NATIVE ELDER CAREGIVER CURRICULUM
2ND EDITION

Caring for Our Elders

A training resource for families and caregivers serving rural American Indian Elders

National Resource Center on Native American Aging, Center for Rural Health, University of North Dakota
National Resource Center on Native American Aging

THE NATIVE ELDER CAREGIVER CURRICULUM

The NECC

2nd Edition 2015

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Left to Right: Melissa Wheeler; Dr. Paula Carter (Director of the NRCNAA); Ann Miller; Patty Stensland

Left to Right: Dr. Leigh Jeanotte; Darlene Nelson; Colleen Burke; Dr. Chris Burd
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With Thanks and Acknowledgement to the Original NECC Curriculum Team (2009)

Dr. 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


Dr. Paula Carter  Director, NRCNAA
Dr. Chris Burd  Tribal CHR Trainer / Tribal Community Health Consultant
Ann Miller  Administrative Assistant, NRCNAA
Dr. Jacque Gray  Director, National Indigenous Elder Justice Initiative, NRCNAA
Spirit Lake Elders  Spirit Lake Elders Advisory Group
Darlene Nelson  UND American Indian Student Support Center
Colleen Burke  UND American Indian Student Support Center
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**PREFACE to the 2nd EDITION OF THE NECC**

The Native Elder Caregiver Curriculum (NECC) has been found useful in helping people in Tribal communities to become better prepared to care for their elders. With the guidance of Native elders of the Spirit Lake Nation, the curriculum was originally designed to meet identified learning needs of family caregivers, as well as Tribal community-based caregivers. For example, in rural American Indian communities, Community Health Representatives (CHRs) historically have focused much of their efforts towards meeting the needs of elders. The NECC is currently being used as part of specialized training for CHRs to provide Targeted Case Management services for elders under a Medicaid State Plan Amendment in North Dakota. The NECC has also been used as a supplement for the training of local caregivers who provide Home & Community-Based Services (HCBS) under Medicaid Waiver and State programs for elders wishing to “age in place”.

We have found the NECC to be versatile in its reach and flexible in its delivery. The NECC can be offered by local health professionals, especially nurses, who have had experience with providing direct care for older adults. It can be adapted to the specific learning needs of caregivers and can be used flexibly to meet training schedules for any given caregiver group. For example, the complete NECC may be offered in an “immersion” type of class, requiring 5 full days to cover all of the modules in-depth, including return “teach-back” demonstrations of skills by trainees. The curriculum may also be offered through a classroom format, through weekly classes over the course of a traditional semester. At the Standing Rock Sioux Tribe, the full NECC has been approved for college credits by the Sitting Bull Tribal College, as a required course within its new Community Health Worker (CHW) Associate Degree plan. With respect to flexibility, it is also possible to use the NECC to provide training on specifically selected modules in an abbreviated “workshop” format.

In keeping with the approach to the 1st Edition of the NECC, we have continued to gather information from Tribal Elders and CHRs related to community care-giving
for elders and their HCBS needs. Based on these conversations, the 2nd edition of the NECC has been expanded to address additional topics and realities that shape the delivery of community-based care for rural Native elders. Our goal continues to be the development of a quality training resource that is responsive to the needs of the elders and their caregivers in rural Tribal communities.

Chris Burd
OVERVIEW

NATIVE ELDERS CAREGIVER CURRICULUM (NECC)
CARING FOR OUR ELDERS

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 in rural Tribal communities as being useful in the provision of community-based elder-care. The development of the NECC curriculum is timely as a response to the steady and significant growth expected in the population of Native elders during the next few decades. The Administration for Community Living reported that in 2007 there were 212,605 American Indian/Native Alaskan elders aged 65 and older. By the year 2050, it is estimated that the population of Native elders over 65 years of age will reach nearly one million in the U.S.¹

Evolving health and social needs among American Indian elders across the United States have been tracked through nation-wide surveys by the National Resource Center on Native American Aging (NRCNAA) on an ongoing basis since 1994.² Based on the projected increase in the elder population of American Indians, it is clear that there will also be an increased need for community-based options to meet these needs. Fortunately, a number of options are newly emerging for promoting community-based care for elders in Tribal communities.

Elders prefer to remain in their own homes within their own communities, that is, they prefer to “age in place”. The Indian Health Care Improvement Reauthorization and Extension Act of 2009 authorized Indian Health Service (IHS) to focus on the provision of Long Term Services & Supports (LTSS). New funding was not specifically provided in the IHS budget to deliver long-term care services³, however, a collaborative effort is currently underway among Tribes and federal health agencies to plan LTSS for Tribal Nations. Now is a good time for each Tribe to explore potential funding mechanisms for the community care of their elders and to develop the necessary “LTSS workforce” who will be needed as caregivers.
Traditional Values as Strengths

In addition to the context of projected demographic changes, the curriculum development has been guided by an awareness of the modern context of rural Tribal 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 NECC 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 traditional American Indian values, such as respect, compassion, generosity, praying, honesty, wisdom, humility\(^5\)
- Holistic perspective of health and wellness
- Increasing trends in chronic disease incidence and 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 developing healthy communities, merging traditional strengths with scientific knowledge of health promotion and disability prevention
- Shared Community concern for the success of future generations
- Living in balance with challenges while planning for future generations
Importance of Networks for Successful Caregiving

In order to effectively plan and implement community-based LTSS programs, health and social service networks need to be strengthened in each American Indian/Alaskan Native community. Programming will need to be developed that recognizes & respects the unique character of each Tribe and regional setting. Recommendations for building and strengthening networks (at local, regional, state and national levels) are included as an integral part of the curriculum.

A special recognition of Community Health Representatives (CHRs) and their dedicated role in the ongoing care of Native elders in so many rural American Indian communities is one of those recommendations. And of course, there is also a need for special recognition of those family members and friends whose assistance remains vital to Native elders everywhere. It follows that there are a number of recommendations in the second edition of the Native Elder Caregiver Curriculum that address the contributions of these caregivers, their stressors, and the essential need to support them. The availability of support and resources for CHRs, Tribal community health workers (CHWs), and family caregivers will be a critical variable in the success of future home & community-based services for elders in Indian Country.
The model in Figure 1 below outlines the type of resource network that has the potential to facilitate successful community-based caregiving for Native elders.

**FIGURE I: Model of Network for Delivery of Elder Care and Community-Based Long-Term Services & Supports (LTSS) in American Indian Communities**

**Dedication of the NECC to Caregivers**

The NECC curriculum has been constructed with caregivers in mind. It is essential to respect their needs, as they live out values of respect, generosity, compassion, and fortitude in honoring their elders. As they journey through life’s seasons of aging and caregiving, it is hoped the NECC will support caregivers with information they need to continue the sacred work of caring for all their relatives. The NECC curriculum is dedicated to them.
SESSION 1.1
Normal Age-Related Changes
SESSION 1.1  NORMAL AGE-RELATED CHANGES

PURPOSE

• Learn about common biologic changes often seen as 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
  o Holistic view of health
  o Cultural viewpoints about elders in Tribal communities
  o Recognizing influence of “Ageism”
“Some 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 elders and their wisdom.

“To everything there is a season” and traditionally, Native people viewed life as a circle of seasons. 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 a most important one along life’s circle. According to Native cultural traditions, 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, 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{11,12,13}

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, 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 biologic 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{14} Figure 2 below combines the biologic and traditional view.

\textbf{Figure 2. Combined Biologic and Traditional Perspective of the dimensions of life for a human being (Burd, 2009)}
A Couple of “Theories” about the Aging Process

There are many theories about the process of aging, but currently two main categories of “modern” theories are used to explain aging:

- 1) “Programmed” Theory
- 2) “Damage” Theory

The “programmed” theory proposes that aging is a result of pre-programmed biologic changes that happen to a human being over a lifetime. These changes are expected and happen on a “schedule” pre-determined by our genes.

The “damage” (or “error”) category of aging theories proposes that aging happens over time as “environmental assaults” are made on the living person. That is, our cells go through a lot of “wear and tear” over the course of a lifetime. Eventually damage accumulates throughout the cells, tissues, organs, and systems of the body at every level. As damage accumulates, at every level, the body just gets “worn out”. It may be helpful to remember that the body is made up of individual cells, and whatever 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.

In reality, 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 Related to Aging

As ordinary human beings 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 become older. A few expected changes related to the aging process in body systems are briefly reviewed below.

Physical Changes in the Body Systems with Aging

- **Nervous System**: Because of a decrease in the number of nerve cells, we may see a slower response time in older people. This may relate to some increased safety concerns, for example, in terms of tasks such as driving.

- **Sleep Patterns**: Older people seem to sleep less in shorter 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)**:
  - Lungs become less “elastic”
  - Chest wall “stiffens”
  - More resistance to air flow
  - Lower oxygen level in the bloodstream.

- **Kidneys**: *Decrease in:*
  - 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
  - Ability to eliminate medications from the body
  - Ability to maintain fluid & electrolyte balance
  - Ability to recognize being thirsty
(*It should be noted that the kidneys still work, but just less efficiently)

- **Bladder:**
  - Increased frequency of urination (“going often”)
  - Increased urgency (“have to go”)
  - Increased 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” medically to see if it can be corrected

- **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:
  - 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!
  - Increased time needed for the *stomach* to empty and for digestion
  - Decreased motility in the *intestines*. The slower movement of the intestines easily leads to *constipation*. In addition, sometimes an elderly person takes 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 high blood pressure issues should not be “straining” on the toilet.
    - The good news is, elders can often prevent constipation by eating more fiber & continuing to be physically active daily
Decreased blood flow to the liver
  - Leads to a decreased ability to get rid of the “byproducts” of medications in the body.

Decreased liver and kidney function are very important considerations in the types of medications and the dosages of medications that are prescribed by the doctor.

Increased gall stones collect in the gallbladder

- **Muscle System:**
  - Decrease in Muscle “bulk”
  - Decrease in Muscle strength
  - Decrease in Lean body mass
  - But, there is good news!
  - Muscle tissue can “regenerate” even into older age!
  - Strength training can prevent muscle loss!
  - “Use it or Lose it!”

- **Bones:**
  - Loss of bone tissue (osteoporosis)
  - Decreased strength of bones
  - Decreased minerals deposited in our bones
  - Increased brittleness of the bones
    - Women are at risk of losing more bone tissue than men
    - Possible loss of height due to curving & changes in the spine

- **Joints:**
  - 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.
  - Knee joints are very often affected in older people
    - Knee problems 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 keep our body temperature steady at all times

- **Changes in the skin:**
  - Becomes more dry, thinner, wrinkled, & less elastic
  - More sensitive to ultraviolet radiation (sunlight)
  - **Decrease** in the blood vessels to the skin layers
  - **Increased** risks for skin infections and irritations
  - **Slower** wound-healing ability
  - **Decreased** sense of touch and pressure
  - **Decreased** ability to respond to heat and cold, resulting in less ability to regulate body temperature

- **Immune System:**
  - **Decreased** immune response which slows down the healing of cuts, scratches, surgical wounds, etc.
  - **Decreased** activity of the “T” cells and change in the function of the “B” cells in the immune system is related to:
    - More difficulty for elderly people to fight off infections
    - Increased risk for bacterial infections especially of the lungs, urinary tract, and the skin
    - Increased risk to develop autoimmune diseases such as Rheumatoid Arthritis*
      (*Elders are also at increased risk for osteo-arthritis, however this type of arthritis is more related to “wear and tear” on the bones and joints, not to the aging of the immune system)

- **Stress Response in Elders:**
  - Can have more difficulty coping with stress
    - Sometimes becomes more difficult to “stay in balance”
    - Our usual “built-in” automatic responses for adaptation to stress are weakened.
    - But there is Good News: there are ways to strengthen the ability to cope with stress through a range of
“non-automatic” practices that we can implement
  o We will talk about coping with stress more in Session 3 related to Health Promotion

- Reproductive System:
  o **Women** go through menopause
  o “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.
  o **Men** have decreased reproductive function
    ▪ Increased urinary problems due to prostate gland enlargement (benign prostatic hypertrophy or *BPH*)
    ▪ Decreased sperm motility, increased number of defective sperm, decreased testosterone levels, increased time for erection

  o **Blood System:**
    o **Increased** risk for anemia
    o **Decreased** function of lymphocytes (white blood cells) which is also related to 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 complaints that elderly people talk about. Even if some changes are considered “ordinary for elders”, they are very difficult to live with and can interfere with daily functioning. There are a wide range of effective interventions to help elders successfully adapt to many ordinary problems. For example, a discussion with a health care provider to resolve constipation symptoms (or joint stiffness or chronic pain) *can lead to a solution* that will improve quality of life and the ability to function on a daily basis. 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 often come with aging.
A “Word of Encouragement”

Normal physical changes are going to happen over time as we grow older. But many of them can be delayed. For example, with healthy nutrition and regular exercise a person can help to maintain nearly all of their body systems in a better condition. While aging is a normal process, disability is not “normal”. Many disabling complications of long-term disease can be prevented through the regular practice of health promotion strategies. Ongoing scientific research is very encouraging. Studies continue to show us many long-term beneficial effects from healthy nutrition, regular exercise, stress management, and family connections.

An Encouraging Example of Successful Aging

An example of an elder who successfully practices health promotion in a “holistic” way is Mr. Vernon Lambert, a Dakota elder who is in his late 70’s. Mr. Lambert continues to enjoy running and playing basketball on a regular basis! 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. Vern Lambert represents the best of what it means to be an “elder”. He also is a model of “healthy aging” and offers “proof” of the power of health promotion, including his dedication to spiritual and cultural traditions throughout a lifetime.

Summary Session 1.1

We all have the ability to balance aging changes in our “biology” by strengthening the social, spiritual, and emotional dimensions of our being. As we journey through the seasons of our lives, it is good to remember that we are “whole” people, more than the sum of our parts and not just our “biology”.
SESSION 1.2
Sensory Changes While Growing Older
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:

- 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 by trainees
“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, that is, in their vision, hearing, taste, smell, and touch. Some of those “not so good” changes will require extra attention to adapt 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 many effective strategies to help the elderly to adapt to their sensory 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 “causes” are affecting an elder’s senses. Again, there may be a reversible cause that can be helped medically, so it is worthwhile to have sensory changes evaluated.

Vision Changes

The eye changes as part of the aging process itself. The cornea becomes less sensitive and injuries might not be noticed. The lens of the eye can become cloudy, less flexible and yellowed, limiting a person’s vision. The pupils of the eye slow down in their reactions to light and dark, so it takes more time to accurately see and then to 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 is much slower in automatically adjusting for distance. So older people often are seen trying to read
a magazine or book holding it farther away at arms’ length! Glare also becomes a problem also since the eyes cannot “accommodate” quickly to changes in lighting.

Bright light is hard to adapt to quickly, but darkness is difficult to adjust to, also. A decrease in dark adaptation (getting “used to the dark”) is quite common. Older people may not be able to adapt to seeing in the dark very well, and they require much more light than when they were younger in order to see more clearly. The combination of having difficulty in adapting to glare, in addition to problems with dark adaptation can make it especially dangerous for older people to drive at night. In fact, even the ability to see safely when getting up at night to walk to the bathroom is decreased. It is easier for older eyes to see yellow, red, and orange colors. So, using a night-light with a red light bulb works better in a dark room than using a white light bulb.

Other changes in the older eye include diminished peripheral vision, which also influences the ability to drive, and can interfere with socializing in a group. There may also be more “floaters” from the shrinking of the gel-like substance inside the eye. If “floaters” appear suddenly, or increase suddenly, it is necessary to be evaluated by a health professional right away. The aging eye also does not produce enough tears, so eyes can become dry. “Dry eyes” need to be treated to keep the eyes moist. This will prevent inflammation, infection, and scarring of the cornea.

**Disease–Related Changes in Vision**

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

- Hypertensive Retinopathy
- Diabetic Retinopathy
- Macular degeneration
- Glaucoma
- Changes resulting from stroke
- Infections

It’s very important for elders to have regular eye exams. A sudden changes in vision need to be “checked-out” at the clinic. Eye check-ups are not “optional”, but are part of routine elder care!

Hearing

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”.

Over a lifetime, hearing can be affected by aging, but also by exposure to noise, damage to the auditory nerve, infections, changes to the blood supply to the ear, injuries, tumors, certain medications, and accumulation of ear wax.

