indian Health in Nine State Medicaid Managed Care Programs*. Mim Dixon. September 1998.

The federal government once dealt directly with tribes on health issues through the IHS, but today it refers tribes to the states on questions arising under Medicaid. Some states in turn refer tribes to health maintenance organizations (HMOs) and similar managed care entities. HMOs rarely enhance Indian access to health care, which already is impaired by problems of distance, transportation, and cultural and linguistic barriers in Indian Country. Most HMOs operate for profit, and typically avoid serving sparsely populated areas because of higher costs. Medicaid can be a shifting resource for tribal health unless careful planning addresses the needs of individual tribes in a realistic way.

Indian Health Service

The Indian Health Service (IHS) provides services directly to more than 1.3 million Indians, principally through the operation of 61 health centers and 38 hospitals. The IHS historically has not attempted to provide community-based or home-care programs or residential care facilities. Federal funding for the IHS, moreover, remains modest at best, making it difficult for the IHS to assume new commitments. The IHS budget is discretionary and not an entitlement like Medicaid or Medicare. As such, its funding suffers in a climate unfavorable to discretionary increases. The average federal expenditure per Indian patient is far lower than the national average and is shrinking further. In 1977, the average federal expenditure per Indian patient was 75% of the national average. By 1999, it had dropped to 34%.

Older Americans Act

The Older Americans Act (OAA) benefits Indian elders in several ways, including through addressing some long term care related needs. Most notably, Title VI of the OAA provides direct grants from the Administration on Aging (AoA), the federal agency with responsibility for the OAA to tribal organizations. Title VI programs can be the foundation for elder services in many Indian communities, providing a potential array of services including meals and chore, home aid, transportation and case management services. Unfortunately, inadequate funding too often constrains Title VI services to meals programs with limited transportation. The current (fiscal year 2002) funding level for Title VI is $25.729 million and supports grants to some 233 federally recognized tribes.

OAA Title III funds that go to states and local area agencies on aging (AAAs) support a wide array of services, including: congregate and home-delivered meals; transportation services; information and assistance services; legal assistance; case management; some respite and other long term care services; long term care ombudsman services; health promotion and disease prevention activities; and others. Although Title VI grants were intended to be somewhat analogous to grants to AAAs, the amounts are so small, that as indicated they do not support much more than a meals program and some transportation services (typically associated with the meals program -- transporting home-delivered meals and elders to and from meals sites). Title VI's primary contribution to long term care is its modest support for limited home aid, case management, transportation and home-delivered meals for frail and chronically ill elders. These types of services, if provided with a strong case management component, could allow frail elders to stay in their homes and not be placed in nursing homes.

In some parts of Indian Country, states have elected to support Title III-funded Indian area agencies on aging. Washington state, for example, has two: at the Colville Nation and the Yakama Nation. Arizona and New Mexico each have a statewide Indian AAA. Nationwide, there are some 10 Indian AAAs. These entities have far more resources than tribes that just receive Title VI services.

The 2000 amendments to the OAA established the National Family Caregiver Support Program (NFCSP), which supports activities at the local level to assist family caregivers through education, information, support groups, and some modest services, such as respite care. The program also includes a component to assist grandparents who are raising grandchildren. When the NFCSP was introduced as a part of pending OAA reauthorization legislation, it did not include a grant-making component for tribes. Vigorous advocacy by NICOA and several others, particularly James DeLaCruz of the Quinault Indian Nation resulted in a separate part of the NFCSP being established in the final legislation to provide grants directly to tribes for caregiver-related services. The present appropriation for the Indian portion of the NFCSP is $5 million out a total of $136 million for the program. The NFCSP funds do provide tribes with an important source of funds for a critical part of long term care – enhancing the ability of informal family caregivers to continue to provide care to their loved one. Given the paucity of long term care services, especially in Indian country, supporting informal caregivers is especially important. The NFCSP also provides authority to the AoA to support national demonstrations and other activities to support NFCSP-related activities. NICOA has proposed to AoA using Title IV funds to support a national technical assistance effort to help tribes plan for and effectively implement family caregiver-related services. To date, AoA has not funded such an effort.

Two other parts of the OAA are important to note. The first is Title IV, the research and demonstration part of the Act. In the past, Title IV funds have been used to provide training for and technical assistance to Title VI grantees to improve their skills and knowledge basis. Unfortunately, the AoA discontinued using Title IV to support training and technical assistance for Title VI personnel and grantees. The final part of the OAA worth noting is the Indian section of Title VII, the Vulnerable Elder Rights section of the OAA. Title VII provides funding and authority for such activities as ombudsmen to investigate complaints of elders in nursing homes and other long term care facilities, legal assistance development services, and activities to combat elder abuse. The 1992 amendments to the OAA established Title VII and included a part B for providing support to Indian country for addressing abuse and other issues facing vulnerable elders. Despite the addition of this new part of the law, the Congress has yet to provide an appropriation to make the promise of Title VII a reality for Indian elders.

Overall, the OAA is an important source of certain services for elders, offering a segment of— even a foundation for— the long term care related services needed in tribal communities with the potential for expansion. Home-delivered meals are a critical component of any long term care delivery system and Title VI does offer that to tribes. The limited transportation available under Title VI is also important. The new NFCSP is especially important given the prominent role of family members in being caregivers for their elderly loved ones. NFCSP should offer a valuable addition to the development of long term care services at the tribal level.

Tribal Resources

More and more tribes now contract and administer their own health services under authority of the Indian Self-Determination Act (P.L. 93-638). The IHS budget, however, remains static and tribes, even when under contract, must find other resources to keep pace with rising costs associated with providing health care. Thus, tribal resources are becoming an important factor in the health financing equation. Resources may be drawn from tourism, casinos or other tribal enterprises. With regard to long term care, the commitment of resources by an individual tribe becomes critical to its ability to assess its own capacities, to start funding a long term care program, and to meet gaps in covered services. Successful adaptation of diverse resources, therefore, can create a foundation for a long term care program.

Long Term Care Data

Despite the substantial and growing need for long term care in Indian country and the lack of long term care services for addressing those needs, there has been little research on and analyses of long term care needs for Indian elders. Outside of the reports previously cited there is little available data about long term care needs and a paucity of study of services and programs.

A 1998 report[7] about long term care needs of American Indian elders in the IHS Santa Fe (NM) Service Unit cited a consensus statement from an IHS roundtable, conducted in 1990 and reported by IHS in 1993, that emphasized the need for systematic data on elders' "long term care status from which service development can proceed," adding that:

> 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 conducted extensively 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.

It is important to note that over the past several years the National Resource Center on Native American Aging at the University of North Dakota has developed a comprehensive instrument for assessing the functional status of elders at the tribal level and has in fact completed many assessments of individual elders in a number of tribes.[8]

In 1996, the Administration on Aging at the U.S. Department of Health and Human Services issued a report on "Home and Community-Based Long Term Care in American

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[7] *Long term Care Service Needs of American Indian Elders in the IHS Santa Fe Service Unit* (draft). Catherine Hagan Hennessey, Robert John, Lonnie C. Roy. July 1998

[8] Author's conversation with Alan Allery, director of the NRCNAA, 2001

Indian and Alaska Native Communities."[9] Examples of the key findings reported by the AoA include:

- The need for home and community-based long term care (HCBLTC) services is extensive but is largely unmet.
- Alternative housing, including retirement villages, assisted living arrangements, personal care boarding homes, group homes, short-term rehabilitation facilities, and intermediate/skilled nursing facilities are rarely available for elders living independently and the need for these services is rarely met.
- Although there is an array of providers and funding sources for HCBLTC services, these are fragmented and insufficient to meet the need.
- Funding levels, lower priority services, little appreciation of local need, limited access to decision makers, and excessive regulation were unanimously identified as barriers to continuing previously authorized federal and state funded programs and to developing new federal and state funded programs.
- The limited financial resources available to tribes form the main obstacle to developing programs and providing HCBLTC services.

National Survey Data

Given the limited information available about long term care for American Indian elders, NICOA together with the National Senior Citizens Law Center (NSCLC) has undertaken a national project to gather information about the current state of long term care in Indian country, and to lay the groundwork for helping tribes to assess their own long term care services and infrastructure and to develop long term care services deemed necessary and appropriate by individual tribes.[10] As the initial stage in this multi-year project a questionnaire was administered to all tribes receiving Title VI funding under the Older Americans Act in fall and early winter 2001. The principal purposes of the survey were to:

- Elicit information about current long term care services available to Indian elders, funding sources for such services, tribal characteristics and tribal plans for long term care services development and expansion.
- Identify potential "best practices" and "important lessons" for future study and applicability throughout Indian country.

