Caring for our elders
Native Elder Caregiver Curriculum

National Resource Center on Native American Aging

Curriculum Developed at the
Cankdeska Cikana Community College, Spirit Lake Nation
and University of North Dakota

Curriculum Team

Twyla B. Baker – Demaray       Dr. Chris Burd
Dr. Leander “Russ” McDonald    Darlene Nelson
Dr. Cynthia Lindquist         Dr. Leigh Jeanotte
Ann Miller                   Soma Vedirewarapu
Melvine Reierson

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Twyla B. Baker-Demaray is an enrolled member of the Mandan, Hidatsa, and Arikara Nations of Fort Berthold, and is originally from New Town, ND. She is the Director of the National Resource Center on Native American Aging (NRCNAA). Baker-Demaray holds a Bachelor of Science degree in environmental geology and technology and earned a Master of Science degree in education general studies with a focus in research methodologies in 2005 from UND. She is currently pursuing her doctorate degree in research methodologies, also at UND. Baker-Demaray has worked on projects with American Indian veterans in North Dakota and has assisted over 300 tribes, Alaska Native villages and Hawaiian homestead in conducting elder needs assessments.

Dr. Leander “Russ” McDonald is the former director of the National Resource Center on Native American Aging (NRCNAA) and is currently Vice President of Academic Affairs at Cankdeska Cikana Community College of the Spirit Lake Nation. At the NRCNAA, Dr. McDonald has assisted over 300 tribes, villages, homesteads and consortia in conducting Native elder social and health needs assessments. The information gathered from the assessment has assisted the tribes to develop long-term care infrastructure and to strengthen grant proposals to address identified needs. His father is Dakota from the Spirit Lake Nation and his mother is Arikara from the Fort Berthold reservation. He has been conducting research among Native populations for the past 12 years, focusing on American Indian and Alaskan Native elderly for the past 10 years. Dr. McDonald’s guidance throughout the NECC project has been very important to its completion.

Dr. Cynthia Lindquist is the President of Cankdeska Cikana Community College of the Spirit Lake Nation. Cindy earned her BA in Indian Studies/English at the University of North Dakota, her Master’s in Public Administration at the University of South Dakota, and her PhD in Educational Leadership at the University of North Dakota. Her leadership has been instrumental in creating a number of quality learning opportunities for American Indian people through collaboration with entities throughout the nation. She is appreciated for her support for the NECC initiative.
Ann Miller is an Administrative Secretary for the National Resource Center on Native American Aging. She provides administrative support to the Center, which includes budget tracking, travel arrangements and assisting with grant applications and needs assessments. Prior to joining the NRCNAA, she spent 15 years working for the Minnesota Historical Society at the James J. Hill House in St. Paul. She also served as the program director for the Arthritis Foundation in Georgia. Miller received an associate of science degree from Roane State Community College in Oak Ridge, TN.

Darlene Nelson is from northern Minnesota. She has an AAS in Services for Family & Aging from the University of MN, an AAS in Computer Science, and a BA in General Studies from University of ND. Darlene is currently in the Masters program in Instructional Design and Technology at UND. She has been working with American Indian students at the American Indian Student Services at UND since 2002 as an administrative secretary. She is also the owner of “Twisted Forks” Web Design in Grand Forks, ND.

Chris Burd has a nursing background in adult health, gerontology, and nursing education. Since earning a PhD in Community Health Science in 1985 from the University of Manitoba, she has been working as a consultant and trainer with Community Health Workers (CHR)s and diabetes outreach programs in American Indian communities in the Dakotas. She has previously worked with the National Resource Center on Native American Aging (NRCNAA) on the “Elders’ Talking Circle” Project. The NECC curriculum is an outgrowth of that project and ongoing work with CHR$s and diabetes outreach workers.

Melvine Reierson is an Academic and Administrative Assistant with the Cankdeska Cikana Community College at Spirit Lake Nation. She earned her Associate of Arts through Cankdeska Cikana and is an enrolled member of the Spirit Lake Nation. Her valuable assistance with coordination and hosting of the elders’ and caregivers’ focus groups at Spirit Lake made a significant contribution to the completion of the NECC project and is very much appreciated.
**Dr. Leigh D. Jeanotte**, is a member of the Turtle Mountain Band of Chippewa. He has served as the Director of American Indian Student Services at the University of North Dakota for more than 30 years. In his position, Leigh advocates for American Indian students, promotes programs that assist students with all aspects of their University experience, advises the administration concerning campus climate and cultural sensitivity, services on the American Indian Programs Council, chairs the Indian related programs meetings, and maintains relationships with the regional American Indian tribes and tribal colleges in an effort to create partnerships and increased opportunities for students. Leigh also serves on a variety of campus committees and is currently the president of the Higher Education Resource Organization for Students (HEROS). Additionally, he is an active member of the National Indian Education Association (NIEA), the North Dakota Indian Education Association (NDIEA), and serves as advisor to the University of North Dakota Indian Association (UNDIA). He completed his education at UND, earning his Ed.D. in Educational Administration in 1981, his M.Ed. School Administration in 1974, and his B.S. in Elementary Education in 1972.

**Soma Vedireswarapu** works as a tutor at the American Indian Student Services, UND helping students with Chemistry, Math, Physics, computers and Statistics. He is currently a Master’s student in Chemical Engineering at UND. He possesses the needed patience required to finalize a project. His generous assistance in contributing his technical computer expertise in producing the final draft of the NECC curriculum is very much appreciated.
OVERVIEW
OVERVIEW

NATIVE ELDERS CAREGIVER CURRICULUM (NECC)

CARING FOR OUR ELDERS

Introduction

Through a collaborative effort between the National Resource Center on Native American Aging (NRCNAA) and Cankdeska Cikana Community College (CCCC), and with special appreciation to elders and community members of the Spirit Lake Nation for their help, this “elder caregiver” curriculum has been developed. The project was supported through a Cooperative Agreement to the NRCNAA by the Administration on Aging.

Influence of Future Demographic Changes

American Indian elders are valued members of their communities. The Native Elder Caregiver Curriculum (NECC) has been designed as a tool to assist caregivers who have the responsibility of caring for their elders. The NECC curriculum focuses on topics that have been identified by elders and caregivers living in rural reservation settings, as useful in the provision of community-based care for Native elders. The development of the NECC curriculum is timely as a response to recent studies projecting a significant growth in the population of Native elders in the next decade\(^1\). Current and future needs of the elderly population in Indian Country across the United States have been documented through nation-wide surveys of Native elders by the National Resource Center on Native American Aging (NRCNAA).

Based on the projected increase expected in the number of American Indian elders in the near future, there will clearly be a need for more long-term care options for American Indian people. Elders prefer to remain in their own home and community settings, that is, they prefer to “age in place”. Because the Indian Health Service is not designed to provide long-term care services, the time for proactively building effective Home & Community-Based Services (HCBS) for
American Indian elders is now. The time to prevent disabilities through a focus on Health Promotion in individuals and in American Indian communities is now.

**Traditional Strengths and Current Context**

In addition to the context of projected demographic changes, the curriculum development has been guided by an awareness of the modern context of Tribal reservation communities, as well as a mindfulness of the historically rich traditions and strengths of American Indian nations. Concepts that served as an “embedded” framework during the preparation of the curriculum included:

- Interdependence of generations
- Increasing life expectancy of American Indian populations
- Expected social roles of elderly members of the community
- Expected social roles of younger members of the community
- Shared American Indian values: respect, compassion, fortitude, generosity
- Holistic perspective of health and wellness
- Increasing trends in chronic disease prevalence
- Potential to limit disability in ADLs & IADLs through health promotion
- Need for caregivers who are culturally competent
- Respect and support for family caregivers
- Strong potential for healthy communities, by joining traditional strengths with scientific knowledge of Health Promotion and disability prevention
- Shared Community concern for the success of future generations
- Living in balance with the ability to realistically identify current problems, while planning for a better future

In order to effectively plan and implement a range of HCBS, networks need to be strengthened in each American Indian community. Recommendations for strengthening needed links in this network (at local, regional, and state levels) are discussed as part of the curriculum. A special recognition of Community Health Representatives (CHRs) for their ongoing dedication to the care of elders in so many communities is one of those recommendations. And of course, the most
critical link in caring for elderly family members remains the support of family caregivers. This curriculum has been constructed with these caregivers in mind. Their needs must be met, so they may continue to live out their values of respect, generosity, compassion, and fortitude while honoring loved ones who need their help. The curriculum hopefully will empower caregivers with some of the information that they need to carry out this important, sacred work for their relatives. This NECC curriculum is dedicated to them.

NECC CURRICULUM

FIGURE I: Model of Necessary Relationships for Successful Home & Community-Based Services (HCBS) for Elders in American Indian Communities
SESSION  1.1
DAY ONE

SESSION 1.1  NORMAL AGE-RELATED CHANGES

PURPOSE

- Learn about common biologic changes often seen while people grow older
- Learn to recognize differences between “normal” biologic changes & those that are related to disease/illness

OBJECTIVES

At the end of the session, participants will:

1. Identify common changes that can occur during the aging process
2. Identify reasons for biologic changes during aging
3. Be aware that some changes are not “normal” and may require further evaluation by a health care provider

LEARNING OPPORTUNITIES

- Talking Circle with Introductions
- Discussion of perceptions of aging process
  - Holistic view of health
  - Cultural viewpoints about elders in Tribal communities
Ideas to think about

The season of aging is a normal developmental process. We change over our lifetimes, with change as a constant companion on life’s journey. Some people don’t think “positively” about getting older, and some even want to avoid it completely. However, we all begin “aging” as soon as we are conceived! According to long-held traditional values, American Indian people have the benefit of a strong cultural perspective that honors the elders and their wisdom.

“To everything there is a season…” Traditionally, Native people viewed all of life as a circle. As the two-leggeds, we live within a circle of physical, mental and emotional, social, and spiritual dimensions. Even life itself is “like a great circle… young ones are born, grow up, become old and then die, and soon more young ones are born to take the place of the old ones. Lame Deer has some words about all this: ‘with us the circle stands for the togetherness of people who sit with one another around a fire … all the families in the village were in turn circles within a larger circle, part of the larger hoop of the nation…”

Growing older, with its accompanying experience and wisdom, has traditionally been respected among Native people. The “season” of being an elder is an important one along life’s circle. According to two respected American Indian elders, the definition of an elder is one who has received “gifts from the Creator” along their life’s path, and who then generously “share these gifts with others to help them”. According to this definition, the practice of leadership and generosity are considered to be essential in the role of an “elder”.

Those in the “early seasons” of life depend on the wisdom and help of those who have moved into the “later seasons”. As we move through life’s seasons life, it might be helpful to think of the important things that can only come by living meaningfully for a long time. “Knots on the root of the oak tree tell of many storms and how deep the roots have forced their way into the earth.”
Physical changes as we grow older\textsuperscript{7, 8}

It is helpful to think about all of the cells of the body as “building blocks”, and during the aging process, each of these “building blocks” will grow older over time. Cells are “building blocks” of every part of the body, such as muscles, bones, blood, nerves, etc. And cells form tissues specific to each organ, such as our hearts, lungs, brain, kidney, etc. Then, the organs form “systems”, such as the cardiac system, the respiratory system, the nervous system, etc. The “systems” work together to keep us “growing and going” throughout our lives, while the aging process is quietly and normally taking place in each system.

However, we are more than our physical systems. Humans are complex beings, with interactions going on all the time in our physical, social, spiritual, and emotional “self”. This holistic view of the human being is a traditional Native perspective\textsuperscript{9}.

\begin{center}
\textbf{Figure 1. Combined Biologic and Traditional Perspective of the dimensions of life for a human being. (Burd, 2009)}
\end{center}
A Couple of “Theories” about the Aging Process\textsuperscript{7, 8}

There are many theories about the process of aging. There are theories of genetic programming, cross-linking in DNA strands, excess of free radicals, autoimmune reactions, wear & tear, stress, disease, imbalance of neurochemicals and neuroendocrines, radiation, imbalance of nutrients, environmental exposures... just to name a few! However, rather than thinking about all these theories, it may be better to remember that all of our body systems are made up of cells, and what happens to each cell during the aging process will determine how entire body systems change with age.

Different body systems age at different rates among individuals, and even in the same person. Scientists have tried to figure out what happens as we get older, and a number of theories have been developed. Just as examples, two theories are briefly described below.

Theory #1: “Wear & Tear”

- Our cells go through a lot of injuries and damage over the course of a lifetime
- The damage from a variety of sources accumulates over time
- Cells get damaged, “used up” and “worn out”

Theory #2: “Gene programming”

- Our cells are “programmed” in our genes to age in a certain sequence or pattern
- Our cells are “pre-programmed” for how long they will last
  - Cells follow the “program” for the number of times they will replace themselves before they quit being able to replenish themselves

In actuality, aging probably takes place through a number of very complex interactions and mechanisms that are all going on at the same time, both inside of us and outside of us. The purpose of this session will not be to dig too deeply into
the research of the aging process. But, it is helpful to think about each and every cell of the body aging, and going through its “birthdays”, just like us!

Expected Changes in Aging\textsuperscript{7,8}

As common people living our own lives, we have seen many people around us get older, including ourselves. And we can make our own observations about what we can expect to see as people get older. A few expected changes related to the aging process in some of our body systems are briefly reviewed below:

- **Nervous System**: Because of a decrease in the number of nerve cells, we may see a slower response time in older people. This may related to some increased safety concerns, for example, in terms of certain tasks such as driving.
- **Sleep Patterns**: Older people seem to sleep less in longer blocks of time; they take longer to fall asleep; they wake up more frequently during the night; and they wake up earlier in the morning.
- **Cardiovascular system**: It is difficult to separate out “expected changes” from changes we see because of heart diseases, but overall there is:
  - Increase in stiffening of the arteries & heart muscle
  - Decrease in responsiveness to nerve impulses which go to the heart
  - Slower reflex control of the heart rate & the blood pressure
- **Pulmonary system (lungs)**: During the aging process these changes may be seen:
  - Lungs become less “elastic”
  - Chest wall “stiffens”
  - More resistance to air flow
  - Lower oxygen level in the bloodstream.
- **Kidneys**: there is a decrease in the:
  - Size of the kidneys
  - Blood flow through the kidneys
  - Filtering rate in the kidneys
  - Number of filtering units (the nephrons)
  - Ability to concentrate the urine
1.1 Normal Age-Related Changes

- Ability to eliminate medications from the body
- Ability to maintain fluid & electrolyte balance
- Ability to recognize being thirsty

(The kidneys still work, but just less efficiently than in younger person).

- **Bladder:** there is an increase in:
  - Frequency of urination ("going often")
  - Urgency ("have to go")
  - Night time urination ("up at night")
    - These "normal" symptoms may be aggravated more by other conditions, such as benign prostatic hypertrophy (BPH) or prostate cancer in men, or urinary tract infections (UTI) in women
    - Incontinence of urine is not a normal condition for older people, and should be "checked out" to see if it can be helped

- **Digestive Tract:** There are common complaints we often hear from elderly people about the "gastrointestinal" system (GI). And actually, there are quite a few changes that occur in the GI system:
  - Starting in the mouth, there is increased loss of tooth enamel, teeth, and taste. There is an increased dryness, too. The loss of taste is highly related to a loss in the ability to smell, and these changes can create quite a challenge to maintaining good nutrition!
  - The stomach empties more slowly, and digestion takes longer
  - There is decreased mobility in the intestines, change in food intake and fluid intake... all of which contribute to constipation. In addition, sometimes an elderly person has to take certain medications that may further contribute to this problem. Constipation can be a serious problem for elderly people, and cannot be taken lightly. For example, a person with heart disease and hypertension issues should not be “straining” on the toilet. The good news is, what a person eats and drinks, and how active they are can really help to prevent the problem of constipation.
1.1 Normal Age-Related Changes

- The liver has a decreased blood flow, and a decreased ability to get rid of byproducts of medications in the body
- The gallbladder seems to have an increase in collecting gall stones

- **Muscles:** In the muscle system, there is a decrease in:
  - Muscle “bulk”
  - Muscle strength
  - Lean body mass... we become “fluffy”
  - But... There is good news, though!
    - Muscle tissue can “regenerate” even into older age
    - Strength training can prevent muscle loss!

- **Bones:** Changes in bone include:
  - Loss of bone tissue
  - Decreased strength of bones
  - Decreased minerals deposited in our bones
  - Increased brittleness of the bones
  - In women, there is more loss of bone tissue than in men
  - Possible loss of height due to curving & changes in the spine

- **Joints:** Changes in joints include:
  - Cartilage in the joints becomes more rigid and fragile
  - Decreased range of motion in the joints, due to aging changes in the muscles and ligaments.
  - Increase in osteoporosis
    - Can result in more fractures
  - Knee joints are very often affected in older people
    - Can really limit mobility and exercise.

- **Skin:** We don’t often think about it, but our skin is the largest organ in the body! It needs to be cared for, as it is a major “defense” organ. The skin is a large “cover” that protects us from infection and helps us to regulate the right range of body temperature at all times. Changes in skin include:
  - Becomes more dry, thinner, wrinkled, & less elastic
  - More sensitive to ultraviolet radiation (sunlight)
  - Decrease in the blood vessels to the skin layers
o Increased risks for skin infections and irritations
o Slower wound-healing ability
o Decreased sense of touch, pressure
o Decreased ability to regulate body temperature because of the skin’s change in its ability to respond to heat and cold.

o **Immune System**: Elderly people have:
  o Decreased immune response which slows down the healing of cuts, scratches, surgical wounds, etc.
  o Decreased activity of the “T” cells in the immune system and the function of the “B” cells changes also, related to:
    ▪ More difficulty for elderly people to fight off infections as well as they did when they were younger
    ▪ Increased risk for bacterial infections especially of the lungs, urinary tract, and the skin
    ▪ Increased risk to develop autoimmune diseases, such as *rheumatoid* arthritis
      - Also increased risk for *osteo*-arthritis, however this is more related to “wear and tear” on the bones and joints, not to the immune system.

o **Stress Response**:
  o Can have more difficulty coping with stress
  o Becomes more difficult to “keep balance” sometimes
    ▪ Our “built-in”, automatic responses for adaptation to stress are weakened.
    ▪ Good news: there are ways to strengthen the ability to cope with stress through other “non-automatic” things that we can do and practice (we will talk about these things more in the DAY 3 Session on Health Promotion).
1.1 Normal Age-Related Changes

- **Reproductive System:**
  - Women go through menopause
    - “Average” age is 51.4 years, but there is a lot of variation
    - The reduction in estrogen does increase women’s risk for osteoporosis and coronary artery (heart) disease.
  - Men have decreased reproductive function
    - Decreased sperm motility, increased number of defective sperm, decreased testosterone levels, increased time for erection, and increased difficulty with urinating due to prostate gland enlargement (benign prostatic hypertrophy – BPH).

