NAMES

Native **A**merican **M**ap for **E**lder **S**ervices:
A Toolkit for Long Term Care Service Development

FOCUS GROUP MEETING

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December 2002

Funding for this project is provided by a grant through the
Federal Office of Rural Health Policy
Health Resources and Services Administration

Welcome from the Director

Welcome to the National Resource Center on Native American Aging's (NRCNAA) web site. The NRCNAA is located at the Center for Rural Health, University of North Dakota School of Medicine and Health Sciences. I am pleased to provide you with some vital information regarding long term care in American Indian country.

The Center has conducted research on the health needs of American Indian elders for over two years. Many tribes and tribal elders have completed the Native Elder Needs Assessment Survey are now looking at ways of using the findings to either plan or improve existing long term care systems. To assist tribes with that task, the NRCNAA called together a focus group of tribal experts in the area of long term care to begin to design a Long Term Care Toolkit. This document is a record of those proceedings.

The Toolkit project began last fall (2002) and is supported in part by a grant from the Federal Office of Rural Health Policy, Health Resources and Services Administration. Although the Toolkit is still in the construction phase, we thought that it might be helpful, and at the very least informational, for those of you who visit our web site to be able to review the proceedings of the focus group.

We hope you enjoyed your visit to our web site. Please feel free to offer comments on the proceedings by e-mailing the center at fmcdonald@medicine.nodak.edu

Sincerely,

Alan J. Allery
Director, NRCNAA

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Long Term Care Planning Toolkit Development Meeting

November 20-22, 2002
Denver, CO
Summary of Meeting

Introduction

The National Resource Center on Native American Aging (NRCNAA), located at the Center for Rural Health, University of North Dakota School of Medicine and Health Sciences, was awarded a grant to develop a toolkit that will assist tribes with interpreting long term care data obtained through a national Native Elder Care Needs Assessment conducted by NRCNAA. As part of the first step in developing the toolkit a Long Term Care Planning Toolkit development meeting was held in Denver, Colorado on November 20-22, 2000. Five staff members of NRCNAA, one facilitator, and twelve participants attended the meeting.

The meeting was structured in the form of a focus group to allow the staff to gather information and direction to develop a long term care planning toolkit that will assist tribes in using long term care assessment data and to develop infrastructure and comprehensive services that respond to local needs and culture. The participants represented a wide range of geographic areas and were chosen because of their working relationship with American Indian elderly, either through tribal elder programs, state elder programs, tribal elder care homes, or nursing homes off the reservation that serve American Indian elders (see Attachment A for a list of focus group participants).

Agency Presentations

The first day of the meeting entailed presentations from various agencies to provide the focus group participants and staff with information on each agency's programs for dealing with long term care issues. The agencies that were invited to present were Administration on Aging, Social Security, Housing and Urban Development, Centers for Medicare and Medicaid, American Association of Retired Persons (AARP), Indian Health Service, National Council on Assisted Living, Administration on Aging Office of Civil Rights, and the Program of All-inclusive Care for the Elderly (PACE) Association. All the presenters were from their respective regional offices located in Denver. Unfortunately, the Indian Health Service presenter was unable to attend the meeting. See Attachment B for a topical summary of each agency's presentation.

Focus Group Discussion

The second and third days of the meeting were devoted to a facilitated discussion on long term care by the focus group participants. Linda Hendrickson of the University of North Dakota's Conflict Resolution Center led the discussion. It was decided by staff prior to the focus group discussion that participants would be given certain questions in the hopes of stimulating conversation on key issues and eventually reaching a conclusion of what would be seen as a priority to be included in the toolkit. The following questions were asked of the group:

1. When someone in your community needs a high level of care, not available through members of his/her family, what do they do? What do you think they should have available?
2. What do you think the most important needs for your people are today and are likely to be over the next 10 years? How are these needs being met today? What are the most adequate in terms of local providers? What are the least adequate? Are there crisis points?
3. What services can meet these needs most effectively in a manner that is consistent with the values or way of life in your communities?
4. How can we best guarantee high quality in long term care for your community? Where are the needs the greatest? How can these best be met – short term and long term?
5. In a proposed solution for long term care it is important to make note of who the stakeholders are – who are the likely supporters or objectors? How do we deal with them?