Of the 236 tribes presently receiving grants under Title VI of the Older Americans Act, 109 tribes responded representing a 46 percent response. While the questionnaire results are currently being analyzed, some preliminary findings are beginning to emerge from the

[9] *Home and Community-Based Long Term Care in American Indian and Alaska Native Communities*. Administration on Aging, U.S. Department of Health and Human Services, Native Elder Health Care Resource Center, University of Colorado, National Resource Center on Native American Aging, University of North Dakota. December 1996.

[10] *Long term Care in Indian Country: A Project to Establish "Building Blocks" for Tribal Use in Planning for the Long term Care Needs of Indian Elders*, a project of NICOA in partnership with the National Senior Citizens Law Center funded by the Retirement Research Foundation (Chicago, IL), and the Geriatric Education Center at the Center on Aging of the University of Kansas Medical Center.

analysis. Those findings are presented here with the caveat that given the early stage of analysis, data are preliminary and may require verification and refinement.

One clarification that is necessary, for example, concerns data from Oklahoma tribes. Because Oklahoma tribes do not reside on reservations and their homelands include a larger and diverse community including numerous cities and towns, the responding 11 Oklahoma tribes significantly skew some of the data. As an example, the first question in the survey instrument asks, "How many people live on your reservation or tribal community?" The mean for all the responses is 8,824 with a high of 312,915. Without the Oklahoma tribes in the analysis, the mean is 3,562 with a high of 31,799. As another example, question no. 5 asks, among a number of questions, if nursing home care is "available on (the) reservation or in the tribal community." With Oklahoma tribes included, there are 27 "Yes" responses. Without the eleven Oklahoma tribes included there are 19 "Yes" responses. This is apparently due to the number of non-Indian nursing homes in communities contiguous with Oklahoma tribes.

What follows are findings from preliminary data from selected portions of the survey analysis that has been conducted to date. For purposes of this paper, while adjustments are made to the survey results analyses, Oklahoma tribes are excluded unless otherwise noted.

Tribal Demographics

The median age at which tribal members are considered elders and eligible for aging services is 55 with a minimum of 50 in 7 tribes and a maximum of 65 in 5 tribes (Question no. 2).

The median for the percent of the tribal population represented by elders is 11 percent and the median number is 179 elders with a range of 4 to 1,813 (Question no. 3).

Nursing Homes

Nursing homes are usually outside the tribal community or reservation. Of those outside nursing homes about two-thirds are located in local communities, and the other third are in distant communities. Nursing homes on the reservation or in the tribal community tend to be medium-sized – about 45-50 beds. Residential care tends to be smaller – about 16-20 beds.

> The median number of elders living in nursing homes is five with a range from zero to 100 (Question no. 4).
>
> When asked "Of the elders living in nursing homes, how many do you think could have remained at home if more health care and/or personal care were available in the tribal community?" the median was 3 or 60 percent of the median number living in nursing homes. (Question no. 4a)
>
> 19 tribes report having nursing homes available on the reservation or in the tribal community with 4 reporting that it is owned by the tribe and 5 reporting that it is

operated by the tribe.[11] 21 tribes report that the "Tribe is planning to create or expand this service" and 16 respondents answered that they "don't know" if there are such plans (Question no. 5).

When tribal members "have to go to a nursing home" 68 report that they go to local communities off the reservation/outside the tribal community and 35 report they go to distant communities (Question no. 9).

The median distance traveled to go to a nursing home is 25 miles with a maximum distance of 200 miles (Question no. 10).

When asked "How good are the nursing homes that are off the reservation in providing care that is sensitive to the particular needs and desires of Indian elders, such as providing traditional foods, employing tribal members as caregivers, honoring cultural health practices, etc.?" 45 rated them poor (26) or very poor (19) while another 28 rated them fair. On the other hand, 12 answered good and 5 said very good. Not surprisingly, outside nursing homes are not considered very good in recognizing Indian-specific needs. The biggest problem is the lack of cultural sensitivity (49%) followed by the significant distance between the tribal community and the nursing home (23%). Note these statistics are for all tribes (Question no. 12).

NICOA conducted a separate but complementary survey specifically targeted to Indian owned or operated nursing homes in March-April 2002.[12] The initial results have been analyzed and a brief summary of findings follows:

12 Indian nursing homes were identified (11 of these are tribally owned and 1 is tribally licensed).
A total of 627 beds are in the 12 facilities.
84% of the beds are filled by American Indian/Alaska Native people.
The total occupancy for 2001 was nearly 65%.

Reimbursement
10 of the facilities report receiving Medicaid payments.
6 report receiving Medicare payments.
3 report receive VA payments.
5 report payments made from tribal funds.

Staffing
8 facilities or 75% have unfilled Certified Nurse Assistant (CAN) positions.
5 have unfilled RN and LPN positions.
3 have unfilled administrative assistant positions.

[11] It is not yet clear whether the "owned by tribe" and "operated by tribe" has overlap within the responses and if so to what extent. In other words, it may be that among the five tribes operating a nursing home 4 of them own the facility. (Question no. 5)
[12] Designed with consultation from Dr. Bruce Finke of the IHS and administered and analyzed by Eva Gardipe and Heather Mann of NICOA.

Available Long term Care Services/Ownership (Question no. 5)
The most frequently reported available long term care services by all tribes, including those in Oklahoma, are:

Transportation (94)
Home-delivered meals (91)
Meals at nutrition sites (88)
Senior Center (82)
Home modification for disabled persons (77)
Home maintenance/repair (76)
Housekeeping (74)

The long term care services (with the most common funding sources in order in parentheses) that are generally available in all tribes including Oklahoma's include:

Home Health Care (Medicare & Medicaid)
Case Management (IHS, tribal funds, 638 & Medicaid)
Housekeeping (tribal funds & Medicaid)
Personal Care (Medicaid & tribal funds)
Home maintenance (mostly tribal funds but with some state funds)
Home-delivered meals (OAA, tribal funds, state funds)
Nutrition Sites (OAA, tribal and state funds)
Senior Centers (tribal funds, OAA)
Transportation (tribal funds, IHS, OAA & state funds)

The least available long term care services were (number reporting service available in brackets)[13]:

Alzheimer's/dementia care (15)
Adult Day Care (19)
Nursing Home Care (27)
Board & Care, assisted living or other residential care facility (29)
Kidney dialysis (34)
Hospice care (36)

(Selected) Services Owned & Operated by Tribes:

Service	Owned	Operated
Home Health Care (69)	23	34
Kidney Dialysis (34)	7	8
Nursing Home Care (19)[14]	4	5

[13] These numbers appear skewed by OK, e.g., 10 of 11 reporting OK tribes report the availability of home health care a far greater percentage than among all other tribes

[14] Excluding OK tribes

Board & Care, ALF, RCF (29)	12	15
Adult Day Care (19)	8	9
Hospice Care (36)	3	6
Case Management (61)	29	41

Family Support
With regard to family support, in general elders often do not get home care needs met, family members are sometimes available, and the family members involved tend to be few. The following questions were asked and the responses were (Questions 6-8):

> "How often would you say your tribal elders get all the assistance they need with activities such as housecleaning, cooking, or personal care?"
>
> | | |
> |---|---|
> | Most of the time | 22 |
> | Some of the time | 39 |
> | Rarely | 15 |
> | Almost Never | 12 |
>
> "Are family members generally available and able to assist elders, if they need it?"
>
> | | |
> |---|---|
> | Most of the time | 19 |
> | Some of the time | 57 |
> | Rarely | 11 |
> | Almost Never | 1 |
>
> "When family members do assist elders, are there usually many family members providing assistance?"
>
> | | |
> |---|---|
> | Many | 8 |
> | Few | 74 |
>
> "Of the families in your tribe who are providing daily care to an older relative, how many could use help with the care they are providing?" (e.g., due to difficulty, stress, exhaustion)
>
> | | |
> |---|---|
> | Most of them | 64 |
> | Some of them | 27 |
> | None of them | 1 |

Respite care was identified as the service that would be the "most helpful" in relieving stress on family caregivers, followed closely by personal care (someone to help with bathing, dressing and other personal care tasks). Farther back on the list is housekeeping and then home health care followed by other services (Question no. 14).

Other
Tribes were asked about participation in the Qualified Medicare Beneficiary (QMB) and Specified Low-Income Medicare Beneficiary)SLMB) programs. With respect to QMB, 56%

said tribal members participate, just 9% said they do not and 35% didn't know. As to SLMB 39% said they participate, 18% said they do not and 43% didn't know (Question no. 17).

