



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*

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Director's Column

November is National Family Caregivers Month and during this month we take time to recognize the millions of American that make extraordinary efforts to care for loved ones who are elderly, chronically ill, or disabled.

"Through their love, dedication, and courage," President George W. Bush wrote in his National Family Caregivers Month proclamation, "these compassionate children, spouses, grandparents, and extended family members strengthen and preserve the importance of family and reflect the true character of our Nation."

Caregiving is especially common among the Native American population. A strong culture that values elders and the good sons and daughters that take care of their parents as they grow older often sees people moving into the roll of caregiver.

However, their dedication to their accepted duties can also wear on caregivers causing stress, fatigue and in many cases increased physical and mental illnesses.

This is the story of such a caregiver:

"My mom and I talk about how many problems I've had. I'm only in my twenties and I've had all these problems (asthma, gynecological tumors, depression, etc.) and I worry about what will happen to me. Right now I am my mother's caregiver, but who will be my caregiver when mom passes on and I need care?"

Studies indicate that most of primary caregivers tend to neglect their own physical and mental health needs to meet the economic and health care needs of their elders and extended family members. Their risk increases by not taking the time to seek regular preventative care and ignoring symptoms of illness. Being sick is simply not an option.

The stress of being a primary caregiver also weighs heavily on mental and physical health. Many caregivers feel trapped in their duties out of social or cultural obligation, or because they feel their siblings or others cannot be trusted to do a good enough job. Living on a limited income or having more than one member of the family needing care can also add to a caregiver's anxiety.

To prevent future health problems, caregivers need to take time to focus on themselves and to keep life in balance. One

(continued on page 2)

"Sixty-two percent of the primary caregivers . . . indicated that they had multiple physical illnesses or a combination of physical and mental illnesses."

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way to do this is by using the seven dimensions of wellness illustrated in the graphic on this page. Easy ways to maintain these seven dimensions include:

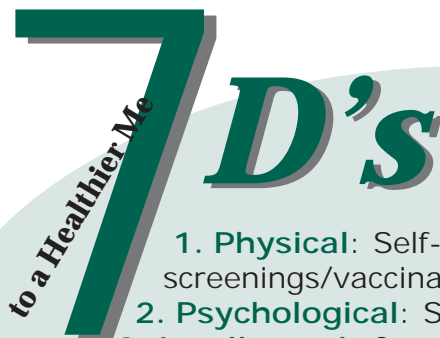
- Get at least 30 minutes of moderate exercise three times a week;
- Explore relaxation techniques;
- Pursue an intellectual effort such as reading or working on a crossword puzzle at least two-three times a week;
- One can meditate, dream a little, smudge, or participate in other ceremonies such as a sweat;
- Become involved in community activities as a way to meet new people;
- Use organization techniques to best manage time and reduce stress; and
- Creating an environment that is warm and inviting can increase the spirits of both caregiver and the person who is being cared for.

To reduce the stress of caregiving, ask the tribe to offer some respite care to give the caregiver time to him or herself; ask siblings to become more involved in caregiving; or contact the Nation Family Caregiver Support Program, managed by the Administration of Aging of the Department of Health and Human Services. The latter program gives family caregivers counseling, information, respite care, and supplemental services.

During National Family Caregivers Month, if you are a family caregiver, don't be afraid to ask for a little relief so that you can focus on you. And for those of who are not caregivers, let us express our gratitude to family caregivers in our communities and ask them how we can help them out to be sure the caregivers are being cared for.

Megwitch!

— Alan Allery



7 D's to a Healthier Me

1. **Physical:** Self-care practices, fitness, nutrition, screenings/vaccinations, safety practices.
2. **Psychological:** Self-esteem, attitude, relaxation.
3. **Intellectual:** Creative and stimulating mental activities, humor.
4. **Spiritual:** Meaning and purpose in life.
5. **Social:** Social connections, relationships, family activities.
6. **Vocational:** Healthy work practices.
7. **Environmental:** Personal, local and global environment/home and work environment.

Source: University of North Dakota Wellness Department

Training Update

by Francine McDonald, MPA

Arthritis Leader Training Workshop

The National Resource Center on Native American Aging teamed up with the North Central Chapter of the Arthritis Foundation and the Minnesota Department on Aging's Wisdom Steps Program to bring an Arthritis Leader Training Workshop to Indian Country. The workshop was held on June 17-19, 2003 at the Dakota Magic Casino in Hankinson, North Dakota.