The focus group also discussed what barriers were in place facing those developing long term care for a tribe.

The participants responded to the questions by openly sharing with the entire group or writing individual answers and discussing their answers in small groups. All information was ultimately shared with the entire group, charted, posted on newsprint, and recorded on the computer (see Attachment C for the recorded notes and resulting themes of the focus group meeting). Effort was made by the facilitator to give each participant a chance to share his/her thoughts.

At the conclusion of the meeting, the focus group participants were asked to review everything that was discussed in the two-day session and to share with the staff what they regarded as priorities for the toolkit. The following is the resulting priority list:

- Define the continuum of long term care service options
- Needs assessment–needs to come before you develop your plan
- Development of a plan – this would include the first step of community involvement
- Examples of programs – use other's information so we don't recreate the wheel
- Differing land and jurisdiction issues. Recognize the differences in context and that programs need to be adapted

The participants were then asked what area of the long term care continuum should be the initial focus of the toolkit. The group responded by listing prevention, community based, and in-home services as priorities.

Conclusion

The Long Term Care Planning Toolkit development meeting was successful in the fact that it gave the staff insight into what is seen as "must have information" for tribes as they begin the process of developing long term care for their elderly. A bi-product of the meeting was the formation of networking relationships among the participants, giving them a forum in which to share information about successes and failures in working with programs that assist the American Indian elderly. This network will continue to serve the toolkit project by informing us and serving as reactors to the emerging product.

Attachment A
List of Focus Group Participants

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Attachment B
Topical Summary of Agency Presentations

Administration on Aging (AoA)

Presenters: Percy Devine, Region VIII Administrator
Elizabeth Clinton, Aging Services Program Specialist

The presentation included an overview of the AoA programs, specifically the Older Americans Act and the Public Health Service Act – Section 398. The overview covered the different parts of the Acts and what possible funding might be available under the Acts. The Assistance Secretary on Aging list of priorities was reviewed. The priorities are to integrate access to health care and social supports, health promotion and disease prevention, care giving, and elder rights. It was suggested that these priorities be in the forefront when developing the toolkit. More information can be obtained at http://www.aoa.gov.

Social Security Administration

Presenter: Steve Potter, Denver Public Affairs Specialist

The presentation centered on the eligibility requirements for Social Security benefits and what to do in case your request for benefits was denied. Possible sources to gain more information about Social Security include Benefitcheckup.org and a new website for American Indians and Alaska Natives: http://www.ssa.gov/aian.

Department of Housing and Urban Development

Presenter: Mike Boyd, Grants Management Director
Northern Plains Office of Native American Programs

Various Housing and Urban Development (HUD) grants that might generate funds to offset housing and utility costs for elder care were reviewed and discussed. Some of the grants reviewed include Indian Community Development Block Grant Program, Rural Housing and Economic Development, Assisted Living Conversion for Eligible Multifamily Housing Projects, and Indian Housing Block Grants. Information on the grants reviewed can be found in the Catalog of Federal Domestic Assistance at http://www.cfda.gov/.

Centers for Medicare and Medicaid

Presenters: Jim Lyon, Region VIII
Gloria Baca, Health Insurance Specialist - Medicaid
Cyndi Gillaspie, Health Insurance Specialist - Medicare

Separate presentations were given for Medicare and Medicaid, however each presentation provided information on eligibility requirements, what services are covered, and the amount that is covered for services provided under these programs. A new initiative, the Nursing Home Quality Initiative, was also reviewed and discussed. This initiative will allow comparison of nursing home quality of care performances. For more information on the Centers for Medicare and Medicaid, vist http://cms.hhs.gov.