Over 70% of the reporting tribes are gaming tribes. Of these, the large majority has full casinos. About half the tribes have "other significant businesses." Without the Oklahoma tribes in the equation, about 2/3 are gaming tribes. Almost all of the reporting Oklahoma tribes are gaming tribes. (Questions no. 18 & 19)

When asked "how important is care of the frail and disabled elders to your tribal council" given all the important concerns of tribal government, 17% said it was the "most important." Forty-seven percent said it was "among the top three most important areas." Another 28% said while not among the top three, that it was among the "top ten." Only 8% said it was not among the top ten most important areas. (Question no. 20)

The questionnaire closes with an open-ended question, "In your opinion, what is the single most important thing your tribe should do to help its elders?" Responses included many suggestions to build nursing homes (20%) or assisted living facilities (13%), or to establish home health services (14%). (Question no. 21)

Roundtable Discussion of Implications and Recommendations Regarding Current LTC Services in Indian Country

1. **Vision:** Be very clear about your community vision of what you want, in as much detail as possible. Do not merely respond to funding announcements to craft your vision, but consult with the community through a collaborative process.

2. **Smaller is Better:** Focus on smaller services, such as Home and Community Based Services as the platform for building more complex levels of care.

3. **Communication is Key:** Communicate early and often with the key stakeholders and potential beneficiaries of LTC services, including elders and persons with disabilities. Make their participation integral to the planning and oversight of services.

4. **Reimbursement and Funding:** Consider how the project will be financed for both start-up and ongoing operations. Medicaid reimbursable services can provide the foundation for operating the LTC system, but it is also important to look beyond Medicaid for potential resources, such as HUD and USDA grants. Trying to isolate tribal programs and limit resources only to tribal funds is a very expensive option.

5. **Leadership:** The more tribal leadership is educated and aware of the full realm of LTC continuum of services and committed to crafting a program that is based upon the needs of the community the higher likelihood for long term success.

6. **Workforce Development:** Consider who will fill the workforce requirements of the LTC programs and initiate training and development to recruit and retain a quality and happy workforce.

7. **Case Management:** Case management is the key to effective Long Term Care. The trend toward more Home and Community Based Services elevates the importance of a strong case management system.

Discussion Paper #2

OPPORTUNITIES FOR MEDICAID FINANCING OF LONG TERM CARE IN AMERICAN INDIAN & ALASKA NATIVE COMMUNITIES

Summary of Issues

- Opportunities exist for tribes to more fully utilize current federal Medicaid and waiver provisions and develop new or improve existing long term care programs for blind, disabled or aged tribal members.

- Despite having higher poverty rates and disability rates, American Indian and Alaska Natives (AI/AN) have lower participation in Medicaid and lower payments made on behalf of AI/AN Medicaid beneficiaries.

- There are many possible root causes for the low rates of Medicaid participation for eligible members of the AI/AN population, including misunderstanding of estate recovery provisions and other technical barriers and inaccessible long term care services and service providers.

- To reduce barriers to participation and maximize AI/AN reimbursement eligibility, programs developed by tribes to meet the unique needs of their population must complement the existing state assistance framework, requiring effort from both the state and tribes.

- In specific terms, this means the relationship between states and tribes requires active and timely tribal consultation, technical assistance and a shared vision.

OPPORTUNITIES FOR MEDICAID FINANCING OF LONG TERM CARE IN AMERICAN INDIAN AND ALASKA NATIVE COMMUNITIES

Mim Dixon[15]

Introduction

Medicaid is a federal-state program to pay for health care for the poor who meet specific criteria.[16] In 1997, the Medicaid program paid about $59 billion for long term care (Tilly 2001), which is nearly 60 percent of a $1 trillion budget.[17] When tribes think of long term care, they usually think about the need for culturally acceptable nursing home care for tribal elders. However, long term care encompasses both institutional care, such as nursing homes, and the kinds of services that can be delivered in a patient's home or in other less restrictive community settings. Home and Community Based Services (HCBS) can include a very wide variety of services.

Medicaid is funded by both state and federal taxes. The federal government provides guidelines and matching funds, while the states actually design and administer the programs. States submit their State Medicaid Plan and waivers to the federal Centers for Medicare and Medicaid Services (CMS).[18] Each state has a different Medicaid program. Thus, tribes that want to influence Medicaid funding for long term care must work with their state governments. Tribes must also work at the national level when changes are needed in the federal laws and regulations that govern the Medicaid program. The purpose of this paper is to identify some of the opportunities for states and tribes to work together.

The Indian Health Service has never provided long term nursing home care. The Bureau of Indian Affairs has been charged with providing institutional residential support for those in need, but it also has never provided nursing home care. If Congress had funded either of these federal agencies to provide this essential element in the continuum of health care, then American Indians and Alaska Natives (AI/AN) would not have to apply for Medicaid.[19] At the present time, Medicaid is not only the leading funding source for long term care for all

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[15] Please address comments on this paper to Mim Dixon, Mim Dixon and Associates, 1618 Spruce Street, Boulder, CO 80302, or via e-mail to mimdixon@hotmail.com, or by FAX at 303-443-4733, or by telephone at 303-674-9513.

[16] This paper relies primarily on information presented in *Understanding Medicaid Home and Community Services: A Primer* (Smith 2000). To make the paper more readable, the only times this reference is specifically cited is when there is a direct quote that is tied to a page number. Unless other references are cited, it should be assumed that the source of information is Smith (2000).

[17] The elderly comprise only about 10 percent of the total Medicaid beneficiaries (Wiener 2000).

[18] Formerly the Health Care Financing Administration

[19] For acute and chronic medical care, Congress has funded the Indian Health Service at less than 60 percent of the need, as compared the the federal employee benefit package.

Americans, but it is also almost the only source of long term care for American Indians and Alaska Natives.

Despite the fact that there are higher poverty rates and disability rates among American Indians and Alaska Natives, there is a lower participation in Medicaid and lower payments made on behalf of AI/AN Medicaid beneficiaries. For example, the 1990 Census showed that 27 percent of American Indians in the 64-74 age group category lived below the poverty level, compared to 10 percent of U.S. All Races (Baldridge 2001). At the same time, it is estimated that 25-44 percent of American Indians have disabilities (Baldridge 2001). Yet only 65 percent of American Indians who are eligible for Medicaid are receiving it, compared to 88 percent of the U.S. All Races category (Baldridge 2001).

It is not clear why American Indians are not fully participating in Medicaid and why less is spent on American Indians with Medicaid than other Medicaid recipients. Possible explanations have been offered that require further research. One potential explanation is that long term care services, which comprise 60 percent of the Medicaid budget, are not accessible and not designed to meet the needs of American Indian consumers and their communities.

It is this hypothesis that that is one of the main themes of this paper. While the level of state consultation with tribes has not been documented with regard to long term care, it has been shown that tribes and urban Indian clinics often are not satisfied with the level of consultation in the development of Medicaid managed care waivers and Child Health Insurance Programs (Dixon 1998, Kauffman 2001).

On July 17, 2001, the Acting Director of the Center for Medicaid and State Operations issued a letter to State Medicaid Directors regarding tribal participation in the planning and development of Medicaid waiver proposals and waiver renewals. The letter did not address renewals of state Medicaid plans. CMS allows states to determine how consultation with tribes will be conducted and only requires that states notify federally-recognized tribes in writing at least 60 days before the anticipated submission date of the state's waiver submittal, that tribes be given a minimum of 30 days to prepare a written response, and that states hold a meeting to discuss the waiver if tribes request it.

On August 17, 2001, the Region X CMS Administrator issued a letter to tribal leaders in that region stating that:

> CMS is not able to stop a review of a Section 1915(b) or 1915(c) proposal to allow for additional time to review the proposal once it has been submitted. Therefore, we strongly encourage your Tribe to work closely with the State during the proposal development process to ensure your issues and concerns are included with the State's final submission to CMS.

The Section 1915(c) waiver is the waiver for long term care home and community based services. This statement suggests that CMS will not take additional testimony from tribes, even if the state is unresponsive to their concerns. This raises issues about the exercise of the federal trust responsibility by CMS.

Further research is needed to determine whether states have effectively consulted with tribes in the development of their State Medicaid Plans and in the development of Home and Community Based Services (HCBS) waivers. Anecdotal evidence suggests that there are very few tribal representatives who have a command of the very complicated topics of long term care, Medicaid regulations, and related issues to be able to review a waiver proposal and provide a written response within 30 days, or to engage effectively in a meeting to discuss waiver plans. Furthermore, it appears that most states do not have people in their Medicaid planning staff who fully comprehend the current and potential roles of tribal governments, the Indian Health Service, and the Bureau of Indian Affairs in the provision of long term care services. This paper attempts to bridge some of the gaps in knowledge between these players without getting into the myriad of technical details that can overwhelm any discussions of strategy.

