Native Aging Visions

A Resource for Native Elders

A Publication of the National Resource Center on Native American Aging
located at the University of North Dakota Center for Rural Health
School of Medicine & Health Sciences

Volume 2, No. 3 Summer 2002

Director's Column

What is the future of long-term care in Indian country? What should the staffing be and what kind of facilities will be needed to meet the needs of a growing number of American Indian elderly?

This issue of *Native Aging Visions* provides a great deal of information about the status and future of long-term care. These papers were initially presented at the Indian Health Service Long Term Care Roundtable in Albuquerque, New Mexico, and have been adapted by the authors for inclusion in this newsletter. Some insight is provided on what professionals in the field are conducting research on, and what they see as the future. Of course contemplating the future is risky in any environment, and especially risky in the area of long-term care for Native elders as we are just beginning to develop a data base on the status of Native elders.

My thoughts are based on the review of the literature and from the standpoint of a current and future consumer for relatives, friends, and family. The challenge is to develop sustainable services and facilities within the capacity of the tribe, and what ever outside resources they can generate.

In order to accomplish that end, tribes should consider the issue of safety, and the traditional values of the tribe. Is there some way that tribal long-term care programs can be less safety driven and thus less expensive? I know of one mother who raised up 10 children. Isn't it possible for 10 children to raise up one mother without concern for the safety of their mother? Perhaps tribes need to consider some changes in their tribal codes regarding the care of elders and elder abuse, perhaps setting a financial limit on legal actions regarding long-term care.

Other sectors, such as the disability services sector, have been able to provide cost effective services to small groups by using group homes and mainstreaming their clients in the community. Is there something tribes can learn from their experience?

In a recent poll conducted by the National Council on Aging and from the personal experience of researchers here at the Center, it is clear that concerns about health are one of the most worrisome issues facing Native elders. When considering facilities and services it is apparent that they must be in close proximity to health care or at least immediately accessible. To keep the cost reasonable, the use of mid-level practitioners trained in geriatrics should be considered. This also opens the door to new careers to stimulate the reservation economy.

It is clear that the current cost of nursing home care, as the main source of long-term care for elders in the country, is beyond means of most states and tribes. As a result, we must look to alternatives such as home and community based care, assisted living, group homes, etc. as alternatives. The new Family Caregiver program is a start, but appropriations for Native elders falls far

(continued on page 2)

Native Aging Visions is supported by a grant, No. 90-AM-2380, from the Administration on Aging, Department of Health and Human Services.

Director's Column *(continued from page 1)*

short of the need, and is being used by many tribes for much needed respite care. More creative ideas are needed to develop new models for Native elders and the Administration on Aging should consider supporting some demonstration programs to determine their feasibility for Native elders.

Most of us, tribes included, are unaware of the spectrum of services provided or available in our country. One of the challenges is to help everyone expand their horizons to the possibilities for staffing, facilities, workforce training, financing, etc. We need to encourage regional meetings and conferences where there is a sharing of ideas about successful projects and how they might be adapted to serve Native elders.

Another issue is the amount and quality of data available to tribes for planning purposes. To date we have in excess of 80 tribes who have completed their data collection. There are over 500 tribes in our country; all tribes should conduct some type of needs assessment to assist them in their planning efforts for long-term care services. A national data base is necessary to help policy makers decide what to support financially. The National Resource Center plans to continue that process and invites more tribes to participate. Key personnel should contact the Center at (800) 896-7628 to start the process of conducting your own local needs assessment.

Please enjoy the summaries of the most recent publications on the issue of long-term care in Indian country. Then ask your tribe to participate in the needs assessment, to look at all of the possibilities, to plan long-term care services that meet the cultural and personal needs of your tribe, and to pursue innovative and model programs that can be tweaked to meet local needs.

Megwitch!