With aging, the structures of the inner ear change creating two important challenges: 1) hearing loss and 2) loss of balance. As hearing decreases, it just becomes more difficult to pick up sounds clearly. In addition, the inner ear is very important in the control of our balance, so the aging process can also diminish an older person’s sense of balance. These changes are not reversible, since they are related to loss/damage of nerve cells in the inner ear, decreasing transmission of nerve impulses.

However, a hearing problem that results from an accumulation of ear wax in the ear canal is reversible. Often when earwax is identified and removed at the clinic, a person can hear better again. Hearing loss is stressful to the person who can no longer hear normally. The loss of hearing makes it progressively harder for elders to make sense of the world around them. Conversations with
others often diminish due to hearing limitations, and hearing loss will often lead a person to withdraw from socializing with family and friends. 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, and felt that hearing loss can affect daily care. Hearing loss is not only a common problem, but can also become a stressful one.

The “good news” is that hearing loss can often be helped by having an evaluation, and being fitted with a hearing aid. Ninety percent of people who decide to use a hearing aid do benefit in many ways! Many not only have improved hearing, but improved mental health and social life.

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 health, interfering with nutrition (smell is part of taste), or if a person is unable to smell smoke or a toxic substance like gas. Smoke/gas detectors are essential “equipment” in the homes of elderly people. The sense of taste does not decrease as much as the sense of smell, but a common change is a decrease in the number of “taste buds” and in the amount of saliva. An older person may want stronger flavors added to their food in order to taste it and enjoy it. These are good points to consider, especially 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. The changes may be due to less blood flow to the nerve endings or to aging changes in the spinal cord/brain. Brain problems, nerve damage or chronic disease (such as diabetes) can make people’s hands and feet
very sensitive, or can make them lose feeling. An older person may also have less sensitivity to pressure, making them at risk for “pressure ulcers” (“bedsores”) if they spend a lot of time in one position, such as in a chair or bed. The loss of sensation also can place older people at risk who cannot determine safe water temperature for bathing or they may not realize when they have an injury because they do not feel it, or they may not know how to dress for protection in extreme weather.

**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 to avoid tripping and falling. *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. The risk of falling is increased with these types of changes. Because of the serious effects of falls on elders, prevention of falls will be discussed further in Session 3.

**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 since ongoing 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 problems 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 who has pain, assisting the elder in getting help from a health care provider. It is important to insist that pain in an elder be assessed on an individual basis.

Summary for Session 1.2

Many sensory changes are “common” as a person grows older. However, it is still important to address these changes, especially since they can impact everyday life. Evaluation by a medical provider may be able to find a reason for a sensory change that can be corrected. For example, chronic pain can (and should be) treated, accommodations can be made through medical procedures or by “equipment” as simple as: eyeglasses, hearing aids, smoke/gas detectors or pressure-relieving cushions. Caregivers can season foods to compensate for loss of taste, helping to prevent nutrition deficits.

In summary, although we can expect some changes as “part and parcel of the aging package”, elders and caregivers can work together with health care providers to maximize daily function and comfort for elders.
SESSION 1.3
Adaptation & Communication
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 for elderly people who have sensory changes
1. Identify common challenges to safety for older adults
2. 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 the safety checklist from the W.E.L.L.-Balanced curriculum²²
“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 in the home. Falls are a frequent source of injury, hospitalization, and loss of independence for elders, but falls are also very preventable! 16, 22, 23, 24

Appendix B of the NECC contains a “Home Safety Assessment” checklist which is an effective tool for preventing falls. The “Home Safety Assessment” is part of a broader falls prevention program called the “W.E.L.L. Balanced Curriculum”. W.E.L.L. Balanced is also available from the National Resource Center on Native American Aging (NRCNAA) website. Caregivers are encouraged to take a few minutes to utilize the “Home Safety Assessment” to make home environments much safer for their elders. 22

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, such as: (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 automatically mean that these sensory losses are “normal”. Many changes in vision, hearing, touch, etc. may be related to illness, and can be medically treated. For sensory losses that cannot be medically treated or “cured”, adaptations can be put into place to minimize the impact of losses and to maximize the remaining daily functions of elders.16

Maintaining Vision 12, 16

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
certain kinds of complaints; and d) adaptations to enhance vision.

**Serious complaints related to the eyes and to vision include:**

- Burning sensation
- Pain in the eyes
- Blurry vision
- Double vision
- Seeing “Spots”
- Redness in the eye
- Runny eye (any kind of drainage 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
- 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:** 12, 25

• Talk to the elderly person so he / she knows where others are in the room
• Touch their arm gently to let the elderly person know when someone is 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, and keep them within easy reach
• Describe things to the elderly person that he / she cannot see, such as food on a plate

**Maintaining Hearing:** 12, 18, 19, 20

As with vision, there are several “adaptations” and practices that may enhance the ability to hear. It is important to encourage the elder to have a hearing exam to determine the type of hearing loss he/she may be experiencing. This is the first step to finding out if a hearing aid would be helpful. It is also a good practice to have the elder go to the clinic for an ear check and hearing screen. Very often the ear canals contain too much cerumen (wax), and this can diminish the transmission of sound. Some elders experience an increase in their hearing ability after they have had wax removed from their ears.
Adaptations for Hearing Loss and Improving Communication: 12, 25

- If an elder has a hearing aid, encourage its use
- Be sure the hearing aid is comfortable & the elder can use it in the most effective way
- Keep the hearing aid 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. Shouting does not help and can even seem disrespectful or emotionally abusive to an elder
- Try to use a lower (deeper) tone of voice since hearing loss affects the hearing of higher pitched more than lower pitched sounds
- Face the person, so it is possible to see lips, gestures & expressions
- Try to be as respectful and patient as possible. It will be very difficult to communicate sometimes, and this can be frustrating for the elder AND for the caregivers. There is a risk if elders feel they are annoying others, they may just give up the effort to communicate altogether
- Speak louder, but do not “shout”
- Write things down if the person just is “not getting” what is said
  - Make up a set of flash cards with large bold print for items that are frequently asked for
o Keep a writing pad and bold colorful markers near the elder, so it is easy to write a quick note to aid communication

o 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 of the stethoscope to amplify the voice.

**Summary Session 1.3**

With a little bit of adaptation and “low-tech” strategies, many sensory deficits can be addressed. Also, it is possible to prevent falls and injuries. Adaptations allow an elder to maintain independence in a safe environment. Caregivers can also be made more to feel more confident in their role, by being better able to communicate with their elders, and successfully helping their elders remain in their home setting by creating a safer environment for their loved one.
SESSION 2.1
Common Chronic Health Conditions
SESSION 2.1  LIVING IN BALANCE WITH COMMON CHRONIC HEALTH CONDITIONS

PURPOSE

- Learn about common chronic health conditions that many elderly people live with on a day to day basis
- 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 for caregivers taking care of elders 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
“Some 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 a 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 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 most chronic diseases and conditions, the goal cannot realistically be a “cure”. But, the goal can realistically be to maximize a person’s “functional abilities”. Functional abilities are abilities to perform activities of daily living (ADL’s) and instrumental activities of daily living (IADLs). Maximum ability in ADLs and in IADLs means 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 illnesses among Native Elders that have been reported.

The most common chronic illnesses among Native elders include: 26

- High blood pressure (Hypertension)
- Arthritis
- Diabetes
- Cataracts
• Congestive heart failure (CHF)
• Asthma
• Stroke
• Prostate cancer in men
• Breast cancer in women
• Other cancers
• Colorectal cancer
• Lung cancer

It should be noted that given the diversity of individual Tribal Nations and the geographic regions in which they are located, alternative emphases for chronic diseases may be identified. For example, the “Alaska Education and Research Towards Health” (“EARTH”) study identified the four most prevalent chronic diseases among Alaskan Native elders as:

• High blood pressure
• Arthritis
• High cholesterol
• Adult bone fractures/breaks

In terms of the most common causes of mortality among Native elders, the top 5 causes of death among people who are 55 to 64 years of age are identified directly below. 26
Top 5 Causes of mortality for People 55-64 years of age:

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

As people get even older, the main causes of mortality seem to change a little bit.

Over age 65, the top five causes of mortality have been reported as:

- Diseases of the heart
- Malignant neoplasms (cancers)
- Diabetes
- Cerebrovascular disease (Stroke)
- Pneumonia & flu
Summary Session 2.1

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”. It is recommended that caregivers ask health care providers for information about specific chronic conditions as they relate to the care of their elders. It is also recommended that caregivers network with local Tribal Health Programs, such as the Community Health Representative (CHR) programs and the Special Diabetes Programs for Indians (SDPI). Use of these resources can help caregivers to better understand chronic diseases and to assist their elders to live with their chronic conditions in the healthiest way possible, with the goal of preventing complications.

Although the elderly may have one or multiple chronic health conditions, a caregiver’s focus is best directed to:

- Maximizing functional abilities (ability to continue “day to day” activities)
- Preventing further complications from diseases
- Preventing disabilities
- Promoting health through healthier nutrition and exercise practices
SESSION 2.2
Health Disparities Among Native Elders
SESSION 2.2  ELDERS AND HEALTH DISPARITIES

PURPOSE

- Learn about the increased rates of chronic diseases among the American Indian population, including Native elders
- Learn about some of the reasons for the increased rates of chronic diseases among the Native elder population
- Learn to recognize the potential for reducing disease rates among the Native elder 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
- Discussion of how to access resources that could help elders
“Some Ideas to Think About”

Health disparities are a reality in Indian Country. Health disparities are defined as: “preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations.” Increasingly, it is recognized that differences in health among different groups are rooted not only in “biology”, but in the “social determinants of health”. These “social determinants” include influences such as: socioeconomic status, access to health care, the physical environment and social environment we live in, as well as literacy/education levels and legislative structures.

A major indicator of health disparity can be seen in statistics related to life expectancy of populations in the U.S. The average life expectancy for American Indian people varies by region, but overall it is lower than that of the general population. The Indian Health Service (2007-2009) reported that the overall life expectancy of the general population of the U.S. was 78.17 years, as compared to the average life expectancy of American Indians and Alaskan Natives at 73.7 years. However, in some regions of the country, life expectancy is impacted quite a bit harder by the social determinants of health.

For example, in 2000, the Indian Health Service reported life expectancy in the Aberdeen Area of Indian Health Service (encompassing Tribes in ND, SD, IA, NE) at 64.3 years as compared to 76.8 years in the U.S. population. Most recently, the state of Montana found that the average life expectancy for American Indians in their state is 20 years shorter than for non-Indians. In response to this finding, Montana has created an “Office of American Indian Health”.

As these examples demonstrate, health disparities are a severe health reality in Indian Country. Tribal responses to this reality will need to approach health disparities from a position of strength, drawn from the culture and traditions of each Tribe. It may be helpful for Tribal community members to look to the
resilience of Tribal Nations to approach health disparities from an “empowered” perspective, rather than from a “fatalistic” perspective. It may be helpful to think about combating health disparities in terms of the “glass is half-full” versus the “glass is half-empty” analogy. The “half-empty” glass or “fatalistic” view might be stated something like this: “Well, according to the high disease rates, it just seems that more American Indian people just get sick... that’s just the way it is.”

In contrast, drawing from the unique strengths of Tribal culture and values, the “glass is half-full” proposes a perspective of empowerment that might be verbalized like this: “Well, there is a lot of scientific knowledge out there to prevent many of the chronic diseases that we see hurting the people in our communities. It is possible to reduce the risk for these illnesses by reducing the risk factors we now know about. Maybe together we can do something to reduce these diseases in our communities, and especially for our children in the future.”

Tribal communities can be encouraged at a “grass roots” level to make a collective choice to follow an “empowered path” to address health disparities, although it will take time. As some Native elders have been heard to say, “it has taken a couple of generations to develop these problems, it may take a couple of generations to remedy them”. In response to the recently reported 20 year disparity in life expectancy in Montana among Native peoples, Kevin Howlett (the Director of the Confederated Salish and Kootenai Tribal Health Department) was quoted as saying: “It’s sad the absence of health care that Indian people have to put up with... The problems didn’t start today and they won’t be solved tomorrow. It’s about the future.” Much wisdom and hope can be found in Mr. Howlett’s words. Health disparities can be reduced for future generations, and the time to decide to be rid of them in future generations is now.

**Examples of Disparities in Chronic Diseases among Native Elders**

For some diseases, there appear to be lower rates by region. It is difficult to analyze the true rates of chronic diseases among all Native elders, since very few
studies specifically among Native American elders have been completed. But overall, it is clear that compared to the U.S. general population, elderly Native people are more likely to experience certain health conditions.

These health conditions that affect Native elders at a higher rate have been identified as including:

- Arthritis 19.5% more likely
- CHF (congestive heart failure) 48.7% more likely
- Hypertension 17.7% more likely
- Stroke 17.5% more likely
- Asthma 4.3% more likely
- Diabetes 173% more likely

Some of these health disparities could be reduced through focused community-based programming. For example, there is now much “evidence-based” (scientific) information that is effective for preventing and controlling hypertension (which can lead to stroke) and diabetes (which can lead to amputation, blindness, kidney failure). Taking an “empowered path” could lead to a plan to get this scientific information directly into the hands and homes of community people, and to teach them to use it in a good way with their families.

Another example of a health disparity that could be reduced through community-based programs is the high rate of death from flu and pneumonia for American Indian people between the ages of 55 and 64. This health disparity could also pose an opportunity for communities to take an “empowered path” to prevent flu and pneumonia. The “empowered” response to a higher rate of flu and pneumonia mortality may be for the Indian Health Service and Tribal Health Programs to join forces for community-wide immunization campaigns.
The campaign could be collaboratively planned and implemented in 5 phases: 1) increase community knowledge about the effectiveness of flu shots and pneumonia vaccines in preventing serious illness; 2) encourage all elders to “get their shots”; 3) set-up rotating immunization clinics in local communities before the start of flu season; 4) offer transportation to assist elders to attend the immunization clinics; and 5) evaluate the effectiveness of the “get your shots” campaign. The “glass is half-full” approach can lead a community to take the perspective that: “Although there are fewer health care personnel in Indian Country, there are also opportunities for stronger health care partnerships with our Tribal and clinic programs because of our shared dedication to our people.”

**Causes of Health Disparities**

A number of causes can be identified that contribute to health disparities, most of which are closely linked to the social determinants of health: \(^{34,35}\)

- Limited use of preventive health care services
- Racism/Discrimination
- Historical Grief
- Limited access to health resources and services
- Lower socioeconomic resources
- Distance from services/transportation issues
- Housing issues
- Social or environmental stressors
Summary Session 2.2

The above discussion may not be how we usually think about how diseases are caused or should be treated. But, in order to prevent health disparities it is necessary to be aware of their roots in social, historical, cultural, economic and environmental issues which impact health care and health status. Promoting quality care of Native elders will require addressing health disparities, as well as promoting health and prevention.
SESSION 2.3
Assessment of Symptoms
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
4. Recognize that pain can and should be treated in elders

LEARNING OPPORTUNITIES

- Discussion of various types of pain experiences
- Discussion of experiences with various types of pain, including experiences with chronic pain
- Discussion of the individual nature of pain for each person & culture
“Some 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 for symptoms which need to be accurately communicated to 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. In a rural Tribal community, this often requires calling for help from an ambulance if ambulance service is available. Without ambulance service, or while waiting for the ambulance to arrive, the local Community Health Representative (CHR) program can be called to help in all emergencies.
SYMPTOMS THAT REQUIRE IMMEDIATE ATTENTION

- 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
- Fainting
- Unusual bleeding of any kind
- Fever\(^36\) or other signs of infection
  - Redness, pus, swelling, flushed skin
  - An elevated fever in elderly needs to be checked out right away!
  - Sometimes an elder will have an infection, but won’t show a fever
  - Risk for infection can also be increased after a surgery
  - Pain with urination can mean a urinary tract infection
Signs of confusion may mean an elder has an infection even if there is not a fever present

- Seizure
- Swelling / hives
- Dehydration: increased thirst, decreased urine output, lightheadedness
- Fast and/or irregular pulse

**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 the following immediately below:

- What kind of pain is it?
  - Sharp? Stabbing? Tingling? Burning?
  - Aching? Deep aching? Deep or Superficial?
  - Throbbing? Dull?
  - All over? In one spot only?
  - Lasts for long periods? Only for a few seconds?
Constant pain? Comes and goes?