While this paper focuses on opportunities for Medicaid funding for long term care in tribal communities, it should be noted that states are also the key players in the planning and administration of other federally-funded services related to long term care. These include the Social Services Block Grants that provide a wide array of special support and home and community-based services, Supplement Security Income (SSI) that provides cash payment for poor and disabled individuals, and the Rehabilitation Act of 1973 that provides services to disabled adults related to vocational training and independent living services. While tribes often receive funding under Title VI of the Older Americans Act (OAA), the majority of the funds appropriated through the OAA are administered through the state and Area Agencies on Aging. These funds provide nutrition, home care, adult day services, respite, transportation, legal advocacy and preventive health services, as well as services authorized by the National Family Caregiver Support Program.[20] The Area Agencies on Aging (AAA) can provide an important technical assistance function.[21] In addition, some states have programs for elders and the disabled that are completely funded through state revenues. Thus, tribal-state coordination in the planning and delivery of long term care services must reach beyond the Medicaid programs.

Overview

Medicaid pays the largest percentage of costs associated with long term care in the United States. In 1998, Medicaid paid for 38 percent of all long term care expenditures, including 46 percent of nursing home expenses. Medicaid expenditures for long term care in 1997 were approximately $59 billion, with 73 percent going to nursing home or other institutional care[22], such as intermediate care facilities for the mentally retarded (ICF/MR) (Tilly 2001). Home and community based services are the fastest growing part of the Medicaid long term

[20] Under OAA, there is great variation in long term care services from state to state and even within states by Area Agencies on Aging.

[21] Some tribal organizations are designated as AAA, including the Inter Tribal Council of Arizona and the Navajo Nation.

[22] According to Tilly (2001) states with large AI/AN populations that have a significantly lower percentage expenditure on institutional care include Oregon with 40-49 percent of the LTC Medicaid budget spent on institutional care; Alaska, Washington, Wyoming, and New Mexico in the 50-59% category; and California, Montana, Utah, Minnesota, Michigan and Wisconsin in the 60-69% category. At the higher than average category is Nevada with 80-89 percent of Medicaid LTC spent on institutional care.

care expenditures. After individual personal expenditures are taken into consideration[23], the next largest payer is Medicare, as shown in Table 1.

TABLE 1
Payment Sources for Long Term Care in the United States, 1998

	Total Long Term Care Expenditures ($117.1 billion)	Nursing Home Expenditures ($87.8 billion)
Medicaid	38%	46%
Medicare	18%	12%
Individual's out of pocket	30%	33%
Private Insurance	8%	5%
All other	6%	5%
Total	100%	100%

Source: Kaiser Commission on Medicaid and the Uninsured, Medicaid Facts, March 2001

Medicaid was originally organized around categories of needy people. The three categories of poor people that Medicaid long term care has been designed to assist are the aged, the blind, and the disabled. Disability is the operative concept. Medicaid covers people regardless of age who are physically or mentally disabled and meet the income criteria. A portion of the institutionalized long term care is designed to meet the needs of people who have serious mental retardation, mental illness or developmental disabilities. So, when tribes engage in consultation with state Medicaid planners, they need to be thinking about people with disabilities of all ages, not just the elderly.

Disabilities are usually defined by an individual's ability to perform everyday activities. These activities are generally classified in two categories:

> Activities of Daily Living (ADL) – eating, bathing, dressing, toileting, transferring from bed to chair.
>
> Instrumental Activities of Daily Living (IADL) – grocery shopping, meal preparation, laundry, housework, using the telephone, money management, medication management.

The severity of disability is usually measured by the number of ADLs that a person is unable to perform.

Nationally, only 12 percent of the people who need long term care are served in nursing homes or other institutions (Kaiser). In 2001, there were 1.3 million elderly people in nursing homes throughout the country, with half over the age of 85 and more than 80 percent severely impaired (requiring assistance with 3 or more ADLs) (Kaiser 2001).

[23] Nationally, 71 percent of adults who require assistance receive it from unpaid caregivers (Tilly 2001). It is possible that the percentage is higher in Indian Country, but that has not been substantiated.

Trend Toward Home and Community Based Services

When Medicaid began in 1965, the federal government mandated that states provide nursing home care for adults. Medicaid expenditures escalated due to the high costs of nursing home care and the high number of people being served, as a result of the growing population of elderly people in our society, as well as new medical technology that has allowed people with congenital and acquired disabilities to survive and live longer lives. This combination of high cost and high demand led to the exploration of more cost effective ways to deliver skilled nursing services. In 1970, the federal government mandated that Medicaid programs pay for home health care services as an alternative to nursing homes.

Beginning in the 1980s, the federal government changed the rules to give states more options to use Medicaid dollars for HCBS. While State Medicaid Plans must provide all services consistently throughout the entire state, section 1915(c) waivers allow states to design HCBS programs for specific populations in specific areas. At the same time, states developed mechanisms, such as requiring Certificates of Need (CON), to limit the construction of new nursing homes that could potentially contribute to the escalation of costs as a result of low occupancy rates.[24] Thus, both states and the federal government have been trying to move the Medicaid program away from it's "institutional bias."

This trend was accelerated by a 1999 Supreme Court case, known as the Olmstead decision. The Court observed that "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment." Under the Americans with Disabilities Act (ADA), the Supreme Court ruled that under most circumstances States must consider providing community-based services for people with disabilities who would otherwise be entitled to institutional care.[25] While many states are actively working to implement the Olmstead decision, the funding and planning for these activities has largely bypassed AI/AN communities because they have never had facilities for institutionalized long term care.

It is easy to confuse Medicare Home Health regulations with Medicaid Home Health regulations. Medicare is the federal health care program for older people. Medicare only pays for skilled nursing home care for a very limited time after a person is hospitalized.[26] Historically, Medicare has paid for most of the home health services for elderly, while Medicaid has paid for most of the nursing home services for the elderly. However, that is changing as Medicaid becomes more involved in home and community based services.

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[24] In 1998, 38 states had CON programs and 19 states had a moratorium on new construction of nursing homes (Wiener 2000).

[25] The Supreme Court qualified this decision to take into account the professional judgment of the appropriateness of the placement, the preferences of the people who are affected, and the resources that are available to support the needs of the entire group of people with disabilities who are entitled to state-funded services.

[26] Medicare was never designed as a long term care program. The Medicare reimbursement guidelines allow for only medically-directed episodic care, not the continuing or chronic care that is the hallmark of long term care.

Medicare's short term, medical services are aimed at rehabilitation; while Medicaid's home care, personal care and home-and-community-based care are long-term habilitation services.

To receive payment under Medicare for home health services, a Home Health Agency must be licensed and regulated by Medicare. The rules and regulations for Medicaid home care may be different. For example, the Medicare program limits home health services to those who require skilled nursing care or therapy services, while Medicaid is less restrictive. Also, Medicare requires a registered nurse to supervise personal care services, but this requirement was removed from the Medicaid program in 1993. In fact, one of the trends in Medicaid is to have consumer-directed home care programs, which is considered less expensive because of lower costs of supervision, fringe benefits and wages (Weiner 2000).

While the national trend has been away from institutionalization, many tribes have been troubled that their elders in need of skilled nursing care have been sent far away from their family and community to nursing homes that are unresponsive to their cultural needs. There were only 12 tribally-operated nursing homes in 1993 (Baldridge 2001). Only 10 of the 34 states with tribes had tribally-operated nursing homes (Baldridge 2001). During the regional meetings held in Indian Country by the Assistant Secretary of the Department of Health and Human Services in 1995, several tribal leaders expressed frustration that tribes were unable to obtain Certificates of Need from states to build nursing homes. Yet, this may have prevented tribes from investing in a service that would not have received the level of reimbursement to be self-supporting. According to Baldridge (2001, p. 150), "Several nursing homes in Indian Country remain in operation today only because tribes heavily subsidize them." Some tribes report difficulty filling their nursing homes to capacity (Kauffman 2001).

While there has been a national trend toward home and community based services, the infrastructure to provide those services also has been lacking in American Indian and Alaska Native communities. Dave Baldridge, Executive Director of the National Indian Council on Aging, explains some of the problems:

> In addition to complicated rules governing nursing care, tribes face an equal number of problems trying to secure Medicaid funding for home-and community-based long-term care services. Under Medicaid, the state may not cover the services offered or needed by the tribe. If they do, the requirements for operating such services may be too difficult for a tribe to meet. The state's Medicaid waiver services may not include the tribe, or the number of individuals approved for services under the state's waiver may be too few to make it economically or geographically feasible for services to reach tribal communities. (Baldridge 2001, p. 153)

Thus, anecdotal evidence suggests that states are not designing their Medicaid long term care programs to meet the needs of American Indian consumers or to facilitate the role of tribes as providers of home and community based long term care services. However, further research is needed to better understand the situation.