During the three day training participants were trained to be leaders in presenting an Arthritis Self-Help Course within their own communities.

Attendees for the workshop were Peggy Johnson and Wanda Johnson of the Sisseton Sioux Tribe of South Dakota; Arlette Hager and Paulette Rowley of the Cheyenne River Sioux Tribe of South Dakota; Lynn Beckstrom and Denise Pike of the Mille Lacs Band of Chippewa of Minnesota; Lillian Reese, Amelia Flocken, and Carol Stauffer of the Leech Lake Band of Chippewa of Minnesota; Lucille Silk and Betty Red Horse of the White Earth Band of Chippewa of Minnesota; Connie Norman and Melanie Tobin of the Minneapolis/St. Paul urban area; and Lois White Eagle of the Standing Rock Nation in North Dakota.

Health Promotion Training

The National Resource Center on Native American Aging sponsored health promotion training during the month of August 2003 for individuals that work with Native

American elderly. The training consisted of two separate courses, Counseling Healthy Behaviors, held Aug. 8-10, and Health Promotion Director training, held Aug. 11-15. Both trainings were held at the Hilton Garden Inn in Grand Forks, North Dakota.

Both training sessions were presented by Carol Mooney and Caroline Williams of the world-renowned Cooper Institute of Dallas, Texas.

Registration for the health promotion training was opened up nationwide to those individuals or organizations that work with Native American elderly. Thirty-four individuals attended the Counseling Healthy Behaviors course and 31 attended the Health Promotion Director training course. These individuals represented 22 different tribal entities across 11

states and came from such places as the Tunica-Biloxi Tribe of Louisiana; Leech Lake Tribe of Minnesota; Tanana Chiefs Corporation of Fairbanks, Alaska; Alu Like, Inc. of Hawaii; Turtle Mountain Band of Chippewa of Belcourt, North Dakota; and the Cherokee Nation of Tahlequah, Oklahoma.

The National Resource Center on Native American Aging would like to thank all the participants that attended our training in June and August 2003. Future trainings are being planned, so please watch for our flyers. If we can be of assistance to you, please give us a call at (800) 896-7628.



Participants attended the health promotion training held in Grand Forks, North Dakota.

The Health of the Caregiver: Taking Care of Yourself

by Francine McDonald, MPA

By the year 2030, an estimated 20 percent of the U.S. population will be 65 years or older.

As the American population ages, a growing number of people will be serving as caregivers for family members. Caregiving refers to anyone who helps a friend, acquaintance, family member, relative or spouse who can no longer manage everyday tasks alone. Caregivers can be spouses, adult children, relatives, friends/neighbors, and volunteers.

While each caregiving situation is different, caregivers are likely to experience enormous stress from their responsibilities in caring for a loved one and neglect their own physical, emotional, social and spiritual needs. Many individuals become depressed or anxious and others report physical ailments associated with the stress of caregiving. AARP has published some things you can do to nurture yourself so that you do not become overwhelmed or burned out in your role of caregiver.

- 1. Take care of your health** – eat nutritious meals, get enough sleep, get regular medical check-ups, exercise regularly, and watch for symptoms of depression (such as crying more, sleeping more or less than usual, increased or decreased appetite or lack of interest in usual activities).
- 2. Maintain or establish social contacts** – isolation increases stress. Having fun, laughing, and focusing on something beside your problems can help you keep your emotional balance. This helps you and ultimately makes you a better caregiver, too.

- 3. Ask for help** – call on your friends, your parent's friends, and relatives for help. You should not feel guilty about asking someone for help.
- 4. Use community resources** – home care aides, meal or shopping services, adult day cares, information and referral services, and volunteers.
- 5. Get support for yourself** – talk with family and friends about the rewards and challenges of caregiving. Join a support group.
- 6. Find time for yourself** – to unwind when stresses pile up. Go for a walk, put time aside to read a book, take a long bath, or cook your favorite meal.
- 7. Organize as much as you can** – set priorities, make a list of what needs to be done, arrange your day to take full advantage of outside help, pace yourself, and set limits.
- 8. Deal constructively with negative feelings** – recognize the anger-guilt-anger cycle and stop it immediately by forgiving yourself for being angry, distance yourself from the situation, and feel good about your accomplishments as a caregiver.

Absolutely the easiest thing for someone to say and the hardest thing to accept is the advice to take care of yourself as a caregiver. By taking care of yourself, you will be better able to provide care for your loved one, physically, emotionally, and spiritually.