- On a scale* of 1 to 10, how would you rate the pain? (10 being the worst, and 1 being the least amount of pain you ever felt)*The “faces” pain rating scales are not as easy to use as the “1 to 10” scale for elders.17

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?
- Does the pain arrive around the time of a meal?
- Is it after working at an activity? After exertion?
- Is there Nausea?
- Is there Confusion?
- Difficulty breathing?

Are there other symptoms with the pain?

- Coughing?
- Sweating?
- Fainting?

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?
  o Do they let you know?
  o Do they mention pain when they have it?
  o Do they hide their pain symptoms?
  o Do they fear what pain might mean?
  o Is the pain changing the “day to day” activities or self-care abilities of the elder?

_Special Considerations with Chronic Pain_

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

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

_Sudden Change in Function_ 21, 22, 23

Some other symptoms also require immediate attention. A sudden change in
a person’s function can indicate something wrong, such as a stroke. Symptoms that the caregiver needs to assess and get 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)
- 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)
The F-A-S-T Assessment

A Caregiver can quickly make use of the “F-A-S-T” assessment if there is a change in an elder, and a concern that a person could be having a stroke:

- **Face:** Ask the person to smile. Does the face droop on either side?
- **Arm:** Ask the person to raise both arms. Does one arm drift downward?
- **Speech:** Ask the person to speak a simple sentence. Able to? Any slurring?
- **Time:** Right away call 911 if the “F-A-S-T” test is failed in any way.

Breathing Difficulties

Sometimes a person has a chronic illness that affects their breathing. A health care provider can prescribe medications that will maximize breathing capacity if a person has asthma or emphysema, 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 who has a *breathing problem* for certain symptoms that can indicate loss of oxygen, 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 (darker colored) when breathing is difficult)

• Difficulty breathing (fast breathing, wheezing, “stridor” or noisy breathing)

• Swelling (perhaps from congestive heart failure or allergic reaction)

• Shallow respirations

• Unconsciousness

The question also needs to be considered when there is a sudden breathing problem is it possible the person choked on something and it is blocking the airway? And, if choking is suspected, has a caregiver been trained to know how to perform the Heimlich maneuver? Difficulty of any kind with breathing is one of those “vital signs” that has to be taken care of immediately.
SUMMARY SESSION 2.3

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

- Sudden Change in Function
- Breathing Trouble
- Unconsciousness
- Unusual bleeding
- Signs of fever and infection
- Pain that is:
  - Severe
  - Related to a fall
  - A headache that is unusual
  - Located in the chest or back, or down the arms, jaw, neck

When in doubt, it is best to call for 911 assistance immediately.
SESSION 2.4
“Day to Day” Assessment
Session 2.4  “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 and/or reported for health care assistance

OBJECTIVES

At the end of the session, participants will:

- Identify the kinds of symptoms that only a caregiver might notice
- Describe symptoms that may be observed in chronic illnesses
- Identify the importance of knowing about the medications that an elderly person is taking
- Describe a system to help elderly people to take medications safely and accurately

LEARNING OPPORTUNITIES

Demonstrate how to accurately assess:

- pulse, respiration, temperature
- blood pressure
- blood glucose (sugar)
- edema (swelling)
- condition of feet
“Some Ideas to Think About”

Caregivers are the “eyes, ears & voice” for helping their elders. They are the most people likely to observe small, 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 providers of daily care and the best advocates for 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 and how to manage them. They can learn symptoms to watch for, such as swelling, fever, pain, etc.

Caregivers can receive instructions about the management of chronic diseases and prevention of complications. Caregivers are the “essential ingredient” that make it possible for elders to age in place.

“Day to day” patterns that caregivers assess:

- Nutritional and eating patterns
- Sleeping and rest patterns
- Mental status, alertness patterns, emotions, behaviors, moods
- Functional abilities in ADLs and IADLs
- Weight loss
- Condition of the skin (especially the feet in people with diabetes)
- Elimination patterns, such as urination and bowel habits
Additional helpful assessment skills to learn:

- Learning to take Vital Signs
  - Blood pressure
  - Pulse
  - Temperature
  - Respiration rate
  - Blood sugar (glucose)
  - Changes related to pain

Simple equipment for home use is available and fairly inexpensive for taking blood pressure and temperature. The ability to make these assessments has been identified as a learning need by elders who themselves have been caregivers for family members. It can be very helpful to take these measurements and record them, so the vital signs and other assessment information can be given to health care providers either over the phone, or at a clinic visit.

For example, it may be very important for treatment of high blood pressure (hypertension) if home-based blood pressure measurements are available to review during a clinic visit. A health care provider can be informed by these additional readings to make more accurate adjustments in an elder’s blood pressure medications.

For an elder with diabetes, it would also be quite valuable to have daily blood glucose readings to compare to the glucose measurements taken at the clinic. Health care providers could adjust diabetes medications more effectively if they had home-based blood glucose readings to use for comparisons. The Special Diabetes Programs for Indians (SDPIs) often have community-based personnel who can teach a caregiver how to measure blood glucose with a glucometer.
And, the newer glucometers on the market are very easy to use!

It is very important to be able to take some of these readings, especially when an elder seems to be having some problems at home. For example, if a low blood sugar (hypoglycemia) is suspected, taking a blood glucose to be able to report to the health care provider is extremely useful to the successful management of diabetes.

However, if caregivers are going to check blood pressures and blood glucose readings on a regular basis, this means that caregivers need to be informed about:

- **Usual readings** for the elder:
  - The “usual” blood pressure
  - The “expected” blood glucose level (“sugar”)
    - If a person with diabetes shows a sudden change, such as unusual behavior, or becoming shaky, sweaty or lightheaded, or even unconscious*, the blood sugar might be “off”. It would be good to check the blood sugar to see if a person’s level is too low or too high. (*if a person becomes unconscious, always call 911 for emergency care).

- **Goal measures** for the elder according to the health care provider
  - The “goal” for the blood pressure
  - The “goal” for the blood sugar: fasting, before meals, between meals, after meals, or before bedtime
Elders’ Difficulties 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 are listed below. 12

**Barriers to taking medications accurately:**

- 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 Elders 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 a public health nurse (PHN). The PHN can help an elder and the family in actually filling the medication boxes or in drawing up insulin into syringes.

*Pharmacists* will also help caregivers to plan for the best way to help elders take their medications regularly and safely. If asked, many pharmacists will directly assist a caregiver with developing a “system” for filling “medication boxes”. *Plastic medication boxes* that hold separate doses of pills for different times of day are inexpensive and a very practical way to organize medications. There are even “*automatic*” *medication boxes* that can be set like an alarm clock to remind elders (and caregivers) of the correct time when medications are to be taken.

Some pharmacies are able and willing to package medications in “*blister packs*” for an elder, so the exact dosages are clearly labeled, ready and easy to take, without having to open and close medication bottles, “pour” out the medications, and count the pills. This “blister pack” system can help greatly to limit errors, and is also helpful to people with arthritis who cannot open and close medication bottles easily. The blister packs also have an advantage of letting the caregiver see when medications are getting “low” and need to be re-ordered.

**Special Issues with Medications**

There are “*legal*” *limits* on who can prepare and administer medications. For example, a nurse or pharmacist may fill medication boxes and administer medications, or may teach a family caregiver how to fill a medication box on a weekly basis for an elderly family member. However, a Community Health Representative (CHR) or a Home Health Aide or a Nursing Assistant is not legally
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. Although this is a safety precaution, this does place an extra responsibility on a family caregiver to have “transportation” to pick up the elder’s prescriptions. In communities where CHRs are allowed to pick up medications, they use a strict documentation system to verify by signature the list of medications at the time of “pick-up” from the pharmacy. The medications are verified again by signature with the elder when the medications are delivered.

**Dangers with People “Sharing” Medications**

As people get older, the kidneys and liver cannot process the “by-products” of medications to get rid of them as well as when they were younger. Elders can be very sensitive to interactions of multiple medications and do require exact dosages of medications to be taken as prescribed by the health care provider. Also, there are always medication allergies to consider at any age. In short, it can be dangerous for elders to share medications with other people.

Another sensitive and potentially dangerous issue is not actually the “sharing” of medications but the problem of people who will take an elder’s medications from them. This is a real and serious concern with family members who have substance abuse problems. The problem is truly “abusive” when the medications taken away from an elder are for pain control. The elder can be left suffering with severe pain when someone else gains access to their pain medications. Pain medications need to be handled very carefully to prevent abuse. If a caregiver runs into this situation, it is best to get help right away from a public health nurse, a CHR, a local pharmacist, or law enforcement personnel to develop a plan to protect the elder from this type of abuse.
Giving Medications Safely

Elders very often take multiple medications for chronic conditions. To promote safety, there are a few “rules to remember” when assisting an elder who needs to take medications regularly and accurately, at different times of the day and evening.

It is very helpful to think of the “6 rights”: 42

- 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 copies of an updated list of medications on hand at all times:
  - With the elder, such as in his / her wallet or purse
  - 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 every visit* to the clinic (or to the hospital)
- Visit with the health care provider or pharmacist about the medications,
and update the list on a regular basis with every change.

- Ask the elder if he/she will give written permission for the caregiver to have access to the elder’s medical information. The caregiver needs to be able to talk with the health care provider about the following:
  - expected effects of prescribed medications in helping to control chronic illnesses that an elder has been diagnosed with
  - possible side effects or possible interactions of medications (especially when new medications are prescribed)
  - what to watch for in the elder, for example, lowered blood pressure, allergies, etc.
  - if other medications have been prescribed by another health care provider and if they are recorded in the medical record
  - keeping an updated list of all medications to have on hand at all times

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**Summary Session 2.4**

Caregivers provide help to elders in so many ways. The “day to day” responsibilities of elder-care make the caregiver role essential to successful community living for elders. Knowing how to take vital signs and keeping records of medications are simple but very important ways that caregivers offer assistance. Caregivers who communicate with health care providers about “day to day” care and learn about the health conditions and medications for their elders can greatly help to assure the provision of quality care, as well as to build support for caregivers, themselves. The role of caregivers cannot be overestimated! They are the “key” to elders’ ability to live safely in their homes, and to remain as active members of their families and communities as they “age in place”.
SESSION 2.5

ADLs and IADLs
SESSION 2.5 Activities of Daily Living (ADLs) & 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
- Invite a therapist to demonstrate and allow elders and caregivers to practice with adaptive equipment
“Some Ideas to Think About”

The decision for an elderly person to move to an institutional setting, such as a hospital or nursing home, is not usually based on medical diagnoses. The need for nursing home placement is much more related to how well an elder can “function” independently in the home setting. The decision that an elder needs to go to a nursing home is also 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 an elder 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 amount of help that will be needed for an elder to live at home. Both of these terms indicate how well a person can “function”, so ADLs and IADLs are also referred to as “functional abilities”. When an elder’s functional ability changes, this can be a warning that something more serious is “brewing”, such as an infection or worsening of a medical condition, so it is important for caregivers to notice changes in “day to day” functional abilities.

General Description of ADLs & IADLs

Activities of daily living (ADLs) are the skills that elders have to feed themselves, bathe and dress, get to the toilet and to move around. Instrumental activities of daily living (IADLs) are the skills elders need to live in a community, such as shopping, preparing meals, using a telephone, taking medications safely, managing finances, paying bills, and going to places around the community. A person may be only partially independent in ADLs and IADLs, and yet is able to continue to function at home 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 quite difficult.

As stated above, 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 are the deciding factor for what kind of care a person needs. The more assistance a person needs to perform ADLs and IADLs can lead to placement beyond the home setting, such as an assisted living or a nursing home facility. For this reason, when a person has one or more chronic diseases, the goal is to control complications and prevent disability. As an example, a person with high blood pressure (hypertension) would not automatically require assistance in ADLs and IADLs. However, if a stroke occurs related to the hypertension, then a person may lose more functional abilities and require quite a bit more care. So, controlling blood pressure is important and is actually very feasible to do!

From their research among hundreds of Tribes across the nation, McDonald 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 most likely need. The table below is a representation of the model they developed:

**Table 1: Need for Long-Term Care: Measures of ADLs and IADLs**

<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, it will usually be possible to serve an elder who has two limitations in IADLs, plus one limitation in ADLs in the community setting, using Home & Community-Based Services (HCBS). However, when limitations arise in two ADLs, more assistance is needed. Needing a lot of assistance with 2 ADLs may indicate a person needs an Assisted Living residence. As functional abilities continue to decrease, for example when a person cannot take care of 3 of their ADLs, then a move to a nursing home for care is very often required. However, each individual’s situation is unique with regard to caregiver availability.

The availability of enough caregivers may make it possible for elders to remain in the home setting, even if assistance is required in 3 or more ADLs. But, if a caregiver has no help and especially if respite services are not available, it is usually not possible for a caregiver to continue providing care. The stress and the exhaustion that result from having no breaks and from not having time to take care of one’s own health needs, often make it impossible physically and emotionally to continue caregiving. Sessions 3.4 and 3.5 will discuss caregiver stress and support needs more in-depth.

When determining the level of “independence in ADLs”, the following paragraph below may help to explain Table 1 above as reported by McDonald, et al:

> 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 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. (p. 497) 12
The “3 point scale” in the above paragraph can be very useful in elder assessments when planning for appropriate LTSS that “fit” an elder and the caregiver situation.

**ADL & IADL INDICATORS**

Below are detailed lists of the ADL and IADL indicators commonly used to assess “functional ability”, that is, how well a person can perform necessary day to day activities. The ADLs and IADLs are influenced by illnesses, but are not “medical diagnoses”. Rather, ADLs and IADLs can be thought of as “independence” and “dependence” measures. When acutely ill and hospitalized with a “medical diagnosis”, a person may be totally dependent in most ADLs and IADLs. However, with medical treatment and rehabilitation, it is possible to regain functional abilities, that is, to regain independence, even if medical conditions are not “cured”. Below are the definitions of the terms “ADLs” and “IADLS”.

<table>
<thead>
<tr>
<th>Activities of Daily Living</th>
<th>16, 45</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Bathing</td>
<td></td>
</tr>
<tr>
<td>• Dressing</td>
<td></td>
</tr>
<tr>
<td>• Toileting</td>
<td></td>
</tr>
<tr>
<td>• Transferring (moving position, such as from bed to chair)</td>
<td></td>
</tr>
<tr>
<td>• Grooming</td>
<td></td>
</tr>
<tr>
<td>• Feeding</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Instrumental Activities of Daily Living</th>
<th>16, 45</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Administering own medication</td>
<td></td>
</tr>
<tr>
<td>• Grocery shopping</td>
<td></td>
</tr>
<tr>
<td>• Preparing meals</td>
<td></td>
</tr>
<tr>
<td>• Using the telephone</td>
<td></td>
</tr>
<tr>
<td>• Driving and Transportation</td>
<td></td>
</tr>
</tbody>
</table>
- Handling own finances/paying bills
- Housekeeping
- Laundry

**Importance of Caregivers**

Although ADLs and IADLs are “ordinary” tasks, they become extremely important in realistically planning for where an elder can live safely on a long-term basis. When elders increasingly cannot do their usual “day to day” activities, they need help to continue to manage daily living in their home setting. It is then that caregivers become “key” to making it possible for elders live at home for as long as possible. Even when a person is discharged from the hospital after being treated for an illness, the option to return to the home setting from the hospital is strongly dependent on the availability of caregivers. And the caregivers’ ability to continue in a caregiving role is dependent on their own ability to have support services.