- **Blood System:**
  - More risk for anemia because of decreased iron levels
  - Decreased lymphocyte function (related to the changes in the immune system)

**A “word of caution”**

Although many physical changes occur “normally” during the aging process, it is important to pay attention to symptoms and/or complaints that elderly people talk about. Even if some changes are considered “normal”, they may be very troublesome to the elder, and can interfere with their functioning. Many of these changes can be compensated for, and the elderly can successfully adapt to them. For example, a discussion with a health care provider to resolve constipation symptoms or joint stiffness can be very beneficial. This is just a reminder that being older does not automatically mean having to live with uncomfortable symptoms! There are ways to compensate successfully for many changes that come with aging.

**A “word of encouragement”**

It is helpful to try to think about the physical changes that occur “normally” as we age from a “holistic” perspective. The physical changes are going to happen over time, but many of them can be delayed. For example, with healthy nutrition and
regular exercise a person can maintain nearly all of the body systems in a better condition. An example of an elder who successfully practices health promotion in a “holistic” way is Mr. Vernon Lambert who is in his 70’s. Mr. Lambert still runs several miles on most days of the week. The benefits of this exercise to his pulmonary, cardiac, muscle, bone, and digestive systems must be wonderful! But, just as importantly, over his life’s journey he has learned much about himself, his people, his spirituality, and his culture, and he generously shares this learning as a teacher and mentor to the younger generations.

Summary

We all have the ability to balance aging changes in our physical dimension by strengthening the social, spiritual, and emotional dimensions of our being. We are “whole” people... more than the sum of our parts, and not just our biology. While aging is a normal process, disability is not “normal”. We have the ability to prevent many of the disabling complications of disease through the practice of health promotion.
SESSION 1.2
DAY ONE

SESSION 1.2  SENSORY CHANGES while GROWING OLDER

PURPOSE

- Learn about common changes in the “sensory systems” often seen while people grow older

OBJECTIVES

At the end of the session, participants will:

1. Identify common changes that can occur during the aging process in:
   - Vision
   - Hearing
   - Sense of Smell
   - Sense of Taste
   - Sense of Touch
   - Sense of Balance (*Proprioception*)
   - Perception of Pain

LEARNING OPPORTUNITIES

- Discussion of changes
- Simulation of sensory changes
Some ideas to think about

Change is sometimes good and sometimes “not so good”. But, while we are alive, there is one thing we can count on... we can expect changes to happen. The challenge is to be prepared for some of the “not so good” changes, and have some “adaptation” strategies ready to use. This session will discuss the kinds of changes elderly people experience in their senses... their vision, hearing, taste, smell, touch. There may be some of those “not so good” changes that will require a little extra attention in these areas. Below is a brief discussion of the sensory system changes that might be commonly experienced by elderly people.

It is good to remember that there are effective strategies to help the elderly to adapt to their limitations, and to improve caregivers’ communication with them. Those strategies will be discussed more in Session 1.3.

Sensory Changes as we grow older

Changes in the sensory system (vision, hearing, taste, smell, touch) can be caused by: (a) “normal changes” of aging; (b) effects of illness & disease; and (c) effects of medications. It is sometimes difficult to determine exactly which “cause” is affecting someone’s senses. Again, there may be a reversible cause that can be fixed medically, so it is worthwhile to have sensory changes evaluated.

Vision

“Normal” changes

The eye changes as part of the aging process itself. The cornea becomes thicker and less curved, and there can be an increase in astigmatism. The lens of the eye can become cloudy, and cataracts limit a person’s vision. The pupils of the eye slow down in their reactions to light and dark, so it takes a bit more time to accurately see and figure out what is going on. Presbyopia is the term used for a loss of “accommodation” power of the lens of the eye. The eye will not automatically adjust to whether something is held close or far away. So, older people often are seen trying to read a newspaper at arms’ length!
1.2 Sensory Changes

A decrease in *dark adaptation* by the eyes is common as people grow older, also. They may not be able to see in the dark very well. And to see more clearly they require much more light than when the eyes were younger. This can especially affect driving ability at night, or seeing well enough when getting up at night to walk to the bathroom safely.

*Disease or Illness – related changes in vision*

Vision can be impaired by a number of common diseases that elderly experience:

- Diabetic retinopathy
- Macular degeneration
- Glaucoma
- Changes resulting from stroke
- Infections

It is very important for elders to have regular eye exams! Any change in vision should be checked out. A *sudden* change or loss in vision needs to be checked out as an emergency. Some of these diseases can be medically treated, and vision can be saved. Eye check-ups are not “optional”, they do need to be a part of routine elder care.

*Hearing*

Hearing loss is stressful to the person who cannot hear as well anymore, and progressively finds his / her world harder to understand. In addition, caregivers have also identified their loved one’s hearing loss as an additional stressor when they are trying to take care of them. In the National Caregivers Survey, 8 out of 10 caregivers were worried about hearing loss in their loved one. So, this is a common problem, and can become a stressful one.\(^{10}\)
One-third of people over age 65 have some amount of hearing loss (also called “presbycusis”). Most commonly, there is a loss of hearing high frequency sounds, and figuring out where sounds are coming from (localizing). It is harder for elderly people to hear sounds of certain letters, such as “sh”, “s”, and “f”. Hearing loss is related to a decrease in the number of nerve cells that are related to hearing, with changes in the inner ear. It is also a possibility that elderly people do not realize they may have cerumen build-up (wax) in the ear canal, which can be taken care of rather simply by a health care provider. It is a good idea to have the ear canals looked at, as part of a routine medical check-up.

**Smell & Taste**

The sense of smell commonly decreases after the age of 60. By the age of 80, there is a serious decrease in the sense of smell. This can be a hazard to safety, especially in interfering with nutrition (smell is part of taste), or if a person cannot detect the smell of smoke or a toxic substance. Smoke detectors are essential “equipment” in the homes of elderly people. The sense of taste does not decrease as much as the sense of smell. A common change is a decrease in the number of “taste buds” and in the amount of saliva. Both of these changes can affect the sense of taste, so the elderly may need more concentrated flavors to enjoy their food. This is a good point to remember if nutritional intake is poor.

**Touch**

Anything that interferes with the nerves can affect the sense of touch. Elderly people may have an increased sensitivity to touch, or may have a decreased sensitivity to touch. Certain illnesses, especially diabetic neuropathy, can make people’s hands and feet very sensitive, or can make them lose feeling.

**Proprioception**

Proprioception is having an automatic sense of the position of the body, and the position of the parts of the body. For example, when running up stairs as a young person, there is an “automatic” sense of where the feet are in relation to the next step, and the stairs can be climbed very quickly and with precision. However,
with a loss of proprioception, a person may need to look carefully at each step, and place the foot carefully on the step, or they may trip and fall. *Proprioception* depends on an “automatic processing” of information from the inner ear (the part of the ear related to balance), as well as from joints and ligaments. As with the sense of touch, anything that interferes with the nerves can interfere with the sense of proprioception. Birds must have a great sense of “proprioception”, as they balance their entire bodies on a little twig!

### Pain

As with the sense of touch, the sense of *pain* in elderly people can be either increased or decreased. Pain perception depends on *many* things, and *must be assessed for each person individually*. It is very important to manage pain, as chronic pain without relief can lead to depression, inactivity, and loss of independence. Pain can often be treated very successfully. There is no reason for an elderly person to have untreated pain. It is a “quality indicator” in every clinic to ask a person if they are having any trouble with pain. This question should be a part of every routine medical check-up. It is a very important role for a caregiver to be the advocate for an elder and tell a health care provider about pain that an elder is having. It is important to insist that pain in an elder be assessed and treated

### Summary

Many sensory changes are “normal” as a person grows older. However, it is still important to address these changes, especially since they can impact everyday life. Accommodations can be made for vision or hearing deficits, chronic pain can (and should be) treated, food can be made to taste better, etc. Evaluation by a medical provider may find a reason for a sensory loss that can be corrected. So, although we can expect some changes as “part of the aging package”, elders and caregivers can work on how to adapt to them.
SESSION  1.3
DAY ONE

SESSION 1.3   ADAPTATION & COMMUNICATION SKILLS RELATED TO SENSORY SYSTEMS

PURPOSE

• Learn about the relationship between sensory changes and safety issues in elderly people
• Learn to adapt communication skills with elderly people who have sensory changes & losses
• Learn to adapt the environment to assist elderly people who have sensory changes

OBJECTIVES

At the end of the session, participants will:

1. Identify the importance of adapting communication & the environment to elderly people who have sensory changes
2. Identify common challenges to safety for older adults
3. Identify specific strategies to assist elderly people in communication & home environment safety

LEARNING OPPORTUNITIES

• Discussion of experiences with sensory losses
• Discussion of safety adaptations that can be made in the home, using safety checklist from the W.E.L.L.-Balanced curriculum
Some ideas to think about

As vision, hearing, touch, proprioception, smell and taste become less “sharp” in elderly people, their caregivers may need to pay more attention to safety through adapting the environment around the home. Falls are a frequent source of injury, hospitalization, and continued loss of independence for elders, but falls are very preventable\(^\text{13}\)! In this session, we will go in-depth in discussing how to do a “home-safety check” using the checklist from the NRCNAA WELL-Balanced curriculum\(^\text{12}\). Caregivers can also help their elders with sensory losses by adopting a few new communication techniques. Implementing just a few strategies can have many benefits for both elders and caregivers: (a) improving safety; (b) maintaining independence and social roles; and (c) decreasing stress.

Sometimes losses in the sensory system are not given much attention because of an attitude that “it’s just old age”. But, being older does not always mean that these losses are “normal”. Many changes in vision, hearing, touch, etc. may be related to illness, and can be medically treated. For sensory losses that can’t be medically treated or “cured”, adaptations can be put into place to minimize the impact of the losses.

**Maintaining Vision**\(^\text{8}\)

Recommendations for maintaining the best vision possible include: (a) an eye exam at least every year; (b) updates in eyeglasses; (c) clinic exam *right away* for complaints of:

- Burning sensation
- Pain in the eyes
- Blurry vision
- Double vision
- Seeing “Spots”
- Redness in the eye
“runny eye” (any kind of discharge coming from the eye)

Severe headache all of a sudden

**Adaptations to compensate for vision changes in elderly**

- Use several softer lights instead of one larger “glaring” light
- When outside, offer the use of sunglasses, a hat, or a visor
- Place sheer curtains over windows to prevent glare
- Try to use brighter colors to help the person find and identify things he/she needs to use
- Use contrasting colors for steps, changes in floor levels, doorways
- Place things to be used by the elderly person within his/her visual field
- Keep a magnifying glass handy if it seems to help with seeing or reading
- Read for the elderly person if it is no longer possible for him/her to read
- Play the radio or music for the elder
- Offer LARGE PRINT books and magazines with brightly colored pictures

**Adaptations to compensate for severe or total vision loss**

- Talk to the elderly person so he/she knows where you are in the room
- Touch their arm gently to let the elderly person know your location when sitting near them
- Keep commonly used things in the same place and close to where the elder spends a lot of time
- Encourage & “coach” the elder to find commonly used items by touch
- Describe things to the elder that he/she cannot see, such as food on a plate when eating
Maintaining Hearing\textsuperscript{8, 10, 14}

- Encourage the elder to have a hearing exam to determine the type of hearing loss he/she may have AND to see if a hearing aid would be helpful
  - Some hearing losses are not helped by a hearing aid
- Encourage the elder to have their ears checked for cerumen (wax) and hearing screen when they go into clinic for a medical exam

Adaptations to compensate for hearing loss and improve communication

- If an elder has a hearing aid, encourage its use
  - Be sure the hearing aid is comfortable
  - Teach the elder to use it in the most effective way
  - Keep the batteries “fresh”
- Patiently repeat what was said when asked by the elder
  - If the person continues having trouble hearing even after repeating, then try to “re-state” what was said. It may be that some “sounds” in the original sentence are difficult to hear. So, changing the words may help and be heard better. Shouting does not help…
- Try to use a lower (deeper) tone of voice
  - Hearing loss affects higher pitched sounds more than lower pitched sounds. Shouting does not help…
- Face the person, so it is possible to see lips, gestures, expressions, etc.
- Try to be as respectful and patient as possible. It will be very difficult to communicate sometimes, and this can be frustrating for the elderly and the caregivers. The risk is that if the elderly feel they are annoying to others, they may just give up the effort to communicate altogether. Shouting does not help…
NECC: Caring for Our Elders
1.3 Adaptation & Communication Skills related to Sensory Systems

- Write things down if the person just is “not getting” what is being said
  - Make up a set of flash cards with large bold print for items that are frequently asked for
  - Keep a writing pad and bold colorful markers near the elder, so it is easy to write a quick note to aid communication
- If there is a stethoscope in the house (for example with a blood pressure cuff), the elder can “put the ears on”, and the caregiver can talk into the round flat piece to amplify the voice

Summary

With a little bit of adaptation and “low-tech” strategies, injuries from falls can be prevented. The sensory losses that an elder might experience can also be lessened, allowing an elder to maintain independence in a safe environment. Caregivers can also be made more to feel more comfortable in their role, by being better able to communicate with their elders. They can also feel more confident in helping an elder remain in the home setting by helping to create a safer environment for their loved one.
SESSION  2.1
DAY TWO

SESSION 2.1  LIVING IN BALANCE WITH COMMON CHRONIC HEALTH CONDITIONS

PURPOSE

- Learn about common chronic health conditions that many elderly people live with
- Learn to focus on the “care” of the person with the chronic health condition, when a “cure” is not possible

OBJECTIVES

At the end of the session, participants will:

1. Identify the most common chronic diseases experienced by American Indian Elders
2. Identify the primary causes of mortality for elderly people in different age groups
3. Identify the primary goal of care for elderly people living with chronic illnesses

LEARNING OPPORTUNITIES

- Talking circle related to experiences that caregivers & elders have had with their most common health conditions
- Discussion of the questions that elders & caregivers have related to common chronic health conditions
**Ideas to think about**

When we talk about disease and illness, it is sometimes easy to keep our focus on “what is wrong”. In fact, many times we hear someone labeled with a disease or health condition as the disease. For example, “he’s a diabetic”, or “she’s an amputee”, or “he’s a paraplegic”. In reality, the people we love and care for are still the PEOPLE we know and love. So, maybe the conversation could better go like this: “my dad has diabetes”; “my grandma had an amputation”; “my uncle has a handicap”. This approach helps us to focus on care for the person who has a health condition. The focus is not the disease, but the person who has the disease. The goal then becomes to help the person with the health condition to live life in the best possible state of health, and to prevent disease complications.

With chronic diseases and conditions, the goal cannot always realistically be a “cure”. But, the goal can realistically be to maximize a person’s “functional abilities”, that is, their abilities to perform activities of daily living (ADL’s) and instrumental activities of daily living (IADLs). Maximum ability in ADLs and IADLs is the ability to live as independently as possible every day. We will discuss and focus more on ADLs and IADLs in Session 2.5. However, for purposes of this session, we will focus on an overview of the most common chronic diseases and causes of mortality that Native elderly people experience. The most common chronic illnesses among Native Elders include:

- High blood pressure (Hypertension)
- Arthritis
- Diabetes
- Cataracts
- Congestive heart failure (CHF)
- Asthma
- Stroke
2.1 Living in Balance with Common Chronic Health Conditions

(common chronic conditions continued)

- Prostate cancer in men
- Breast cancer in women
- Other cancers
- Colorectal cancer
- Lung cancer

In terms of the most common causes of mortality among Native elders, the top five among people who are 55 to 64 years of age are: 16

- Diseases of the heart
- Malignant neoplasms (cancers)
- Diabetes
- Unintentional injuries
- Liver diseases

As people get older, the main causes of mortality change a little bit. Over age 65, the top five causes of mortality are: 17

- Diseases of the heart
- Malignant neoplasms (cancers)
- Diabetes
- Cerebrovascular disease (Stroke)
- Pneumonia & flu
Summary

It is important for caregivers to be aware of the most common medical problems that elderly people often have to live with “day to day”. However, although the elderly may have one or more of these health conditions, the caregiver’s focus is best directed to:

- Maximizing functional abilities
- Preventing further complications from diseases
- Preventing disabilities
- Promoting health through healthier health practices
SESSION 2.2
DAY TWO

SESSION 2.2  HEALTH DISPARITIES AMONG NATIVE ELDERS

PURPOSE

- Learn about the increased rates of chronic diseases among the American Indian elderly population
- Learn about some of the reasons for the increased rates of chronic diseases among the American Indian elderly population
- Learn to recognize the potential for reducing disease rates among the American Indian elderly population

OBJECTIVES

At the end of the session, participants will:

1. Identify common diseases that elderly American Indian people experience more often than the general population
2. Identify community strategies that can help to reduce rates of chronic disease in American Indian populations

LEARNING OPPORTUNITIES

- Discussion of experiences with health disparities that caregivers have had in their own families
- Discussion of ideas that might work in caregivers’ communities to address prevention for common diseases, especially in the future
Ideas to think about

A range of “health disparities” are a reality in Indian Country. Health disparities are defined as “gaps in the quality of health & health care across racial, ethnic, and socioeconomic groups.” The average life expectancy for American Indian people is lower than the general population. The average life expectancy age is varied by geographic region, with a high “average” of 76.3 years in California, and a low “average” of only 64.3 years in the Aberdeen Area of Indian Health Service (ND, SD, IA, NE). In contrast, the average age in the general U.S. population is 76.9 years.

However, despite the reality of health disparities, it may be more helpful to look at them from an “empowered” perspective, rather than from a “fatalistic” perspective. We might think in terms of the “glass is half-empty” or the “glass is half-full”. The “half-empty glass” or “fatalistic” view might be stated something like this: “Well, according to the disease rates, it just seems that more American Indian people just get sick”.

In comparison, a “half-full glass” or an “empowered” view might say: “Well, there is a lot of knowledge out there to prevent many chronic diseases that we see in our communities. It is possible to reduce the risk for these illnesses by reducing the known risk factors. Maybe we can do something to reduce these diseases in our communities, especially for our children in the future”. From an “empowered” perspective, each community can make a decision to proactively address health disparities, and improve health.

Examples of disparities in chronic diseases among Native elders

Compared to the U.S. general population, elderly Native people are more likely to experience certain health conditions, such as:

- Arthritis  19.5% more likely
- CHF (congestive heart failure)  48.7% more likely
- Hypertension  17.7% more likely
- Stroke  17.5% more likely
2.2 Health Disparities among Native Elders

- Asthma 4.3% more likely
- Diabetes 173% more likely

For some diseases, there appear to be lower rates in various regional areas. It is important to realize, though, that these rates may actually demonstrate that people who have those diseases do not survive long. For example, if it seems there are low rates of a certain cancer in a region, that may mean that people who have that cancer die quickly from it; that is, the rates are “artificially” lower because those people who die quickly are never counted in the rate.