Upcoming Tribal Listening Sessions

- February 25, 2004 – Phoenix, Arizona
- April 28, 2004 – Rapid City, South Dakota

For further information, contact:

Kaufmann and Associates, 425 West 1st Ave., Spokane, WA 99201
Tel: (509) 747-4994, or by email at: info@olderindians.org

North Dakota's American Indian Family Caregivers: Results of a Survey

by Richard Ludtke, PhD, and Leander "Russ" McDonald, PhD

As part of a North Dakota statewide effort funded by the North Dakota Department of Human Services, Aging Services Division, a family caregiving survey was conducted on the four reservations and in the Trenton Indian Service Area. The collaborative effort between the Center for Rural Health, the North Dakota State Data Center, and the Department of Child Development and Family Life at North Dakota State University found social significant differences in the patterns between the reservations and the general population samples.

These results are important to American Indian populations as the reservations are rural, relatively isolated and are underserved by most long term care programs such as skilled nursing homes, assisted living and home and community based services. Consequently, reliance on their strong traditions of extended family supports often represents the primary option for providing care to elders or for providing child care.

Data collection on the five reservations was conducted on a face-to-face basis with data collectors trained by the project staff on use of the instrument. The data were collected from July 1, 2002 to February 28, 2003. Approval for this study was granted by the tribal councils for all five tribes and they assisted in making the data collection a success. The survey produced 383 useable surveys representing both informal caregivers and grandparent caregivers.

The American Indian sample ultimately contained 231 informal caregivers and 152 grandparent caregivers. This then suggests a proportion of 60 percent informal and 40 percent grandparent caregivers as an imprecise measure of the distribution of family caregiving between the two types. By contrast, the statewide, non-Indian data resulted in a ratio of 86 percent informal and 14 percent grandparent caregivers. More

grandparent caregivers were obtained from the five reservation sites than from the remainder of the state. One must conclude that grandparent caregiving is much more common among American Indians in North Dakota. This is quite likely a result of a combination of greater need and strong value placed on extended family relationships.

The following summary presents the highlights of the findings from this survey. More complete findings can be located on the National Resource Center on Native American Aging web site, <http://medicine.nodak.edu/crh/nrcnaa>.

Characteristics of Informal Caregivers:

- 25% retired
- 33% work full-time
- 69% female
- 61% married

Characteristics of Grandparent Caregivers:

- 23% retired
- 40% work full-time
- 86% female
- 39% married

Intensity of Care:

- The intensity of informal care is relatively low because of the age of the American Indian elders.
- Informal care is of short duration but very time consuming.
- Grandparent caregivers have a high proportion of children requiring 24 hour, seven day a week care.
- Moderate amounts of special needs are present among the grandchildren.

Caregiver Burden:

- Informal caregivers had a low sense of burden – out of 13 items, all scored below 2.0 on a 5 point scale in which 5 indicated serious difficulty.

- Highest concern reflected conflict between a sense of duty to provide care and accepting help in providing care. (Score was still very low)
- Conclusion – Burden is not a major problem for informal caregivers.
- Grandparents also had a low sense of burden, but slightly higher than for informal caregivers.
- Grandparent caregivers, as with informal caregivers, produced low scores.
- Duty among grandparents was also the highest concern and a barrier to accepting help – but it also produced a low score.
- Conclusion – Burden is not a major problem.

Support From Other Caregivers:

- 41 percent of the American Indian *informal caregivers* had help from other caregivers compared to 51 percent in the general population.
- 44.7 percent of the American Indian *grandparent caregivers* had other family members helping compared to 67 percent in the general population.

The cultural value of familism on reservations appears to assure informal and grandparent care when needed, but does not extend to supporting the caregivers, especially for grandparent caregivers. Caregiving is often a solo enterprise.

Availability of Formal Services:

For recipients of care

- Almost all services are less available to Indian elders than to the general population.
- Over half of the services were available to less than 50 percent of the Indian respondents.

For the children

- Lower availability was found on seven of eight services when compared to the general population.
- Counseling, tutoring, scholarships and mentoring were available to less than 50 percent.

For caregivers

- Caregiver education is more readily available for informal caregivers.
- Respite care is less available.
- Information about services and assistance in accessing services for informal caregivers were both low, reflecting the low range of services locally available.
- Uniformly, fewer support services are available for grandparent caregivers.

Services Caregivers Provide:

- They do it all! Especially, they provide socio-emotional support, household tasks and transportation.
- Legal assistance and help getting other family involved were low among informal caregivers.
- Also grandparents were “all things” to the child. Especially providing meals, transportation, companionship and discipline.
- Getting other family members involved and cross cultural education were low among grandparents.