American Association of Retired Persons (AARP)

Presenter: Vicente Serrano, Volunteer

A brief description of AARP and its strategy for long term care was given. AARP's strategy is to focus on prevention, to prolong healthy living and independence; empowerment, to expand information resources and confidence to make decisions; more and better choices to increase options in services and care settings; and more and better financial tools to expand choices for financing care and for support.

National Council on Assisted Living

Presenter: David Skipper, Director of Public Relations
Colorado Health Care Association

The National Council on Assisted Living is trying to move away from institutional type of care for the elderly and focus more on assisted living or home based care. The presentation included statistical information on assisted living residences and residents, methods of payments, regulations, and trends in assisted living.

Office of Civil Rights

Presenter: Velveta Howard, Region VIII Manager

The Office of Civil Rights enforces the laws under Title VI of the Civil Rights Act, Section 504 of the Rehabilitation Act, the Americans with Disabilities Act, and the Age Discrimination Act. The presentation gave a general overview and possible violations were given for each act. The recent Olmstead court decision involving institutionalized care was also reviewed.

National Programs of All-Inclusive Care for the Elderly (PACE)

Presenter: Tom Ryder, Total Longterm Care

National Programs of All-Inclusive Care for the Elderly (PACE) Association is the concept of providing total quality care and services to elderly who need support to stay independent and out of a nursing home. The information presentated focused on the Denver PACE program and the success it has had being based in an urban area.

Attachment C
Recorded Notes from Focus Group Meeting

1. When someone in your community needs a high level of care, not available through members of his/her family, what do they do?

- Contact the tribal advocate, social services, to help them get in touch with any services available.
- If medical program, they'd go to a clinic, physician, hospital.
- If not medical, social services, protective services or law enforcement.
- Come to Indian Health Service (IHS) clinic for diagnosis and referral. Referral process to specialists, Public Health Nurse/Community Health Nurse (PHN/CHN) assess case manager to find other available services. Case manager/CHN develop care plan. Any services to keep the person at home. Service providers include tribal (CHN, PHN) injury prevention (home safety inspection), housing, CHRs, aging) SPC and county Qualified Service Provider (QSP), Low Income Home Energy Assistance Program (LIEAP), Community action, weatherization, social services). Deliver care until placement necessary. Assist with placement. Continue appropriate care assistance.
- Family member contacts the tribal agency to find out what needs to happen to keep the elder at home. Coordinate with county agencies and other services. Many times the family just needs to know what their options are. Provide information and referrals.
- Senior Linkage Line, plugs into the national resource database. Need to make sure the tribal resources are included in this database.
- Family cares for them.
- Eventually needs to go to the hospital in Anchorage.
- Doctors refer to nursing home. Doctors don't know what services are available.
- Home health 14 years than to nursing home.
- Call tribal executive, tribe contacts others that need to be involved, tribe provides assistance, i.e., $$, needs.
- Contacts the IHS discharge planner, they usually contact the Montana elder protection team. Help to find new apartment. Contact programs, variety of programs, assess welfare of senior, provide support - flexibility, compassion, Montana has a directory which people use, Advocate needs.
- Home/Community based waivers.

What do you think they should have available?

- Not a local acute or long term care rehab facility, intensive therapy not available.
- Shortage of beds and "good" nursing services/facilities (regional or tribal issue).
- Missing support for families who want to keep their elders at home - not respite.
- Programming for Native Americans - need cultural competence, to have Native people working at a nursing home that's located near a reservation.
- Too few elder service teams to make sure that needs are met with services.
- Someone to follow-up on referrals.
- Need to increase case managers, community nurses.
- All of the community based services.
- Medicaid and non-Medicaid resource person.