— Alan Allery

National Resource Center on Native American Aging (NRCNAA) Staff Testifies Before Senate Committee on Indian Affairs

The NRCNAA was invited to testify at an oversight hearing on the health status of Native American Elders before the Senate Committee on Indian Affairs on July 10, 2002. Mr. Russ McDonald and Dr. Richard Ludtke provided formal testimony on the health status of Native Americans. Alan Allery, Director, accompanied them and assisted with responding to questions from the panel.

Senators Inouye (HI), Night Horse Campbell (CO), and Conrad (ND) questioned the panel indepth about what could be done to improve the health status of elders and forego an anticipated crisis with regard to long-term care services.

Mr. Edwin Walker and Dr. Yvonne Jackson of the Administration on Aging opened the hearing by testifying on behalf of the Department of Health and Human Services. The Administration on Aging provided the resources for the needs assessment project through a cooperative agreement with the University of North Dakota. They were followed by Dr. Kathy Annette, Dr. Craig Vanderwagen, and Dr. Bruce Finke from the Indian Health Service.

Mr. Dave Baldridge from the National Indian Council on Aging and Mr. Fred Baker from the Three Affiliated Tribes closed out the testimony.

The NRCNAA maintains the only health and social data base for Native Elders in the nation. The Center plans to continue to expand its data base by working closely with tribes to improve the data and services offered to tribes.

Copies of the testimony are available on the web at http://medicine.nodak.edu/crh/nrcnaa/presentations.html

The testimony can also be viewed at http://indian.senate.gov/nsmainpage.htm

Developing Long-Term Care Services: A Necessity and Challenge for Tribes

by Linda J. Redford, RN, PhD
University of Kansas Medical Center

The family is currently and will probably remain the primary resource for long-term care of elders in the American Indian community. The ability of families to be the sole source of care is, however, becoming more tenuous. Many young are leaving rural reservations for educational and employment opportunities in urban areas. Women, the primary caregivers, are entering the workforce in large numbers and are unavailable to provide full-time care. There is also concern that the ravages of diabetes and other chronic problems will leave increasing numbers of middle-aged adults unable to care for their older relatives.

Recognizing that families may need help and that some elders have no one to care for them has spurred many tribes to undertake the development of long-term care services. A systematic assessment of needs and resources, both within the tribe and the surrounding community, is critical to effective planning of services. The suggestion that needs assessments and surveys should be conducted is often met with resistance, primarily because the process of service planning too often starts and stops with the assessment. To be of value, assessment data must be analyzed and interpreted in a way that informs service planning. Needs assessments, such as the one available through the National Resource Center on Native American Aging (NRCNAA), lay the foundation for services, as well as provide a baseline for future evaluation. Need must be quantified and preferences must be explicit.

Funding is an important component of long-term care service delivery, but should not drive the process. Too often services "follow the money" or the latest service fads, rather than the needs. Tribal planners must understand the role and limitations of Medicare, Medicaid, Indian Health Services, Older Americans Act and other federal sources in financing long-term care. Likewise, they must be aware of the role of the state. States play a key role in long-term care provision, including control over allocation of some federal funds. Since tribes are accustomed to negotiating directly with the federal government, they often have little relationship with the state and are unaware of available state resources.

State and federal resources, though important for developing and sustaining a comprehensive set of long-term care services, also come with many rules and regulations that may limit the flexibility needed to develop culturally sensitive services. It is sometimes possible for tribes to negotiate with the federal government or the state for a portion of monies that can be tribally controlled. In other instances, tribes may at least be given a voice in the design and allocation of services. If tribal resources are available, they need to be strategically combined with public funding to insure programs are culturally appropriate.

Before embarking on the development of tribally owned or operated services, tribes must determine their capacity and limitations in providing various forms of care. A vexing problem for many tribes is the lack of an infrastructure to provide, facilitate and sustain services, even when funding is available. Transportation resources, adequate roads, accessible and safe housing, and the recruitment and retention of needed professional and ancillary workers are critical factors in long-term care service delivery and are lacking on many reservations. Addressing these issues may need to precede or be carried out concurrently with the development of long-term care services.