Most Valued Information:

- Information generally was less valued by North Dakota’s American Indian respondents.
- Information questions often referred to services not locally available.
- Top categories of interest:
 - > Information about medical conditions.
 - > Counseling/support programs.
 - > Financial support.
 - > Assistance in dealing with agencies.
- Resistance to information was found – 36 percent wanted none.
- Again, the absence of local services made information about services difficult to appreciate.
- Top categories.
- Financial support.
- Discipline.

The Impacts on Caregivers:

- Relatively low impacts were observed among American Indian informal caregivers, probably as a result of the

relatively young ages of the caregivers and recipients.

- Dementia is less of a problem in the Indian population.
- Work conflicts are the most common impacts.
- Grandparents also reported low impacts – 60 percent reported no changes!
- Again, grandparents reported that work conflicts were the dominant impacts – getting to work late, leaving early, adjusting schedules, etc.

The fit between North Dakota's American Indian caregivers and data produced by a variety of national studies suggests that family caregivers on reservations in North Dakota are unique in many respects. Reservation communities struggle to “catch up” with respect to support services, while the concerns at the national level often deal more with issues of cost containment (including how to limit services) and dealing with a shrinking labor force pool that is producing fewer potential long term care workers. These national issues are not germane to reservations.

Sociologist, Neil Bull listed major barriers to rural services that also apply to reservations. Economic deprivation produces a weak economic market for services and leaves them to be met with public programs. Geographic isolation and a lack of public transportation produce a strains on access to regional services and existing local service infrastructure is slowly eroding in sparsely populated regions. He also reported an oversupply of rural nursing home beds that combines with an undersupply of home and community based services, leaving rural elderly little choice when confronting activity limitations. Ironically, this oversupply of skilled nursing home beds is absent for North Dakota reservation communities, leaving only the undersupply of support services.

Some national programs such as Program for All-inclusive Care for the Elderly (PACE) assume the availability of a wide array of services that need to be managed or coordinated to provide cost effective and high quality care. While the PACE program is seeking to develop a “rural model” for care, Indian reservations in North Dakota represent the extreme case of rurality and underservice and are likely to prove difficult to include in this model. Reservation communities struggle to develop the essential array of services needed to assure optimal quality of care by family caregivers. Generally, these support services are derived from the same array of home and community based services that support long-term care. The data presented above suggest the following list of key services as necessary to support family caregiving.

Necessary Services for Family Caregiving:

- Home health
- Personal care
- Nutrition
 - > Dietician
 - > Home delivered meals
 - > Congregate meals
- Homemaker services
- Chore services
- Transportation
- Respite care
- Outreach

Family caregiving for North Dakota's reservations is consistent both with the general belief that the extended family support system continues to function as it has in previous generations for American Indians and that family care on reservations operates largely in the absence of a complete array of support services or institutional options. Improving the availability of support services is critical to assuring high quality care by family caregivers.



**Center for
Rural Health**

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Family Caregivers Resources

AARP – www.aarp.org

Alzheimer’s Association – www.alz.org

Alzheimer's Resource Room
www.aoa.gov/alz

Elder Care Online – www.ec-online.net

Eldercare Locator (800) 677-1116
www.eldercare.gov

Family Caregiver Alliance
www.caregiver.org

Grandparents Raising Grandchildren
[www.aoa.gov/prof/notes/
notes_grandparents.asp](http://www.aoa.gov/prof/notes/notes_grandparents.asp)

National Alliance for Caregiving
www.caregiving.org

National Family Caregiver Association
www.nfcacares.org

National Family Caregiver Support Program
[www.aoa.gov/prof/aoaprogram/caregiver/
caregiver.asp](http://www.aoa.gov/prof/aoaprogram/caregiver/caregiver.asp)

State Units on Aging
[www.aoa.gov/eldfam/How_To_Find/
Agencies/Agencies.asp](http://www.aoa.gov/eldfam/How_To_Find/Agencies/Agencies.asp)

The National Family Caregiver Support Program

Family caregivers provide an invaluable resource to their loved ones as well as to America. Their courage, compassion and dedication to family members and friends allow the elderly and persons with disabilities to remain in a loving environment, often at great cost - economic, physical and mental - to the caregiver. I am pleased that we are now able to assist caregivers and provide them with resources in their communities so that they may continue their support.

~Tommy G. Thompson
Health and Human Services Secretary

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.