There are other preventable health disparities, also. For example, American Indian people between the ages of 55 and 64 die from pneumonia and flu at a very much higher rate than the U.S. population. As mentioned above, this example may pose one of those opportunities for communities to have an “empowered” view related to health disparity information. Flu and pneumonia vaccines are widely available and accessible in American Indian communities. The “empowered” response to a higher rate of flu and pneumonia mortality may be to increase the knowledge about the availability of the “flu shots”, to disseminate more information about the effectiveness of pneumonia immunizations, and to provide more immunization clinics for adults in a variety of settings.

**Causes of Health Disparities**

A number of causes can be identified that contribute to health disparities include:

- Limited use of preventive health care services
- Racism
- Limited access to health resources
- Lower socioeconomic resources

These causes of health disparities are closely related to those identified by the Centers for Disease Control’s (CDC) list of the Social Determinants of Health.
2.2 Health Disparities among Native Elders

- Socioeconomic status
- Transportation issues
- Housing issues
- Access to services
- Discrimination
- Social or environmental stressors

These may not be the usual ideas we have when we think about how diseases are caused. These are community issues. Communities do have the power to determine how they choose to address health disparities.

Summary

While it is important for the health care system to be improved in terms of access and quality of care, communities need to try to address other issues that influence the health status of their people. So much is known about health promotion and disease prevention that can be applied to reducing health disparities. But, it will also take the commitment of communities to set out and lead in this direction. It can be done.
SESSION 2.3
DAY TWO

SESSION 2.3  ASSESSMENT OF SYMPTOMS

PURPOSE

- Learn about symptoms that elderly people may experience related to chronic health conditions
- Learn to recognize specific symptoms which are serious and need immediate medical attention

OBJECTIVES

At the end of the session, participants will:

1. Identify the possible meaning of certain symptoms that can occur in the elderly
2. Identify questions to ask to assess pain that the elderly person is experiencing
3. Identify symptoms that need immediate medical evaluation for the elderly person
4. Recognize that a person may not admit to having pain

LEARNING OPPORTUNITIES

- Discussion of various types of experiences with serious symptoms
- Discussion of experiences with various types of pain
  - Cultural influences on the expression of pain
  - The individual nature of pain for each person
Ideas to think about

In the sessions on “sensory changes”, we found out it is important to address the need for safety among elderly people. Really “listening” to the symptoms that elders have, can also be a form of providing “safety”. There are some common symptoms that may be ongoing as part of a chronic health condition. Different conditions can be related to specific symptoms, but sometimes symptoms can be very general and may relate to several health conditions. Caregivers are probably the best “listeners” for symptoms and observers of change in an elder. A caregiver does not have to be a doctor or a nurse to be able to be a good observer, “listener” and recorder of an elderly person’s symptoms.

“Symptoms” are not the same as “diseases”. Symptoms are the way the body “talks to us” about how a person is feeling; caregivers do need to “stop, look, and listen”. Symptoms may not be very specific, and that can make it difficult to figure out the underlying cause. However, although it may not be possible for a caregiver to “diagnose” what the symptoms mean, it is possible for a caregiver to “stop, look, and listen” carefully to what the “body is saying”, and then to help the elder describe how he / she is feeling to health care providers. Caregivers are not “diagnosticians”, nor can they be expected to be! But, they are the best observers and listeners of symptoms, which need to be accurately communicated to the elders’ health care providers.

For “safety” reasons, there are some symptoms that need to be paid attention to right away, and require that the elderly person be taken to the clinic or emergency room:

Symptoms to pay special attention to

- Pain that is “different” from what the elder usually experiences (for example, an uncomfortable knee pain with arthritis)
  - Chest, neck, arm, back pain, even feelings of nausea or heartburn or indigestion can be symptoms of a heart attack
  - Unusual or severe headache can be related to stroke
Pain in a joint that limits mobility suddenly (especially after a fall)
- Sudden change in function (such as inability to move or speak)
- Breathing trouble
- Unconsciousness or decreased awareness or fainting
- Unusual bleeding of any kind
- Fever\(^*\) or other signs of infection
  - Redness, pus, swelling
  - *An elevated fever in an elder needs to be checked out right away!
  - *Sometimes an elder will have an infection, but won’t show a fever

**Pain**

Pain is a “direct communication” from our body. The body is trying to tell us: “Something is not right!”, “This is a warning!”, “Pay attention!”, “Do something to comfort me!” There are many types of pain, depending on the “cause”. Questions that need to be asked by the caregiver are: “Does this seem to be related to a chronic problem?” Or “Is this a warning of a serious acute problem?”

**Types of Pain: Acute & Chronic**

Questions that might be helpful to assess when an elderly person has pain include:

- What kind of pain is it?
  - All over? In one spot only?
  - Lasts for long periods? Only for a few seconds?
2.3 Assessment of Symptoms

- Constant pain? Comes and goes?
- On a scale of 1 to 10, how would you rate the pain? (with 10 being the worst, and 1 being the least amount of pain you ever felt)

- Where is the pain located?
  - Does it stay in one spot? Does it move around?
  - Is it in the chest? Does it feel like indigestion?
  - Does it travel down the arm? Or travel down the neck?
  - Is it around the time of a meal?
  - Is it after working at an activity? After exertion?

- Are there other symptoms with the pain?
  - Coughing?
  - Sweating?
  - Fainting?
  - Nausea?
  - Confusion?
  - Difficulty breathing?

*Other questions to ask when trying to assess a symptom or complaint of pain in an elderly person include:*

- Is this a NEW symptom? A NEW type of pain? A NEW location of the pain?
- How does the elder usually react to pain?
  - Do they let you know?
  - Do they mention pain when they have it?
Do they hide their pain symptoms?

Do they fear what pain might mean?

Special considerations with chronic pain

Chronic pain is a special type of challenge for anyone, and especially for elderly people who have many other challenges in their lives. Chronic pain can interfere with a person’s whole life. Chronic pain affects people:

- Physically ("ouch! this hurts! I can’t even walk")
- Socially ("can’t deal with family, no one understands")
- Emotionally ("depressed, tired, sad, worn out, scared")
- Spiritually ("Why me? Where is God?")

Sudden Change in Function

Some other symptoms also require immediate attention. A sudden change in a person’s function can indicate something wrong, such as a stroke. Symptoms to assess and get immediate medical attention for include:

- Change in vision: such as, loss of vision, blurry vision, double-vision
- Change in ability to move: such as not being able to move on one side of the body, or one side of the face
- Change in ability to speak, slurred speech or to understand what is said
- Sudden change in hearing, sudden loss of ability to hear
- Feeling of numbness or loss of feeling
- Sudden confusion (or a worsening of confusion if a person has dementia)
- Severe or unusual type of headache
- Dizziness or vertigo ("spinning" or “room is swimming” sensation)
2.3 Assessment of Symptoms

- Loss of balance
- Unconsciousness, loss of awareness, fainting
- Nausea / vomiting / diarrhea
- Sudden loss of bowel or bladder control
- Trouble swallowing
- Suicidal thoughts
- Swelling anywhere (especially in lower legs accompanied by pain)

**Breathing Difficulties**

Sometimes a person has a chronic illness that affects their breathing. A health care provider can help to prescribe medications that will maximize breathing capacity if a person has asthma or other chronic obstructive pulmonary disease (COPD). Diuretics might be prescribed to help a person with Congestive Heart Failure (CHF) to reduce swelling that can affect breathing. However, if a person is showing changes in breathing and is having “trouble getting their breath” this is an emergency that needs to be taken care of right away. The caregiver can assess the elderly person for certain symptoms, such as:

- Shortness of breath (“I can’t get my breath”)
- Restlessness
- Confusion
- Fear / panic
- Irritability (sometimes is a first symptom, along with restlessness)
- Color change in the skin (can look at the area around the mouth and/or at the nails. These areas may become discolored when breathing is difficult)
- Difficulty breathing (fast breathing, wheezing, “stridor” or noisy breathing)
2.3 Assessment of Symptoms

- Swelling
- Shallow respirations
- Unconsciousness
- Possibility the person choked on something

Difficulty in breathing is one of those “vital signs” that has to be taken care of immediately.

Summary

Caregivers have the best perspective on changes in the elderly people they care for. Caregivers see an elder more often than others, and some caregivers are with an elder every day. Caregivers need to “trust their gut”, when they think there is “something not right” with the elder they care for. They may not know exactly what is happening or what the “diagnosis” is, but, no one is better equipped to see and recognize even small but important differences in their elder’s condition, and to get medical help for the elder.

To review, there are several major categories of symptoms to pay attention to because they may indicate an emergency situation that requires immediate care from a health care provider: Pain, Sudden Change in Function, Breathing Trouble, Unconsciousness, Unusual bleeding, Signs of fever and infection.
DAY TWO

Session 2.4  Caring for Our Elders: “Day to Day” Assessment

PURPOSE

• Learn about the special importance of caregivers in observing changes in an elderly person’s condition
• Learn about common symptoms that may occur “day to day” that need to be assessed

OBJECTIVES

At the end of the session, participants will:

1. Identify the kinds of symptoms that only a caregiver might notice
2. Demonstrate how to assess & describe symptoms that may be observed in an elderly person
3. Demonstrate how to accurately assess:
   • pulse, respiration, temperature
   • blood pressure & blood glucose (sugar)
   • edema
   • condition of feet
4. Identify the importance of knowing about the medications that an elderly person is taking
5. Describe a system to help elderly people to take medications safely and accurately
Ideas to think about

Caregivers are the “eyes, ears & voice” for helping their elders. They are most likely to observe subtle changes in the “day to day” condition and functioning of the elders they care for. With the information from their assessments, caregivers will also be the best advocates for providing and accessing quality care for their loved ones. On a “day to day” basis, caregivers assess the safety of the home environment where the elders live. They attend clinic with their elders, and learn about the medical conditions they must learn to live with. They can learn symptoms to watch for, such as swelling, fever, pain, etc. There are “day to day” patterns that only a caregiver may notice, but which are so very essential to an elderly person’s health status.

“Day to day” patterns that caregivers assess

- Nutritional and eating patterns
- Sleeping and rest patterns
- Mental status and alertness patterns
- Emotional behaviors & moods
- Functional abilities in ADLs and IADLs
- Weight loss
- Condition of the skin (especially the feet in people with diabetes)

Additional helpful assessment skills to learn

- Learn to take vital signs
  - Blood pressure
  - Pulse
  - Temperature
  - Respiration rate
Simple equipment for home use is available and fairly inexpensive to take these “vital signs”. The ability to make these assessments has been identified as a learning need by some Native caregivers. It can be very helpful to be able to take these measurements and to have the information to give to health care providers either over the phone, or at a clinic visits. For example, it may be very important to the treatment of an elder who has hypertension if home-based blood pressure measurements are available to review. A health care provider could be more informed by these additional readings, when adjusting an elder’s hypertensive medications. Health care providers could also be helped to adjust diabetes medications more effectively if they had a pattern of home-based blood glucose readings to go by, in addition to the laboratory values that are only taken during clinic visits.

It is important when an elder seems to be having some problems at home, to be able to take these readings for comparison and to report to the health care provider. This means that caregivers need to be informed about:

- Usual readings for the elder
  - The “usual” blood pressure
  - The “expected blood sugar”
    - if a person with diabetes shows a sudden change, such as unusual behavior, or becoming shaky or lightheaded, or even unconscious, the blood sugar might be responsible. It would be good to check the blood sugar to see if a person’s level is too low or too high

- Goal measures for the elder
2.4 Caring for Our Elders: “Day to Day” Assessment

- The “goal” for the blood pressure
- The “goal” for the blood sugar: fasting, before meals, between meals, after meals, or before bedtime

**Difficulties that elders may have with taking their medications**

Elderly people often need help with taking their medications. There are a number of things that might interfere with an elder’s ability to take their medications accurately as prescribed. Some of the difficulties that an elderly person may have with trying to take their medications correctly may include:⁸

- Decreased vision
- Inability to read
- Confusion or forgetfulness related to dementia
- Confusion related to too many medications
- Confusion related to complicated schedules for medications
- Difficulty opening medication bottles
- Difficulty drawing up insulin in a syringe accurately
- Inability to keep track of when medications are running out
- Difficulty with transportation to go to the pharmacy to pick up medications
- Difficulty understanding what the medications are for
- Difficulty self-administering eye drops

**Tips for caregivers to help elderly people take their medications accurately**
Caregivers may be called on to help an elder with taking medications. This help may take many forms, depending on the elder’s need. The help needed may range from simply giving the elder “reminders” to actually having to make a referral to the public health nurse (PHN). The PHN can help an elder and the family in actually pouring the medications or drawing up insulin into syringes. There are “legal” limits on who can prepare and administer medications. For example, a nurse may prepare or administer medications, or may teach a family caregiver how to prepare medications for an elderly family member.

However, a Community Health Representative (CHR) or a Home Health Aide or a Nursing Assistant is not allowed to prepare or administer medications, as they are not licensed to do this. In fact, in some communities, CHRs are not even allowed to pick up and deliver medications from the I.H.S. pharmacy. This places an extra responsibility on the family caregiver, to provide “transportation” to pick up the elder’s prescription.

In general there are some helpful “rules to remember” for helping an elder to take their medications accurately. It is helpful to think of the “6 rights”:

- The *right* medication
- The *right* person taking the medication
- The *right* time for the medication to be taken
- The *right* dose of the medication prescribed for the person
- The *right* way to take it (for example by “pill” or by “needle”)
- The *right* record of when it was taken (keep a little notebook)

**Other important “tips” for caregivers helping with medications**

- Keep an **updated** list of medications on hand at all times:
Native Elder Caregiver Curriculum
2.4 Caring for Our Elders: “Day to Day” Assessment

- Keep copies:
  - With the elder, such as in his / her wallet
  - In an accessible place in the home, such as on the refrigerator,
  - With the caregiver, such as in the caregiver’s purse or wallet

- Take the list of medications to any visit to the clinic (or to the hospital / ER)
- Visit with the health care provider about the medications
  - The caregiver will need to be given written permission by the elder to have access to his / her medical information
  - Ask about the actions and possible side effects of medications
  - Ask about possible interactions of medications as new medications are prescribed
  - Ask about what to watch for in the elder, for example, lowered blood pressure, allergies, etc.
  - Tell the provider if another health care provider has prescribed a new medication or changed the dosage of a medication

Summary

Caregivers deliver help to elders in so many ways. There are many areas of responsibilities that fall to the caregiver who is with the elderly person “day to day”. Knowing how to take vital signs and keeping a record of medications are simple but important ways to help. The role of these caregivers cannot be overestimated! They are the “key” to the ability of their loved ones to remain in their homes as they “age in place”.

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SESSION  2.5
DAY TWO

SESSION 2.5  Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs)

PURPOSE

- Learn about the meaning of “functional status”
- Learn to assess ADLs & IADLs
- Learn the importance of maintaining ADLs & IADLs as long as possible in the elderly

OBJECTIVES

At the end of the session, participants will:

1. Identify the meaning of “ADLs” & “IADLs”
2. Identify the categories of “functional limitations”
3. Describe the relationship between level of “functional status” and the ability to live in the home setting independently
4. Describe the relationship between level of “functional status” of elderly person and the caregiver’s ability to provide home care
5. Describe the impact of the “baby boomers” on long-term care planning in American Indian communities

LEARNING OPPORTUNITIES

- “Show & Tell” different home adaptive equipment
Ideas to think about

Interestingly, the decision for an elderly person to be placed in an institutional setting, such as a nursing home, is not usually based on the medical diagnoses that he or she has. The need for nursing home placement is much more related to how well an elder can “function” independently in the home setting\textsuperscript{23}. The decision for an elder to go to a nursing home is very heavily influenced by the availability of a caregiver, who is willing to provide help with Instrumental Activities of Daily Living (IADLs) and with Activities of Daily Living (ADLs). In the best situations, more than one caregiver is available to help with IADLs and ADLs, so caregivers can have support and take breaks on a regular basis.

ADL’s & IADLs

The term ADL’s is short for “Activities of Daily Living”. The term IADL’s is the abbreviation for “Instrumental Activities of Daily Living”. These are important terms in determining the care for an elderly family member. The terms indicate how well a person can “function” and will also be referred to as “functional abilities”. The ADLs include a person’s ability to walk, bathe, eat, use the bathroom, etc. The IADLs include a person’s ability to go to the grocery store, use a telephone, pay the bills, etc.\textsuperscript{25}

When a person cannot do these “day to day” usual activities, they need help to be able to continue to manage in the home setting. When an elder begins to have increasing difficulty with performing ADLs and IADLs, then caregivers become the “key” to making it possible for the person to live safely in their home setting. So, it becomes important to assess how well an elder “functions”, that is, to determine the elder’s “functional abilities” in the ADLs & IADLs.

Importance of Caregivers

As long as a person can be helped to maintain IADLs and ADLs at home, then the decision for institutional care (nursing home) can be delayed or even avoided altogether. Again, the caregiver is the “main ingredient” in this situation! Caregivers are \textbf{necessary} to provide the help that is needed for an elderly person.
to remain in the home. Without the caregivers, as deficits in ADLs accumulate, the elder becomes more at risk for nursing home placement\textsuperscript{26}. The medical care system through IHS does not provide for in-home long-term care services. There are other mechanisms through state Medicaid programs, however, that can assist a family to care for an elder. Some states are in fact, very generous with their Home and Community-based services (HCBS) for elders.

Because of the significance of caregivers in providing elder-care, on DAY 3 of the curriculum we will spend more time discussing the importance of support & respite for caregivers. In the current Session 2.4, we will focus on the meaning of ADLs and IADLs, and their relationship to providing elder care in the home setting.

**Activities of Daily Living ADLs**

Activities of daily living (ADLs) are the skills that a person has to feed themselves, wash and dress, get to the toilet, and to move around. Instrumental activities of daily living (IADLs) are the skills a person has to be able to take care of things that are needed to live in a community, such as shopping, preparing meals, using a telephone, taking medications safely, managing finances, paying bills, and going to places in the community\textsuperscript{25}. A person may be partially independent in ADLs and IADLs, and able to continue to function with the help of a caregiver. However, if a person becomes totally dependent on others to meet their ADLs and IADLs, the option for continued care at home becomes difficult. For this reason, when a person has a chronic disease, the goal is to prevent disability. This can be done.

**Assessment of ADLs**

The need for care and institutional care is not always directly related to particular diseases that an older person might have. Instead, the impact of aging and the effects of diseases on the ability to perform ADLs and IADLs is a deciding factor for what kind of care a person needs. For example, a person with hypertension would not automatically require assistance in ADLs. However, if a stroke occurs related to the hypertension, then a person may lose functional ability and require quite a bit of care. So, controlling blood pressure is important!
From their research among hundreds of Tribes across the nation, McDonald\textsuperscript{26} and his colleagues created a model that relates the number of ADL and IADL limitations to the kinds of care that an older person may need. The table below is a presentation of the model they developed:

**Table 1: Long-Term Care Measures**

<table>
<thead>
<tr>
<th>Categories</th>
<th>Limitations</th>
<th>Recommended Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Little or none</td>
<td>No ADL limitations; up to one IADL limitation</td>
<td>No services required; Health Promotion</td>
</tr>
<tr>
<td>Moderate</td>
<td>One ADL limitation with fewer than two IADLs</td>
<td>Home and Community-Based Services (HCBS)</td>
</tr>
<tr>
<td>Moderately Severe</td>
<td>Two ADL limitations</td>
<td>Assisted Living</td>
</tr>
<tr>
<td>Severe</td>
<td>Three or more ADL limitations</td>
<td>Skilled Nursing Facility</td>
</tr>
</tbody>
</table>

As can be seen from the above table, having two limitations in IADLs in addition to one limitation in ADLs will make it possible to serve the elder in the community setting with HCBS. However, when limitations arise in two ADLs, more assistance in care is needed, such as can be provided in an Assisted Living residence. However, when a person cannot take care of three of their ADLs independently, then nursing home care is usually required.