Choices that Shape State Medicaid Programs

Most states are concerned about controlling the costs of their Medicaid programs to limit the portion that is funded by state expenditures. Costs are controlled by manipulating the following variables:

Covered Services
Eligibility
Reimbursement Structures and Rates

In addition to meeting the federal requirements, states can add optional services and determine the duration and intensity of those services. While the federal government requires states to cover some people, the states may expand eligibility on the basis of income, disability and/or geographic area. All of these state decisions can affect Medicaid services to eligible tribal members and whether a tribe can be reimbursed for services they are already providing. If a tribe is providing services reimbursable by Medicaid, the level and structure of reimbursement will also affect tribes.

Medicaid expansions are highly political. There are advocacy groups that represent consumers with specific health care problems that want more types of services. There are organizations that represent different types of health care providers that want to be included in Medicaid coverage and to have higher rates of reimbursement. There are taxpayer groups that want to limit state expenditures for Medicaid and resist any changes that would increase the cost to the state. In many states, the number of tribes is so small and the number of tribal members is such a small percentage of the state population that tribes are "not even on the radar screen" for Medicaid Directors. So, tribes must not only participate in the development of Medicaid plans, they must also network with other groups to achieve their goals.[27]

IHS/HCFA MOA
In 1996, the Indian Health Service and the Health Care Financing Administration (HCFA)[28] signed a memorandum of Agreement (IHS/HCFA MOA) that redefined payment for Medicaid services provided in an IHS facility to include tribally-operated facilities and tribally-owned facilities. Under this agreement, states can receive 100 percent Federal Medical Assistance Percentage (FMAP). This resulted in an atmosphere of greater cooperation between states and tribes in the development of Medicaid policies and plans (Dixon 1998).

However, there has been some question about the interpretation of the specific wording in the IHS/HCFA MOA. Part III.B.1 of the agreement states that HCFA shall:

[27] An excellent example of this type of synergy on the national level was the passage of the Diabetes Grant funding for Indian health that was approved on the coattails of a broad campaign for diabetes funding by national advocacy groups, such as the American Diabetes Association.
[28] Now called Centers for Medicare and Medicaid Services (CMS).

> Revise its payment policy to provide 100-percent FMAP with respect to amounts expended by the state for Medicaid services to eligible AI/ANs received through tribally owned facilities operating under a 638 agreement. . .

At issue is the interpretation of the word "through." Some states have taken the most narrow interpretation to mean "in a facility." Others have taken a more liberal interpretation to mean "administered through a facility." Thus, a home or community based long term care service administered through a tribal facility could be eligible for 100 percent FMAP.

A federal match of 100 percent would not only fulfill a federal trust responsibility, but it would also provide a win/win situation for states and tribes to work together to design long term care programs.

Currently, the provisions in the IHS/HCFA MOA are being codified in the proposed language for the Reauthorization of the Indian Health Care Improvement Act. It would be wise for tribes, the IHS, and CMS to look at the proposed language to see if it would result in 100 percent FMAP for home and community based long term care services provided by tribes.[29]

Types of Services

State Medicaid Plans and waivers specify what types of services will be provided.
The federal government requires that all home health services provided under the Medicaid program must be authorized by a physician as medically necessary and be part of a written plan of care. The federal government mandates that states provide some types of home health services including:

Nursing
Home health aides
Medical supplies
Medical equipment
Appliances suitable for use in the home

States have the option of providing additional services under home health care in their State Medicaid Plans, including:

Personal care services
Physical therapy
Occupational therapy
Speech pathology
Audiology
Rehabilitation

[29] As a policy alternative, if the federal government were going to fund long term care in Indian Country through state Medicaid programs, they could carve out that funding to go directly to tribes and circumvent the costly step of negotiation and billing Medicaid. While this might be the preferred approach, it is not the subject of this paper.

Private duty nursing
Transportation

States may use the 1915(c) waiver authority to cover the optional services listed above and/or additional services, such as:

Case management
Homemaker
Home health aides
Personal care services
Adult day health
Habilitation
Respite care
Home modifications
Vehicle modifications
Assisted living
Chore services

All states are using this waiver authority. In 2000, there were 242 waiver programs approved by the federal government. But, states must decide which types of services will be covered for which populations under their waiver programs. Tribal participation in that decisionmaking could affect the types of services available to tribal members, the reimbursement to the tribe for existing services, and the employment opportunities for tribal members.

Tribes may be uniquely positioned to provide certain types of services that are optional under State Medicaid Plans or waivers. In fact, tribes may already be providing these services, but not receiving needed reimbursement from Medicaid. Yet, if a state does not choose to include these options in the State Plan or a 1915 (c) waiver, then tribes will not be able to receive the Medicaid funds.

More importantly, tribes that provide these services with Medicaid reimbursement can build a tribally-based long term care system. This infrastructure enhances the capacity of tribes for self-determination and self-governance, a goal shared by the federal government.

Personal Care Services
Personal care services may include assistance to individuals in activities of daily living (ADL), such as bathing, dressing, eating, toileting and transferring from a bed to a chair. It may also includes Instrumental Activities of Daily Living (IADL), such as personal hygiene, light housework, laundry, meal preparation, transportation, grocery shopping, using the telephone, medication management and money management.

Tribes are extremely well positioned to organize the provision of these types of services, particularly since they do not have to be supervised by a medical professional. Not only would Medicaid funding enhance the quality of life for tribal members with disabilities, but it would also provide a form of employment for tribal members. Under the Medicaid regulations, relatives can be paid for providing personal care services, except for spouses of patients or parents of minor children who are patients.

Homemakers
Homemaker services include such tasks as meal preparation, cleaning, and grocery shopping. While these activities are often performed by personal care attendants, a person may need homemaker services without requiring assistance with activities of daily living. This could provide a source of employment for tribal members.

Chore Services
Chore services are different from homemaker services because they are more sporadic and they may be beyond the capability of the homemaker. For example, chores may involve snow shoveling, installing grab bars, heavy lifting of furniture or washing windows. It could also include home repairs. Again, these tasks could usually be performed by community members.

Home Health Aide Services
States can use any criteria to define home health aides. Home health aides do not have to be associated with a Medicare approve home health agency. This allows tribes and tribal members to participate in the provision of these services. In Arizona, 5 tribes are contracting with the Arizona Long Term Care System (ALTCS) to provide home health services either through tribal operations or self-employed individual providers who are tribal members (Kauffman 2001)

Respite Care
When disabled family members are cared for at home, the caregivers often need a break. In a tribal setting, people would be more comfortable having family or tribal members provide respite care. Under the Medicaid rules, these individuals could be paid for providing these services.

Case Management
While case management is usually regarded as a medical or nursing activity, the Medicaid program gives the states an option of using "targeted case management" to assist Medicaid recipients in "gaining access to needed medical, social, educational and other services." This is called "targeted" because it is intended to serve a limited, specified population. This activity can occur outside of a medical setting and include such activities as assistance in obtaining food stamps, energy assistance, emergency housing, and legal services. Tribes may already be providing these types of activities to Medicaid beneficiaries without receiving reimbursement. These types of services could be provided through the social service programs funded by the Bureau of Indian Affairs, where staff may not be knowledgeable about Medicaid or equipped to bill Medicaid. In Arizona, an urban Indian clinic is providing case management under ALTCS for 15 tribes (Kauffman 2001).

Transportation
Most tribes try to provide transportation to medical appointments for the elderly and disabled. Reimbursement for medically-related transportation should be covered under the regular Medicaid program for those who are eligible for Medicaid. Under HCBS waivers, Medicaid can also cover transportation to other community-based services that are part of the person's plan of care, such as day programs for people with mental retardation and other developmental disabilities.

Home Modification
Home modifications can include installing wheelchair ramps, widening doorways, and retrofitting bathrooms and kitchens. The high level of diabetes and subsequent complications leading to amputations has resulted in a disproportionate number of American Indians who are wheelchair users. Funding of home modifications could be an important program in Indian Country.

Assisted Living
While Medicaid will not pay for housing, food, or utilities, it can cover the types of services that augment "room and board" in an assisted living setting. These settings must maintain a "homelike environment." Thus, it has to be a residential model, rather than an extension of a nursing home. Some states have developed programs combining subsidized housing with Medicaid HCBS waivers to provide assisted living alternatives for low income people. This approach may appeal to tribes that have been unable to achieve their goals of having a tribally-operated nursing home. However, at least one tribe has closed their assisted living facility due to low utilization because HCBS enables elders to live at home until they require nursing home care.