(continued on page 8)

Rituals of Respect: Medicine for the Spirit

by J. Neil Henderson, PhD
University of Oklahoma

Never before have so many Indian people lived for so long. Accordingly, the need for long-term care has never been so important for Indian Country. Yet, the experience of long-term care is often dreadful. At the same time, the people of Indian Country have great respect for elders and want them to be happy with their long life. Can the two mesh? Can the delivery of care be done in a way that gives elders the respect they deserve?

There is a way to give long-term care *and* give honor by using "Rituals of Respect." Rituals are behaviors that are symbolic of cultural values, designed for a purpose, are patterned, and repeated. There are types of rituals that include "passage" (a transition from one stage of life to another), "renewal" (reminders that a person is *still* valued), "intensification" (reinforcement of one's status as an elder), and "revitalization" (recapturing old roles and breathing new life into them).

The ritual of passage is a "Ritual of Respect" appropriate when one's status changes. For example, when elders complete intake forms to become users of long-term care (LTC), they change from an independent person to one dependent on long-term caregivers. The "intake" process for LTC services is actually a rite of passage. However, it typically is just a session of completing forms, devoid of anything but scripted pleasantries. This gets information for the LTC system, but in a way that is experienced as barren of human empathy for the huge impact that LTC has on a person's self image, life and spirit.

On the other hand, the intake process can become a "Ritual of Respect" in the following way. LTC service providers can develop an appropriate *celebration of inclusion* into their services. For example, in an elder's home, the providers have preplanned the required intake process with a "Ritual of Respect" of the rite of passage type. They come to the house with an appropriate person considered worthy of offering a blessing to the elder. This person may be a spiritual leader of the tribe or someone else agreeable to the elder. These people greet the elder explaining that they are there to get to know the elder and the family as well as for the elder to get to know the people of the service agency. The providers and the spiritual leader will welcome and honor the elder as a person they will provide special care for. The spiritual leader may offer a prayer, smudge the elder by using a feather fan or eagle feather to move the smoke of sage and/or cedar over the elder, or sing a prayer song. After this blessing, an appropriate gift can be given to the elder. Gifts may be of a kind important to tribal culture, such as valued foods, art, or books that are considered appropriate. It may include tobacco, corn, or other items of cultural importance. This "Ritual of Respect" should convey a strong sense of caring and honor for the elder. It should convey a future in which the elder thrives in the emotional and spiritual sense in the midst of caring others. The intake forms can be done and a short leave-taking blessing should occur.

This is just one example. Cultural practices are highly variable, so the rituals developed should be appropriate for the elder's tribe. Also, an entire program of "Rituals of Respect" can be crafted. "Rituals of Respect" is a way to provide elders with the medicine of long-term care and the "medicine" to sustain their spirit for themselves, their families, and their tribe.

For more information, please contact: J. Neil Henderson, PhD, Associate Professor and Vice Chair, Department of Health Promotion Sciences, College of Public Health, University of Oklahoma Health Sciences Center, 801 NE 13th Street, PO Box 26901, Oklahoma City, OK 73190, Tel: (405) 271-2017, ext. 46756, Email: neil-henderson@ouhsc.edu

Staff Testify on Health Status of Native Elders

by Russ McDonald, MA; and Rick Ludtke, PhD
National Resource Center on Native American Aging at the Center for Rural Health

The staff of the Resource Center were invited to testify before the Senate Committee on Indian Affairs on July 10th. The testimony represented some of the major findings taken from the community assessments. We hoped to call attention to disparities in life expectancies, health status, and functional limitations and to call attention not only to the needs of the present, but the pending growth of the over 55 age groups in Native American communities.

Life expectancies for Native Americans remain well below the national averages and a substantial variation is found among the Indian Health Service areas. While one expects improvements in life expectancies, the disparities are large and serve as a foundation for a call to action.

Chronic disease historically has been found to increase in populations that have longer life expectancies as a consequence of more people simply being exposed to the probability of becoming afflicted with diseases like arthritis, or heart disease and as a result of people surviving with chronic diseases that were fatal in earlier times. Our data suggest that chronic disease rates are higher, rather than lower for Native American elders, suggesting that many other factors must lead to these disparities including life style factors, levels of living and access to timely and adequate care.