When determining the level of “independence in ADLs” that a person has, the following paragraph nicely complements the above table:

“Since keeping the skills to perform ADLs is so clearly related to the kind of care that is needed for an elder, assessing how “dependent” a person has become in ADLs is an important thing to consider. It can be helpful to think of the ADLs along a 3 point scale of “total independence”, “partial independence” and “dependence”. As an example in terms of the ADL of eating, if a person can use all utensils, cut up their meat, butter their bread, and drink from a cup or glass, this would be considered “total
2.5 ADLs and IADLs

*independence*. If a person needs a tray set up, cannot cut up their own foods or butter their bread, and needs encouragement and reminders to eat, then this would be called “partial independence”. However, when a person cannot feed themselves, even when someone can help them to get set-up, then that would be considered “dependence” in the ADL of eating.\(^8\), p.497

Each of the ADLs (eating, hygiene, dressing, toileting, bladder and bowel control, walking and transferring) can be assessed using this type of three point scale. Then a judgment can then be made about the kind of long-term care that would best help an elder with the kind of care that is needed.

**Summary**

It can be seen that the amount of care that is needed will “set the pace” for the caregiver. It is one thing to take care of grocery shopping for an elder twice a week, or to take them to a medical appointment; but it is a totally different situation if a caregiver has to live in the home around the clock helping someone to eat, toilet, dress, etc. Many of the elders in Indian Country at this time are “young elders” who are part of the “baby boomer” generation\(^27\). The *prevention of disability through health promotion* while people are “young elders” cannot be emphasized too much! A person can become older, while still retaining many “functional abilities”. The practice of Health Promotion activities as a “young elder” can really make an impact on preventing disabilities, and maintaining ADL function throughout the lifespan.
SESSION 3.1
DAY THREE

SESSION 3.1 HEALTH PROMOTION FOR NATIVE ELDERS & THEIR CAREGIVERS

PURPOSE

- Learn about the meaning of health promotion
- Learn about the importance of health promotion and its relationship to “functional status” in ADLs and IADLs
- Learn a holistic perspective related to health promotion

OBJECTIVES

At the end of the session, participants will:

1. Identify meaning of health promotion
2. Identify 5 good self-care “medicines”
3. Identify simple ways to incorporate health promotion into everyday living for elderly and caregivers
4. Identify ways to encourage community involvement in health promotion activities
5. Demonstrate at least 2 easy ways to practice health promotion in everyday life

LEARNING OPPORTUNITIES

- Practice realistic planning for healthy meals & exercise programs
- Talking Circle to discuss:
  - potential stress relievers
  - ways to involve communities in health promotion
Some Ideas to think about

At this point, it may be a good idea to re-visit some of the previous sessions we have had in the curriculum. When we are talking about “health promotion”, we are looking at “how to stay healthy”, how to “promote health”. This is different from “treating diseases”. Health Promotion and Disease Prevention are close relatives. When a focus is maintained on “staying healthy”, there is a direct link to preventing disease. And, if a disease is already present, the risk of disability and complications from a disease can be limited by health promotion activities.

Re-visiting Health Disparities

As we mentioned before in Session 2.2, there are two ways we can think about Health Disparities:

- 1) “more American Indian elders get sick from certain illnesses” or
- 2) “we have the ability to reduce risks for many diseases”.

Both of these statements are true. However, it is important to the health of a community, to decide which of these statements to choose as a focus. If a community decides to focus only on “we have more diseases than others”, a fatalistic view can take root, and the glass will remain “half empty”. But, if a community chooses to take the information about health disparities, and meet this challenge with the knowledge of health promotion, this “empowered” view can make the glass “half full”.

American Indian people are very resourceful, and have adapted through thousands of years of change. It is possible to recognize and focus on changing the things that can be changed. Elders have always been respected in Native culture. Elders hold a place of honor and continue their role of contributing to their families in many ways. Being “older” does not mean “being sick”. Being an elder means enjoying friends and family, guiding and caring for grandchildren, enriching the community with their wisdom. For this reason, the “half-full” glass perspective is an important one to claim. Promoting Health and maintaining function pays off ... better than Bingo!
It is possible to prevent premature disability; it is possible to maximize IADL and ADL function; it is possible to minimize the need for nursing home care, and to maximize the chances of staying in the home setting with family, to keep the elder in their rightful role within the community.

Health Promotion: Five good self-care medicines
The “recipe” for health is really somewhat simple. There are 5 good self-care medicines that are very effective in preventing disease and maintaining health: regular physical activity, healthy nutrition, adequate rest, spirituality, and strong family connections.

Health Promotion: Four types of exercise
There are so many benefits to regular physical activity. Exercise is a very strong medicine. There are four major types of exercise\textsuperscript{28, 12}:

1. Aerobics
2. Strengthening
3. Stretching
4. Balancing

General Recommendations to Begin Regular Exercise\textsuperscript{29, 30, 31}

- Check up with a health care provider for an “exercise prescription”
- Wearing comfortable clothes and shoes
- Building up activity little by little
- Inviting an activity “buddy”... family or friends
- For people with diabetes, bringing along a source of “sugar” in case the blood glucose level runs a little too low (hypoglycemia) during exercise

How to Fit in a Little Exercise on a Regular Basis
Although a gym or health club is nice to have, many people do not have easy access to such a resource. However, the idea of exercise can “fit in” with many every day activities; using a gym or fitness center is not necessary to keep physically active. For example, in terms of aerobic exercise for elders, there are
many forms this can take, for example, gardening, walking, swimming, pow-wow
dancing, riding a bike, or chasing grandchildren at a playground. Any activity that
requires ongoing movement for a period of time can help meet “aerobic” exercise
needs. It is not necessary to maintain exercise for long periods at one time, for
example, taking three brisk 10 minute walks throughout the day can add up to the
30 minutes of activity that is recommended five days a week.\textsuperscript{30}

There are many forms of exercise that do not take any “special equipment”. At a
diabetes prevention conference in the Northern Plains, everyone smiled when
one speaker raised his arms and legs, and stated that they were “his exercise
equipment”. Some Tribes have a pool at their casino hotels which they set aside
for a few hours each week for their elders to swim. Many Tribal communities
have walking trails that provide a smooth, safe surface for walkers of all ages. The
only “equipment” that walking requires is a pair of comfortable, well-fitting,
supportive shoes. The Nike Company has even developed a shoe with extra room
in the toe box for comfortable, non-friction walking for American Indian people.\textsuperscript{32}

Some elders have even talked about how they practice pow-wow dancing with
their grandchildren at home while listening to pow-wow music being played on
the Indian radio station. It really does not matter what a person chooses as the
activity of choice, the main challenge is to make a commitment to MOVE every
day, in some way! And again, activity can be in a “block” of time for 30 minutes,
or in “chunks” of time for 10 that will add up throughout the day.

**Strengthening, Stretching, Balance**

Exercise can help to maintain and improve health. The National Resource Center
on Native American Aging has developed a very useful curriculum for “\textbf{W}ise \textbf{E}lders
\textbf{L}iving \textbf{L}onger” (WELL-Balanced curriculum)\textsuperscript{12}. The \textit{WELL-Balanced Curriculum} is a
health promotion resource for helping elders with strengthening, flexibility and
balance exercises. The goals of the “\textit{WELL-Balanced Curriculum}” are for elders to:
increase their physical strength; improve their ability to prevent falls; better
manage diabetes, arthritis, and hypertension; engage in social activity; and increase their level of exercise.

The *WELL-Balanced* curriculum can be accessed through the National Resource Center on Native American Aging (NRCNAA) at no cost. It is possible to set up a community class for presenting the “*WELL-Balanced*” curriculum so elders and caregivers can learn exercises that they can use at home. Then, they can take just a few minutes a day to practice the stretching, balance, and posture exercises that they have been taught. ([nrcnaa@medicine.nodak.edu](mailto:nrcnaa@medicine.nodak.edu))

In many communities, under the Special Diabetes Programs for Indians (SDPI) fitness experts are available who could be asked to offer a fitness program for elders, or a “train the trainer” workshop for CHRs or diabetes outreach workers who could assist elders to learn exercises they can do in their homes. Just as one example, a person can use different sized canned goods as small weights to lift for strengthening. Chair exercises are also easy to teach and use at home. At the Turtle Mountain Chippewa Tribe, a long-term CHR (Mr. Kenny Keplin) has designed a series of chair exercises that he offers regularly to elders (and at workshops) with a great record of participation and fun! Some elders in this program have become strong enough through the chair exercises, to begin an individualized walking program.

Some Tribes are focusing more intently on gardening as a healthy source of activity, as well as source of access to healthy nutrition. And, with their grandchildren involved in gardening, elders can be helped with weeding and watering, while the children can learn a lifelong skill of growing healthy nutritional foods. In short, there are many ways to “fit in” some physical activity on a regular basis, in usual “day to day” living. We only need to look for these opportunities. Entire families can “catch” good exercise habits!
Health Promotion: Healthy Nutrition
Nutrition is actually “fuel” for all the work done by all of the systems of the body. We might as well use “premium fuel” to keep the engines running in tip-top shape. Healthy nutrition is strongly linked to good health\textsuperscript{33, 34}. Healthy nutrition can positively impact blood pressure, blood sugar (glucose), and cholesterol levels. Again, nutrition is something that does not take “special equipment”, just some healthy food choices and grocery shopping that fit into our “day to day” lives.

Special Dietary Instructions related to Specific Health Conditions
For certain conditions, such as diabetes, hypertension (high blood pressure), hypercholesterolemia (high cholesterol) and obesity, it is very helpful to visit with a dietician. Every IHS clinic has dietician resources, and some of the SDPI programs have their own dietician as part of the program. It is quite easy to get an appointment to visit with a dietician to work on an individualized nutrition program.

Some “Common Sense” Approaches to Nutrition\textsuperscript{34}
Although each person’s nutrition may need to be tailored to their specific needs, there are a few dietary instructions that fit all sizes and shapes of people:

- Eating a variety of foods
  - It is very healthy to especially eat a variety of “brightly colored foods”, that is, all kinds of fruits and vegetables that are loaded with fiber, antioxidants, and vitamins!
  - Take a look at the grocery cart: is it “full of color”?
- Avoiding grocery shopping when hungry, some “extra stuff” can find its way into the grocery cart when we are hungry while we shop
- Avoiding high sugar, high fat, high salt, high calorie foods... and how can a person do this?
  - Learning to read food labels!
  - Label-reading is empowering!
- Watching portion sizes
o An IHS dietician has offered a “quick-reference, user-friendly”, method of controlling portion sizes called the “picnic plate method”. Divided “picnic plates” have 3 sections on the plate that can serve to guide the healthy selection and amounts of food. For example, when using the “picnic plate method”, a person would fill one small section with meat, one small section with potatoes, and the large section with vegetables.

• Eating in “balance”
  o food intake needs to balance energy output
    ▪ “Calories in = Calories out”
  o Too many calories “in” or too few calories “out” creates a surplus of calories, resulting in overweight or obesity. What we eat is the “calories in” part of the equation. How active we are is the “calories out” part of the equation. Regular exercise and balanced portions of food can decrease the surplus.
  o “Eat to live”…. Not “live to eat”
    ▪ As a Lakota leader in diabetes prevention has said, “It is important to respect food as a gift. Think about how something has to die for us to eat... a plant, an animal... we should treat food with respect”
    ▪ As a Chippewa elder has said “it is wrong to take more than what we need to live, this offends God”
    ▪ As another elder has observed: “when we watch the four-leggeds and winged, they seem to know what they need to eat”

• “Shopping the perimeter” at the grocery store. A lot of the most nutritious foods are located around the outer rim of the grocery store aisles, where the vegetables, meat, dairy, & fruit are usually found.

• Recognizing “everyday” foods and “sometimes” foods
  o Some foods, like vegetables & fruits should be eaten “every day”
  o Some foods, like cake & candy should only be eaten “sometimes”
  o Children can be taught these lessons early in life
• Remembering “real” traditional foods and how to prepare them, and even grow them!
  o As one long-time HoChunk diabetes educator said with a smile, “fry bread is not a traditional food” 😊
• Adding a healthy nutrition habit to a healthy exercise habit
  o A powerful combination for health!
• Losing even a small amount of weight\(^{36}\)
  o weight loss makes a significant difference in blood glucose control.
  o Losing as little as 7 \% of body weight can make a significant difference in preventing diabetes
  ▪ For example, if a person weighs 210 pounds, losing just 14-15 pounds can make a very big difference for preventing diabetes and improving health

**Health Promotion: Quitting Smoking**
The health benefits that result when a person quits smoking are so beneficial, that it has been said that if a person could only make one change for all around better health, quitting smoking would be the best possible change. Smoking has what are called “systemic” effects. That is, the smoke does not affect only the lungs, but its contaminants get absorbed into the blood stream and affect the entire body. The blood vessels “take a beating” when a person is smoking. This contributes to high blood pressure, loss of circulation, heart disease, and additional complications for people with diabetes. Smoking also causes emphysema and other chronic lung diseases, as well as cancer. If a person can stop smoking, overall health becomes better.\(^{37,38,39}\)

It really can be very difficult to quit smoking, as smoking is extremely addictive. However, health care providers can help a person to quit, using a selection of “tools” that have been developed specifically to help in “tobacco cessation”. Outside of use in ceremonies, it is difficult to find good reasons for smoking. Second-hand smoke is tough on others in a home or work setting, and especially tough on children’s young lungs. Children and grandchildren often suffer
increased rates of respiratory illnesses when they are exposed to second hand smoke, and may be more likely to become smokers. 

Within weeks to months, as soon as a person quits smoking all kinds of good health benefits start to “kick in”. For example, when a person quits smoking for one year, the “excess risk of coronary heart disease is decreased to less than half of that for a smoker”. All in all, quitting smoking is a major accomplishment that can save lives in the present and in future generations. And a full range of tools are available to help a person accomplish this important “health promotion” strategy.

Health Promotion: Stress Management
Stress is a part of normal living, but too much stress becomes unhealthy for a person. Too much stress causes “distress”. From a holistic perspective, stress is rooted in human responses to all kinds of stressors, from all kinds of situations or “triggers”. Stress can be imposed by disease, disability, challenging family situations, loss, grief, spiritual struggle, fear, financial difficulties... anything that we have to deal with in life can become a stressor if coping is not effective.

Our bodies do not know the difference in sources of stress, our bodies just “react” to whatever is perceived as stressful. So, for example, if a person is running away from a mountain lion who is trying to make dinner out of him, the body reacts very strongly with a whole array of chemical and circulation changes to try to survive. But, then if a person loses a family member, the body also reacts very strongly, in the same way, with the whole array of chemical and circulation changes to try to survive the emotional stress. Whatever causes stress... whether the root is physical, emotional, social, or spiritual... the body reacts to survive the threat. When our bodies react for too long a time, and there is no “let up” or relief from the stress, a person can lose their “balance”. A person who is under constant “dis-stress” with little relief can become physically sick, emotionally disturbed, depressed, or unable to perform their role in the family or at work.
It is important, especially to caregivers, to be able to identify sources of stress and to learn strategies to adapt to the stress, to control the source of stress, and to get away from the stress for a break. Caregivers may be those who care for elders in their families, and many elders are caregivers also, often providing care for grandchildren.\textsuperscript{42} In both of these situations, demands are made on caregivers to perform in multiple roles. These demands can create quite a bit of stress, especially when people have to juggle jobs, family care, elder care, child care, economic concerns, disabilities, illnesses, etc. As the demands continue to increase, people can get a little “worn around the edges”, and may not be able to continue their caregiver duties. It is essential to learn and practice effective coping strategies, in order to keep one’s health in “balance”.

Unfortunately, there is not one “medicine” for stress. Each person in a caregiving situation really does need to assess the “dynamics” they are living in. This may take the help of an “outside” perspective, such as with a health care provider, social worker, spiritual advisor, counselor, or even a trusted friend. The relief of stress for each person may be achieved in different ways. It is important for people in caregiving situations to find the strategies that best help them to cope. These strategies will be as different as people are different. But for each individual caregiver, the search to find the way to maintain strength for the caregiving journey must involve asking the question “How can I do this the best way for my family member and for me?”

Caregivers would benefit from practicing each of the “5 good medicines” for health promotion to relieve stress. It is important to make it a priority to take the time to relieve stress. There are serious consequences if caregivers become too “worn-out”. Their own health suffers, and then the option for an elder to stay in the home setting is no longer feasible. One of the primary reasons family members are placed in institutional care settings is because the caregiver is no longer able to cope, and the stress has caused them to become sick or no longer able to function. It is very important for caregivers to realize that in order for them to help the people they love, they have to take care of themselves, also!\textsuperscript{43,44}
Summary
There are many health promotion strategies that elders and caregivers can put into place. Health promotion has the potential to prevent disability, and to make it possible for elders to live in their homes and communities. Five good “medicines” are: physical activity, nutrition, rest, spirituality, and connectedness to family and friends. Stress management as part of health promotion can help people to keep their “balance”. Caregivers often do not address their own stress. However, it is important that they do. Their own health, as well as continued home care for a family member, depends on being aware of stress and dealing with it in a healthy way. It is important for caregivers to realize the importance of their role and their health. Caregivers need to be able to say with conviction: “In order to take care of others, I must take care of myself, and this is ok”.
SESSION  3.2
DAY THREE

Session 3.2  Caring for Our Elders: Accessing the Health Care System & Resources for Native Elders

PURPOSE

- Learn about the range of health services & health providers in the health care system related to elder-health
- Learn about the different sources of funding involved in the health care delivery system
- Learn about eligibility determination for funding resources for elderly people in the health care system

OBJECTIVES

At the end of the session, participants will:

1. Be aware of the roles of specific health care providers
2. Be aware of the role of social services in the care of elderly
3. Be aware of the range of services provided by the I.H.S., Tribal Health programs, and Contract Health services,
4. Be aware of the different sources of health care funding specifically related to the care of elderly people
5. Identify the eligibility criteria for Medicare & Medicaid
6. Identify potential HCBS for elderly people

LEARNING OPPORTUNITIES

1. Panel discussion with IHS staff, County staff, Tribal Health staff
Some Ideas to think about

It is often quite a challenge to figure out how to access the health care system, as well as other resources that can be helpful to elders. Actually, there may be quite a few services available in any given community, but trying to figure out how to access them can sometimes be like getting through a “maze”! The process of accessing care can be confusing! Recurrent questions are heard:

- Who do we go to?
- Where do we go?
- How do we pay for our care?