Rehabilitation
States have found a great deal of flexibility in using the rehabilitation option. It can be applied to people with either physical or mental disabilities, including psychosocial rehabilitation for people with mental illness. Further exploration is needed on the opportunity for funding tribally-operated alcohol and drug abuse treatment programs for people with dual diagnoses.

Eligibility for Services

Eligibility for Medicaid is based on both financial criteria and categories that are defined in federal law. The categories that are relevant for long term care are: aged, blind, and disabled. However, as states design their 1915 (c) waivers, they often target specific populations for specially designed services. To be eligible for those services, a person who meets the financial criteria must also meet the criteria for the targeted population. Waivers may be designed to target populations in a limited geographic area, which could include or exclude tribes.[30] Participation in the development of State Medicaid Plans and waivers would give tribes the opportunity to have their unique needs considered as eligibility criteria are developed.

Tribes have already made great strides in getting the Health Care Financing Administration (now the Centers for Medicare and Medicaid Services (CMS)) to address some unique issues relating to the counting of resources. Following a study of *Indian Health Care in Nine State Medicaid Managed Care Programs* (Dixon 1998) and a national meeting held by the National Indian Health Board, the State Medicaid Manual was revised to clarify that tribal lands, trust and settlement income, objects that have cultural significance, and other uniquely Indian resources were not subject to estate recovery (Kauffman et al 2001).

[30] At the present time, no waivers have been proposed to target tribal areas.

Categories
The three Medicaid categories identified in federal law for Medicaid coverage that generally apply for long term care are: aged, blind, and disabled.

For Medicaid, the aged category is defined as 65 years old or older. This is also the age for eligibility for Medicare, the federal program that serves elderly people regardless of income. It should be noted that Medicaid provides many services not covered by Medicare, such as prescription drugs and long term care. When both programs cover the same services, federal rules state that Medicare pays before Medicaid. There are programs that use Medicaid dollars to pay for the premiums, co-pays and deductibles for Medicare Part B.

Federal Medicaid criteria for blind and disabled are substantially the same as those set by the Social Security Administration for Supplemental Security Income (SSI). The blind category is separate from the disabilities category, probably because most blind people do not meet the criteria for disabled. Yet, they require some types of specialized assistance.

Disabled is defined as having a long-lasting, severe, medically determinable physical or mental impairment. To be eligible for Medicaid in the disability category, an individual must be unable to work at a level of income more than $700 per month.
In addition to meeting the conditions for these categories, an individual must be a U.S. citizen[31] and a resident of the state, as well as meet financial criteria. States may not restrict Medicaid eligibility based on medical condition, type of services needed or place of residence.

Targeted Groups
One way for states to control costs is to limit eligibility for certain types of services to very specific populations. These are called "targeted groups." This can only be done through the waiver process. An example of a targeted group used in Medicaid HCBS waivers are children from birth to 21 who have chronic health problems.

It has been noted that "one group for which states have historically not developed specific programs or service systems is persons ages 18 to 64 who have physical disabilities – a group that is frequently underserved" (Smith 2000, p. 60)
A subset of this group, people ages 40-64 with physical disabilities, covers those people with disabilities resulting from complications from diabetes who are too young to qualify for Medicare. There is a tremendous opportunity for tribes, states and the federal government to work together to address the needs of this group.

Financial Eligibility
Financial eligibility for Medicaid is based on both income and resources. Anyone who qualifies for other Medicaid programs will also qualify for long term care programs, if they are needed. However, there are some provisions for long term care that make people eligible who would not otherwise be eligible for Medicaid.

For all Medicaid programs, the federal government requires states to cover individuals at a specified threshold below the poverty level. States may choose to expand that coverage to

[31] Some types of immigration status also qualify for Medicaid.

people at the 100 percent of poverty level, and to extend it even further to people above the poverty level who are considered medically needy. However, the federal government sets a ceiling on the income level for its participation in medically needy programs.[32] States must cover medically needy pregnant women and children before they can extend the benefits to elderly persons or persons with disabilities.

Most states use SSI as the basis for determining financial eligibility.[33] However, states may develop their own ways of counting resources. For example, states may chose to extend their Medicaid coverage to more people by disregarding some types of resources that are limited by SSI, such as the cash value of life insurance policies. Disregarding specific types of resources is one area where tribes can help states develop policies that would not penalize American Indian and Alaska Native people for resources that result from their tribal status.

Long term care financial eligibility rules for Medicaid require states to deduct income to provide for a spouse of an individual in a medical institution.[34] However, states make the decisions about how much income to reserve and what amount of assets to reserve for spousal protection. This is another area where tribes can advise the state to assure that the cultural, social and economic situation in Indian Country is considered appropriately.

Certain approaches are used to allow people with high medical costs to access Medicaid when they are over the income and resources limits. One approach is the "spend down" provision, when Medicaid covers the costs of health care after the individual has spent their own income to cover costs to the point where they would be eligible. Another approach is the Miller trust, which allows people to divert their income into a trust fund that specifies that the state will receive any amounts remaining in the trust after the person's death up to the amount of Medicaid benefits paid.[35]

Parity between Institutionalization and Home and Community Based Care

Both the federal government and the state governments have tried to eliminate financial eligibility rules that create incentives for people to choose nursing homes, or other institutional care, over home and community based care.

Recognizing the high cost of institutional care, the Medicaid program originally allowed states to extend benefits to people with higher incomes who required nursing home care or other types of institutionalization. This was called the "300 percent income rule." It allowed people with a gross income of 300 percent of the SSI level to be eligible for Medicaid if they were residing in a medical institution.[36] In 1981, when HCBS waivers were enacted into law, the 300 percent rule extended to people who could be served in the home and community. States are allowed to provide HCBS waiver services to children without regard to their parent's income or assets, and to married people without regard to their spouse's income.

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[32] This ceiling for federal participation is 133.3 percent of the highest amount paid to a family of the same size that receives Aid for Families with Dependent Children (AFDC).

[33] 40 states provide Medicaid automatically to everyone who receives SSI payments in any month, while 11 states are more restrictive.

[34] Also, the funds needed to support a disabled adult child must be deducted.

[35] This is often considered a Medicaid Qualifying trust, designed more to assure eligibility rather than to result in recovery.

[36] In 2000, the 300 percent of SSI was the equivalent of $1536 per month.

However, there is a "post-eligibility cost-sharing burden." This requires individuals to use a portion of their income for medical expenses. States have flexibility in determining how much income an individual can retain.

In 1982, the Katie Beckett, or TEFRA, option was enacted into law. Prior to this time, children who were severely handicapped were eligible for Medicaid if they were institutionalized, regardless of their parents' income. Under those rules, institutionalized children were not considered part of their parents' households; but children living with their parents were not automatically qualified for Medicaid because they were considered part of their parents' households and parent income and assets were deemed available to the children. This institutional bias was changed with the Katie Beckett or TEFRA option. Now, a child with severe disabilities may qualify for Medicaid regardless of parental income if the child requires the level of care normally provided in an institution, and the cost of community services does not exceed institutionalized care, and home care is considered appropriate. States may respond to this mandate either through a TEFRA option in their State Medicaid Plan or through a HCBS waiver. Families would not have cost sharing under the TEFRA option, but states could impose cost sharing under the HCBS waiver.

Estate Recovery

Federal law requires that two groups of Medicaid beneficiaries use the assets remaining after they die to pay back the Medicaid program. These two groups are people who were 55 years old or older when they first received Medicaid benefits[37], and those who received Medicaid nursing facility or ICF/MR benefits regardless of age. States can use the probate laws in their state to define the estate, or they can use a broader definition that captures additional assets.

Many AI/AN who would otherwise be eligible for Medicaid have been unwilling to apply because of the estate recovery provisions.[38] However, the recent clarifications by CMS regarding tribal property that is exempt from estate recovery could change this. Recent changes to the State Medicaid Manual include the following instructions for states (Kauffman 2001, p. 13):

1. Certain AI/AN income and resources (such as interests in and income derived from Tribal land and other resources currently held in trust status and judgment funds from the Indian Claims Commission and the U.S. Claims Court) that were exempt from Medicaid estate recovery by other laws and regulations:
2. Ownership interests in trust or non-trust property, including real property and improvements:
    a. Located on a reservation (any federally recognized Indian tribe's reservation, Pueblo, or Colony, including former reservations in Oklahoma, Alaska Native regions established by Alaska Native Claims

[37] This includes people receiving home and community based services.

[38] Despite a prohibition of "Medicaid estate planning" in the Balanced Budget Act of 1997, there is a thriving industry to advise middle class and wealthy individuals about how to transfer, shelter and under-report their assets to qualify for Medicaid nursing home care without the consequences of estate recovery (Weiner 2000).