One outcome of chronic diseases is increased functional limitation and an increased need for long-term care services. At the beginning levels of functional limitation there is a need for personal care services that are often a good fit for home and community based services. At the higher level of functional limitation, a need appears for assisted living or skilled nursing care. These needs exist today at all levels and will increase dramatically over the next ten years as the generation referred to as the "Baby Boom" reaches the age of elder status. These growing needs require the development of local options for long-term care and increased efforts to prevent activity limitations. Efforts that would hold down the levels of limitation in functional status would have a great impact on the quality of life for elders and carry an enormous potential savings by keeping people independent.

Our hope is that this testimony will serve to encourage congress to pay special attention to the disparities in health, length of life and disabilities and to promote a concerted effort to provide local options for those in need.

Copies of the testimony are available on the web at http://medicine.nodak.edu/crh/nrcnaa/presentations.html

The testimony can also be viewed at http://indian.senate.gov/nsmainpage.htm

The Center for Rural Health website has a new look and a new address. Check it out at http://medicine.nodak.edu/crh

Opportunities for Medicaid Financing of Long Term Care in American Indian and Alaska Native Communities

by Mim Dixon

Medicaid, the federal-state program to pay for health care for the poor who meet specific criteria, is the largest payer of costs associated with long-term care in the United States. When tribes think of long-term care, they usually think about nursing home care for tribal elders; however, long-term care (LTC) also encompasses services for people with disabilities, as well as Home and Community Based Services (HCBS). This article explains some of the opportunities and constraints of the Medicaid and waiver programs.

Despite the fact that there are higher poverty rates and disability rates among American Indians and Alaska Natives (AI/AN), there is lower participation in Medicaid and lower payments made on behalf of AI/AN Medicaid beneficiaries. Many AI/AN have been unwilling to apply because of the estate recovery provisions; however, the recent clarifications regarding tribal property that is exempt from estate recovery could change this. Another reason for low participation may be that LTC services and service providers are not accessible. It appears that states are not designing their LTC programs to meet the needs of American Indian consumers or to facilitate the role of tribes as providers.

States are concerned about controlling the costs of their Medicaid programs to limit the portion that is funded by state expenditures. States' choices about covered services, eligibility, and reimbursement affect participation in Medicaid by AI/AN consumers, as well as participation by tribes as providers. States may show more flexibility in planning services for AI/AN, if the Indian Health Service/Health Care Financing Administration Memorandum of Agreement is clarified and/or codified to make LTC administered through a tribal facility eligible for 100 percent federal funding.

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, and provides reimbursement at rates that cover expenses. Highly coordinated statewide programs are probably going to exclude tribes. The goal of quality care must be balanced with the goal of access to care.

To turn these opportunities into action requires tribal consultation, technical assistance and a shared vision.

For more information, please contact: Mim Dixon, Mim Dixon and Associates, 1618 Spruce Street, Boulder, CO 80302, Tel: (303) 674-9513, Email: mimdixon@hotmail.com

To obtain a copy of the American Indian and Alaska Native Roundtable on Long Term Care: Final Report 2002, visit the Elder Care Initiative's website at: http://www.ihs.gov/MedicalPrograms/ElderCare/What'snew.asp The report summarizes the proceedings, implications, and recommendations which emerged from the meeting held April 11-12, 2002 in Albuquerque, New Mexico.

Long Term Care in Indian Country Today: A Snap Shot

by William F. Benson

While there has been limited research about long-term care for Indian elders, it is clear that there are few long-term care services available in Indian Country, despite the great need for them. This conclusion is the subject of *Long-Term Care in Indian Country Today: A Snapshot*, a paper recently released by the Indian Health Service (IHS), written by William F. Benson, a consultant to the National Indian Council on Aging (NICOA).