These are important questions, and there are answers to them. But, overall, the answers will be both “general” and “specific”… “general” in terms of understanding federal systems, such as CMS and IHS, in addition to state-based and local resources, such as Medicaid and Tribal Health, but “specific” in terms of seeking health care resources for a specific person, in a specific community, in a specific state, by contacting specific people. It might be best to learn about these resources “one piece at a time”, with the understanding that they actually do work together in a “system” of care, although we do seem to have to deal with the system “one piece at a time”. Below, we will talk about several resources, commonly asked about by Native elders.

Indian Health Service (IHS)

Although a small number of rural elders may have private health insurance, the Indian Health Service (IHS) is the primary source of health care services for older American Indian people. IHS is a federally funded source of health care for American Indian people, which includes:

- Medical services in hospitals and clinics
- Public health nursing
NECC: Caring for Our Elders
3.2 Accessing the Health Care System

- Dental care
- Pharmacy services

IHS does not provide Home & Community-Based Services” (HCBS) such as long-term care services, assisted living, nursing home or hospice services. Although health care is rooted in Treaty rights, the services that IHS can provide are determined by: the federal budget, presence of alternative services, contract care partners, and the Service Area where a person lives. Most Tribes have “contract” arrangements where some health services are provided directly by the Tribe, utilizing IHS funds (often referred to as the “638 contracts”). Other Tribes have “compacted”, that is, the Tribe has negotiated to receive the full amount of health care dollars that they would have received, and they have the total responsibility to plan for health services and to spend those dollars in the way they determine is best for their Tribal communities.

Community Health Representative Program (CHR)

The CHR programs are the “vital link” between the formal health care system and tribal members in reservation communities. CHR programs are an example of a program which has been “contracted” under the “PL 638” mechanism. CHR programs have enormous potential to assist and advocate for elders in their communities. Many CHR programs provide a gateway to resources for elders to access a range of the services they need. The CHR programs have been in existence for 41 years now. With this lengthy history, CHR programs could be considered the prototype of the currently expanding national movement for utilizing Community Health Workers (CHWs) to improve the health of individuals and communities.

Tribes decide the priorities for their respective CHR programs, and consequently, CHR services can vary significantly by Tribe. However, there are some Tribes who have recognized the special role that CHRs can play in promoting and maintaining the health of their elder populations. In addition to their usual duties, these
Tribes expect the CHRs to make “eldercare” a major priority for their CHR programs. These CHR programs can make very good health partners for elders and caregivers who need some help to access services.

CHRs in programs with an “eldercare” focus make regular rounds on their “elderlies” in the community, and perform assessments, such as identifying needs for public health nursing services, social service referrals, and personal care or chore services. CHRs whose primary scope of work is targeted to regular home visiting for a group of elderly clients, are uniquely positioned to:

- Assist with arranging health education for elders and families,
- Assess the availability of family in the area to provide help with IADLs & ADLs,
- Address safety issues in the home
- Track health indicators between clinic visits, such as blood pressure, blood glucose, foot care, edema, and make reports to the public health nurse,
- Arrange transportation to the clinic or hospital
- Make referrals through their Tribal Health supervisors for other needed services
- Identify progressive changes in an elder, that might otherwise be missed if the elder only has intermittent care in a clinic setting
- Identify progressive changes in an elder, that might otherwise be missed if the elder only has intermittent care in a clinic setting

An anecdote related to this last item provides an example of a CHR’s assessment skill. One CHR knew she had to make a referral for additional help for an elder, when out of her usual hospitality, the elder offered the CHR a piece of pie that had a very obvious layer of mold across the top. The CHR then realized that the elder was having an increased level of difficulty with her long-standing vision loss,
and was at increased risk in her home. The CHR was able to arrange an assessment for the elder, to access additional in-home services through Medicaid funding.

Other Tribal Health Programs

Tribes can vary in the kinds of Tribal-specific health programming available to their members. The advantage to Tribal health programs is that access is offered to all Tribal members, and the programs are administered by Tribes directly. However, it is not always possible to procure funding for all the types of programs that Tribes would like to offer to their members.

Contract Health Services

Contract Health Services (CHS) is the mechanism that the IHS uses to purchase health care services that cannot be provided by IHS or Tribal facilities. CHS monies are determined annually. However, when contract health service funds are “used up”, it is difficult to find additional dollars for contract services until the following fiscal year. This can pose a serious problem for many Tribal members who are dependent upon payment for contract services through IHS funds. Several limitations are inherent in the Contract Health Services mechanism:

- The person must be referred to receive contract health services by the IHS (no self-referrals)
- Eligibility is usually restricted to people living on or near their reservations, and to students/dependents who are away from their home reservations at school
- Because of limited annual funding, priority for expenditure of CHS funds often is reserved for “life-threatening” & “urgent needs”, so other needed health care services often cannot be accessed

Diabetes Programming through IHS
Because of the importance of diabetes prevention among American Indian people, there is a need for special diabetes-related programming. The IHS Division of Diabetes provides for diabetes prevention, research, clinical guidelines, education services, and the Special Diabetes Program for Indians (SDPI). The SDPI programs operate locally, and may be administered by either the IHS clinic/hospital or by the Tribal Health program. Usually the SDPI programs address diabetes prevention based on local needs. For example, some SDPI programs focus exclusively on children, while others focus on outreach activities and prevention with adults.

**Medicare & Medicaid**

Very important information about long-term care services and/or Medicare & Medicaid services (CMS) in Indian Country is available from a number of sources. For this session, much of the information was obtained from 5 helpful sources: 1) the “Tribal Guide for Elder Care: A Primer on Long-Term Care Services & Financing for Indian Elders”; 2) the “Native American Map for Elder Services (NAMEs)”; 3) the 2009 Centers for Medicare & Medicaid Services, States, and Aberdeen Area Indian Health Service Conference in Sioux Falls, SD; 4) the “Medicaid Home Care and Tribal Health Services Tool Kit” for developing new programs; and 5) “Medicare Part D: What Every Indian Elder Needs to Know”. The health care financing system is a bit complex! However, below we will present a very “basic” overview of Medicare and Medicaid funding.

**Medicare**

Medicare is a federally funded health insurance program for people who meet the following eligibility requirements:

- Age 65 or older
3.2 Accessing the Health Care System

- A documented work history of enough hours for entitlement to benefits
  - A spouse is also entitled to the benefits based on the work history of their husband/wife

If a person is not yet 65 years of age, there is a “special eligibility” for people who are disabled. This is a little more complicated, in terms of meeting and documenting the disability requirements. Consultation with a Contract Health Services (CHS) staff person at IHS would be very helpful to determine this eligibility and how to apply. In fact, to get help with determining eligibility for many different sources of funding, an elder (or family member of an elder) can go to IHS for this information through Contract Health Services (CHS). The CHS staff work with eligibility determinations on a regular basis, and are very knowledgeable about these issues.

What does Medicare Cover?

This is a very important question! First, it is necessary to discuss the different parts of Medicare. Medicare benefits are organized into Medicare A, Medicare B, Medicare C, and Medicare D.

Medicare A

Medicare A benefits are paid for stays in hospitals (including IHS hospitals) and nursing homes. However, nursing home payments are temporary, and related to a specific health problem. Medicare will not cover ongoing long-term care.

Medicare B
Medicare B benefits are paid to hospitals and clinics (including IHS hospitals and clinics) to cover health care services from: doctors, mid-wives, clinical social workers, clinical psychologists, registered dieticians, physical therapists, and occupational therapists.

**Home Health and Hospice**

Medicare can cover Home Health and Hospice care. However, this coverage does not help people in many rural reservation communities, since there are no accessible Home Health or Hospice services. And, although Home Health benefits can be covered by Part A or Part B, Medicare will *not* cover ongoing Personal Care Services (PCS) in the home, such as bathing, toileting, etc. A prescribed medical intervention for a defined medical problem is required to receive PCS under Medicare, but PCS coverage will be for a limited time. When health professionals no longer need to provide skilled services, PCS is no longer provided under Medicare. Hospice care benefits are provided through Part A of Medicare.

In order for Medicare to pay for Home Health care, there are specific requirements:

- The person must require “skilled” care in the home that must be delivered by a professional provider, such as a nurse, physical therapist, etc. If the person has these “skilled care” needs, the professional can allow the person to receive personal care services (PCS) in the home also, for example, from a nurse aide, for a limited amount of time. Once the skilled professional services are no longer needed, then the personal care services (bathing, dressing, feeding, toileting, etc) will no longer be provided under Medicare.

- The person must be “homebound”, that is, the person cannot access the services in any other way, because their condition has required them to be at home all the time. There are few exceptions to this: the person can attend an adult day care program, can go to a clinic or to a hospital.
appointment, and can attend a religious service. Otherwise, the person must be “homebound”.

**Medicare C**

Medicare C insurance is not available in American Indian communities, nor to many other people. It is a specific type of program that is offered in connection with a managed care insurance organization. So, Medicare C is not an available type of Medicare coverage at this time in Indian Country.

**Medicare D**

Medicare D insurance is the “prescription drug benefit” of the Medicare program. CMS has approved the IHS as a “creditable coverage” prescription drug provider under Medicare D and elders can access their medications through the IHS. It is recommended to visit with the benefits coordinator at IHS to see if an elder could (or should) apply for Medicare D benefits.

**What does Medicare insurance cost me?**

There are many rules and regulations involved with Medicare funding. Some parts of Medicare require a deductible or a monthly premium. It is best to determine a person’s individual coverage, and any specific additional Medicare costs with a resource person, such as from the IHS benefits coordinator, or contract health service staff, or County Social Services, or State Health & Human Services staff. This has been an “overview”, but there are sources of help to guide a person towards getting the maximum benefit from Medicare eligibility. Now… we will be switching gears to *Medicaid benefits*.

**Medicaid Funding**

Medicaid is different from Medicare, but is a Federal-State funded program. The Federal government provides a cost-sharing arrangement with each state. However, Medicaid is a STATE administered program. Each state individualizes its
Medicaid programming, and therefore, services and eligibility vary from state to state. Many states provide helpful Home and Community-Based Services (HCBS) for elders funded under Medicaid. Again, the resources as mentioned above at the IHS, County and State level would be good people to visit with, to obtain information about available elder services in each state.

**Medicaid Eligibility**

Eligibility for Medicaid is based on financial need. Unlike Medicare, Medicaid is not based on work history. Medicaid is available to people in all age groups, including elders. Elders’ eligibility criteria include the following:

- Elders who are 65 years of age and older
- Elders who are disabled
- Elders who are on Social Security Income (SSI)

Because Medicaid is based on financial need, the elder must qualify for Medicaid benefits through an assessment of their financial assets. The amount of allowable income and assets for Medicaid vary from state to state. But, overall, a person’s income and level of assets have to be low. However, in determining assets, an elder’s home, car, clothing, burial plot, and household goods are not counted towards the limit of assets.

If an elder is not eligible for Social Security Income (SSI), then a monthly “deductible” payment is calculated, based on the elders’ income. If the income is very low, then the “deductible” payment will be very low. When health care services are needed, the elder pays the “deductible”, and Medicaid pays the remainder of the bill for health care services. IHS can waive deductibles.

In contrast to Medicare, the Medicaid program will pay for nursing home care. Elders’ resources have to be extremely limited, but they can keep a car, their home and belongings. However, after an elder passes away, the state may take...
money from the estate. **BUT, Medicaid will NOT be allowed to take tribal land or income from tribal land, or items with spiritual or cultural significance to the Indian community.**

**Medicaid Home & Community-Based Services (HCBS)**

Many Medicaid programs in various states are interested in keeping people out of expensive nursing home settings, and will pay for HCBS that will help elders to “age in place”, that is, to stay in their own homes. In some states, the Medicaid program will routinely pay for personal care services and some chore services (bathing, toileting, dressing, cooking, and cleaning). The Medicaid focus is more “non-medical”, as compared to Medicare (which is “medically-oriented”).

Some states are committed to elder care, and provide generously through the Medicaid program for elders across a range of income levels. It is necessary to individually determine the services available for an elder, as Medicaid services are dependent on Medicaid guidelines in each state.

**Summary**

In summary, Medicare and Medicaid both are government funded and administered health care insurance programs. Medicare is a Federal program with eligibility guidelines based primarily on work history. Medicaid is a Federal-State program with eligibility based on financial needs. Medicare provides the same services across the nation, under strict criteria. Medicaid services vary state by state, and many states have a wide array of HCBS for elders. In order to determine an individual’s eligibility for either program, it is recommended that the Benefits Coordinator, Contract Health Services staff (CHS) at the IHS or the Social Service staff at the County or State level be contacted. Although the
“system” often seems like a “maze”, it is possible to learn about the variety of available resources “one piece at a time”... and to use them!
DAY THREE

Session 3.3  Caring for Our Elders: “Navigating the System”

PURPOSE

- Learn how to approach the system of health care & other resources for elders & families
- Learn how to effectively utilize the people in the system in order to access resources

OBJECTIVES

At the end of the session, participants will:

1. Identify at least three ways to obtain help to access services needed for elders
2. Identify at least three people in the local system who can help with accessing resources
3. Identify the role that elders & families can play in their own communities in strengthening access to elder resources

LEARNING OPPORTUNITIES

1. Creating an assessment of “what is really needed?” for individual participants’ families & communities
2. Creating “pictures” of each participant’s community resources
3. Creating lists of each participant’s resource people
4. Discussion of other strategies that might be effective to improve access to resources in the local community
Some Ideas to think about

After learning about various programs that can be helpful to caregivers and elders who wish to continue to live in their own homes, at this point it might be helpful to “brainstorm” how to access these programs. It may be a good idea to even think about how communities can be “proactive” in helping to build HCBS programming in their own settings. We know the system can be like a “maze”. So, sometimes it is necessary to “rise above the system”, as well as to “work within the system”. A community needs to become aware of what is needed, then to develop the tools to “navigate” a unique way around their system and within their system. Below are a few “tips”, learned from people who “have been there, done that” 😊.

#1 Tip: Know what you need: A family needs assessment

A useful tip for elders and families is to do their own “family needs assessment”. A good question to ask is, “If we could change or add something to make the care of __________________ better for them, and less stressful for us, what would it be?” (Fill in the blank with the name of the person who needs care Grandma, Grandpa, Dad, Mom, Auntie, Cousin, etc). Then a family “brainstorm” session can take place about what might make in-home care easier, safer, feasible, and long term. The need might turn out to be something very technical, like having assistance with a tube feeding. Or, it may be something related to very routine “day to day” tasks, like having help with taking the trash out to the end of the yard when someone cannot walk too far, or preparing a meal, or shoveling snow off the walkway, etc.

It would be helpful for the elder and family members to set aside a time to really discuss and answer a few questions together:

- What do we need to take care of our family member in the best way possible?
- What do we already have to work with?
• Who is already helping?
• Who could offer more help?
• What is missing that we really need?
• What would really be helpful to us to maintain our loved one at home?

The answer to the question:

“If we could change or add something to make the care of our loved one better for them, and less stressful for us, what would it be?”

will vary from person to person, and family to family. Realistically, it will take some effort and time to discuss these questions and agree upon answers. Also, realistically, there may be some family members who do not want to meet with other family member, or there may be longstanding family problems that will hold people back from working together. And realistically, it is good to be prepared for the fact that some people in the family will become more committed to the work of caregiving than others. Realistically, each family will have its own set of challenges to work through and barriers to overcome. And realistically, some barriers cannot be completely overcome.

But, before trying to access services, it is truly important to clearly identify the elder’s needs given the circumstances in a particular family situation. Then, within those circumstances, the caregivers can seek out the resources to best match the needs. It is so helpful if everyone in the situation can realize they all are working towards the same goal...that is, the best care for an important family elder over the long term.

#2 Tip: People are the KEY!

Once the family discussion has identified what is needed in their particular situation, the next useful tip to remember when working through the “maze”, is that people actually make up the system of resource services. People run the system; there are people who know the “in’s & out’s” of the system; people who know the available HCBS. So, a good solution to learning how to access and
obtain needed services is learning how to access the people who know it. The next step becomes finding out: Who are the service providers? What do they provide? Where are they located? How can we contact them?

Every community will have an array of programs. And very often, people who work in one program know of the people who work in other programs. There are a number of Tribal programs that can fill a gap. A CHR program that provides routine home visits to elders may be the link to monitoring chronic diseases, such as hypertension. A Tribal SDPI (diabetes) program with outreach services can help to monitor a diabetic condition with home-based blood glucose checks. A Social Services program can help to assure that an elder is being cared for safely in the home. A Senior Meals program can help with providing healthy nutrition, either at a meal site, or through “Meals on Wheels”. Senior Service programs often provide transportation for medical and social appointments. An active elders’ group can advocate for additional needed services, such as installation of safety equipment in homes by Tribal Housing services.

The Indian Health Service provides medical care, which includes: pharmacists who can answer questions about medications; public health nurses who can provide a safety net for assuring that the elder’s medications are being taken correctly; and dieticians who can help with medical nutrition education. IHS also can assist with providing transportation to appointments at distant medical centers. A discussion with CHS or the Benefits Coordinator in the IHS or County Social Services may help to determine that a person is eligible for personal care services and chore services under state Medicaid funding. A counselor through IHS, Social Services, or the spiritual advisors in the community can provide comfort to an elder who is having trouble coping with social, emotional, grief, or spiritual issues.

There are many services available, but finding the answers to the “who, what, where, how” questions need to be found first. And “who” is most important.

**#3 Tip:** Identifying the type of need from a holistic perspective
When a family is identifying needs, the “assessment” is most helpful from a holistic perspective. Questions that might be asked are: “What is “out of balance? Is it a medical problem? An emotional problem? A family / social problem? A financial problem? An substance abuse problem? An elder-abuse problem? A spiritual concern? A cultural issue?” When the cause of the concern is clear, it is much easier to obtain a specific type of assistance from specific people in the system.

#4 Tip: Draw a picture of the health care system and services in your community

Literally, “drawing a picture” of the services in a community is very helpful. It is ok to use boxes or circles or lines... whatever! But brainstorming about a wide range of possible resource in the community and getting it into the “big picture” is very empowering. This can be done as an individual, as a family, or as a group, such as an elders group. It may take some time to get all of the information for the picture, but once it is finished, the family (and community) has a useful “map” of the system. Figure 1 below is an example of a “picture” of the services that may be “mapped out” in a local community.
For each entity identified in the above picture, “follow-up” charts can be drawn, and the following information can be added:

- Services they provide
- Names of the providers
- Location of the services
- Contact phone number for the service
3.3 Navigating the System

- Days and times that the services can be accessed
- Payment information, that is, funding source for the services through this particular agency

The following table is just one example of how a chart can be developed to help improve access to services. (This chart uses some of the available I.H.S. services as an example, but any service system could be “mapped”).