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. However, as deficits in ADLs/IADLs increase, an elder becomes more at risk for nursing home placement if there is not a dependable caregiver(s). Loss of functional abilities can lead to serious problems, such as: falls, skin breakdown, depression, social isolation, urinary incontinence, and malnutrition. In addition, chronic medical conditions may worsen if a person cannot manage their medications or make arrangements to get to routine clinic appointments. Caregivers are the “key ingredient” for successful aging in place.
Summary Session 2.5

It can be seen that the amount of care that is needed for ADLs and IADLs will “set the pace” for both elders and caregivers. The necessity of having to use nursing home services is often primarily decided on the availability of a dependable caregiver. And, the ongoing dependability of a caregiver is very much related to the ability of the caregiver to “keep up” with the amount of care required by an elder. In the following sections, the impact of caregiver stress will be discussed and related to the importance of health promotion practices for both elders and caregivers.
SESSION 3.1
Health Promotion for Native Elders & Caregivers
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 maintaining “functional status”
- Identify the potential relationship between health promotion and fall prevention
- Identify a holistic perspective related to the practice of health promotion strategies

OBJECTIVES

At the end of the session, participants will:

1. Identify meaning of health promotion
2. Identify “self-care medicines”
3. Identify simple ways to incorporate health promotion into everyday living for elderly and caregivers

LEARNING OPPORTUNITIES

- Discuss realistic planning for healthy meals & exercise programs
- Talking Circle to discuss:
  - potential stress relievers for the support of caregivers
  - local and regional respite care options
“Some Ideas to Think About”

When we are talking about “health promotion”, we are looking at “how to get and stay healthier”. This is different from “treating diseases”. However, Health Promotion and Disease Prevention are “close relatives”, since 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 regular health promotion practices.\(^\text{51}\)

The prevention of disability through health promotion while people are “young elders” cannot be emphasized too much. Chronic health conditions among elders are very common. More than three-quarters of older adults have two or more chronic health conditions; at least one quarter have behavioral health issues, such as depression and anxiety; and more than one-third experience a fall each year.\(^\text{52}\)

However, in spite of these statistics, it is possible for a person to live with chronic conditions while becoming older, yet still retain “functional abilities”. The practice of health promotion activities can prevent disabilities and help to maintain functional abilities for longer periods of time throughout the lifespan. Although chronic diseases are the most costly and serious of health problems, they are also the most preventable!\(^\text{51}\) Even a modest investment in health promotion can help to counteract chronic disease.

American Indian /Alaska Native people are very resourceful, having adapted through thousands of years of change. Elders have traditionally been respected, and Native elders remain committed to future generations. “**Elders can share knowledge about how to understand, solve, and prevent problems...Elders speak strongly about cultural values and rules on how to conduct oneself within the family and community...Through elders, wisdom becomes a living oral knowledge applied to current contexts.**”\(^\text{cited in 53}\) Elders who practice health promotion can teach future generations about health. Being “older” does not mean “being
sick”. Being an elder means enjoying friends and family, guiding and caring for grandchildren, enriching the community with wisdom.

**Balance as a Primary Health Goal**

We started off Session 1 with a foundational thought, that human beings are “not only their biology”. Human beings are holistic beings and are healthiest when all human dimensions are in balance, physically, emotionally, spiritually, and socially. To practice health promotion means to pursue balance in these dimensions. As the various dimensions of life and health are challenged, changed, and sometimes even impaired, we continue to pursue our balance on the human journey. This may mean that a deeper spiritual life and stronger social connections with family and friends will be pursued to help to balance physical changes that may occur due to disease, injury, or changes that occur naturally in the aging season.

Health promotion practices for Native elders can pay off in the maintenance of health. Health is promoted when a “balance” is maintained physically, emotionally, spiritually, and socially. It is possible to focus on changing things that can be changed. From “western thought” there is a theory called “self-efficacy”. This theory can be helpful when thinking about practicing health promotion. Self-efficacy means having a belief that the practice of specific behaviors will lead to specific outcomes. The idea of self-efficacy could be linked to the traditional Lakota value of “wowicala” which means “belief”. Wowicala means to truly believe in something, not just “hope” something.

With a belief (wowicala) in self-efficacy, people can strive to make an investment in health promotion practices, knowing that this effort has the potential to: a) maximize IADL and ADL function; b) minimize the need for nursing home care; c) maximize the chances of staying in the home setting with family; and d) make it possible for elders to keep their valued roles as teachers, advisors, and wisdom
keepers within their families and communities. The remainder of Session 3.1 will shine a spotlight on 5 “self-care medicines” that are effective in preventing disease and maintaining health. The “medicines” are physical activity, healthier nutrition, oral health, smoking cessation, and stress management.

Physical Activity is A Good Medicine

There are many benefits to regular physical activity. The Centers for Disease Control and Prevention (CDC) Guidelines for Physical Activity recommend: 1) at least 150 minutes of moderate exercise (such as brisk walking) in a week’s time, and 2) muscle-strengthening exercises at least 2 times a week. So, about a half hour of exercise each day has the potential for a very big pay-off in terms of better health! To prevent falls, the CDC additionally recommends exercises to improve balance in adults over the age of 65. (Fall prevention will be further discussed later in this section).

The Summary of the 2008 Physical Activity Guidelines for Americans also tells us a lot of “good news”, such as: a) “Some exercise is better than none”; b) “Additional benefits of exercise occur as the amount of physical activity increases”; c) “Regular physical activity reduces the risk of many adverse health outcomes”; and d) Health benefits of physical activity happen in all age groups, and even for people with disabilities.
In terms of disease prevention, regular physical activity can lower the risk of:

- earlier death
- coronary heart disease
- stroke
- high blood pressure
- type 2 diabetes
- breast and colon cancer
- falls
- depression

General Recommendations to Begin a Physical Activity Program

- Check in with a health care provider for an individualized “exercise prescription”
- Wear comfortable clothes and shoes
- Build up activity little by little over time, and keep at it over time
- Invite an activity “buddy”, a family member or friend
- Join an exercise group
- Bring along a source of “sugar” (hard candy, glucotabs) in case the blood glucose level runs a little too low (hypoglycemia) during exercise, especially if being treated for diabetes

How to Fit in a Little Extra Physical Activity 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, extra physical activity can be worked into many of our everyday activities. There are many forms this can take: gardening, walking, riding a bike, swimming, pow-wow dancing, or playing with grandchildren at a local playground. Any activity that requires ongoing movement for a period of time can
help meet exercise goals. It is not even necessary to maintain exercise for long periods at one time. For example, taking three brisk 10 minute walks throughout each day can add up to the 30 minutes of activity that is recommended for at least five days a week.

Many opportunities for exercise do not take any “special expensive equipment”. At a diabetes prevention conference in the Great 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. Some elders talk about how they practice pow-wow dancing with their grandchildren at home when listening to pow-wow music on the local Indian radio station.

Let’s Move!

It really does not matter what a person chooses as a favorite activity. The main goal is to make a commitment to “MOVE” every day, in some way! Again, activity can be done in a “block” of time for 30 minutes, or in “chunks” of time for 10 minutes each that will add up throughout the day. For example, a caregiver may not have time to take a walk for a full half hour, but perhaps it is possible for a caregiver to find 10 minutes for a break a few times in a day. It may even be possible for an elder to take a shorter walk with the caregiver.

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! And walking works very well for improving health! The Nike Company has even developed a shoe with extra room in the toe box for comfortable, non-friction walking specifically for American Indian people, many of whom have diabetes and need to prevent foot ulcers. First Lady, Michelle Obama, has launched the national “Let’s Move” initiative to prevent
obesity and related health conditions among youth. But the motto “Let’s Move” is an “across the board” motivator that can definitely be applied to all age groups.

An Example of a Community-Based Physical Activity Initiative

In the Wakpala District of the Standing Rock Sioux Tribe, the Wakpala CHR (Marlo Free) has gotten permission to open the community gym after school at least one afternoon each week for youth to walk, play and visit about nutrition. Non-sugared drinks and a “healthy snack” are offered each week, and an occasional community meal is prepared for holidays. Youth play with $1.00 kites outside and $2.00 kickballs inside, and count their steps with $4.00 pedometers. Elders will often come to the gym to watch the youth activity and sometimes there is a community “walk” the larger community will join for special holidays or memorial occasions. This is truly a low cost community venture which has turned out to be quite effective in inviting youth to “move”.

Discussions are now taking place to build upon the youth health promotion initiative in Wakpala. One proposal is to begin a walking program for elders, which could also include exercises for fall prevention. As a community, Wakpala is modeling a “low cost investment” in health promotion which holds promise for a “high value return” for health. Figure 3, immediately below on the following page, is the health promotion model that has been developed by Marlo and Ron Free for their home District of Wakpala (used with permission). The “Free Model” integrates the Medicine Wheel dimensions of physical, emotional, spiritual and social health with depictions of traditional health promoting activities.
In the Marlo & Ron Free health promotion model above, the moccasins represent the tradition of walking and running, the meal being cooked over the fire represents the preparation by families of healthy traditional foods, and the bow and quiver represent the tradition of hunting which required a substantial amount of physical activity to provide food for all members of the Tribe. Most importantly in the model is the depiction of the adult teaching the young child how to use bow and arrow. This represents the strong traditions of family connections, the importance of teachings being transmitted from the older generation to the younger, and the
preparation of the future generation to learn how to provide for the people. The ongoing youth health promotion project in Wakpala does honor the spirit of this model.

**Using Local Resources for Physical Activity**

In many communities, under the Special Diabetes Programs for Indians (SDPI), fitness experts are available who can be asked to offer a fitness program for elders, or a “train the trainer” workshop for CHRs or other CHWs, such as diabetes outreach workers. The CHWs can be trained to assist elders to learn simple exercises they can do in their homes. Just as one small example, a person can use different sized canned goods as small weights to lift for strengthening. The use of inexpensive “rubber stretch bands” can also be used to increase muscle movement and strength in a safe way.

Chair exercises are another easy and safe way to promote physical activity for elders. At the Turtle Mountain Chippewa Tribe, a long-term CHR (Kenny Keplin) has designed a series of chair exercises that he offers regularly to elders in their local retirement setting, with a great record of participation and fun! Some elders who have participated in this ongoing activity of chair exercises through winter months have become strong enough to begin an individualized walking program by spring. Others have been able to have their diabetes medications reduced because of the positive glucose-lowering effects of exercise. Kenny Keplin, as a CHR interested in elder health promotion, has offered the chair exercise program to elders for over 20 years and as a great “side effect”, Kenny is in great shape himself!

In recent years, many Tribes are focusing more intently on gardening as a healthy source of activity, as well as a source of healthy nutrition. With grandchildren involved, elders can be helped with weeding and watering, while the children can learn a lifelong skill of growing traditional foods, fresh from the garden. In short, there are many ways to “fit in” some physical activity on a regular basis, in usual “day to day” living!
Preventing Falls and Strengthening Physical Capabilities

Exercise can help to maintain and improve overall health and certain kinds of exercise can be targeted to assist elders to prevent falling. The prevention of falls is very important to elder health and the ability to continue living at home. “Unintentional injuries are a leading cause of death in older adults, and falls comprise two-thirds of these deaths”. Hip fractures alone occur in 325,000 people each year in the U.S. Falls can lead to a spiral of negative events including broken bones, severe pain, surgical procedures, hospitalizations, rehabilitation therapies, and nursing home placement.

Many times, falls result from a combination of risk factors. A fall may be much more likely to cause a broken bone if osteoporosis is present, a common diagnosis especially among older women. Broken hip injuries are not only common, but are also associated with a 18%-33% risk of death in the year after the fracture. In addition, once an elder has a fall, a pattern often emerges that includes a fear of falling again.

This fear may restrict the elder’s willingness to be active, which in turn reduces physical capabilities. As discussed above in Session 2.5, the loss of ADL and IADL function can lead to eventual nursing home placement. Figure 4 below is a diagram that outlines this pattern (diagram is from the WELL-Balanced Curriculum).
Risk Factors for Falls

Risk factors that make an elder more prone to falling include the following:\textsuperscript{63}

- Muscle weakness
- Previous falls
- Unsteady walking pattern ("gait")
- Unsteady balance
- Decreased vision
- Arthritis
- Decreased functional abilities
- Depression
- Confusion/Decreased thinking ability, such as in Alzheimer’s disease
- Dizziness
- Environmental obstacles that cause “accidents”
- Elder Abuse
Preventing Falls among Elders

Knowing specific risk factors that an elder may have for falls is actually the first step in preventing falls. Many risk factors can be modified through: balance and strengthening exercises; training in the use of adaptive equipment; and home safety assessments. Caregivers can help to make important environmental modifications based on a home safety assessment.

A caregiver can also visit with an elder’s health care provider about how to address additional risk factors for falls, for example, by asking for additional training for an elder who is not exactly sure of how to use a cane safely or making sure a walker is fitted to the correct height. A caregiver can also contact the Tribal Housing Department to ask for installation of adaptive devices such as shower grab bars or to ask for repairs, such as new railings on stairways.

Fall Prevention Exercises

A number of fall-prevention exercise programs are undergoing evaluation across the U.S. However, many of them may be difficult to use in Indian Country, as they are designed to be implemented by teams of licensed health professionals including Occupational and Physical Therapists. However, many rural regions in Indian Country are designated as “health provider shortage areas” (HPSAs). Physical therapists and occupational therapists are scarce resources in rural Tribal Nations! It is necessary to offer alternative fall prevention programs that do not require a Physical Therapist or Occupational Therapist to implement them.

As one alternative, the National Resource Center on Native American Aging has developed a “train the trainer” falls prevention program. The “Wise Elders Living Longer” curriculum (WELL-Balanced curriculum) is a user-friendly health promotion resource for helping elders with strengthening, flexibility and balance exercises. The 5 goals of the “Well-Balanced Curriculum” are to: 1) increase physical strength; 2) improve the ability to prevent falls; 3) better manage diabetes,
arthritis, and hypertension; 4) engage in social activity; and 5) increase the level of exercise. The training can be offered in rural Tribal communities, using a “train the trainer” approach. The WELL-Balanced curriculum allows local “coaches” to be trained to follow a prescribed outline of fall-prevention activities, which then can be offered by the “coaches” in a structured program in local Tribal settings.

As mentioned previously, the WELL-Balanced curriculum also includes the “Home-Safety Checklist”* supplement that can be used to assess an elder’s living space at home, in order to identify changes in the home environment to prevent falls. As an example, the WELL- Balanced Home Safety Checklist has been used by CHRs at the Standing Rock Sioux Tribe to do safety assessments during elder home visits.

Based on the Home Safety Checklist, there are many minor but effective modifications that can be made, such as removing throw rugs, replacing burned out light-bulbs or night-lights, clearing walkways of clutter, placing non-skid bath mats in the shower area, etc. For more intensive modifications, such as the need for new handrails or repair of steps, etc. the Housing Departments of the Tribes can be asked to do the needed repairs. (*Again, as a reminder, the Home-Safety Checklist is included in Appendix B at the end of the NECC).

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 the “WELL-Balanced” curriculum, so elders and caregivers can learn exercises that they can also practice safely at home. Then, elders can be empowered to take a few minutes each day to use the stretching, balance, and posture exercises that they have been taught. These exercises can lead to a decreased risk for falls, as well as “counting” towards meeting 30 minutes of the recommended 150 minutes of weekly physical activity for adults.59
Healthy Nutrition is A Good Medicine

Nutrition is actually “fuel” for all the work done by all of the systems of the body. We might as well start as early as possible to use “premium fuel” to keep the engines running in tip-top shape! About two-thirds of American adults and 20% of children in the U.S. are obese or overweight, putting them at risk for many chronic diseases, such as heart disease, type 2 diabetes, certain cancers, and stroke.67 Although healthy aging is related to health status in youth and the middle years, health promotion practices have enormous benefits for elders68 and healthier nutrition is strongly linked to good health.69, 70

Healthy nutrition can positively impact blood pressure, blood sugar (glucose), and cholesterol levels. Many valuable nutrition and dietary guidelines for healthier eating are easily available on any number of websites. However, for a very simple but informative discussion of “practical” food preparation and healthy eating tips, it is hard to beat the USDA “MyPlate” information. MyPlate is a wonderful visual representation of a balanced approach to preparing meals and eating healthy. Immediately below is the MyPlate model from the USDA website: ChooseMyPlate.gov. The model and logo for MyPlate is presented below on the following page.
The “plate” provides an entire meal planning “lesson” for elders and caregivers that is easy to follow. Visually, it is possible to see at a glance, all the food groups and the portions of each that make up a healthier meal. For example, it is easy to see that larger portions of grains and vegetables are recommended, while protein and fruits are recommended in smaller portion sizes on the “plate”.

Other USDA MyPlate materials are also very “user-friendly” and visually appealing. The materials make healthier food choices and meal planning easier, and they are accessible to everyone, available to be printed directly from the internet. The “Choose MyPlate 10 Tips to a Great Plate”71 includes the following “tips” that are each followed with a very brief, understandable explanation. The “Tips” are presented directly below.
“Tips to a Great Plate”

1. Balance Calories
2. Enjoy your food but eat less
3. Avoid oversized portions
4. Foods to eat more often
5. Make half your plate fruits and vegetables
6. Switch to fat-free or low-fat (1%) milk
7. Make half your grains whole grains
8. Foods to eat less often
9. Compare sodium in foods
10. Drink water instead of sugary drinks

A Word on Special Dietary Instructions for 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 or nutrition educator. It is usually possible to get an appointment to visit with a nutritionist/dietician to be educated about special dietary guidelines for elders and caregivers who have certain chronic conditions.