Settlement Act, and Indian allotments) or near a reservation as designated and approved by the BIA, or;

b. For any federally recognized tribe not described in (a), located within the most recent boundaries of a prior Federal Reservation, or;
c. Protection of non-trust property described in (a) and (b) is limited to circumstances when it passes from an Indian (as defined in section 4 of the IHCIA), to one or more relatives (by blood, adoption, or marriage), including Indians not enrolled as members of a tribe and non-Indians, such as spouses and step-children, that their culture would nevertheless protect as family members; to a tribe or tribal organization; and/or to one or more Indians.

3. Income left as a remainder in an estate derived from property protected as described above, that was either collected by an Indian, or by a tribe or tribal organization and distributed to Indian(s), as long as the individual can clearly trace it as coming from the protected property.
4. Ownership interests left as a remainder in estate in rents, leases, royalties, or usage rights related to natural resources (including extraction of natural resources or harvesting of timber, other plants and plant products, animals, fish and shellfish) resulting from the exercise of Federally-protected rights, and income either collected by an Indian, or by a tribe or tribal organization and distributed to Indians(s) derived from these sources as long as the individual can clearly trace it as coming from protected sources; and
5. Ownership interests in or usage rights to items not covered by 1-4 above that have unique religious, spiritual, traditional, and/or cultural significance or rights that support subsistence or a traditional life style according to applicable tribal law or custom;
6. Government reparation payments to special populations are exempt from Medicaid estate recovery.

CMS has not issued a consumer-friendly interpretation of these directives, so many AI/AN are still confused about estate recovery.

While these provisions go a long way to address American Indian concerns, there is a larger issue that could be considered as part of a national Indian political agenda. In Child Health Insurance Programs (CHIP) where Medicaid is augmenting Indian health care, the premiums, deductibles and co-pays have been waived. Estate recovery can be regarded as a type of deductible. So, there is a strong argument that estate recovery should be waived entirely for American Indians and Alaska Natives.

Reimbursement Structures and Rates

Both states and the federal government try to control the costs of Medicaid programs by limiting the amount of reimbursement. This has been done through both rate setting and reimbursement structures.

Particularly with programs that serve elders, tribes are the preferred provider because they are most able to deliver culturally competent care (Dixon 2001). Furthermore, tribal operations are located in the rural areas where Medicaid recipients need the home and

community based services. However, it is often difficult for tribes to figure out how to become contractors for certain types of state Medicaid programs. For example, Community Health Representatives (CHRs) working for tribes provide a variety of home and community based services, often including transportation, usually without Medicaid reimbursement. A state outreach effort to tribes is needed. As noted repeatedly, the state has a great deal of flexibility in designing Medicaid programs, so it is possible to design programs with tribal input that would allow tribes to deliver the services most efficiently to tribal members.

Reimbursement Rates

Medicaid often pays below the rates charged by health providers to other payers. This approach has worked in the past in many private settings due to cost shifting – private insurance companies and private payers paid higher rates that subsidized public programs. However, in the age of managed care, profit-making health care organizations and competition, the rates paid by almost all purchasers of health care have been lowered to the point where there is little room for cost shifting.

In the Indian health system, there has never been room for cost shifting because Congress has failed to fully-fund the Indian Health Service and most American Indian and Alaska Native people do not have private or employer-paid health insurance. So, if tribes are going to be service providers under Medicaid long term care programs, they must be paid at a rate that covers their expenses.

Reimbursement Structures

There is a growing trend toward highly coordinated systems. This seems desirable to avoid duplication of services, to combine Medicaid and Medicare resources[39], and to provide a single point of entry for consumers. However, highly coordinated statewide programs are probably going to exclude tribes. One reason is that tribes are most interested in serving their own tribal members. They are unlikely to bid on, or be awarded, a contract to serve a population that is primarily not tribal members. One approach to dealing with this is to create a carve out for tribes.

In the current economic system, highly coordinated systems usually involve managed care and a capitated approach to reimbursement. Assuming risk in a capitated reimbursement structure is difficult for tribes. If states want tribes as Medicaid long term care providers, they must develop some small scale, fee-for-service programs, or fixed-price contracts with a defined scope that limits liability.

The Program for All-Inclusive Care for the Elderly (PACE) is one model that is receiving a lot of attention, particularly since the Balanced Budget Act of 1997 changed it from a demonstration project to a permanent program under Medicaid and Medicare. On Lok Senior Health Services, the first demonstration project that led to PACE, did, in fact, serve a small group of ethnically distinct elderly. However, most subsequent demonstration projects have been designed at the state level and none have been operated by tribes (Alper and Gibson 2001). While PACE is generally intended to treat groups of less than 200 adults,

[39] Weiner (2000) regards this as an attempt by states to shift costs from Medicaid to Medicare. He points out that the Medicare program has resisted this trend, both to control costs and to protect Medicare beneficiaries' freedom of choice of providers.

experts suggest that "it may not work well in sparsely populated rural areas" (Alper and Gibson 2001, p. 108). There may be a need to develop a similar model in conjunction with American Indian communities that are designed from the ground up, in the same way that the On Lok model evolved.

Another model that has been suggested for Indian Country is Independent Living Centers designed to support disabled individuals by providing services such as skills training, information and referral, advocacy, peer counseling, legal services, communication services and Social Security assistance. These services qualify for Medicaid funding.

For tribes to participate successfully in the delivery of home and community based services, it may be best to proceed incrementally. Tribes could assume responsibility for the tasks that they are best suited to perform or coordinate, adding other programs over time. Under the Arizona ALTCS managed care system, for example, tribes are able to provide some home and community based services without having to provide all services (Kauffman 2001). One tribe in Wisconsin is providing caregiver services under the Community Options Program (Kauffman 2001) This approach requires states and tribes to work closely together with a shared vision.

It is more expensive for states to administer many small scale contracts than to issue three or fewer large contracts with managed care providers. However, the large contracts are likely to be awarded to large profit-making managed care organization that are headquartered outside the state and are not familiar with specific conditions, needs and services in Indian Country.

Tribal participation in state long term care planning activities can help assure that the reimbursement structures are at a scale and use an approach that would enable tribes to become Medicaid providers. Tribes can also advise the state about requirements that are prohibitive for their participation as long term care providers. For example, Kauffman (2001) found that there was not tribal participation in Michigan's Long Term Care System due to a variety of factors:

> Michigan's Long Term Care System provided limited access for tribal members and tribal facilities. Although tribes may contract to provide Home and Community Based services, no tribes were currently enrolled to provide Home Health services, Home Visit Nurses, Hospice services, Long Term Care services or Nursing Home services. . . Some concerns related to tribes providing long term care services included: (1) limited contract health dollars, (2) difficulty meeting the 24 hour supervision requirements for state licensing, (3) staff-client ratios that were too high, (4) distance from tribal members communities and (5) financial and labor investments necessary to maintain quality staff. (P. 152)

Another barrier cited by tribes in other states is the state screening and certification of personal care givers, which is contrary to the principles of tribal sovereignty. The Inter-Tribal Council of Arizona (ITCA) has found that start up costs may be prohibitive for tribes. Also, ITCA has found that the number of tribal members who quality for Arizona Long Term Care Services (ALTCS) is often too small to make it feasible to delivery HCBS.

Both states and tribes need to balance the goals of quality of care with access to care. Setting standards that are too costly may result in tribes being unable to qualify as providers of services; and, without tribes as providers, Medicaid beneficiaries may not have access to covered services. The implications of having different standards of care for Medicaid recipients residing in different parts of a state may create a liability for states. Some potential solutions for this dilemma are: 1) provide higher rates of reimbursement for tribes; 2) provide subsidies or grants to tribes to help them achieve standards; 3) support training for potential employees in Indian Country to reduce the costs of recruitment and retention, and 4) create a carve out for tribes that is managed separately from other state programs and has appropriate standards developed through tribal consultation.

Summary

Recognizing that Medicaid is the leading source of financing for long term care in the United States, this paper has identified many opportunities to develop Medicaid long term care programs to better meet the needs of American Indians and Alaska Natives. States' choices about covered services, eligibility, and reimbursement affect participation in Medicaid by AI/AN consumers, as well participation by tribes as providers. To turn these opportunities into action requires tribal consultation, technical assistance and a shared vision.

Tribal Consultation

Tribal consultation is the process by which states can learn about the needs of tribes and tribal members. Through tribal consultation, states can formulate their Medicaid programs in a way that will meet the needs of state citizens who are tribal members. If the state recognizes that a tribe may be the best provider of culturally-appropriate and accessible services for tribal members, the state can design its programs to assure that tribes can participate as providers.