**Table 1. Example of a “Follow-up Chart for I.H.S. Services”**

<table>
<thead>
<tr>
<th>Service</th>
<th>Name of provider</th>
<th>Location</th>
<th>Contact phone number</th>
<th>When open for service?</th>
<th>Who pays?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Appointments</td>
<td>Dr. Apple</td>
<td>Field Clinic</td>
<td>555-777-6666</td>
<td>Mon &amp; Thurs 8:30 AM to 4:30 PM</td>
<td>Medicare B</td>
</tr>
<tr>
<td>Pharmacy</td>
<td>Mr. Bee</td>
<td>Main Clinic</td>
<td>555-777-8888</td>
<td>Mon-Friday 9 AM to 5PM</td>
<td>Medicare D through I.H.S.</td>
</tr>
<tr>
<td>Diabetes Clinic</td>
<td>Nurse Practitioner Cathy</td>
<td>Main Clinic</td>
<td>555-777-4444</td>
<td>Tuesdays 10 AM to 4PM</td>
<td>Medicare B</td>
</tr>
<tr>
<td>Dietician</td>
<td>Nutritionist Debbie</td>
<td>Field Clinic</td>
<td>555-777-9999</td>
<td>Tuesdays 10 AM to 4PM</td>
<td>Medicare B</td>
</tr>
<tr>
<td>PHN</td>
<td>Nurse Elaine</td>
<td>Tribal Health</td>
<td>555-777-7777</td>
<td>Tues – Friday 8 AM to 4:30 PM</td>
<td>I.H.S.</td>
</tr>
</tbody>
</table>

Once this kind of information is gathered, it can be printed and laminated, and even distributed to other caregivers, both families and professionals. If the chart
is set-up and kept on a computer file, it can be easily updated as people and contact information change.

### #5 Tip: Find the “key” person

Although there may be many agencies and services in a community, much time and effort might be saved by finding a “key” person who is connected to many other service providers. It may be this person who will “unlock” the maze! This “key” person will be someone who knows names, who has phone numbers, or who knows someone who does have phone numbers, etc. One recommendation is to start with Senior Services & Meals program staff, and work from there. However, the “key” person may also be found in other programs… perhaps the CHR Director, District CHR worker, Tribal Health Director, Tribal Health Administrative Assistant, Tribal Council Secretary, Council HEW Committee member, Public Health Nurse, Elder’s Group President, Contract Health Staff, SDPI Director, IHS clinic provider, etc.

It is only necessary to find one key person. That one key person can open up several “locks” that will lead to all the other key people and programs that an elder needs to maintain the ability to live in the community. If it is not clear right away who that key person might be in a community, it is good to start asking around. This task will involve some work for a caregiver, and it might seem to be a challenging “job” to ask other families, other elders, relatives, Tribal leaders, State agencies, medical providers, etc. But, this strategy will pay off. Someone will know and will refer the family to those “key” persons who can help.

### #6 Tip: Branch out: Strengthen connections to other resources

If it is understood that programs and services are only as good as the people who provide them, then it may be helpful to look around a community to find “untapped potential” in people who perhaps have been overlooked as resources. Is there a caregiver support group in the community? If not, can someone help to create one? Is there an **active** elders group in the community? If not, can
someone help to get them started with regular meetings? Is there a person who can be identified as a catalyst to “jumpstart” the process?

Is there a Tribal College in the community? Will the College President assist in providing resources such as meeting space for elders groups and/or caregiver support groups? Can a Tribal College provide a space for a community “shareholders” organization targeted to elder needs? Computer access? User-friendly Website links for elders and caregivers? Educational sessions on topics of interest to elders and caregivers? Assistance with grant-writing for funding elder’s community-based needs? Opportunities for elders to teach and share their wisdom with younger community members? The “take-home” message is, there may be resource people who will be very willing to help, and who just need to be asked!

Summary

There are several “tips” to follow in successfully accessing available services and resources in a community. People are the strength of these resources. People can join together to strengthen resources for entire communities. Families can create useful “maps” and “charts” of available services, as well as seek out additional resource possibilities. Successful “navigating” requires building a future direction that fits a community. Finding and working with “key” people can unlock the maze!
SUMMARY
SUMMARY OF THE PROJECT

The modules in this curriculum hopefully will help caregivers to have a little extra information about the important work that they do. There are many informational resources available to caregivers that can help to make it possible to plan for the future of elder-care in community settings. Educational resources are available to help people learn more about how to become and remain healthier. In addition to newer clinical care initiatives for elders by IHS, much is known about maintaining functional abilities and health through Health Promotion activities.

Also, a number of really good ideas for programs have been developed for providing long-term care services in the community setting. There is no shortage of ideas! Actually, the challenge is for American Indian elders and caregivers to learn more about Home and Community-Based Services (HCBS), and to lead their communities in planning for quality eldercare now and into the future. The task ahead is to find out how to effectively access federal, state, and local resources, and then to adapt them to the specific needs of each Tribal Nation. Many elders wish to stay in their homes for as long as possible, we want to honor this wish.

The work ahead to provide well for the health of our elders is sacred. They are:

“...the keepers of the language, medicine, values, traditions, stories, songs, and dances of our people. Oral traditions have been passed down from generation to generation throughout our history, and older people bore the responsibility of keeping these stories alive to share with the younger generations. These accounts of our history are told not only to entertain people but also to provide direction on how we should live and care for one another. Our goal as the next generation is to pay back our elders for their contributions to our families, societies, and communities by doing our best to increase or maintain their quality of life by providing them autonomy in how they wish to live.” ¹, p.65
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   or
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APPENDIX A
Appendix A

Ideas for Classroom Activities for NECC

Each location for the NECC training will determine the best way to offer the Native Elder Caregiver Curriculum (NECC). How each Tribe decides to structure the NECC sessions, and how much time is allotted to each session will influence the type of classroom activities that might be offered as part of the learning process. In this Appendix A, a few ideas that might be used to make the learning more “engaging” are presented. Adults often express that they learn best when they can learn “hands-on”. Some of the sessions easily lend themselves to “hands-on” learning, while others are more “informational” in nature. This section just offers some ideas for each of the sessions, hopefully to enhance the learning for the community members who take the NECC course.

Each session is presented below, with its “purpose”, and then a few ideas for classroom activities that relate to each respective session.

DAY ONE

SESSION 1.1   NORMAL AGE-RELATED CHANGES

PURPOSE

- Learn about common biologic changes often seen while people grow older
- Learn to recognize differences between “normal” biologic changes & those that are related to disease/illness

Since this is the first session, it is good to have each person introduced in a comfortable way. Time set aside for a “talking circle” is encouraged to make time for the introductions and to help participants to talk with one another, maybe to share what has brought them to the NECC course.
The initial session is mostly “informational” in nature. The “talking circle” may provide the opportunity for the community people to network with one another. One goal of the NECC curriculum is to empower “grass-roots” people with knowledge of how to strengthen the care of elders through Home & Community-Based Service options. Making stronger community “networks” could be a good outcome from the curriculum, especially if the participants decide to follow-up with some of the recommendations for community action together. Sharing ideas about being and becoming an American Indian elder and its traditional meaning, may be helpful to create a positive perspective on the course, and to honor this season of life.

DAY ONE

SESSION 1.2 SENSORY CHANGES while GROWING OLDER

PURPOSE

• Learn about common changes in the “sensory systems” often seen while people grow older

This session on sensory changes contains information that does lend itself to some “hands-on” learning. It is possible to “simulate” some of the sensory losses that elders may experience. Having a few items set up and on hand for the simulations during class will help when the “teachable moment” arrives 😊! Or, the group can gather into the circle again, and systematically try each of the “sensory loss simulations”.

• Cotton balls to go into the ears to simulate hearing loss

• Eyeglasses with Vaseline streaked across the lenses with instructions to read from a book, can help to simulate vision losses
• Sunglasses worn indoors can also simulate vision changes requiring more light for vision
• Bubble-wrap paper to walk on in socks feet can simulate change in nerve feeling in extremities
• Thin gloves worn while trying to take notes with a pen can simulate changes in touch and perception
• Having participants hold their noses while they eat or drink can help to simulate the loss of taste and smell

DAY ONE

SESSION 1.3 ADAPTATION & COMMUNICATION SKILLS RELATED TO SENSORY SYSTEMS

PURPOSE

• Learn about the relationship between sensory changes and safety issues in elderly people
• Learn to adapt communication skills with elderly people who have sensory changes & losses
• Learn to adapt the environment to assist elderly people who have sensory changes

During this session, it would again be helpful to have some items set-up and ready to use at a “teachable moment”. Or, as with Session 1.2, the “circle” can be used for discussion and demonstration time. The following items would be helpful to have on-hand to use “hands-on”:

• Safety checklist from the W.E.L.L.-Balanced curriculum from NRCNAA can be used on-site to take a “safety tour” of the setting
• Safety checklist could also be assigned as “homework” for participants to take home to assess the elders’ residence

• A throw rug can be used to demonstrate risk that rugs pose for falls

• A lamp with four different light bulbs, with a range of watts (25 W, 40 W, 60 W, 75 W) can be used to demonstrate compensation for vision loss

• Glare from harsh lighting can be demonstrated with a 100 W bulb

• Visors, sunglasses, hats can be used for adapting to bright sunlight

• A stethoscope can be used to “talk” through to a participant with cotton in the ears to simulate adaptation for hearing enhancement

• 5” x 7” index cards and bright bold colored markers can be used to demonstrate making “flash cards” for hearing impaired

• Small table with variety of items (tissues, remote control, glasses, drink of water, food, radio, etc) can be used to demonstrate “set-up” for a person who is vision impaired

DAY TWO

SESSION 2.1 LIVING IN BALANCE WITH COMMON CHRONIC HEALTH CONDITIONS

PURPOSE

• Learn about common chronic health conditions that many elderly people live with

• Learn to focus on the “care” of the person with the chronic health condition, when “cure” is not possible
This session is one of those that are more “informational” in nature. It is recommended that some time be set aside for participants to discuss the kinds of chronic health conditions they deal with in their families, and the special needs these conditions create. The discussion can include the special role of the caregiver, who is going to be called upon to “care” over a long period of time, as a person deals with chronic diseases that do not have a “cure”.

DAY TWO

SESSION 2.2 HEALTH DISPARITIES AMONG NATIVE ELDERS

PURPOSE

- Learn about the increased rates of chronic diseases among the American Indian elderly population
- Learn about some of the reasons for the increased rates of chronic diseases among the American Indian elderly population
- Learn to recognize the potential for reducing disease rates among the American Indian elderly population

Session 2.2 is like 2.1, in that it is more “informational” in nature. However, this session presents a good opportunity to get the participants discussing how they may be able to work with their family and community towards a “glass is half-full” perspective 😊! This discussion can set the stage for a more in-depth discussion of Health Promotion later in the course.
DAY TWO

SESSION 2.3  ASSESSMENT OF SYMPTOMS

PURPOSE

- Learn about symptoms that elderly people may experience related to chronic health conditions
- Learn to recognize specific symptoms which are serious and need immediate medical attention

The importance of caregivers in being the “advocates” for elders who have troublesome symptoms makes this session essential to the course. A role-play exercise is recommended here as the learning activity:

Role-play of a variety of symptoms that need to be assessed

a. the participants can be placed into small groups of 3-4

b. a scenario will be given to each group of a set of symptoms that are occurring in the elder they take care of

c. participants will decide who will be the “elder” and who will be the “caregiver”, and the other person(s) can be another family member, or a health care provider

d. each group will act out their scenario, as the other groups “assess” what is going on

e. each group will then share their assessments of the scenarios in the other groups
DAY TWO

Session 2.4  Caring for Our Elders: “Day to Day” Assessment

PURPOSE

• Learn about the special importance of caregivers in observing changes in an elderly person’s condition
• Learn about common symptoms that may occur “day to day” that need to be assessed

“Day to day” assessment is an important function of a caregiver. Caregivers we have talked with have asked to have some instruction in taking basic measures, such as temperature, pulse, blood pressure, and blood sugar. Elders have expressed that it would be helpful to be able to take some of these measures at home, and to be able to communicate them to a health care provider either at a clinic visit, or by telephone. Health care providers do benefit from having more information about “day to day” measures related to chronic conditions. They can better understand a person’s function, response to medications, etc.

For this session, the participants can be taught how to take basic measures of vital signs and blood sugar readings. Materials that would need to be available include:

• Blood pressure cuff: electronic models can be used by almost anyone, and are fairly inexpensive for home use
• Thermometer: as with the blood pressure cuff, electronic thermometers are very easy to use, and quite inexpensive to purchase for home use
• Stethoscope: for anyone who would like to learn to use a regular blood pressure cuff, instead of an electronic model. Also could be used to listen to the heart beat, and to take an “apical” pulse on elders who may be on cardiac medications.
• Blood glucose monitor: these also have become very inexpensive, are very easy to use, and are usually available from the IHS clinic or the SDPT diabetes program. Having a “track record” of blood glucose readings in between diabetes clinic visits is extremely helpful to the person with diabetes and his/her health care provider in managing and controlling diabetes. If a person has an emergency situation, such as loss of consciousness, it is very helpful to check a blood sugar reading before an ambulance arrives, as well as other vital signs.

• Watch with a second hand: this would be used to teach participants to be able to check a pulse or respiration rate, which are very simple “low-tech” skills.

DAY TWO

SESSION 2.5 Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs)

PURPOSE

• Learn about the meaning of “functional status”
• Learn to assess ADLs & IADLs
• Learn the importance of maintaining ADLs & IADLs as long as possible in the elderly

For this session, it is recommended to obtain various types of adaptive equipment that an elder may use. For example, a cane, walker, toilet seat riser, shower grab bar, etc. It may be helpful to visit with a therapist or medical equipment store who could assist in obtaining “show & tell” items for the class. If a therapist is available, it would be most helpful to invite him/her as a guest speaker to demonstrate the use of the equipment also. This availability, of course, will vary by community.
DAY THREE

SESSION 3.1  HEALTH PROMOTION FOR NATIVE ELDERS & FAMILY CAREGIVERS

PURPOSE

- Learn about the meaning of health promotion
- Learn about the importance of health promotion and its relationship to “functional status” in ADLs and IADLs
- Learn a holistic perspective related to health promotion

This session is really a “centerpiece” for the curriculum. If elders are going to be able to maintain health and avoid disabilities, the knowledge and practice of health promotion activities is essential. Three learning strategies are recommended for this session:

1) A discussion of health promotion resources in the community, how they are used, how they could be used, how to get all generations aware of the health promotion opportunities that are available to them.

2) Set up a table with a variety of foods: a) have people read labels, b) make the healthiest food choices from what is on the table; and c) create a “healthy balanced meal” from what is available.

3) Place participants in groups of 4, and have each group choose a physical activity that many community members could do. Then, have each group create a “formal” plan about how they would implement a program that would offer this activity, and would successfully involve community participation.
DAY THREE

Session 3.2    Accessing the Health Care System
& Resources for Native Elders

PURPOSE

• Learn about the range of health services & health providers in the health care system related to elder-health
• Learn about the different sources of funding involved in the health care delivery system
• Learn about eligibility determination for funding resources for elderly people in the health care system

AND

DAY THREE

Session 3.3    Caring for Our Elders: “Navigating the System”

PURPOSE

• Learn how to approach the system of health care & other resources for elders & families
• Learn how to effectively utilize the people in the system in order to access resources

These two sessions are combined, as they are closely related. Session 3.2 is a fairly “heavy” session with lots of information to share and absorb about health related services and funding! Session 3.3 is focused on “navigating the system”, with an emphasis on learning who the people are who can help elders with accessing a range of resources. So it is recommended that a panel be invited to have a discussion with the NECC participants about the health care system. Each
member on the panel would be invited from local resource agencies, including IHS, Social Services, Senior Services, Tribal Health, and Tribal Council. An open “question and answer” session could be very helpful to elders and caregivers in putting “faces with names”, in order to know who can help them to “navigate the system”. If each panelist would bring their professional business cards to give out to the participants, then the participants could begin to “stock” their resource reference “recipe boxes” 😊!

DAY THREE

Session 3.4 Caregivers & Resources: Recommendations

PURPOSE

- Emphasize the important role of caregivers
- Identify examples of a range of resources for caregiver support

A talking circle would be a good idea to allow the caregivers to discuss their roles as caregivers. This would provide an opportunity for the participants to share ideas, solutions, and to maybe even conceptualize a plan to start a support group. The talking circle would also allow participants to summarize what they have learned throughout the course. Since this would be the final session, it is recommended that before closing the final talking circle, participants would have the chance to evaluate the course.
Evaluation

Evaluation of the course can be done at the close of each day. It is possible to offer “workshop days” one at a time, especially if it is not feasible for some people to attend for three consecutive days. Again, this will be driven by the decision of the community and individual community members.

Some of the “evaluation” of the course will be done by the instructor, in the course of class activities. For example, the instructor for the course will observe the vital signs skills, and will be able to see if they were learned satisfactorily. Other class activities worked on collaboratively by participants will have other kinds of “outcomes” that can be observed. For example, for the Health Promotion session, it will be possible to observe the planning and choosing of food items to prepare a meal; or to observe and read the plan that is created by the participants for engaging communities in an intergenerational exercise opportunity.

In terms of the participants having a chance to evaluate the course, a basic evaluation form with four simple, open-ended questions can be used. Participants can be assured that the evaluations will be used to improve the sessions for the next course that is offered, and that no names are to be placed on the evaluation forms, to assure confidentiality.