This would be especially true if a caregiver is trying to plan meals and healthy foods for an elder who is on kidney dialysis or who has become very “frail” and has been losing weight. When nutritional guidelines are essential to the management of specific medical conditions, the “common sense” approaches that are recommended below would have to be “tailored to fit” those special medical circumstances and nutritional needs that an elder may have.
Some “Common Sense” Approaches to Nutrition

Although each person’s nutrition may need to be tailored to their specific needs, there are a few common tips that do help to promote overall healthier nutrition, especially for elders whose health would be better with a little weight loss:

- 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
  - Eating in “balance”
    - Watching portion sizes
  - Food intake needs to balance energy output
  - 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”, also known as “excess weight”
  - “Eating to live”.... Not “living 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 pointed out, “it is wrong to take more than what we need to live, this offends God”
- As another elder 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
  - Some foods, like vegetables & fruits should be eaten “every day”
  - Some foods, like cake & candy should only be eaten “sometimes”
  - These simple but very effective nutrition lessons about “everyday” and “sometimes” foods can be easily taught at any age through the CDC series of the “Eagle Books”

- Remembering “real” traditional foods and how to prepare them
  - Gardening traditional foods, such as squash, beans, pumpkin, corn
  - Reminding community people, as one long-time HoChunk diabetes educator did (with a smile), that “fry bread is not a traditional food!”

- Linking a healthy nutrition habit to a healthy exercise habit
  - Drinking water instead of a sugared drink after a walk

- Losing even a small amount of weight if overweight or obese
  - Weight loss makes a significant difference in blood glucose control
  - Losing as little as 7% of body weight can make a significant difference in preventing diabetes
    - For example, scientific research has shown if a person weighs 210 pounds, losing just 14-15 pounds does make a difference!
Oral Health is A Good Medicine

When discussing any of the nutrition tips above, it is necessary to keep an elders’ “oral health status” in mind. To be adequately nourished assumes that an elder has the ability to eat nourishing foods. If there are mouth and teeth problems, healthy nutrition will be a more difficult goal to reach. Some elders do not receive preventive dental care due to various barriers, such as other health conditions and disabilities, or lack of access to services or financial resources, or because they do not feel it will benefit them. So, the pattern of using dental services by Native elders is most often because they are suffering from a dental problem.\textsuperscript{75}

The two areas of dental needs that have been identified through thousands of surveys of Native elders (by the National Resource Center on Native American Aging 2007-2014) are: 1) teeth needing to be filled or replaced; and 2) work on dentures.\textsuperscript{75} But, as another “good medicine”, routine, preventive oral health care can have significant benefits for promoting adequate nutrition and overall health.

Quitting Smoking is A Good Medicine

The health effects 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 the thousands of chemicals\textsuperscript{76,77} in the smoke 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.\textsuperscript{76,77}
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 the health of 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, such as asthma, when they are exposed to second-hand smoke, and they may also be more likely to become smokers. Most people who do not smoke by age 25 will not become smokers. So, it is very beneficial to youth to not be exposed to second-hand smoke, and to have role models in their families who do not smoke.

Within weeks to months, as soon as a person quits smoking (and other forms of tobacco, such as chewing tobacco) all kinds of good health benefits start to “kick in”. Risks for smoking-related diseases go down year by year after quitting. All in all, quitting smoking is a major accomplishment that can save lives in the present and in future generations. Quitting smoking at any age has benefits to health, and a full range of tools are available to help a person accomplish this important “health promotion” strategy.
Managing Stress is A Good Medicine

Stress is a part of normal living, but too much stress becomes unhealthy for a person. Too much stress causes “dis-tress”. From a holistic perspective, stress is a normal human response to all kinds of stressors that come 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.

Our bodies have a “stress response” to whatever is perceived as stressful. 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 changes throughout the body systems. We can run and breathe faster, we have more strength in our muscles to fight the lion, and our hearts pump fast so we will have enough oxygen in the emergency. The goal is to survive the stressor!

However, if a person loses a family member, or has no money, or has no help in a very demanding caregiving situation, the body reacts in the same way to the emotional stress as it does to the mountain lion. The same stress-responses happen throughout the body when our emotions are under “attack”. We were not “built” to live with continual high emotional stress.

Long-term Stress

Whatever causes stress, whether the root is physical, emotional, social, or spiritual, the body reacts to survive what it perceives to be a 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 stress without relief can become physically sick, emotionally disturbed, depressed, or unable to perform their role in the family or at work. Every person will react differently to various life events or situations. What is stressful to one person may not be at all stressful to another.
However, each person can be affected by stress to the point where it becomes “dis-tress”. It is important to recognize when stress levels are reaching that point, and to have some “coping strategies” ready to “de-fuse” the stress. The cause of stress may not be possible to control entirely, but it is possible to control our response to stress through the practice of coping skills that work for us.

The American Heart Association has a very helpful resource webpage that recommends helpful tips for coping with stress, including 3 “easy ones” below:

- **Positive Self-Talk**
  - For example, telling ourselves positive messages when things go wrong like: “things will work out”; “we all make mistakes”; “I can deal with this for now”

- **Emergency Stress Stoppers**
  - For example, counting to 10 before reacting emotionally; driving in the slower lane on the highway; going for a walk; saying “I'm sorry”; taking 3 deep breaths; dealing with a bigger problem by breaking it down into smaller parts

- **Enjoyment of Little Things**
  - For example, finding one thing you like to do each day that only takes 15 minutes; talking to a friend over coffee or a meal; listening to music you like or watching a favorite movie

Stress is a common part of being a human being, it is impossible to live without stress impacting our lives. “Our job” is to figure out how best to react to stress, so we can maintain our balance and stay as healthy as possible. Because of the very unique kinds of demands upon caregivers that last for very long periods of time, stress can often become a serious problem. Session 3.5 of the NECC will expand the discussion of stress and stress management as related to the many and ongoing responsibilities of caregivers.
Summary Session 3.1

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 healthier in their homes and communities. Five “good medicines” are: physical activity, nutrition, oral health, quitting smoking, and stress management. Practice of health promotion can help all of us, elders and caregivers, to keep our “balance” and maintain our health.
SESSION 3.2
Health Care System & Financing of Health Resources
Session 3.2  Health Care System & LTSS Resources

PURPOSE

- Learn about the range of services & 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 availability of long term services and support (LTSS) in the community setting for Native elders
- 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 array of services that are potentially available for community elders
2. Be aware of the types of services provided by different segments of the health and human service systems
3. Be aware of different funding sources for health care services specifically related to the care of elders: IHS, Medicare, Medicaid, QHPs
4. Identify the current and future potential to build a HCBS system to deliver LTSS to elders who want to “age in place”

LEARNING OPPORTUNITIES

- Panel discussion with Tribal, IHS, County, State, and local resource programs for Q & A
“Some Ideas to Think About”

It is often quite a challenge to figure out how to access the health care system and community resources that can be helpful to elders who want to “age in place”. There continues to be an increasing demand for a full range of health and social services as the “baby boomer” generation ages. As mentioned previously, it is anticipated that there will be 4 times as many American Indian/Alaska Native over the age of 65 by the year 2050.¹

A range of services and resources are available for elders, however, the development of a “seamless” system to access those resources is still “under construction”. Federal and state governments are very aware of the urgent need to improve access to community-based Long Term Services and Supports (LTSS) resources, as it is estimated that by 2020, one in six people in the U.S. will be 65 years of age and older.⁸⁵

The Older Americans Act has been a “living law”, being amended over time to meet emerging needs in the older population. The need to “streamline” access to LTSS services was recognized in a 2006 amendment to the Older Americans Act. In 2006, Congress directed the Administration on Aging to establish an “Aging & Disability Resource Center” (ADRC) in each state. The ADRC’s are to serve as a sort of “one stop shop” which can: a) provide reliable information about LTSS options, and b) assist in coordinating smoother access to LTSS services for people who need them.⁸⁵

As ADRCs take root and expand in each state, there will be stronger coordination among the entire “aging services network”⁸⁵ of entities across states, counties, Tribes, and other local agencies. There is hope that access to LTSS will improve significantly in the future. In the meantime, the aging services network is made up of 56 State Agencies on Aging, 629 Area Agencies on Aging, 246 Indian Tribal and Native Hawaiian organizations, 20,000 Service Provider Organizations, and
thousands of volunteers.85

Each State Agency on Aging is not funded sufficiently by the Older Americans Act to meet all the needs demanded of their aging services networks. However, each state does have the flexibility to work with a broad range of other federal and non-federal entities to meet the needs of elders. The strategic task ahead is to find out how LTSS programs are organized in each state, as each has its own unique structure. While this task is important within each state, it is a task of critical importance to rural Tribes, where LTSS planning is in its beginning phases.

The 2011 federal appropriation for the Older Americans Act (OAA) was nearly $2 billion, nearly three-quarters of which is dedicated to Title III services. Title III funds primarily provide for Elderly Nutrition Programs, although there are smaller amounts dedicated to other programs, such as supportive services and the Family Caregiver Support program. Title VI of the OAA is dedicated specifically to the needs of Native Americans, but Title VI makes up only 1.8% of the entire funding from the OAA appropriation.85 Many rural Tribes strive to find funds to supplement their Title VI monies with Tribally generated funds, as they appreciate that many of their elders truly depend on the Title VI Elderly Nutrition Program for regular meals.

**Current Concerns of Native Elders**

In discussions with rural Tribal elders, certain “themes” are very commonly heard in “grass roots” conversations about their current needs.

> Who do we go to for help with services? Where do we go? How do we pay for it? Is there anyone who can help us at home? I cannot get to my appointments because I don’t have a ride or money for gas. She needs someone to go check on her every day, and no one ever goes to see her. He does not have a ramp, and he fell outside his trailer and ended up in the hospital. She got the flu and did not have enough food in her house. He is
getting sicker and confused and weaker every day. You don’t know what you have to go through when you are old. I could not use my Farmer’s Market voucher because I did not have a ride. I don’t have lights. They dropped her off at the clinic uptown, and she waited for hours without anyone picking her up. She cannot walk, but does not have a walker.

These are very important questions and comments. Within them, it is possible to clearly “hear” elders stating their needs for: transportation, nutrition, caregivers, income, chronic disease management, care for frail elders, adaptive equipment, and protection. There are resources to answer these needs, but unfortunately, the resources are not yet “packaged up” in one resource location, where they can be easily accessed. It can take a lot of effort and time to get these types of concerns resolved. In reality, the type of support services that are needed are often available, but the effort is in trying to figure out how to access them! The process of accessing community-based LTSS can sometimes feel like finding a path through a “maze”!

In the meantime, it is necessary for American Indian communities to search out the range of funded LTSS programs through state aging service networks and human services departments. Because of the complexity of services, it might be helpful to think about available health care and LTSS resources “a piece at a time”. Understanding the full range of services that are available can then lead Tribal communities to “weave” them into a “user-friendly system” of LTSS care. Currently, the Centers for Medicare/Medicaid Services (CMS) is working with IHS and Tribes to strategically plan for LTSS in Tribal communities. Hopefully, in the future this work will create “easy access points” for community-based LTSS for elders in each local community.

The remainder of Session 3.2 will identify other resources available for elders. Later, Session 3.3 will offer “tips” for caregivers about how to “navigate” access to resources in their local settings.
Common Health Care Resources

Indian Health Service (IHS)

The Indian Health Service (IHS) is responsible to offer primary care health and preventive services to approximately 2.2 million American Indians and Alaska Natives. The obligation to provide health services to Native people falls under the federal trust responsibility of the U.S. government, established by long-standing treaties and laws. Healthcare through IHS includes medical care, dental care, public health nursing and pharmacy services. Across the U.S. there are 612 IHS and Tribally administered health facilities, usually on or near reservation lands. However, although the IHS is obligated to provide health care services, the actual access and use of those services varies across states between 20% to 80%.

Contract Health Services (now called “Purchased/Referred Care” or PRC) are paid for by IHS to refer people for health care services that cannot be offered at a local IHS clinic or hospital, such as advanced testing or surgeries. A number of health services are also “contracted out” by the IHS to be directly provided by Tribal entities in local communities. These contracts can be limited to community-based services, such as the Community Health Representatives (CHRs), or can include entire clinic facilities.

However, since IHS is historically underfunded as compared to need, local IHS and PRC services are also often limited. Despite the federal obligation to fund health care for American Indians/Alaskan Native, IHS budgets frequently are not able to meet the health care needs in Indian Country. There are also about 33 urban Indian Health Centers in cities throughout the U.S., however, these facilities are limited, especially since they are not able to make referrals through PRC. In short, the limitations in the annually appropriated IHS budget are so severe, that “individuals who rely solely on IHS for care without any form of insurance coverage are classified by the U.S. Census as uninsured.”
LTSS and IHS

The Indian Health Care Improvement Act (IHCIA) was made permanent in 2010 at the time the Patient Protection and Affordable Care Act (ACA) was signed into law by President Obama. Major changes were included in the updated IHCIA law, including authorization for IHS to address a range of community-based health services, including: hospice, assisted living, long-term nursing home care, and home & community-based services (HCBS) \(^{88,89}\). There has been an ongoing partnership among the IHS, CMS, the American Indian/Alaskan Native LTSS Technical Assistance Center, and the Administration on Aging to strategically plan for LTSS in Tribal communities\(^{90}\). However, since full funding to IHS for the new LTSS authorizations has not yet been provided, this means that IHS is not yet able to fund hospice, assisted living, long-term nursing home care, and HCBS.

Community Health Representative Program (CHR)

The CHR programs are the “vital link”\(^{91}\) between the formal health care system and tribal members in reservation communities. CHR programs are an example of a community Tribal program which has been “contracted” under the “Public Law 638” mechanism for community-based services. CHR programs have enormous potential to assist and advocate for elders in their communities. In the formal absence of an integrated LTSS structure, CHR programs have served rural Tribal Nations for 47 years, providing an informal gateway to resources and direct provision of care for elders. 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.\(^{92}\)

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 make very good health partners for elders and caregivers who need
“hands-on” help in accessing 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, housing-related needs, 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 and extended 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
- Make arrangements for visits with the public health nurse
- Arrange transportation to the clinic or hospital
- Make referrals through their Tribal Health Department to arrange 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

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 “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 now at increased risk in her home. The CHR was able to arrange an
assessment for the elder to access home-based services under Medicaid.

Based on their special attention to rural Tribal elders, CHRs were approved in 2012 under a Medicaid State Plan Amendment in the state of North Dakota to provide Targeted Case Management for elders who need assessments for HCBS.93 Hopefully, as IHS and CMS and Tribes work together towards creating a network of LTSS in rural Tribal communities, CHRs in the Targeted Case Management role will be designated as the “entry point” to a coordinated LTSS network for elders.

**Diabetes Programming through IHS**94 **and Tribal Programming**95

Because of the epidemic rates of type 2 diabetes in Indian Country (especially among elders) there is a need for special diabetes-related programming.96 The IHS Division of Diabetes94 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 youth prevention programming, while others focus on outreach activities and prevention with adults.

**Medicare**97

Medicare is a federally funded and administered program. Those Native elders who meet eligibility for Medicare can have improved access to health services, as compared to elders who are totally dependent on IHS. Medicare is a federally funded health insurance program for people who meet the following eligibility requirements:

- Age 65 or older

- A documented work history of enough hours for entitlement to benefits

- A spouse is 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. The disability designation is a little more complicated in terms of meeting and documenting disability requirements for Medicare and Medicaid benefits. Consultation with the Purchased Referred Care (PRC) staff at IHS (formerly known as Contract Health Services) would be very helpful to determine this eligibility and to assist with an application. In fact, to get help with determining eligibility for many different sources of funding, it is recommended that an elder (or family member) go to IHS for this information. The PRC staff and Benefits Coordinator work with insurance eligibility determinations on a daily basis. They have been found to be very knowledgeable about these issues and willing to help elders and their family caregivers.

What does Medicare Cover?
This is a very important question, as Medicare has several parts to it. Medicare benefits are organized into Medicare A, Medicare B, Medicare C, and Medicare D.

Medicare A
Medicare A benefits pay for stays in hospitals (including IHS hospitals) and nursing homes. However, nursing home payments by Medicare are very temporary. Medicare will only pay nursing home costs related to a specific health problem, for example, for recovery and therapy after being in the hospital. 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. In terms of preventive services, Medicare (and
Medicaid, also) will pay the cost for elders to receive the flu vaccine, the pneumococcal vaccine, and hepatitis B vaccines.