- Transportation services, less restrictions.
- Adult day health.
- Better management of Indian Health dollars.
- State of Montana has 33 investigators for adult protective services, but none service the reservation.
- Geriatricians or a geriatric focused clinic, staff need special training.
- Dieticians and nutritionist.
- Certify elder nutrition staff.
- Physical therapy in home.
- Preventive health care, physical fitness.
- Minimum - range of motion.
- Organized preventive health programs.
- Comprehensive tribal directory of available services.
- Do information and assistance - do follow up to make sure they connect with service.
- Look internally, know who/what's available.
- Find others in the community, elders, who are healthy - Senior companions.
- Informal caregivers.
- Want to stay at home and be cared for by family members - need support/funding for family caregivers.
- Tax credits or other incentives for someone to care for elder
- Additional funds for caregiving.
- Uniformity across states for family member's eligibility to receive funding for caring for elder - uniform state regs. - Medicaid.
- Look at proactive states, find best practices, list of things states are doing.
- Someone to overcome barriers - tribal advocate.
- Demonstration projects need to be better funded $300,000 per year for a minimum of 3-5 years.
- System to assess community needs - case management.
- Evercare program looks at the treatment of elders in supervised care - Medicare/Medicaid reimbursed, report to doctor, safe guards to elder abuse, weekly monitoring.
- Hospice/end of life care.
- Health insurance, supplemental to Medicare/Medicaid or IHS funding.
- Adequate reimbursement of Medicaid reimbursement and less work.
- "Funding is one thing, adequate funding is another" (quote, LK).
- Direct funding from the government.
- Documentation impacts care and costs - compliance issues.
- Programs that identify client needs.
- Quality of live.
- Activities of daily living.
- Socialization.
- Spirituality.

2. **What do you think the <u>most important</u> needs for your people are today and are likely to be over the next 10 years? How are these needs being met today? What are the most adequate in terms of local providers? What's there works.**
    - Home and community based waivers
    - Elder nutrition centers
    - Tribal case managers
    - Informal or family caregivers are the most important and most stable
    - Acute
    - Institutional
    - Rehab
    - Adult day care
    - Long term care facilities
    - Elder houses or independent living center
    - Assisted living
    - Varies by region, provider

What are the least adequate?

- Same list as above
- Lack of funding for caregivers
- Lack of focus on quality of life, medical focus vs. social, example could be safety
- Federal to state information communication, tribes need to be at a more equal point
- Accountability
- Cost effectiveness
- Looking at holistic options
- Transportation
- Preventive health
- Quality of services
- Quantity of services
- Services available
- In home services
- Staffing
- Housing and housing rehab
- Mental health - stigmas attached
- Mental health providers don't know how to provide services to elders
- Lack of mental health education and awareness
- Confidentiality

Are there crisis points?

- Confidentiality
- No family
- Not Medicare eligible, didn't work enough quarters or paid under the table (* Alan wants to bring up in Baltimore)
- Lack of urban services (no IHS)
- Getting to the crisis point without even knowing about services, information not available, outreach

- Isolation of urban elders
- Degradation of good and natural foods, and lack of practice of preventative health
- Lack of access to providers
- Wasted funds, going to ER, funds misspent
- Lack of competency
- Lack of implementation of good information
- Lack of comprehensive health plan
- Lack of multi disciplinary team approach, i.e., facility, community
- Decreased workforce traditional workers, indigenous to area
- Abuse issues, such as physical, financial, elder, self neglect,exploitation

3. **What services can meet these needs most effectively in a manner that is consistent with the values or way of life in your communities? (Again - move to filter the list with some type of nominal group process)**
   - Elders need to be where they want to be
   - Where they want to be
   - Foods they want to eat
   - Making personal decisions
   - Independence, autonomy
   - Use own community based people to provide services to the elders - training them to be providers
   - In home, community based highest priority, less regulated and more flexible
   - Traditions and values came from family members first, the community second
   - "In the perfect world, we'd have family members caring for the family" (quote, LK)