1. Can you identify 3 things that you learned today, that are new to you?

2. Can you explain how you think you may be able to actually use at least 2 of the things you learned today?

3. Can you think of at least 2 other things that you would like to learn more about?

4. Can you tell us at least 3 things that would have improved the learning experience for you today?
Home Safety Checklist

*Use this form to conduct a safety check of your home. If you answer “No” to an item, try to identify an action to correct the safety problem. Bring this completed form back to your WELL-Balanced group session.*

<table>
<thead>
<tr>
<th>ALL ROOMS</th>
<th>YES/NO ACTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you use carpet with short pile (thin carpet)?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Have you applied double-sided carpet tape to rugs that can slip?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Is your furniture arranged so you can easily walk around it?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Are electrical and extension cords in your walking path?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Can you turn on lights without having to walk through dark areas?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Do you use nightlights?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Can you easily reach a light switch when you come into a room?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Do you keep exits and hallways clear?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Do you use stable chairs with armrests to help you get up?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Do you always watch that your pets are not underfoot?</td>
<td>□ Yes □ No</td>
</tr>
</tbody>
</table>

**TIPS:**
- Put a chair at the entrance of your home to remove or put on your shoes and boots.
# Home Safety Checklist

<table>
<thead>
<tr>
<th>STAIRS</th>
<th>YES/NO ACTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are there handrails on both sides of the steps?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Action:</td>
<td></td>
</tr>
<tr>
<td>Can you reach the handrails easily?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Action:</td>
<td></td>
</tr>
<tr>
<td>Are the steps even?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Action:</td>
<td></td>
</tr>
<tr>
<td>Do you use non-skid, rubber stair treads, or coated skid resistant surfaces on non-carpeted steps?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Action:</td>
<td></td>
</tr>
<tr>
<td>Do you make repairs to worn or loose steps promptly?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Action:</td>
<td></td>
</tr>
<tr>
<td>Is there good lighting in the stairway?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Action:</td>
<td></td>
</tr>
<tr>
<td>Do you stack objects on the stairs?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Action:</td>
<td></td>
</tr>
</tbody>
</table>

**TIPS:**
- To help avoid taking a misstep, you can paint wooden or concrete steps with a strip of contrasting color on the edge of each step or on the top and bottom steps.
- Don’t rush going up or down stairs. Rushing is a major cause of falls.
## Home Safety Checklist

<table>
<thead>
<tr>
<th>BATHROOM</th>
<th>YES/NO ACTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are there rubber bathmats or strips in bathtubs and showers?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Do bath mats next to the tub or shower have rubberized backing or are they secured in place to keep them from slipping?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Have you installed grab bars in the bath tub?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Do you use raised toilet seats and/or handrails if you are unsteady?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Do you clean up water from the floor to avoid slipping?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Do you have a nightlight in the bathroom?</td>
<td>□ Yes □ No</td>
</tr>
</tbody>
</table>

**TIPS:**
- Some tile and bath cleaning products increase slipperiness. Be careful when using such products.
# Home Safety Checklist

<table>
<thead>
<tr>
<th>OUTSIDE</th>
<th>YES/NO ACTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have handrails along outdoor steps?</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td>Do you spread sand or salt on icy walkways?</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td>Do all your entrances have an outdoor light?</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td>Are the front steps and walkways around your house in good repair and free of clutter, snow or leaves?</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td>Can you reach your mailbox safely and easily?</td>
<td>☐ Yes ☐ No</td>
</tr>
</tbody>
</table>
“I’LL GRANT YOU THAT* !”
Making the case to Foundations
(borrowed from Burke & Prater, 2000)*

GOOD MORNING !
TWO GROUND-RULES…

- Bring in the coffee, and no one gets hurt!
- “snoring out loud not permitted”
TODAY’S AGENDA

1. Foundations as source of funding
2. Think about possibilities for elder care grant for SLN elders
   ◦ First… Nominal Group Process to generate ideas
   ◦ Second… come up with an idea to “run with” and submit
   ◦ Tomorrow… start running?

NOMINAL GROUP PROCESS

- The question:
- *given the priority areas for the USDA RFA…*
- WHAT COULD CCCC OFFER TO BETTER MEET THE HEALTH & LONG TERM CARE NEEDS OF THE GROWING POPULATION OF ELDERS & FAMILY CAREGIVERS AT SLN?
GROUND RULES FOR NOMINAL GROUP SESSION...

1. silent generation of ideas… SILENT
2. round robin… *no commentary*, only the person with the idea speaks when it is their turn
3. all ideas are welcome!
4. when ideas run out… just “pass” on the next round
5. if another idea comes up for you… jot it down and share the next round

Nominal Group Process

1. silent generation of ideas
2. round robin listening to ideas
3. clarifying ideas
4. prioritizing ideas
5. selecting ideas to go with…

And hopefully #6… write grant!
AGAIN… The question:

- given the priority areas for the USDA RFA…
- **WHAT COULD CCCC OFFER TO BETTER MEET THE HEALTH & LONG-TERM CARE NEEDS OF THE GROWING POPULATION OF ELDERS & FAMILY CAREGIVERS AT SLN?**

---

**Grant-writing Expertise**

- Experiential Approach*  
  ◦ “code language”  
  ◦ Which means…

  “see one, do one, teach one”  
  “Expertise… is shared”
Story of “an expert”...

Grant-writing: A PROCESS

- Linking the research process to the grant-writing process
  - Purpose statement
  - Background / Literature Review
  - Population
  - Methods / Implementation
  - Analysis / Evaluation
Linking the Research process to the Grant-Writing process

- **Purpose**
  - WHAT do you need? WHAT do you want to do?

- **Background**
  - WHY do you need it? WHY would it help? WHO ELSE has tried something like this?

Linking Research to Grant-writing ... the keyword is PROCESS

- **Population**
  - WHO needs it?

- **Methods / Implementation**
  - HOW will you get the project done?

- **Analysis / Evaluation**
  - Did the Project do what you said it would do?
Show me the money...

- **Budget**
- How much will this idea of yours cost?
- How carefully will the dollars be used to match the Purpose?
- How will you *keep this project going*?

Process: from Writing to Reporting

- **Reporting Results**
- “the good, the bad, and the ugly”
- What happened?
- Telling the story
Why “Foundation” Funding?

- “Experiential Findings”
  - “code” for “the way it worked for me”
- FOUNDATIONS:
  - Open to community–based projects

Why Foundation Funding?

- Foundations:
  - Philanthropic mission
  - Understanding of real world dynamics in communities
  - Project officer “shepherd” throughout the time–line
A few tips… *(again “experiential”)*

- Phone call contact with a Foundation Officer
  - Different people assigned to different types of projects

A few tips…

- E-mail connection
- Phone call connection
  - Ask if I can “run and idea” by them
  - Want to know if I am barking up the wrong tree!
A few tips...

- Know the Mission Statement for *my* group
  - Project ideas have to be *congruent* with what the organization is all about

  - Eg. Probably not a good idea for the college to ask for funding for starting up a retail appliance store
A few tips…

- Read–up on the Foundation
- Go to their website
  - Know THEIR Mission Statement
  - Think about how the project I would like to do matches the Foundation’s mission

A few tips…

- Know something about their application process
  - Ask good questions:
  - Demonstrate I have been on their website
  - That I have “done my homework”
A few tips...

- Follow instructions from Foundation Officer
  - For example, e-mail, letter of intent, follow-up call, new contact in the Foundation, etc.
  - Send short note of thanks for visiting on the idea
    - To a specific person, *not* to the “Foundation” in general

A few tips...

- If Foundation Officer seems interested... be prepared!
  - They may ask a lot of questions!
    - Know the answers!
    - Or how to get the answers *quickly!*

  - *Anecdotes... lost opportunities!*
A few tips...

- They may ask for a phone call to gather more info *or* to have a visit “on-site” with me & the group
  - Have the calendar next to me!
  - Have dates of when group could meet together if asked
A few tips...

- Verification of Community Support for the Project
  - Begin with a few community share-holders who have been involved with the “idea” on an ongoing basis
  - Community members who can speak to the idea
  - Not “after the fact” or as “window-dressing”

  - LETTERS OF SUPPORT FROM COMMUNITY MEMBERS, WRITTEN IN THEIR OWN HAND... AND THEIR OWN WORDS... POWERFUL.

“You already know what you already know…”

- Rigorous following of application guidelines
  - Read RFA multiple times… and multiple times...

  - FOLLOW THE FOUNDATION’S OUTLINE *EXACTLY*
    - *Don’t want to aggravate the readers!*
  - Keep to page limit
  - Easy to read font
  - Multiple copies as requested
  - No binding if not requested
**DRAFT NARRATIVE EXAMPLE for GRANT APPLICATION for ELDERS PROJECT**

Section 1: Introduction

A. *Significance of the Project*

   Every day, American Indian elders and their families face the challenge of weaving together a fragmented network of eldercare (aka “long term care”) services within the realities of reservation settings. The proposed project (“Strengthening Home & Community Based Services”) is significant, as there has been a growing awareness about addressing concerns of Native Elders, a population whose demographic profile is changing within Tribal Nations. The two long-term goals of this project are: 1) to assist the community in building the necessary infrastructure to provide a sustainable system of Home and Community-Based Services (HCBS) for the elderly population; and 2) to pilot a model for developing a community-based process to create sustainable HCBS for Native Elders who live in rural reservation communities.

   The short-term goals are to ensure that the elderly people & families of will: a) have improved access to health and social services over time; b) be empowered with information related to the promotion of health, nutrition, long-term care options (HCBS), funding resources; c) be assisted to determine their eligibility for services which may help them to maintain functional abilities* and to remain in their own homes as they age (*Activities of Daily Living & Instrumental Activities of Daily Living – ADL’s & IADL’s); d) have improved access to safety equipment in the home; e) be supported in their needs for assistance with elder caregiver responsibilities, such as personal care, home maintenance, meals & respite services; and f) have special transportation needs met for very frail elders (such as those who are wheelchair bound). The project is quite timely, as there has been a growing concern about the need to address the concerns of the elderly and their family caregivers.

   Families and their elders are often faced with “patching together” resources, without benefit of knowing: a) *what* is available by way of Home & Community-Based Services (HCBS) in the community; b) *how* to access HCBS that are available; c) *who* to contact for health information, social services and in-home services related to their specific needs; d) *where* to learn more about access to potential resources. This project will empower elders & their family caregivers to find the answers to these questions.

Disparities in Rates of Chronic Illness

The Health Disparities in increased rates of chronic illnesses affecting Native elders is well-established. Most Tribes recognize “older” adults at the age of 55, related to lower life expectancy and higher and earlier rates of chronic diseases. As disabilities increase related to the increased prevalence of chronic diseases, accompanying limitations in ADLs and IADLs also increase the risk for institutionalization.
B. Demographic Changes

The older American Indian adult population has been projected to increase by 148 percent between 1990 and 2020\(^1\). This increase in longevity is a welcomed trend among American Indian populations, given the discrepancy in Native life expectancy (71.1 years) as compared to the general U.S. population (76.8 years)\(^4\).\(^5\) The disparity in life expectancy is even more pronounced within the Aberdeen Area of Indian Health Service, with Native people having a life expectancy of 64.3 years.\(^4\)

C. Need for Community-based Eldercare

Older Native people prefer to “age in place”,\(^2\) as their lives are very much embedded within their families and culture. The federally funded Indian Health Service (I.H.S.) is the major provider of health care services for American Indian people in rural reservation settings. However, the IHS is primarily structured to provide acute and episodic care in clinic and hospital-based facilities. Beyond follow-up provided by dedicated (but very “stretched”) public health nurses, IHS has no formal mechanism nor funding, to provide the effective delivery of *in-home, community-based long-term care* services for elderly people and their family caregivers.\(^1\).\(^6\) It is not feasible at this point in time to look to IHS as a provider of long-term care services, given that over the years, IHS has been chronically underfunded to the point of having significant difficulties in meeting current acute health care needs in American Indian communities for which they are responsible.\(^1\)

In terms of planning for future health care, within a context of progressive increases in care costs and numbers in the older population, “Informal caregiving is the backbone of the American long-term care system where the value of the services provided by informal caregivers is estimated to be $257 billion annually, two times the amount currently spent on homecare and nursing home care”.\(^7\) It is crucial at this time to proactively plan with families for long-term HCBS.

D. Overall Goal of the Proposed Project

Looking proactively towards future needs of an increasing cohort of older Native people, the plans to assist in building *community capacity*\(^8\) for a sustainable system of elder-focused HCBS for. The College proposes to formally partner with the Senior Services Program and the Elders Advisory Committee to provide the necessary leadership in our communities to address HCBS. Throughout the project, we will expand our collaboration to build a “resource web” of elders, families, community groups, local, county and state agencies (for example, IHS, Tribal Health program, Extension programs, and Human Services). This “web” of shareholders will work together to strategically plan a coordinated network of HCBS, to specifically meet the self-identified health, education and resource needs of elderly members & family caregivers.

E. Background of the Proposed Project
Native elders are challenged by chronic diseases & related complications at a high rate.\textsuperscript{1,9} Nationally, it is projected that the demographic profile of American Indian Tribes will reflect a large increase in their elderly populations and particularly to an emerging need for HCBS among Tribal nations.\textsuperscript{1,6} Further support for this proposal is rooted in 3 local sources of data, documenting the need for the tribe to proactively develop a system of HCBS for their elderly. Each of these 3 sources is presented below. The specific objectives & activities for this project have been directly derived from a review of each of these information sources, targeting areas which: a) intersect the needs identified within the 3 sources; b) are related to the priority areas identified by the USDA/CSREES RFA; & c) relate to the mission of each of the project partners.

   a. Guided by the NRCNAA, a survey of Elders was conducted using the “Survey of Elders II” instrument. Of the 374 people who were 55 years of age and older, a random sample of 208 people completed the survey. The data from this survey illuminated the overall health status of the older people, with the results providing a direction to address the following: a) self-reported prevalence of chronic diseases, b) health risk & health promoting behaviors, c) nutritional intake, d) sensory deficits, e) Activities of Daily Living (“ADLs”), f) Instrumental Activities of Daily Living (“IADLs”), g) medical provider access, and h) desired Home & Community-Based Services (HCBS).

2. Focus Groups: Elder’s Board members & Community-based Service providers.\textsuperscript{2}
   A group of elders came together to discuss what their experiences have been across a wide range of health care and social issues for themselves and other family members. They contributed significant insights about what they most need to be able to successfully “age in place”.
   This Focus Group was followed up by a group discussion with providers. Their information was particularly significant in terms of identifying existing services for older people within the Tribe, and in identifying the “gaps” in available services and resources. This project is primarily designed to “fill the gaps”. In addition, at separate times, we were able to elicit input from a former public health nurse and a contract health services worker in the IHS system about access issues & educational needs related to access to health care services.

3. Nominal Group Process: 30 faculty & staff members from the College (A workshop session utilizing the Nominal Group Technique was held with faculty and staff members. Based on the NGT session, four priority areas were identified that could be realistically addressed by the college within its mission as a Tribal college. These four priority areas identified by the group “overlapped” well with the information obtained from the Survey of Elders and from the two Focus Groups. Based on the input from these sources, six objectives were ultimately derived for the project (presented below in \textit{Section 3}).
Section 2: Statement of Need, Site Location, Potential Benefits

A. How will the project address issues and audience to be reached?

Need: As stated above, the IHS is the primary provider of Health services for American Indian Elders. However, IHS budgets are routinely funded below actual need, and IHS is not responsible for the provisions of long-term care services. The native elder population is projected to increase by 110% by the year 2020.\(^3\) Elder American Indian people have higher rates of potentially debilitating illnesses\(^1,11\), and this applies to the elderly population of. The community wants to proactively plan for the increase in the number of elders who may need HCBS, and to impact the potential level of disability through health promotion & education.

Site: The activities of the project will take place on-site in the communities. The project will be housed at the college, but actively coordinated with the two formal partners: the Elders Advisory Committee and our local Senior Meals Program.

Potential Benefits: Long-term goal: The tribe will build an infrastructure that will evolve into a sustainable system of HCBS for elders. Elders have expressed their preference to remain in their own homes, with needed services provided in the home setting. Short-term goals: The proposed project will help us to meet the following short-term goals, which are essential towards meeting the stated long-term goal: Elderly people & their family caregivers: a) will have improved access to available health & social services; b) will be empowered with information related to health promotion, nutrition, long-term care / HCBS options, & potential funding resources; c) will be assisted to determine their eligibility for services which may help them to better maintain functional abilities\(^*\) necessary to remain in their own homes as they age (\(^*\)ADLs & IADLs); d) will have improved access to safety assessments and needed safety equipment provided in their homes; e) will have access to needs for assistance with ongoing caregiving responsibilities, such as personal care, heavy home chores & maintenance, & respite services; f) will have improved access to specific transportation services for frail elders, such as for those who are wheel-chair bound or who are hemodialysis patients, or who have terminal illnesses.

B. Criteria used to select rural location/community

As referenced above in Section 1, multiple sources of relevant, local data have clearly indicated the needs of the elderly population. In keeping with our goals of creating sustainable partnerships and a “web of resources”, the initial steps towards “community mobilization” have already been taken, according to recommendations in the Native American MAP for Elder Services developed through the NRCNAAN.\(^11\) The Healthy People 2010 document states: “Over the years it has become clear that individual health is closely related to community health. Community health is profoundly affected by the collective beliefs, attitudes and behaviors of everyone who lives in the community.”
C. Targeted health issues to be addressed & importance to health of the older population

The identification of these health conditions corresponds closely with national prevalence rates reported among elders, although native elders do experience higher rates. Each of these conditions pose potential risks to health and can lead to loss of functional abilities in ADLs. The incidence of elders’ injuries due to falls, with associated morbidity, mortality, and disability has also been well-established. In turn, loss of functional abilities often requires additional care from family caregivers, and if family is not able to continue care, nursing home placement becomes an expensive (and often emotionally wrenching) necessity.

Importance to Health of the Older Population

The above list of chronic disease conditions can be framed as a “bad news – good news” story. The “bad news” is the high prevalence of the illnesses identified above, & their potential for causing disability & handicaps. There are currently 374 people who are 55 years of age and older. Based on demographic projections, the number of older people will more than double, by the year 2020. As chronic disease increases among older people, accompanying rates of disability are increased, and the need for in-home assistance with ADL’s & IADL’s increases, as well.

However, the “good news” is that the risk for most of these diseases is modifiable. Assisting older people to address these risk behaviors over time, potentially will decrease rates of chronic disease, and reduce disease-related disabilities. We believe that our elders people can be assisted to not only “age in place”, but to “age in place while maintaining the best possible health”. In addition, the Focus Group data from the Elders Board specifically identified the elders’ interest in learning health information, and knowing more about specific health conditions that they live with and need to manage at home.

D. How the Project will enhance health care and accessibility by elders

The primary “permanent product” of this project will be the building of a sustainable partnership with the Elders Advisory Committee and the Senior Meals Program. We also anticipate that we will be successful in developing a web of partners & shareholders who will maintain a focus on meeting the long-term care needs of elderly & family caregivers. We also know from our experience with other Tribes, CHR program, Senior Meals programs, and Tribal colleges that we may be successful in developing a prototype of elder-directed, community-based services to allow Native elders to “age in place”. The objectives & activities of the one-year project period will incorporate a multi-pronged approach to enhance the long-range development of HCBS:

First: Empowering elders and their families with knowledge of existing services & available HCBS & funding resources; Second: Providing assistance to make application for existing HCBS for which they are eligible; Third: Providing safety assessments in homes of elderly living on the reservation; Fourth: Creating an Elder Health Promotion & Caregiver Resource Center
(including an elder’s website) for the community; Fifth: Offering training for a cohort of 16 Certified Nursing Assistants (C.N.A.), so interested community and family members can be prepared with skills to provide a full range of HCBS for the elderly (as well as have an opportunity for employment); Sixth: Filling a clearly identified, ongoing transportation need for frail elders who cannot be safely transported by families because of their overall health condition.