**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.

**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, so elders can access their medications through the IHS. It is recommended that an elder/caregiver visit with the benefits coordinator at IHS to see if an elder could apply for Medicare D benefits, and if the IHS Pharmacy can be the provider.

**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 many rural Tribal communities without access to either Home Health or Hospice services. And, although Home Health benefits can be covered by Part A and Part B, Medicare will not cover ongoing Personal Care Services (PCS) in the home, such as bathing, toileting, dressing, etc. PCS types of services are a mainstay for “aging in place”, so Medicare cannot be the primary funder for planning community-based LTSS. However, Medicare can be the primary provider for hospice services.

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 person may be allowed to have 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 home health through Medicare funding.

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

**What does Medicare insurance cost me?**

There are many rules and regulations involved with Medicare funding, for example, Medicare B can require a monthly premium. It is best to determine a person’s individual coverage, and any specific additional Medicare costs with a benefits resource person. Again, it is recommended in rural Tribal communities to consult on insurance coverage with advice from the IHS Benefits Coordinator, or Purchased Referred Care staff at IHS (formerly Contract Health Service), or perhaps county social services.

**Has Medicare been Changed by the Affordable Care Act? (ACA) 98**

Medicare is not part of the “Insurance Marketplace” under the new health care law (ACA), so Medicare will continue to provide the same benefits it has in the past. There are some new preventive services that are also provided by Medicare under the Affordable Care Act, such as mammogram, colonoscopy, and an annual “Wellness” visit. These services will be provided under Medicare now at no cost to the “Part B” coinsurance or deductible.

The information directly above has been a very brief “overview” of Medicare, but it is highly recommended that eligible elders access the many benefits Medicare offers. Now, the discussion below will switch gears to Medicaid benefits.
**Medicaid Funding**  

Medicaid is different from Medicare, although it is sometimes easy to get the two types of insurance mixed up! It is possible a person could even receive both Medicare and Medicaid benefits, if he/she is “dual-eligible”. Medicaid is a Federal-State funded program, with the Federal government having a cost-sharing arrangement with each state. However, Medicaid is a *state-administered* program. Each state individualizes its Medicaid programming, and therefore, Medicaid *services and eligibility vary from state to state*.

Medicaid insurance is similar to Medicare in providing coverage for necessary medical services, such as hospital stays, clinic visits, physician services, home health services, lab services, and immunizations. However, in contrast to Medicare, long-term nursing home care can be funded under Medicaid. Medicaid also will provide payment for transportation to non-emergency medical care appointments. In addition, there are many other services which can be “optionally” chosen by states to provide under their respective Medicaid programs. As stated above, Medicaid coverage will vary from state to state.

**Medicaid Eligibility**

Eligibility for Medicaid is based on *financial need*. *Unlike Medicare*, Medicaid is *not* based on work history. American Indian / Alaska Native people who meet the Medicaid eligibility requirements in their respective states are eligible for benefits. Medicaid has changed since the implementation of the Affordable Care Act (ACA). Medicaid had previously been available to children, low income elders (over age 65), and adults with special medical needs. However, under the ACA, low-income, non-disabled adults who are younger than age 65 may now apply for Medicaid insurance *in states which have adopted Medicaid Expansion*. About 30 states have adopted “Medicaid Expansion”, and others are considering adoption. It is estimated that thousands of American Indians and Alaska Natives may be able to enroll in Medicaid under the new guidelines of the ACA.
Elders’ eligibility criteria for Medicaid include the following:

- Elders who are 65 years of age and older
- Elders who meet the guideline for being low income
- 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 eligibility vary from state to state. But, overall, a person’s income and level of assets have to be quite low. However, in determining a person’s assets, an elder’s home, car, clothing, burial plot, and household goods are not counted towards the limit of assets.

In contrast to Medicare, the Medicaid program will pay for long-term nursing home care if need for such care is clearly documented according to state regulations. Elders’ resources have to be extremely limited, but they can keep a car, their home and personal belongings. However, after an elder passes away, the state may pursue “estate recovery” for nursing home related Medicaid expenses. 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.

Home & Community-Based Services (HCBS) under Medicaid

Many States have chosen to provide Home and Community-Based Services (HCBS) for elders and people with disabilities under the Medicaid Waiver program. Through State HCBS Waiver programs, the wishes of elders and people with disabilities to continue living in their own home settings can be honored. At the same time, State Medicaid programs are quite interested in keeping people out of expensive nursing home settings, by offering services through less the costly HCBS programs. If determined to be eligible, elders may receive personal care services
(bathing, toileting, dressing) and chore services (cooking, cleaning, etc.) under Medicaid funded programs. Overall, in comparison the HCBS Medicaid focus for home-based care is more “non-medical”, as compared to Medicare Home-Health services which are more “medically-oriented”.

The expense associated with nursing home care is a serious challenge to all state Medicaid budgets. Since community-based LTSS are significantly lower than costs associated with institutional nursing home care, newer options have been proposed, such as the Tribal “Money Follows the Person” program (MFP). The “MFP” holds promise for allowing people residing in nursing homes to have the support to return to a home setting. Other alternative models are also being proposed under the Affordable Care Act (ACA) to increase access to LTSS under Medicaid, such as the “Community First Choice” program.

In some states, elders whose incomes are “close to Medicaid eligibility” are allowed to pay a portion of the HCBS fee “out of pocket”, so they can still access community-based LTSS benefits under Medicaid. Some states also offer other LTSS-types of programs that are funded completely by state funds, for people whose income is too high to be eligible for Medicaid, but who do still need financial assistance to pay for community LTSS expenses.

In short, each state may decide which LTSS services to provide. To determine if an individual elder is eligible for Medicaid and for community-based LTSS programs, it will be necessary to contact the Medicaid office in the state in which an elder lives, or to visit the local county office, or to contact the PRC (Purchased Referred Care) personnel or Benefits Coordinator staff at the local IHS clinic.

The Affordable Care Act (ACA) Qualified Health Plans (QHPs)

A discussion of health care resources needs to include the Affordable Care Act of 2010, and the implementation of the Health Insurance Marketplace. American Indians and Alaska Natives who do not qualify for Medicare or Medicaid may choose to enroll in a Qualified Health Plan. But, they may also continue to receive
health services from an Indian health care provider in their community.105

Due to the amount of new information related to health insurance since the passing of the ACA law, “Assisters”106 (or “Navigators”107) have been funded to assist people who want to seek insurance coverage through the new Insurance Marketplace. Navigators have special training to expertly guide people through the health insurance plans on the “exchange”, and to also help people to find out if they may be eligible for Medicaid. In the Great Plains region, the Tribal Chairmen’s Health Board (GPTHB) has implemented a “Navigator” program.108

The Navigators travel throughout the Great Plains region to hold community information sessions, to help individuals sign-up for insurance, and to explain the many “rules” that go with the new mandatory requirement for everyone to have an approved health insurance plan.

In the Great Plains region, the GPTCHB Navigators have been very helpful to the American Indian population, as they are not only knowledgeable about the Insurance Marketplace, but are also able to answer questions about the details of Medicaid Expansion benefits that have been adopted in North Dakota.108
Summary Session 3.2

In summary, the complexity of the health care system is very real. In addition to IHS resources, Native elders may be eligible for Medicare or Medicaid or both. Medicare is a Federal program with eligibility guidelines based primarily on work history. Medicaid is a Federal-State program with eligibility based on financial need. Medicare provides the same services across the nation, under strict criteria. Medicaid services vary state by state, but many states have a program of HCBS for elders to continue living in the community with LTSS.

In order to determine an individual’s eligibility for these programs, or for a private insurance plan under the Insurance Marketplace, it is recommended that elders and family caregivers seek assistance. Help can be accessed through the Benefits Coordinator or PRC staff at IHS or ACA Navigators in the community. It is also possible to contact an entity within the state Aging Services Network, the state Aging Services Department, or state Human Services department, or a Title VI Nutrition Program Director on the reservation. There are many resource people who can be approached, to assist elders to create a plan to access community-based LTSS. Although the “system” may seem like a “maze”, it is possible to learn about the variety of available resources “one piece at a time” and to use them!
SESSION 3.3
Navigating “Tips” in Health Care & Social Services
Session 3.3  “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 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 him, 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 feasible for the 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. For example, “overall, 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 following question will vary from person to person, and family to family, but it is an important question to answer:

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

Facing Realistic Challenges

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 in a good way. 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 are “networked” with 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 Purchased Referred Care (formerly Contract Health Services) 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 finding “who” is the important first step.
#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? A 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.

#4 Tip: Draw a picture of the health care 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 5 below is an example of a “picture” of the constellation of services” that may be “mapped out” in a local community. From each entity identified in the Figure 5 “picture” below a “follow-up” chart can be created (see Table 2) and the following information can be inserted:

- Services they provide
- Names of the providers
- Location of the services
- Contact phone number for the service (or website)
- Days and times that the services can be accessed
- Payment information, and funding source for services
Figure 5: A Constellation of Community Services for Successful Aging in Place

Accessing and Mapping Existing Services

The following table below is just one example of how a chart can be developed to help improve access to services. (This chart happens to present some of the...
available services that an Indian Health Service Clinic might offer as an example, but any service system could be “mapped” in this way).

Table 2. 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 5 PM</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 updated as changes in services occur. Copies of this kind of “individualized” chart of current health care services can be distributed to other caregivers (family, friends and professionals) and updated as needed.
**#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.

The point being made here is that 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, just ask!

Summary Session 3.3

There are several “tips” to follow in successfully accessing and keeping track of 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!
SESSION 3.4
Caregivers: Contributions & Stressors
SESSION 3.4  CAREGIVERS: CONTRIBUTIONS & STRESSORS

PURPOSE

• Understand the essential role of caregivers in the LTSS system

• Understand sources of caregiver stress and risk for burn-out

OBJECTIVES

At the end of the session, participants will:

1. Identify the indispensable contribution that caregivers make in providing LTSS to elders and to the entire health care system

2. Review the challenges to informal (family/friends) caregivers

3. Identify common stressors and stress responses of caregivers

4. Identify symptoms that signal “burn-out” in caregivers

LEARNING OPPORTUNITIES

1. Talking Circle focused on needs of caregivers

2. Identify assessment information that can be used to assess stressors for caregivers

3. Identify potential resources to approach quickly when burn-out seems likely
“Some Ideas to Think About”

Importance of Caregivers

The importance of caregivers cannot be overstated in the ongoing care of elders across the U.S. We will present just a few “statistics” here to help frame the “context” of why caregivers are not only important, but are actually essential to the entire health care system. By the year 2040, there will be 82.3 million people over the age of 65, a number which is more than double the number of people over 65 reported in 2000. Significantly, it has also been estimated that between the years 2013 – 2040, the number of elders over the age of 85 will triple in the general population. Given the increasing number of chronic conditions and related disabilities that increase with age, it will become even more challenging for the health care system to accommodate the many “day to day” needs of the increasing numbers of elders.

The challenge to accommodate increasing needs of elders will become even more true for American Indians and Alaskan Natives as the population of Native elders quadruples by the year 2050. The Native elder population has higher rates of many common chronic conditions including diabetes, arthritis, hypertension, obesity, and vision loss. These, as well as other conditions, can lead to disabilities which impact “day to day” living, making it necessary to have assistance with ADLs and IADLs, as was discussed in Session 2.5.

Overall, Native “elders living in rural areas, by almost all economic, health, and social indicators are poorer, less healthy, have limited and poorer housing, have fewer options in transportation, and less access to health professionals and community-based services”. The reality of providing care to rural Native elders will mean that the provision of support for elder caregivers in rural Tribal communities must become a high priority.
Remaining Discussion for Session 3.4

Given the above information, the topic of “caregivers”, as the saying goes, is: “where the rubber hits the road” for successful care of elders in the community setting. The success of “aging in place” is closely intertwined with the “support of caregivers”. The remainder of Session 3.4 will be organized into three topic areas that relate to caregivers in their important role of caregiving:

- **Who are caregivers?**
- **Contributions of caregivers**
- **Caregiver stress and risk of “burn-out”**

Session 3.5 will then address the following three topic areas to propose recommendations and solutions to the challenges of caregiving:

- **Tips for relieving caregiver stress**
- **Resources for caregiving support**
- **Meeting training needs of caregivers**

**Who are Caregivers?**

The definition of a “caregiver” is “someone typically over age 18 who provides care for another. It may be a person who is responsible for the direct care, protection, and supervision of children in a child care home, or someone who tends to the needs of the elderly or disabled. It is generally one who gives assistance to another person who is no longer able to perform the critical tasks of personal or household care necessary for everyday survival”.

Caregivers may be “paid” (such as those hired by a health care agency or institution) or “unpaid” or “informal” (those who donate their time and effort as family and friends). The remainder of Session 3.4 will apply to those “unpaid” or “informal” caregivers, who are family and friends caring for elders in the home setting, making it possible for them to “age in place”.

Caregivers are us! “Most Americans will be informal caregivers at some point during their lives”.115 Most caregivers are middle-aged, 61% are women, and 59% of caregivers have “other” jobs, besides their caregiver duties.115

Contributions Made by Caregivers to “the System”

Of course it is a “given” that caregivers contribute to the quality of life for their elders. But, it needs to be recognized that the contributions made by caregivers will continue to be the backbone of providing health care to the elder population of the future. From a health care system perspective, the contribution of caregivers is not only linked to quality of life for individuals, but to the survival of the long term care system in the U.S. It is estimated that informal (unpaid) caregivers provide at least 80% of long term care in the U.S.!115 In fact, the contribution of caregivers is so critical to the long term care system that the Centers for Disease Control and Prevention (CDC) has identified that caregiving is emerging as a critical public health issue.

Public health efforts need to focus on improving and maintaining caregiver health and well-being.116 The fact that about 13% of caregivers are themselves aged 65 and older makes health maintenance all the more important among elders caring for elders.115 In the community setting, focusing on the training needs and support of caregivers is, and will continue to be, as critical to the health of elders as strategic planning for Home and Community-based Services (HCBS) at a systems level. Carol Levine (Director of the Families and Health Care Project for the United Hospital Fund in New York) very clearly summarized the need for supporting the informal network of caregivers:

“If the family caregivers are not able to carry out this function, then there will be an incredible drain on the formal (paid) caregiving system. So there is a very strong interest that is benevolent, but also pragmatic, that we have to keep these caregivers on the job, or we are going to be in very big trouble.”116
Just in terms of the economics of health care, caregivers contribute an estimated $450 billion in unpaid services in the home setting annually. Additionally, in 2009 it was estimated that the unpaid caregiver workforce numbered 42.1 to 61.6 million caregivers who provided some level of care to an adult with limitations in ADLs and/or IADLs. Just to have an idea of how much $450 billion is “worth”, this is more than the total sales of the Walmart corporation in 2009!

**Caregiver Stress & the “Sandwich Generation”**

The range of caregiver duties will be unique to each elder who requires care to “age in place”. The commitment to care for a family member who needs help is an act worthy of great respect and among Native people, caregiving is considered one of the highest duties that one can provide. However, although the decision to be a caregiver may come from a sense of dedication and bonds of loving relationships, the ongoing nature of caregiving can demand more from a caregiver physically, emotionally, and financially than a person is able to offer over time.

An increasingly common “stressor” for caregivers is the feeling of being “sandwiched in”. The “sandwich generation” describes caregivers who are clearly caught in between generations, trying to meet the needs, demands and obligations to elderly parents while also responding to those of their children. Another increasingly common situation in Indian Country is that 56% of American Indians/Alaska Natives over the age of 30 have grandchildren living in their homes, and they are the primary caregivers for their grandchildren.

Having grandparents raising grandchildren is often considered a valued cultural practice, offering many benefits for both the children and the grandparents. However, if younger grandparents also have caregiving obligations for family elders, they will be “sandwiched in” with additional stressors. If the grandchildren living with their grandparents have emotional issues related to their parents’ absence, or if there are substance abuse issues, or if resources (including financial resources) are limited, then the stress for caregivers can be significantly increased for caregivers who are raising grandchildren in addition to caring for elders.
The characteristics of each caregiving situation will influence the amount of caregiver “burden” and the long-term feasibility of providing caregiver services in the home setting:

- amount and frequency of care needed
- types of chronic health conditions than an elder has
- extent of disabilities
- presence of cognitive deficits
- prior relationship between an elder and the caregiver

For example, it may be a big help to an elder and quite “manageable” for a caregiver to do grocery shopping once a week, or to arrange transportation for a monthly medical appointment, or even to check in once a day to prepare a meal for an elder who has been a loving member of the extended family. But it might be quite another situation to provide “round the clock” care to assist an elder who has dementia, and/or requires assistance with eating, toileting, dressing, bathing, ambulating, managing finances, taking medications, etc.