While some states have a designated representative on an advisory committee or board that provides direction for state Medicaid planning, this is insufficient to constitute tribal consultation. Tribal consultation requires that the state contact the elected tribal official of every federally-recognized tribe in the state to invite their participation in a discussion of issues. Some states do this through regular quarterly meetings with tribal leaders and tribal health directors, while others use ad hoc meetings.

Tribal consultation is more than states listening to tribes. In the federal context, tribal consultation is about a government-to-government relationship that equalizes power in decision-making. When the federal government transfers its responsibility to states to formulate Medicaid plans and waivers, the federal government still has a trust responsibility to assure that the needs of tribes are addressed appropriately. Over time, CMS has assumed this oversight role in the review of 1115 waivers and 1915 (a) and 1915(b) waivers. It is not clear whether this is also being done with 1915 (c) waivers.

The federal government may require states only to notify tribes and to allow them to comment during a comment period. This is bound to be ineffective. Few tribes have employees who can take the time to read, analyze and respond to the highly technical documents that comprise State Medicaid Plans and waiver applications. Furthermore, this is not a culturally appropriate style of communications. Tribal consultation requires that tribes

actually understand the issues, and further that there is a face-to-face discussion. To actually understand the issues, there may need to be a training period.

Not every tribe can afford to devote the resources to understanding the issues and to participating in meetings. It would be helpful to have planning grants for tribes to increase tribal participation. Another approach would be for tribes in a particular state to organize themselves into an association, or use an existing association, and elect one or more representatives to participate in the consultation process on their behalf. This can also be problematic if the information and issues are not conveyed back to all the tribes.

It should be noted that states often work on tight deadlines and that tribal consultation often takes a long time to achieve consensus. Therefore, the long term approach to building relationships and knowledge is usually more effective than an ad hoc meeting to gain input.

Technical Assistance

Medicaid is a highly technical area that few people fully understand. Tribes will need technical assistance to structure or restructure programs to be Medicaid reimbursable, to become Medicaid contractors, and to submit their bills in a way that maximizes the resources available to deliver services.

One model for technical assistance is the Inter-Tribal Council of Arizona, which received funding from the Indian Health Service to assist tribes in developing home and community based services that would be eligible for ALTCS reimbursement (Dixon 1998). Arizona holds quarterly meetings with tribal long term care contractors and quarterly in-service training for tribal long term care case managers (Kauffman 2001). In addition, they publish a quarterly newsletter for tribal long term care providers (Kauffman 2001).

Vision

The most important element for developing Medicaid long term care programs that meet the needs of American Indians and Alaska Natives is a vision that is shared by tribes, state governments, and the federal government. To develop a shared vision requires good communication between the parties, as well as model programs that provide tangible evidence of successful and sustainable approaches. A first step in developing a shared vision is to make sure that all the stakeholders have the same goals.

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Roundtable Discussion of Implications and Recommendations Regarding Medicaid and LTC Financing

1. **Better Understanding of LTC Services:** At the local tribal and urban Indian community level, Long Term Care (LTC) programs are generally disjointed and not well known by the community leaders or health administrators. Most of the existing services available for LTC are channeled through state agencies and may not be incorporated into tribal or urban health systems. Too often, the community perspective of LTC is limited to the physical construction of a "nursing home", although this is the most costly, most restrictive and least desirable by beneficiaries of all the LTC options. More information is needed at the local level about options to develop and finance "home and community based services" to meet LTC needs.

2. **Support for Planning:** The Federal Government, via CMS, IHS, AoA and other sources, should provide funding for LTC planning that will include tribes, states, counties and Agencies on Aging to, (a) support tribal participation; (b) provide training for both tribes an states; (c) fund needs assessments; and (d) help develop a shared vision for LTC in Indian country. We need to better break-down the components within the continuum of Long Term Care, so that local communities understand that LTC is more than just nursing homes. Funding should be provided to develop educational materials that can be adapted to the unique circumstances of each tribal or urban community.

3. **Demonstration Projects:** The Federal Government should embrace and support a partnership across various federal agencies to support Demonstration Projects in Indian Country that are community based LTC, that are small in scale, incremental, using local providers and which are not risk-based. There was some discussion that there may be a few tribal communities with the centralized population and resources to support programs similar to "On-Loc" or PACE, but require added technical assistance to get the programs started. Most tribal communities will require assistance to develop alternative demonstration projects that better meet their dispersed populations across several rural communities.

4. **LTC Research Agenda:** A formal research agenda should be established for LTC in Indian Country, which would include studies in the following priority areas:
   - Economic viability of nursing homes in Indian Country;
   - Economic viability, sustainability and community acceptance of Assisted Living Centers in Indian Country;
   - Economic viability, sustainability and community acceptance of Independent Living Centers in Indian Country;
   - Case studies which will help determine, (a) a registry of tribal programs; (b) best practices in LTC; (c) Lessons Learned from past experiences.

- Home and Community Based Services, to assess existing waivers and to determine the needs and acceptability of services in tribal communities. To evaluate successful skilled nursing and Home and Community Based Services.
- Assess and evaluate state consultation with tribes and urban Indian providers regarding state LTC plans, waivers and delivery of services;
- Evaluation and research regarding the under-enrollment of American Indian and Alaska Natives in Medicaid for purposes of receiving assistance for LTC.
- Examine existing reimbursement practices and rate structures for LTC services in Indian Country.

5. **CMS and State Disclosures to Tribes and Individuals:** States, CMS and tribes should develop a "disclosure form" to reveal the full realm of potential liabilities or protection from liabilities to individual Indians making application for enrollment for Medicaid services, so that consumers will know in advance, if there will be future liabilities, such as estate recovery, cost-sharing or spend-down requirements for services. CMS should issue a paper to all states clarifying the services included in the 100% FMAP. These services should specifically include tribally delivered Medicaid covered home and community based services.

6. **Diabetes and LTC:** The Indian Health Service, CMS, tribes and urban Indian health programs should develop model programs to target diabetes related disabilities in relation to the prevention or delivery of Long Term Care services. These model approaches could include combining multiple resources to ensure services are provided to maximum benefit of communities. These models could include efforts and initiatives to:
   - Prevent the advancement of complications due to diabetes that lead to requiring Long Term Care services;
   - Maintain current functioning and independence among diabetics;
   - Leverage funding and services to include Medicaid, Medicare, Diabetes Grants and other Sources.

7. **State Consultation and Coordination with Tribes:** State LTC Plans should not be approved by CMS without documented evidence that the state engaged in meaningful tribal consultation in the development of the plan and any amendments. While the CMS requires states to consult with tribes in the development of "waivers" submitted to CMS, states are not required to consult with tribes when amending their State Plans. This is an oversight and should be corrected. More education and assistance to tribes and to urban Indian programs is needed to better service American Indian and Alaska Naïve elderly and disabled populations in need of LTC services., including education on Medicaid, Medicare, QMB and SLMB options. Each state with a significant American Indian or Alaska Native presence should employ a "liaison" staff position with specific responsibility to bridge the gap between tribal and urban Indian communities and state programs including Medicaid. As tribes become providers of Medicaid reimbursable services, such as LTC, they will be more involved in enrolling AI/AN eligible patients.

8. **Indians with Disabilities**: Discussion and planning about LTC needs in Indian communities, must be expanded to reflect not only the needs of the Indian elderly, but also the needs of Indians with disabilities who may also require LTC services. More collaboration is needed between these two populations in developing LTC options. Local health providers, community leaders and policy-makers must involve both these groups as key stake-holders in planning LTC services.

9. **Start-up Funding:** There is a sizeable disparity among tribes with regard to existing infrastructure and each tribe's ability to start up LTC services. Many tribes do not have the start up costs to develop reimbursable Home and Community Based Services or other LTC services. Once started these programs could become self-sustaining with adequate reimbursements. It is recommended that start up funds be provided to tribes to cover the initial planning and start-up costs.

10. **Ombudsman for Indians:** While each state is supposed to have an ombudsman to oversee and investigate complaints about mistreatment in nursing homes, a consistent theme arose in Roundtable discussion suggesting that complaints are not responded to. More advocacy is needed through existing or expanded ombudsman services for Medicaid patients who are mistreated, dropped from programs unfairly, or for other causes. A possible federal role may be needed to oversee state responses to tribal complaints.

11. **Task Force on Indian Long Term Care:** The Federal Government should keep tribal and urban Indian LTC providers informed of activities, plans and actions taken resulting from a recent initiative involving the Administration on Aging (AoA), the Administration on Native Americans (ANA), the Center for Medicaid/Medicare Services (CMS) and the Indian Health Service (IHS) to work together in developing a task force to address Long Term Care issues in Indian Country. Additional agencies, such as Housing and Urban Development (HUD) should be added to this important effort.