**Section 3: Objectives - Specific Aims**

**Objectives**

Specific activities of the project (derived from our 3 sources of local data) will address the following objectives: CREATION of: 1) a formal partnership with our local elder’s group and Senior Meals program to facilitate ongoing strategic planning for needs of current and future generations of elderly & their caregivers; 2) an expanded web shareholders among local, county, & state entities; 3) a multi-faceted outreach strategy using “Community Navigators” (CN) to advocate and assist elders and family members to effectively: a) access available HCBS, b) learn of alternative funding resources for services, c) advocate for additional HCBS they identify as needed; d) learn the “map” of how resources are best accessed; and e) assess & modify elders’ homes for improved safety, especially in prevention of falls; 4) an “Elders Health Promotion & Caregiver Resource Center” to coordinate educational opportunities for community-identified priorities; 5) training opportunities for a cohort of community members to become Certified Nursing Assistants (C.N.A.) & Certified Quality Service Providers (Q.S.P.), who will be prepared to perform a range of caregiving tasks for local elders and families who have varying levels of need for assistance; 6) handicapped accessible transportation system.

**Section 4: Methods**

**Sustainability**

Meeting the above six objectives will create community capacity and a beginning infrastructure within which to plan for the provision of HCBS for elderly in the years to come. After the grant project period, it is expected that the college will be positioned to continue to: a) provide leadership for HCBS by actively working with our partners, and the “web of resources”; b) coordinate activities for the Elder Health Promotion & Caregiver Resource Center, with ongoing invitations to local, regional & state agencies to provide educational sessions to elders & families. (The ND Department of Human Services has already been approached, & has indicated an interest to provide a community education session on-site; c) assist the Senior Meals Program to search for additional and stable economic resources to continue at least one “Community Navigator” position through the Senior Meals Program and to maintain a handicapped accessible van; d) maintain network with other educational partners as a continuing resource for C.N.A. & Q.S.P. training for Tribal members.
Sequence of Activities

The project activities are directly related to the 6 objectives above, which will be addressed concurrently during the project. The tasks that will be required to carry out each major activity will be carried out by the Project Coordinator and the 4 Community Navigators. *(Please study the attached Grid at the end of the narrative for a coordinated listing of objectives, activities and outcomes)*

Techniques to be employed

The activities of the one year time period will be primarily directed to the building of infrastructure which will sustain the goal of providing elder-focused HCBS. Sustainability of the project will be critically linked to the #1 task, that is, the building of strong relationships among community and professional shareholders who live in and serve the community. The project will need to focus on developing a mechanism to maintain a strong advisory group who will commit to the goals of building HCBS for the older population for the future. Therefore, the “techniques” for this aspect of the project will primarily be “people intensive”, in terms of active outreach and recruitment of shareholders who will commit to the ongoing work of the advisory group. Given that the Community College is an established entity and that its mission relates to providing empowerment through education for the people, the college is well-positioned to provide significant assistance in implementing the activities of the USDA-CSREES project.

Kinds of results expected

Some of the results of this project will be “tangible”, for example, the educational programs, the improved safety equipment in homes of elderly, the handicapped accessible van for transportation for frail elders, the additional numbers of people who will be using QSP services in the home, and the creation of an “elder-friendly” informational website. However, “intangible” results will be as important to the ongoing success of the project. Expected “intangible” results will include the strengthened network of community shareholders, dedicated to the common purpose of enhancing HCBS and meeting the needs of elders and their families. Another intangible, but valuable result will be the creation of employment opportunities for people who receive the C.N.A. & Q.S.P. training. The unemployment rate for reservations is a serious problem. Native people do prefer to have family members care for them, people who understand & honor their cultural & spiritual needs. While meeting the elders’ need for holistic, respectful care, the creation of additional employment on the reservation will also meet our community’s need for job creation.

From a strictly “policy” perspective, an investment now in promoting health, education & safety, minimizing disability, & providing improved access to HCBS to support family caregivers, far outweighs the burden of funding institutional long-term care in the future. However, perhaps more importantly, in terms of “social and emotional” costs, our elders will not have to “pay
dearly”, by having to prematurely leave their homes & communities to seek long-term care in nursing homes, far away from their families and cultural ties.

The importance for implementing this project arises from the information that the tribe has already gathered and analyzed. While health and disability issues should be realistically anticipated in this population, health promotion and education resources can proactively diminish the level of disability. In addition, access to HCBS resources can allow “aging in place” and support for family caregivers. As stated by a young adult Indian leader: “Our goal as the next generation is to pay back our elders for their contributions to our families, societies, and communities by doing our best to increase or maintain their quality of life by providing them autonomy in how they wish to live.”

Data and Analysis

The data collected and reported for this project will be primarily of a descriptive nature, using narrative, lists, frequencies, tables, bar-graphs, pie-charts. The “process outcome measures” will be used to guide the documentation of ongoing progress towards the completion of each step entailed in project activities. The “final outcome measures” will describe how well each of the major objectives has been met. Data for this project will be organized and stored in separate files, according to each objective. Examples of data which will be collected related to each objective are presented below:

**Objective #1: Partnerships**: a) the process of actively meeting, planning, working in partnership with the Elders Advisory Committee and with the staff of the Senior Meals program; number of people on the Advisory Committee who have agreed to meet regularly on the project; b) Project group meeting minutes monthly; c) ongoing tracking and follow-up of recommendations from this group;

**Objective #2: Web of Resources**: a) the number of “shareholders” who are actively participating in the project activities as service resource people and educational resources people. Number of meetings that they will attend when invited by the project partners, and minutes of these meetings.

**Objective #3: Community Navigators (CN’s)**: a) the number of people who have been contacted by the community navigators outreach program regarding existing HCBS; b) portfolio of outreach materials used for “marketing” the project activities and objectives; c) number of people who have made application for existing HCBS through CN outreach activities; d) number of people who successfully access resources through outreach; e) number of people who have had a safety assessment, and additional safety equipment provided in their homes.

**Objective #4: Elder Health Promotion & Caregiver Resource Center**: a) copies of the course and topic outlines of health promotion and caregiver education classes; b) number of people who attend education sessions; c) evaluations from people who attend and evaluate the education
sessions; d) listing of recommendations from older people and caregivers for continuing education topics of interest to them; e) portfolio of materials used to market the Elder Health Promotion and Caregiver Resource Center to community elders and families; f) meetings (and minutes) with educational resource people, for planning the identified educational offerings through the “Elders Health Promotion & Caregiver Resource Center”; g) Elders Website “hits”.

**Objective #5: C.N.A. Training:** a) process outcomes of determining location and setting up of the classroom and clinical lab skills space for C.N.A. & Q.S.P. training; b) results of recruitment efforts for the C.N.A. program, i.e., number of enrollees; c) number of students who successfully complete the C.N.A. curriculum; d) number who pass the ND State C.N.A. Certification exam; e) number who become certified through the County Q.S.P. program; and f) number who become employed in the care of elderly people as C.N.A.s or Q.S.P.s.

**Objective #6: Handicapped Accessible Van for safe transportation of frail elders:** a) number of people who have been assessed as in need of handicapped accessible transportation; b) agreement with other shareholders who assist elderly in how best to use the new handicapped accessible van; c) the number of people who actually do make use of the van for safe transportation, for example, to medical appointments; d) process evaluation of progress towards the community plan for maintenance of the van and driver services after the grant period.

**Pitfalls that may be encountered**

The “real world” of community health projects can be fraught with unexpected detours and community dynamics! Although these are sometimes unavoidable, the best prevention is strong engagement by community leaders. In American Indian communities, elders are respected for their wisdom and looked to for guidance. Therefore, the first essential task of the project will be to form a strong advisory group through the Elders Advisory Committee. The ongoing consultation with inclusion of dedicated local & regional shareholders (particularly tribal leaders, elders and family caregivers from each of the 4 reservation districts), will be a priority.

**Limitations to proposed procedures**

Limitations which may arise during the course of the project may include: unsuccessful recruitment for the educational offerings for health promotion/caregiver support, “trust” issues & concerns among elders about applying for government services, such as Medicaid; a longer amount of time than expected to engage the advisory group and/or to develop the cohesion of the advisory group, delaying its efficacy. We are aware of these potential barriers, and will work to limit them.
Section 5: Evaluation Design & Methodologies

Focus of evaluation as to audience

The evaluation from this project will be used as a tool to guide continuation of the project activities into the future. The outcomes throughout the project period will be studied by the project staff, the Senior Meals/Services staff and the Elders’ Committee for information that can guide the creation of progressive goals and implementation plans for elder-focused HCBS at.

The full impact of this project will be seen in “incremental” changes and adaptations in future years. We do expect an improvement in the way eldercare is provided, with the identification of the enhanced “web of resources” that can be identified and accessed easily by elders and families. In this project, we realistically do not expect to make radical changes in elders’ issues with access to medical/clinic/hospital care, related to the I.H.S. and/or Medicare reimbursement. However, we do realistically anticipate that through tapping into the existing resources of the ND State Medicaid program, the project will lay the groundwork to make an impact on maintaining self-care abilities, ADLs, IADLs, as well as changes in health behaviors, such as smoking, nutrition and exercise. As the project continues to connect “synergistically” with existing resources and programs in the community (such as the Senior Meals program, Public Health Nursing, Special Diabetes Project, Extension Services, USDA Garden program, Community Health Representative Program, and County “QSP” program) it is expected that over time, the health status of our elders will improve. This expectation seems quite feasible, given that elders and their families will have increased access to health promotion information and assistance from a broader network of health, nutrition, & social service resource professionals.

Identification and review of previous evaluations, literature, needs assessment and other information relevant to the evaluation

The National Resource Center for Native American Aging (NRCNAA) has worked with Tribes throughout the U.S. to determine needs of the elderly Native population. We will be tracking our programming over time, & will be able to make comparisons with national aggregated data for other Tribes. By using the data from the 2006 Survey of Elders as our own “baseline” for comparison, we also have the ability to track changes in elders’ self-reported health status, health risk behaviors, and ADL’s and IADL’s. In this way, we can further evaluate the impact of the programming for elders that we expect will evolve through this project. If the activities of the project prove successful, we will be happy to share our experiences, and resulting model of eldercare nationally with other Tribal Nations. It is accurate to say that most rural Tribes also have to face the challenges of providing services for an increasing population of elders in their communities.

Methodological framework
As mentioned above in the *Data & Analysis* section, the data for this project will be primarily descriptive in nature. Numbers of participants in any portion of the project will be recorded, advisory group meeting minutes will be reviewed and filed, evaluation comments from participants in educational sessions will be collated and reviewed, and certification status of C.N.A. & Q.S.P. trainees will be recorded. In addition, a focus group with community members (who are not advisory group members) will be scheduled annually to determine if the outreach & educational programs are becoming integrated into daily community life for elderly people and their caregivers.

*Data Collection instruments*

Program-specific forms will be created and designed to capture information related to the project. For example, sign-in sheets for education sessions provided through the Elder Health Promotion & Caregiver Resource Center; outreach program forms to document contacts with community members interested in Medicaid/HCBS information; Web-site “contact us” page; etc. As activities are planned & implemented, the Project Coordinator & Project Consultant will develop & adapt appropriate data forms to collect all pertinent information related to the activities of the grant.

*Sampling*

The community will be blanketed with information about the project and its activities, using flyers, Tribal radio, and local newspaper, presentations to all service agencies, such as I.H.S., Tribal Health programs, County Extension Services, County Social Services, and other community groups. The Community Navigators (CN’s) will actively inform & recruit people in each of the four reservation districts to take advantage of the project activities. Those who respond to the invitation to participate in the activities of the project will comprise a “self-selected convenience” sample. Existing CMS & state-specific eligibility informational materials will be utilized as outreach tools. A number of these have already been obtained through CMS and the ND Department of Human Services.

*Analytical procedures to be used*

As stated above under “*Data & Analysis*”, the nature of the project will primarily require narrative description and descriptive statistics to report the outcomes of the project. Our 3 recent data sources will be used as a baseline to compare, guide & interpret the progress towards meeting the objectives.

*Identification of opportunities for ongoing program sustainability or improvement*

The long-term goal of this project is to develop an effective and responsive system of HCBS for older American Indian people. As stated above under *Sustainability*, meeting the six objectives of the project will create an infrastructure for the ongoing provision of HCBS for elderly in the
years to come. After the one-year grant project period, it is expected that the college will continue to partner with the Elders Committee and the Senior Meals Program to: a) continue progress on the development & delivery of elder-HCBS through the “web of resources” throughout the local & regional community; b) assist community members to learn to access local & regional resources for elders, c) coordinate the Elder Health Promotion & Caregiver Resource Center; d) offer a gateway to C.N.A. training and local employment opportunities, and to encourage Tribal members who may wish to pursue a healthcare career in the future; e) increase our focus on safely transporting frail elders and in improving their safety in the home setting, and f) disseminate our approach to other Tribal Nations who are also looking for culturally honoring ways to take care of their elderly people in the years to come.

Section 6: Communication Plan

We propose to form a “dissemination team” with our partners & shareholders to make presentations and consultations to other Tribal Senior Services programs throughout the state. We have included funds in our budget to do this, and will work with the President of the Aberdeen Area CHR Program to formulate a plan to offer meetings with Tribal elder groups throughout the region.

We also will work with our Extension Program, as well as the county & state Extension agents’ network to jointly offer presentations to County Extension Program staff and rural elders. We also plan to provide a summary (with a PowerPoint presentation) of the project to the National Resource Center on Native American Aging at the University of ND, which they may upload to their national website. In addition, we will make this summary / PowerPoint presentation related to the success of our project available to: ND Aging Services, ND Department of Health, and the ND Department of Human Services. The consultant on our project is a member of the Olmstead subcommittee on ND Direct Service Workforce (headed by the Department of Aging Services), and is a member of the ND Health Disparities Committee. She will have the opportunity to make a presentation on the progress and outcomes of the project throughout the grant period. The people on these committees will also serve as part of the “resource web” to our project, as they represent a full array of services and programs throughout the state of ND.
DRAFT example of a grant narrative focused on elder needs

Elder-Care Project Grid: Objectives, Activities, Process Evaluation, Time-frame, Outcome Evaluation

<table>
<thead>
<tr>
<th>Objective</th>
<th>Activities</th>
<th>Process Evaluation</th>
<th>Time-frame</th>
<th>Outcome Evaluation</th>
</tr>
</thead>
</table>
| #1: Community Advisory Group will be in place to facilitate ongoing strategic planning for elderly population needs | -PARTNER with Elders Advisory Committee, & Senior Services  
- Set up schedule of monthly meetings with Elders’ Board as Elders Advisory Committee. Elders who are (or have been) family caregivers will be represented. Project progress will be reviewed monthly.  
- Meet with Program Representatives: staff, County staff, Extension to ask for assistance with sharing of resources on the project  
- Meet with County CMS staff to plan collaboration effort | - Elders Advisory Committee will advise the project on a monthly basis, minutes of meetings will reflect their input & follow-through by project staff  
- Senior Meals Program staff will agree to serve as project partners  
- A Tribal Council member will agree to serve as advisor to this project | First meeting of Advisory Group will take place within one month after notice of award  
Monthly meetings thereafter; location to be announced after consultation with the initial meeting with the Elders Advisory Committee | - By the end of the grant year:  
* Elders Committee will have had monthly meetings & a record of meeting minutes will be collated  
- There will be a commitment to sustaining the Elders Advisory Committee as an integral part of providing HCBS for elders  
- There will be a mechanism to rotate Elder Committee advisors on a biennial basis  
- Other shareholders will agree to continue to serve as resources to the project  
- Elders Committee will have developed Year 2 goals & objectives to continue the project goals |
| #2: Expand a “web” of shareholders with local, county, and state entities | - Develop Project Coordinator & Community Navigator position descriptions  
- Advertise for Project Director & Navigator positions according to policy  
- Train community Navigators for their job responsibilities | - Position descriptions (PDs) will be developed for the Project Director Navigators according to policy  
- Navigators will be hired  
- Navigators will be trained & fluent in “active listening”  
- CN’s will begin working in the community | - PD’s developed by the end of the first quarter of the grant period  
- By the beginning of the second quarter of the grant, the hiring of CNs will be done  
- By the end of the second quarter of the grant period the CNs will be trained  
- By the beginning of the third quarter (about 6 months into the project) the CNs will be “on the job” | - By the end of the grant period;  
* Will have a plan to continue ongoing partnership with Elders Committee & Senior Meals Program  
* Community Navigators (CN’s) will be successfully trained & informed  
* CNs will have assisted at least 35 elderly & families throughout the four reservation Districts |

#3: Outreach strategy using “Community Navigators” (CN’s) will be developed & implemented to empower elders & their family caregivers to successfully access HCBS & funding sources. Project overseen by qualified Project Coordinator.
#4: A plan for Elders’ Health Promotion & Caregiver Resource Center will be developed & implemented to offer educational opportunities

- Work with Elder Committee to identify educational interests & needs for information & services
- Develop presentations on variety of Health Promotion & Caregiving topics
- Set up schedule for regular Health Promotion sessions
- Request help from Extension Services to locate & invite presenters for the Health Promotion & Resource Center on topics of interest to elders & families, particularly nutrition
- Request help from other local & regional presenters, eg. I.H.S., ND State Aging Services, SDPI, Tribal Health
- **Develop website for elderly & families to access pertinent information**
- Discussion of educational topics with Advisory Group completed
- At least 6 presentations prepared for the project period
- At least bi-monthly schedule set up for Health Promotion/Caregiver seminars
- Website developed of links to requested information and information potentially of interest to elderly & their families
- Advertising of locations of “elder-friendly” computers in 4 accessible locations
- At first Advisory Group meeting, by the end of first quarter of grant period
- By end of second quarter of grant period, 4 presentations will be prepared
- By end of second quarter of grant period, the educational sessions will be scheduled
- By end of third quarter of grant period, website will be “up and running”
- By end of third quarter of project period, advertising for the “elder-friendly” computer locations will be done

#5: Cohort of C.N.A. students will complete certification

- Recruit 10 community members who are interested in C.N.A. training
- Meet with County Social Services to determine current & potential need for Quality Service Providers (QSP) for HCBS
- 10 students will begin classes
- Estimate of number of elderly & families who could qualify & utilize QSP services currently
- Estimate of number who may qualify in the future
- All activities done by end of second quarter of grant period

#6: Special “safety-focused” transportation plan for Frail Elderly people will be in place & operating daily

- Purchase of handicapped accessible van
- Hiring & special training of van driver
- Van will be “converted” & purchased
- Van driver will be hired & trained
- Van purchased within 6 months of project beginning
- Van driver trained & ready to work within 6 months

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#4: **Discussion of educational topics with Advisory Group completed**

- At least 6 presentations prepared for the project period
- At least bi-monthly schedule set up for Health Promotion/Caregiver seminars
- Website developed of links to requested information and information potentially of interest to elderly & their families
- Advertising of locations of “elder-friendly” computers in 4 accessible locations
- At first Advisory Group meeting, by the end of first quarter of grant period

#5: **10 students will begin classes**

- Estimate of number of elderly & families who could qualify & utilize QSP services currently
- Estimate of number who may qualify in the future

#6: **Van purchased within 6 months of project beginning**

- Van driver trained & ready to work within 6 months