A more complicated stressor may also be imposed on the task of caregiving if there had previously been a “rocky” relationship between the caregiver and the person receiving care, such as if there has been a history of the caregiver being abused by the elder in the past. Yet another added stressor of financial strain is commonly added to caregiving. Very often, a caregiver has to cut back on their paid work hours or has to resign from the workplace in order to continue caregiving tasks. It is important to clearly identify not only caregiving needs, but the resilience of the caregiver and the availability of supports.

**Negative Health Effects Experienced by Caregivers**

Research has shown the following negative health effects on caregivers who have trouble coping with the ongoing demands of their caregiving duties:

- Increased symptoms of depression or anxiety
- Increased incidence of long-term medical problems
• Increased levels of stress hormones
• Decreased immune system response to the flu or flu vaccine (can result in decreased effectiveness of the flu shot)
• Decreased ability for wound healing (takes longer to heal)
• Increased levels of obesity
• Increased risk for mental decline, such as memory or attention skills

In fact, it “makes sense” that caregivers may have increased health problems, as caregivers have also reported that they are less likely to: \[124\]

• go to the clinic for their own medical appointments
• fill their own prescriptions due to increased costs
• schedule routine mammograms for themselves
• get enough sleep
• cook healthy meals for themselves to eat
• get regular physical activity

**Signs of “Burn-Out” for Caregivers** \[116, 124\]

Caregivers are so often focused on “getting everything done”, that they do not have the luxury of paying attention to signals that may be telling them they are at risk for “burn-out” that is, being overwhelmed by the activities of caregiving in everyday life. Realistically, it is not considered an option for caregivers to “give up” their caregiving role unless an emergency type of situation arises. But, if they can recognize the signals of too much stress, it may help them to validate that “yes, in fact, I am having trouble” and prompt them to reach out for help.

Many caregivers feel they no longer have time or energy to maintain relationships with other family and friends. However, when “overwhelmed”, it is the right time to seek out friends or family who can help directly with caregiving tasks, or at least can assist in finding available resources. It is also a good thing for family and friends.
to check in with caregivers, to assess how they are coping, and to offer them assistance. It is “ok” for caregivers to expect that others can and will help them when recognizing symptoms of stress from caregiving duties. Caregivers who do not recognize “burn-out” or who do not know how to ask for help, can put themselves at higher risk for poor health, making mistakes in giving medications, “emotional explosions”, or even abusive actions.

The following “signals” have been identified that caregivers need to “pay attention to”, so they can reach out for help. It is essential for caregivers to balance their own health with their caregiving duties:

- Feeling overwhelmed
- Sleeping too much or too little
- Gaining or losing a lot of weight
- Feeling tired most of the time
- Losing interest in activities they used to enjoy
- Becoming easily angered or irritated
- Feeling constantly worried
- Feeling sad frequently
- Having frequent pains, headaches, or other physical problems
- Abusing alcohol or drugs (including prescription drugs)

These are stress symptoms that “signal” that a caregiver needs help quickly. It is especially important to recognize these symptoms as a caregiver, or as a friend or relative of a caregiver. To continue to try to perform the role of caregiving in an overwhelming situation may reach a point where a caregiver may harm herself/himself or may become physically or emotionally abusive to an elder. At this point, it is essential to get help from a health professional or counselor right away.
Summary Session 3.4

Family and friends who serve elders in Indian Country as caregivers are truly irreplaceable. Their contributions make it possible to maintain elders safely in their homes, and to honor their elders’ wishes to age in place for as long as possible. However, it is important to recognize not only the contributions that caregivers make directly to their own elders, but to the entire long term care system in the United States, and especially in Indian Country.

As discussed above in Session 2.5, an elder’s “functional status” in ADLs and IADLs will greatly influence the feasibility of caring for an elder in the home setting over the long term. In fact, the placement of an elder into an institutional setting, such as a nursing home is very often due to increasing stress and burden on a caregiver who begins to suffer negative health consequences herself/himself. So, it is essential to also recognize the significant amount of effort that is often involved in caregiving, as well as to recognize when the effort does become “too much”, to the detriment of the caregiver’s health. In the following Session 3.5, the discussion will turn to strengthening supports for caregivers, so they may continue in this most valuable role.
SESSION 3.5
Caring for the Caregiver:
Recommendations
SESSION 3.5  CARE FOR THE CAREGIVER: RECOMMENDATIONS

PURPOSE

• Understand specific ways to manage the stress of caregiving

• Understand how to access resources for caregivers for stress management, learning new caregiving skills, finding local and regional resources

• Learn of available resources for services and planning LTSS

OBJECTIVES

At the end of the session, participants will:

1. Identify common approaches to stress management that can be realistically practiced by caregivers

2. Identify community and regional resources caregivers can access for additional help

3. Identify learning needs of caregivers

4. Identify strategies to plan for LTSS that meet local Tribal needs

LEARNING OPPORTUNITIES

• Talking Circle to share / brainstorm a list of available and desired resources for support of caregivers

• Create a map of the most useful LTSS resources that are locally accessible

• Create a realistic stress management plan
“Some Ideas to Think About”

Session 3.4 focused on stressors and responses to stressors which caregivers commonly experience. Session 3.5 will focus on approaches to problem-solving by caregivers. Realistically, caregivers will experience stress at varying levels throughout the entire time they serve as caregivers. In short, the role of caregiver will never be a “stress free zone”. However, the ability to continue to perform as caregivers can be strengthened by learning to effectively manage stress and to access helpful resources. Session 3.5 will address the following areas:

- Tips for relieving caregiver stress
- Resources for caregiving support
- Meeting training needs of caregivers

Tips for Relieving Caregiver Stress

Many of the recommendations commonly proposed to relieve caregiver stress do fall under the category of health promotion practices. Various caregiver-related websites seem to encourage caregivers in similar ways to reduce stress. Below will be a “long list” of what we will call “stress-busters”, many taken from recommendations on the Womenshealth.gov websites, under the U.S. Department of Health and Human Services. Just the fact that there are government websites and national organization websites that are entirely devoted to the support of caregivers gives us an indication of how very important the caregiver role is to the entire health care system, as well as to individuals and families.

Each of the recommendations proposed below is helpful and will be effective if practiced. However, it is acknowledged that not all of them will be automatically “easy” to incorporate into a caregiver’s daily routine, a routine that is already full of daily obligations and often “surprise” stressors. All of life is a journey and change is a certainty! So, adaptation and flexibility are essential tools to be carried
along on the caregiving journey. But, it is recommended that in approaching the journey, that three “hard and fast” rules be adopted: 1) “take one day at a time”; 2) “seek out a supportive listener”; 3) “ask for help when needed”.

Caregivers are encouraged to identify a few recommendations from the “stress-buster” list below that seem to offer the most support to their unique caregiving situations. Prioritizing just a few of the recommendations to put into practice will be a good way to start improving stress management and coping skills. Over time, additional “stress-busters” can be tried, and the eventual adoption of many (or nearly all) of the recommendations may actually be possible over time. For “starters” though, choosing 1 to 3 “tips” that seem to offer the most benefit to unique caregiving situations may be the best approach.

The recommendations that are offered below are meant to be helpful, not to become additional stressors that overwhelm a caregiver! A gradual approach and commitment to stress reduction can offer the most realistic potential for a caregiver to find out “what works” to steadily decrease stress levels that are associated with the long-term, ongoing work of caregiving.

Planning to Address Caregiver Stress

As an overall strategy, it may be helpful for caregivers to first spend a little time thinking about how to best accomplish the following 4 goals:

1. Identify sources of stress
2. Learn strategies to adapt to stress
3. Control the source of stress as much as possible
4. Take breaks from the stress

Unfortunately, there is not one “medicine” for stress. But fortunately, there are many strategies which can be combined, providing improved “care for caregivers”.

Unfortunately, there is not one “medicine” for stress. But fortunately, there are many strategies which can be combined, providing improved “care for caregivers”.
Stages of Change: Getting Ready to Make Changes

When deciding to start practicing new stress-relieving strategies it is important for caregivers to recognize that there are “stages” to “behavior change”. In fact, there is a formal “stages of change” theory (developed in 1983 by Prochaska and DiClemente) which can help a caregiver to “size up” her/his current readiness for change. A self-assessment is an important step towards making changes.

Having a trusted person to talk with about stressors and strategies is a big part of stress management. As will be seen within the “stages of change” below, it would be very helpful to be able to talk through strategies at each “stage” with someone who understands the caregiving situation and who will be supportive. Finding a person who can “care for the caregiver” by listening and offering useful and encouraging feedback is one of the “hard and fast rules” for the caregiving journey.

The “stages of change” model explains that people move through a cycle of stages getting ready to make a change. A very short summary of the stages is presented here:

- **Pre-contemplation**: “I don’t think there is anything wrong, nothing to change”
- **Contemplation**: “Well, maybe I might have a problem, I might have to start thinking about making some changes to make things better”
- **Preparation**: “I am going to make some changes. I am planning what they will be, and I am going to try them out soon, like within the next month”
- **Action**: “Well, I have started and am steadily practicing the changes I decided that would work best for me, and they are actually working for me over these past few months”
- **Maintenance**: “I don’t even have to think about it much anymore, I have made the healthy changes in my life a routine now for months”
- **Relapse**: “Well, I lost my good habits. Things just got tough, and a lot of
problems came up and got me off track. I know what happened, but I don’t have the energy to just start right back on track. I guess I am back to “contemplation”. I know I have to get re-started on my stress management practices. I know I can get it done, I was successful before, and I will be again.”

Below in Figure 6, is a representation of the cycle for “stages of change”. As can be seen, the arrows represent motion from step to step to step. Change is truly a process that is never quite finished. It is good to remember, also, that “relapse” is as much a part of the process of change as “preparation” or “action”. The stages of change model allows for “re-grouping” when a relapse occurs, and the arrows direct the person back to the cycle to keep going.

**Figure 6: Stages of Change Representation**
Strategies for Successful Stress Management

The lists of helpful stress-reducing strategies below can look pretty long! And they all cannot be put into place overnight! But, this list of “stress-busters” can be prioritized and choices can be made about how to begin the process of “de-stressing”. A note of encouragement is offered here: it is not expected that anyone can “immediately” make many changes at once. It is realistic to appreciate that caregivers will need to have time to take steps that will relieve stress over time. As stated above, prioritizing just a few of the “stress-busters” from the lists below will be a good way to start improving stress management.

“Stress-Busting” Tips for Self-Care for the Caregiver

• Ask for and accept help when offered. Keep a ready list of things that someone could help with, such as taking an elder for a walk, or doing the grocery shopping for a week
• Stay in touch with friends and family to feel “connected”
• Find time to be physically active every day. If not possible to take a longer walk, remember that three 10 minute walks will do the trick! And if only 10 minutes of activity is possible on some days, then remember that “some exercise is better than none!”
• Establish as much of a regular daily routine as is possible in the situation you are in
• Look to community and faith-based groups for support and assistance
• Join a support group for caregivers with similar responsibilities
• Hire paid help to assist you if it is at all affordable. You cannot “afford” to not have help! You cannot afford to lose your health!
• Ask family for help with financial resources, even if only temporarily
• Take some time every day for yourself. Have coffee, take a walk, listen to music, pray, take a warm bath, read, take a nap, watch a favorite movie, make a short visit to other relatives or friends
• During the day, take mini-breaks for two minutes at a time of relaxation: taking a few deep breaths and exhaling slowly, relaxing tense muscles, concentrating on a pleasant thought, finishing up the mini-break with one more deep breath, and exhaling slowly. Do not expect to be a “perfect” caregiver. Just do the best a person can do, realizing that no one can be a “perfect” caregiver. It may be ok to be sad or regretful that things are the way they are. But, do not carry guilt for not making everything “perfect” in the situation. Perfection is not possible.

• Get enough sleep when at all possible. If not possible, look into purchasing paid overnight caregiving services or sharing night caregiving duties with another family member or friend.

Getting at least a few full nights’ sleep each week is essential to staying healthy. Not getting enough sleep on a regular basis is not an option. Long-term sleep deprivation is almost guaranteed to impact caregivers’ health in a negative way!

Additional Tips for “Stress-Busting”

• Find a resource person to help find supplementary caregiving resources in the community for you
• Ask for financial help from relatives if having to leave a job, or more expenses have come up to take care of an elder
• Take a break from a job under the Family & Medical Leave Act or even quit a job. If not possible financially, call for a family meeting to discuss options for financial support or for hiring additional caregivers
• Say “no” if asked by others to do outside tasks that take time away from caregiving and some time for self-care.
• Identify what can and what cannot be changed, pray the Serenity prayer for acceptance, courage and wisdom in the situation
• Change your approach or reaction to situations that just cannot be changed
• Set goals that are realistic by breaking large tasks into smaller “chunks” that can be accomplished successfully a step at a time
• Prioritize goals and make “to do” lists for each day
• Keep a routine as much as possible
• Seek advice from other caregivers on caregiving tips
• Identify learning and training needs
• Try to keep a sense of humor
• Get medical check-ups and immunizations on a regular basis
• Recognize symptoms of depression and burn-out & seek help quickly
• Find and use respite through family, friends, community-based resources
• Get out of the house for some recreation every week and search for formal respite services if other family and friends do not help

Other “Human” Resources to Ask for Help to Find Services

• Health care providers in the local health care system, such as dieticians, physicians, nurses, nurse practitioners, public health nurses, counselors, benefits coordinators, pharmacists
• Tribal Elderly Nutrition Programs (Title VI)
• Traditional Tribal leaders and spiritual advisors
• Local clergy and faith-based groups
• Tribal and County social workers
• Tribal Health Programs, especially Community Health Representatives (CHRPs)
• Tribal Council leaders and District representatives
• Tribal Elders’ Advisory Groups
• Tribal Law Enforcement
• Tribal Housing Office
A useful strategy would be for a caregiver to find the contact names, phone numbers and websites for each of these “human resources” above, then post a list of them on the refrigerator and keep the list handy by the telephone. This task of collecting resource information may actually take too long (or create more stress) for a caregiver to complete. However, this task is a great example of exactly the kind of task to ask family or friends to do. In fact, a list with all of the contact information may already be available, sitting on someone’s desk! Remember the tip: “Ask for and accept help”.

**Tips for Finding Medical Supplies Resources**

There are some non-profit and volunteer programs that can offer assistive devices at no cost to make physical caregiving tasks safer and easier, such as toilet riser seats, shower safety bars, shower chairs, non-skid mats, wheelchairs, walkers, canes, etc. If an elder is on Medicaid or Medicare, accessing these tools can often be worked out with a primary health care provider. Local Housing Programs can be asked to assist with installation of “assistive devices”, such as shower bars or handicapped ramps.

Disability service programs at the county and state level can also guide a caregiver to accessing appropriate “tools” for an elder who is disabled and would benefit from assistive technology. For example, in North Dakota, the Interagency
Program for Assistive Technology (IPAT) offers a full array of consultation services and “hardware” that can be accessed either at no cost, or for a reasonable rental fee to help people manage in the community with disabilities. Some disability-related programs will even help to find financing for hearing aids for elders who could benefit from them.

A personal care item which is often needed, but causes financial stress is disposable adult incontinence undergarments (diapers). These are used by elders who have difficulty with incontinence (not able to control bladder and/or bowel). Having the disposable diapers available can make a significant difference in easing the physical caregiving workload every day.

Adult diapers are expensive and their cost may contribute to financial hardship in addition to the physical hardship of providing incontinence care. Caregivers are frequently stressed by the management of incontinence issues in the home setting. Without the availability of adult undergarments (diapers) to facilitate incontinence care, the physical effort of maintaining cleanliness for the elder can eventually lead to caregiver exhaustion and nursing home placement for an elder.