4. **How can we best guarantee high quality in long term care for your community?**
   - High quality, caring, valued workforce
   - Choosing long term people who will do the job well for training
   - Lack of support, positive feedback
   - "If we don't have a workforce, why would we even bother to develop a resource" (quote, KB)
   - "Workers want the community to know they're doing this so the elders can stay at home. Isn't this what you wanted?" (quote, KB heard from one of the workers)
   - Accountability, poor workers are keeping their jobs, compromising quality and safety
   - Consumer board, achieve goals, meet the needs or their community and those their serving. To develop local accountability, quality control - instead of state and federal/ Joint Commission on Accreditation of Healthcare Organizations (JAHCO). "Regulations don't provide any diversity." (quote, LK)
   - Develop a zero tolerance policy.
   - "Tribal initiated and implemented, comprehensive long term care services" (quote, SW)
   - Clear goals - identified outcomes
   - Strategic, comprehensive plan
   - Adequate funding (connected to money)
   - Look at how we're going to make more money, not how we're going to cut back

- Involvement of the immediate and extended family. Better training and education of all gate keepers for the recognition of problems. Reporting the problems for early intervention.
- Everyone who comes into contact with the elders has a responsibility.
- Everyone in community involved in housing. Health people should be involved from the beginning.
- Obtain necessary expertise to make sure the facility is accessible to disabled, blind, safety, etc.
- Elders involvement in location, cultural clearances
- Tribally funded facilities
- Need data on future projections of the elderly
- Building in a continuum of care, future plans
- Develop an educational program to teach the children about caring for elderly parents
- Elders need to plan ahead with their children their expectations, desire to stay at home

Where are the needs greatest? How can these best be met - short term and long term?

- Not enough plans to figure out the full range of operation expenses, projections
- Short term - Toolkit for developing an assisted living facility (Kay Branch has developed this - it's on her website)
- Continuous network
- Need to know what the projections are for occupancy rates for facilities for the first several years so adequate planning for $$ are in place
- Model to address training and education in the areas you have needs
- Working on a way to increase our workforce

5. In any proposed solution for long term care it is important to make note of who the stakeholders are - who are the likely supporters or objectors? Here we can list groups of people who are likely to support new programs as well as those who would object. We should note the substance of the expected support or objections - the whys. We should examine how to deal with them and whether policies might need to be changed.

Stakeholders/Supporters/All possible objectors

- Tribal chairperson
- Tribal council
- Health boards
- Membership
- IHS, HUD, Housing, CMS, AoA, AARP
- Federal and state programs
- Associations and foundations that are supportive of long term care
- Communities
- Elders
- Congress
- Employees
- Service providers
- Hospice

- Medical community
- State nursing home association (American Healthcare Association)
- Non-Indian community
- Disability community (in Montana)
- National Congress of American Indians, National Indian Council on Aging (NICOA), national and regional tribal organizations, affiliated tribes of the Northwest
- Spiritual and traditional medicine people
- Caregivers
- State organizations
- Families
- Nursing homes
- County, city govt., legislators, colleges, vo techs, tribal colleges, school systems
- IHS physicians

Best Approach
- Educate county workers about trust land issues
- Educate legislators
- Educate the stakeholders and supporters
- Fairness issues not being addressed
- Children and family divisions are very interested in aging issues
- Involve from beginning to end
- Open communication
- Develop a comprehensive, continuum of long term care plan (independent living, assisted living, nursing home, hospice)
- Coalitions/partnerships
- Focus on the elders staying at home for a higher quality of life
- Need to push for more waivers
- Tap additional resources such as Title III, Temporary Assistance for Needy Families (TANF)
- Catch people that are falling through the cracks
- Better use of elderly waiver
- Have to go to the state to get language that say tribal operated not county operated
- Culturally based, functional assessment
- Change language
- Use of a mediator

Objectors
- State and federal - wood work effect
- Elders
- Stakeholders/supporters are afraid of change
- Tribal and state policies