Drawing upon work done by NICOA, IHS, the National Resource Center on Native American Aging (NRCNAA), and the U.S. Administration on Aging (AoA), the paper describes elders' long-term care needs and the limited responses to those needs. It cites NRCNAA's finding that there is a "greater level of need for personal assistance among the Native American elders than in the general population." It also reiterates NICOA's 1995 conclusion that "Long-term care is the single most critical issue facing American Indian elders" reported in their landmark report, *National Indian Aging Agenda for the Future*, which pointed out that for elders residing on reservations the problem is further compounded by "rural isolation, poverty and access barriers."

NICOA has a 3-year grant from the Retirement Research Foundation (RRF) to study the current state of long-term care in Indian Country, and to develop several tools to help tribes in their planning for long-term care for their elders. A major part of this project is a national survey of tribes that receive Title VI funds under the Older Americans Act. Of the 236 tribes presently receiving Title VI grants, 109 (46%) tribes responded to the survey. While the survey data was still being studied at the time the paper was written, the preliminary analysis underscores the lack of long-term care services for elders and suggests some important new findings.

Not surprisingly, the most commonly available long-term care services in Indian Country are those that are likely to be a result of Title VI funding, such as home-delivered meals, transportation, home maintenance and repair services, and housekeeping. The least available services include nursing home, assisted living and other residential forms of care, adult day care, hospice, kidney dialysis, and Alzheimer's/dementia services. Tribes report that assistance by family members may be less available than commonly assumed and that the majority of those who are caregivers need help. Sixty-eight percent said that family members are available some of the time or rarely available "to assist elders," with only 19% reporting that family members are available "most of the time." Sixty-four percent report that most families who provide daily care could use help with the care they provide and 27% report that some of them could use help. Respite care is the service identified as "most helpful" in relieving caregiver stress, followed closely by personal care (e.g., help with bathing and dressing).

When asked, "what is the single most important thing your tribe should do to help its elders?," one-third said build nursing homes and assisted living facilities, and 14% said establish home health agencies. Tribes were also asked about the importance of "care of the frail and disabled elders to your tribal council." Seventeen percent said it was the "most important," 47% indicated it is "among the top three most important areas," and another 28% said that although it did not rank in the top three priorities "it was among the top ten."

Note: William F. Benson serves as National Policy Advisor to NICOA. He is also president of The Benson Consulting Group and is the former acting head of the U.S. Administration on Aging.

Copies of the report can be obtained by contacting Mr. Benson at 7106 Maple Ave., #2, Silver Spring, MD 20912, or by email at tbcg@erols.com

Center *for* Rural Health

National Resource Center on Native American Aging
P.O. Box 9037
Grand Forks, ND 58202-9037

NON PROFIT ORG.
U.S. POSTAGE PAID
Grand Forks, ND 58201
Permit No. 10

Address Service Requested

Developing Long-Term Care Services *(continued from page 3)*

Tribal communities must look internally and externally for resources that will facilitate the development of a comprehensive long-term care system to meet the diverse needs of the frail elders and their families. Some tribes may have the resources to assume full control over the development and management of services. Most tribes will need to combine tribal resources with external funding and forge strategic alliances with some providers external to the tribal community to develop and sustain a comprehensive system of care.

American Indian/Alaskan Native communities will face increasing need for long-term care services over the next several decades. Now is the time for tribes to be systematically planning for current, as well as future long-term care needs of their populations and taking educated risks to experiment with models of care that are culturally sensitive, yet viable within the constraints of the current environment.

For more information, please contact: Linda J. Redford, RN, PhD, Director, Geriatric Education Center and Quentin N. Burdick Rural Interdisciplinary Health Training Program, Center on Aging, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160, Tel: (913) 588-1636, Email: lredford@kumc.edu

Native Aging Visions wants to hear about outstanding people and programs that provide health care and other services to Native American elders. If you know of any that deserve recognition, please let us know so we can share the information. We hope to highlight some of these people and programs in the upcoming issues.

If you receive duplicate copies of ***Native Aging Visions***, please route to others who do not receive addressed copies or call us at (800) 896-7628.