Policies
- Fairness of issues not being addressed

Long term care

- A continuum of care
- Home support
- Eligible, income, disabilities
- Non eligible - little help to remain independent
- Chore services, homemaker aid, Title III, TANF - resource temporary 20-hours
- Catch people that are falling through the cracks. Chore service, a lot of elders don't qualify for certain things, they just need help with housecleaning, shopping, etc.
- Prevention piece
- Waiting lists - follow up, plan
- What do you need? Ask the elders what they want?
- How do you support?
- States accept tribal assessment
- Tribal operated

Tool kit

- Overlying everything should be the right to self determination (first and foremost)
- Culturally based assessment tool
- Create a roadmap, each area will have to figure out how it will work for them
- Establish what the continuum would be - define continuum, could pick what's most appropriate for your area
- Roadmap - Identify each service, list each program and it's components to make it easier to identify where each elder/disabled person fits in. This would include program options, funding source requirements.
- First steps in community organization
- Community needs to take ownership
- Needs to be "real" especially as it relates to funding, capacity, sustainability
- Calculate financial formulas - look at PACE's website (note to Julie)
- Needs assessment or use information that's already available, some elders have been surveyed so many times
- Examples of what already exist
- Other websites, links or references to (look at University of Kansas' community tool box, excellent guide on how to do community organization)
- Examples of programs, model projects, exemplary programs, best practices
- Demographic break down based on total enrollment - specialized information. List tribes into groups by size and by differing land status. Self-governance, 638 tribes, treaty tribes, etc. (i.e., jurisdiction issues)
- Examples of state regulations, modification, model languages, etc.
- Encouraging networking
- Evaluation, programming, process
- Training model, resources - continuum
- Definition of the waivers
- Definition of terms
- Adult protective service codes, could go under the definition of continuum

- Clear definition of Adult Protective Services (APS). Tribes often don't have their own APS codes. They follow the state laws.
- Working with states.

Toolkit - Most important areas to focus on (in order)
- Define continuum.
- Developing your plan - first step is to work with the community on what the plan should be. Possibly include the evaluation in the plan.
- Examples of programs - use other's information so we don't recreate the wheel.
- Needs assessment - needs to come before you develop your plan.
- Differing land and jurisdiction issues.

Toolkit Focus of type of Long Term Care
- Community based
- Prevention is the concept not the service
- Bolster in home services

Overcoming barriers
- Tribal leaders - relationship with state
- Federal leaders need to be involved - those with power

Themes from Focus Group Meeting

Prepared by Linda Hendrickson

1. One-size fits all programs will not work. Each tribe has individual needs and programs. The toolkit needs to be a resource that can be used as options for a variety of needs, allowing them to pick and choose. Roadmap, links, programs, assessment data, networking options.
2. Self-determination is important on all levels from programs to the elderly individual.
3. Programs that support peoples' ability to stay in their home need to be given priority. The continuum of care needs to include more programs to support this concept—support for caregivers as well as prevention elements.
4. There are many barriers to establishing programs. Acknowledging the barriers and examples of ways to address them need to be included.
5. This group brainstormed many content areas that could be included in the toolkit—list of stakeholders, best approaches, examples of ways that they have dealt with barriers, crisis points, etc.
6. Identifying, communicating, and partnering with stakeholders is key to the success of any project.
7. Thorough planning is key to success. The toolkit needs to include help in this area—definitions, best practices, resources, realistic data and evaluation, future projections.
8. As well as accessing rightful federal dollars, there was also some desire to achieve economic sustainability/independence that would lead to more tribal control. The resource most identified by those in the room was **networking** which created much energy among the participants. The toolkit could encourage widespread networking.
9. Networking may also help the programs become economic development. As training for support/caregivers and providers also creates jobs. These programs/jobs should be culturally relevant and run by the tribe.
10. Lack of consistency creates issues—states differ in how they approach/cooperate and address issues in Indian Country. Medicaid, being state run and a source of program funding, is inconsistent.