There may be other avenues to access incontinence supplies. For example, contacting the primary medical provider can assist with access to a limited supply per month for an elder enrolled under Medicaid. There are even some philanthropic / volunteer organizations that can respond to a request for adult diapers. For example, in the Great Plains region the American Indian Relief Council (AIRC) collects many kinds of donated items, then moves them by truck to distribute in rural Tribal communities. Some CHRs make a special request for their “elderlies” to be put on the AIRC list to receive adult diapers on a monthly basis at no cost.
Tips for Using Simple Technology Resources in Care of Elders

Simple technologies can also be used to ease the worry of a caregiver. For example, an inexpensive “baby monitor” can be used as an intercom, so a caregiver can hear an elder when in other parts of the house. Emergency response systems are also available at a monthly cost “out of pocket”. The cost for the monthly fee may be something a family could provide for the elder, to make the job of the caregiver less stressful. These emergency response systems just involve having an “emergency button”, worn on a necklace or bracelet. The elder (or caregiver) can push the button to make an emergency call that will be transmitted to emergency medical services, as well as to other designated family members or friends.

Emergency response systems are not designed for people with “thinking problems” (dementia), since they may not remember what the button is for, or how to activate the button. But, an emergency response system is valuable for situations such as when someone has fallen and is unable to get up, or when there is another type of medical emergency, such as the onset of stroke symptoms or heart attack symptoms, or breathing distress which need medical care right away.

Another “low cost” technology is a “pay as you go” phone or a specially designed cell phone for elders that has larger buttons. If an elder can still use a phone, these phones are small and portable to be easily carried with them into any room in the house or bathroom or even into the backyard. This is not as safe a solution as an emergency response bracelet or necklace, since a fall may happen where the elder cannot reach the phone, or the phone is not in a pocket where it could be reached. However, some elders wear the lightweight phone in a small pouch around their necks.

A higher cost technology strategy would involve using a webcam video camera, like the “security cameras” in stores. The webcam system can be set up to not
only “hear” the elder in another part of the house as a baby monitor/intercom would, but would also allow the caregiver to “see” the elder. Still another higher cost technology is a “mobility monitor” similar to those used in nursing home settings for people with “thinking problems and confusion” (dementia). The monitor is worn on an ankle or wrist, and sets off an alarm if the elder gets out of range, such as leaving the house.

Of course, a most valuable technology that can open access to every kind of information about resources and services for caregivers is the internet. In fact, the contact information for nearly the entire list of “human resources” mentioned above could probably be accessed and printed in an hour with access to the internet and a good printer! However, the cost of computer hardware is still quite expensive for rural Tribal elders and their families.

And although the cost of computer technology is steadily decreasing and it may soon become more feasible for families to purchase a small computer or inexpensive “tablet”, nearly a third of Tribal residents did not have access to DSL or cable broadband, as stated in a report just a few years ago by the Federal Communications Commission.131

The FCC states it is a goal to have universal broadband access available throughout the country by 2020, however in the meantime, internet resources may not be available in many rural reservation homes for a while yet. For those communities that do have access, the internet can be an invaluable resource to caregivers. And for those elders and caregivers who do not have residential access to the internet, communities with Tribal colleges are usually offered computer access at no cost through the college libraries or other campus locations which remain open for many hours every day.

If a caregiver (or friend / family) does have access to a computer with internet access, a very useful website to bookmark is the “Eldercare Locator”. This site has been developed as a public service by the Administration on Aging, to help
families and other caregivers in locating any kind of Long Term Services & Supports programs throughout the U.S. The “Eldercare Locator” is a very helpful resource to begin an internet search for any type of elder services in specific geographic locations that match family needs. Other useful links can be “bookmarked” for quick access to a wide range of elder-care resources, such as the National Resource Center on Native American Aging, the Alzheimer’s Association, or the National Alliance for Caregiving.

Again, as internet access does become more available, resource and training materials can be obtained for almost any caregiving purpose, from reading about prevention of diabetes complications to watching a You-Tube video on how to give a bed bath! The future of caregiver training is increasingly hopeful as internet access will become more established in rural areas.

**Finding Help: the National Family Caregiver Support Program**

Congress created the National Family Caregiver Support Program (NFCSP) in 2000 to provide caregiver support grants to states, based on their populations of elders over the age of 70. Within the NFCSP is the Native American Caregiver Support Program. The establishment of the NFCSP was in itself a national recognition of the invaluable contribution made by caregivers to the entire LTSS system.

The National Family Caregiver Support Program (NFCSP) was specifically designed to provide family caregivers with the following 5 services:

1. Information about available services
2. Assistance to access services
3. Individual counseling, organization of support groups, and caregiver training
4. Respite Care to enable caregivers to take needed breaks & prevent the negative consequences of unrelieved stress on their own health
5. Supplemental services, on a limited basis, to complement family care
Under the 2006 Reauthorization of the Older Americans Act, the National Family Caregiver Support Program identified categories of caregivers as eligible to receive NFCSP services:

- Family caregivers of older adults age 60 or older
- Caregivers of a person with Alzheimer’s disease or a related disorder (regardless of age)
- Grandparents and relative caregivers aged 55 years or older, of children 18 years of age and younger
- Relative caregivers (not including natural or adoptive parents) 55 years and older who care for a disabled adult 19-59 years of age

When having difficulty in finding services, it would be beneficial to make contact with the NFCSP located within each state. Services will vary from state to state, so learning which services are available is valuable information. The NFCSP can answer questions of how to access services or how to be referred to needed services. The NFCSP has served over 2 million caregivers, with priority given to those people having the greatest social and economic needs. Annual surveys of caregivers through the Administration on Aging have overwhelmingly validated the value of the NFCSP in the support of family caregivers who have used their services.

Training Needs and Resources for Caregivers

As mentioned above, the NFCSP acknowledges the need for caregivers to have access to training so they can carry out their caregiving duties. Addressing the training needs of informal caregivers is very much a reflection of the acknowledgement that caregiver support is becoming a critical public health issue as the population ages. Nationally, LTSS programming will be challenged to keep pace, and caregivers will be increasingly needed.
Training Challenges in Rural Tribal Communities

Caregivers living in rural reservation communities need to be assisted to seek out training materials or to be provided with training materials if they do not have access to libraries, Tribal colleges, internet access, or local classes such as for Certified Nursing Assistants. Home & Community-Based Services (HCBS) programs at the state level do provide access to training for home-makers and personal care service providers who are paid under Medicaid Waiver or state-funded programs. However, training options can be variable within states and between states. Also, since most caregiving falls under the “informal” category (family and friends), “formal” state-based training programs would not be as readily available to informal caregivers.

In rural Tribal communities, it would be best for family caregivers to be referred, or to make a self-referral for individualized training from public health nurses, physicians, dieticians, diabetes educators and Community Health Representative (CHR) programs through the Tribal Health Departments or the Indian Health Service (IHS). It would be very helpful if one local health care provider could become a “training broker” for caregivers, plugging them into whatever kinds of resources that they will need. For example, a public health nurse in the Tribe might contact a dietician at IHS to assist a caregiver in planning appropriate meals for an elder on dialysis treatments.

Some Tribal Colleges can also be training partners. For example, a college may occasionally offer a training course for Certified Nursing Assistant (CNA) training, although this does require special funding and instructors. The Sitting Bull College at the Standing Rock Sioux Tribe has offered training using selected modules from the Native Elder Caregiver Curriculum (NECC) for CHRs throughout ND. The option of using the NECC as a training tool for CHRs, home-makers and personal care attendants working under state HCBS Waiver programs, and for family caregivers is quite feasible. The NECC can be offered through a “train the trainer” model partnering with local nurses, potentially being useful in Indian Country.
Post-Hospitalization Training Needs

Training needs for caregivers are particularly important to address when an elder is being discharged from a hospital. As the health care system continues to trend towards shorter hospital stays, it turns out that elders are often discharged to the home setting with complex medical care needs. In rural Tribal reservation communities, the need for home health assistance can become dire. Due to the location of reservation-based Tribal Nations, home health services (often associated with hospital systems) are simply too far away and are not made available to many rurally located Tribes.

The option to even plan for creating local HCBS or home health services is extremely challenging, as 92% of counties with primarily American Indian/Alaska Native populations are in official Health Professional Shortage Areas.135

This lack of health professionals and limited access to health care facilities in reservation communities also contributes to the inability to offer end-of-life care through the hospice model. The lack of hospice services will pose more difficulties to families as the American Indian/Alaskan Native population ages. Given elevated rates of chronic diseases and complications, elders may require end-of-life care more often in the future, and caregivers will need the support of hospice teams.

Training needs will vary for each caregiving situation. After hospitalization, some caregivers may need an intensive level of training to meet 24 hour “around the clock” care needs, including management of medical and nursing-oriented tasks. For example, an elder may require tube feedings, or may need maximal assistance in transfers. The risk of heavy lifting for a caregiver may require training to use a Hoyer lift safely for transfers. Even training for everyday tasks of bathing, dressing, and assisting an elder in and out of chairs (or cars) can help to prevent back injuries and muscle strains.
The challenge for caregivers during an elder’s hospitalization is to continue their own “stress reduction” and health promotion strategies, as they try to “juggle” hospital visits, lengthy stays at the bedside with a vulnerable elder, and other duties, such as keeping a job or caring for grandchildren. The hospitalization of an elder can be a significant source of additional caregiver stress, and “care for the caregiver” becomes even more important during this time.

Despite being worried about the elder’s condition, it is also necessary to be mentally and emotionally prepared to resume caregiving that may be more complicated after hospital discharge. During the hospitalization, it is “ok” for the caregiver to ask to leave the bedside for needed rest, nutrition, and exercise. It is also “ok” to ask for training from hospital staff before the elder is discharged if there will be new caregiver tasks to be provided in the home.

It is also “ok” to refuse to take an elder home if training and planning for assistance with new complex tasks has not been provided to the caregiver. Taking an elder home from the hospital without proper preparation can be dangerous to the health of the elder and extremely stressful for the caregiver. If a caregiver is unsure about how to take perform certain procedures or operate newly prescribed equipment, a request can be made to the hospital social worker to organize a meeting with family and professional staff to discuss training and caregiving issues. It is also a good practice to ask the social worker to help to make contacts with public health nurses and CHRs in the Tribal community.

**New Laws Related to Training of Family Caregivers**

Recently, at least 13 states are now requiring hospitals to actually train family caregivers in specific caregiving skills that will need to be performed once a family member is discharged to home. Lawmakers have approved what are called CARE laws, standing for: Caregiver, Advise, Record, Enable. This is a positive trend, as lack of training can add to caregiver stress and burden. There is also a risk to elders who may quickly require another admission to the hospital if appropriate
care is not provided in the home setting. As mentioned above, it is “ok” to refuse to take an elder home from the hospital who has complex medical and nursing needs if no health services have been planned for and/or no training has been provided to a capable caregiver. A caregiver can expect a social worker from the hospital setting to assist in preparing a safe and appropriate discharge plan.

**Common Caregiving Skills**

Many caregivers could benefit from training for a number of very common **caregiving skills** such as:

- Assisting with ADLs
- Setting up the home environment for caregiving
- Managing and organizing medication preparation and schedules
- Recognizing side effects of medications
- Operating equipment such as oxygen tanks/concentrators
- Managing chronic pain
- Communicating effectively with health care providers
- Making adaptations for sensory losses
- Managing safety and communication needs for elders with dementia
- Adapting homes for care-delivery as related to an elder’s condition

**Dementia Caregiving Skills**

Caregivers would also greatly benefit from specialized training to care for an elder with dementia. Caregiver support and training to special verbal and non-verbal communication skills are especially needed when caring for people with one of the types of dementias (such as Alzheimer’s disease, multi-infarct dementia, Parkinson’s related dementia, Lewy body dementia). The term “dementia” means “loss of thinking ability”. A person may not become physically disabled with dementia for many years, but “thinking ability” is progressively damaged from the onset and throughout the course of a dementia-related disease.
It is very helpful for caregivers of elders with dementia to realize 3 things and to remind themselves of these often: 1) dementias can only be managed, but cannot be “cured”; 2) the behaviors of a person with dementia can be very stressful to live with; and 3) the stressful behaviors of a person with dementia are due to a disease in the brain, and are not due to any intentional thinking or planning. It is not possible for a person with dementia to think or plan to be “annoying”. The disease in the brain causes the behaviors. This point is worth re-emphasizing.

Behaviors related to dementia may become increasingly difficult to cope with, but the elder with dementia has no voluntary control over a progressive brain disease that damages the ability to think clearly, to plan, to remember, to make judgments, and eventually to even recognize family members.

If another disease does not cause death, people do eventually die from diseases such as Alzheimer’s and Parkinson’s. There is no set “time-line” for the progression of dementia, so care is truly planned and delivered a “day at a time” by a caregiver who critically needs the support of health care providers and respite services.

The third “reminder” above is most important, as caregivers who are under non-stop stress (even “paid” caregivers) can become irritated and angry with the behaviors of a person who has dementia. This is why it is essential that caregivers have regular respite services, attend a support group if at all possible, and get training in how to use easy & effective communication techniques with people who have dementia. Dementias will significantly impact the health care system and LTSS programming into the future, since dementia becomes much more common in the oldest age groups, and this population is growing.

Excellent support information is available for caregivers on the Alzheimer’s Association website as a resource, and most of the information on that website is also pertinent to the care of persons with any type of dementia.
Because there is not yet a “cure” for dementia, at this time the most valuable “treatment” for a person with dementia is consistent care from an understanding and patient caregiver who becomes knowledgeable and trained in skills that “fit” dementia disorders... and who has a support network of her/his own!

Alzheimer’s disease and other dementias are progressive. This will mean that the care for elders with dementia will change over time. Sometimes the need for caregiving can last for years, making “around the clock” care a reality. Again, for caregivers involved in dementia care, the benefit of a support group cannot be over-emphasized. Caregivers have a wealth of experiences to share with one another as they journey through the various stages of dementia care during years of caregiving. Sharing ideas on a regular basis with other knowledgeable caregivers can make a difference in providing home management of an elder with dementia for a longer period of time.

Having good communication with a primary health care provider is also very important for both the management of dementia, as well as for the support of the caregiver. It is not easy to figure out the cause of extreme behavior changes when they occur and medical advice is sometimes needed. In some situations a sedating medication may be helpful, but very often a person with dementia can become over-sedated. In fact, in 2012 the federal government began regulating the use of sedating, anti-psychotic medications in nursing homes for people who have dementia because of evidence that they can be linked to many complications, even death. A much better response to difficult dementia-related behaviors can be learned through adaptations in verbal and non-verbal communication strategies and other approaches that are effective in “de-escalating” extreme behaviors.

It is true that behaviors of people with Alzheimer’s (and other dementias) can be quite unpredictable day to day. As the disease progresses caregivers must remain on the alert, especially to prevent safety-related problems. Respite services are
critically needed as time goes on. If other family caregivers or formal respite care is not made available to a full-time caregiver, it finally does become impossible to continue caregiving, literally “around the clock”, *plainly due to exhaustion*.

Website resources for caregivers of elders with dementia provide helpful links for every possible resource that a caregiver and family may need for help. If there is no way for a caregiver to access the internet directly, it is “ok” to ask a public health nurse or other health care provider, or a friend to find and provide the specific referral and education resources that are needed.

**Delirium as a Complication Affecting the Brain during Hospitalization**

Delirium is a separate category for a problem that affects “thinking ability” and behaviors. It may look like dementia, but it is a different health problem. Delirium symptoms can include an inability to focus, hallucinations, confusion, sleep problems, memory problems, changes in levels of consciousness, and disorganized thinking. Delirium most often happens during hospitalization of elderly patients. It is different from dementia, as it comes on suddenly, not gradually as dementia does.16

There is no one cause of delirium, but many causes are suspected that are related to being in the hospital, such as: medication reactions, infections, low oxygen levels, low blood pressure, trauma or surgery. It is estimated that delirium may affect 10% to 52% of hospitalized patients over the age of 65. And, more often delirium does seem to affect people who already have a dementia diagnosis before they are admitted to the hospital.16

It is difficult to be sure how to prevent delirium but current recommendations include: keeping patients mobile as much as is feasible in the hospital setting, preventing sleep deprivation, being sure patients wear their glasses and hearing aids, and using “cognitive orientation” with patients, that is, frequently reminding people of where they are, what time and day it is, why they are in the hospital, who is with them, etc.
So, even though elders may need to be placed in the hospital setting, they may need their caregivers with them more than ever to help with these preventive strategies! Delirium often goes away once the patient is discharged and returns to a familiar environment, but it can last for a while also. After hospital discharge, the primary care provider can evaluate the status of the delirium.

**What Kinds of Resources are Needed for Caregivers in Tribal Settings?**

It first needs to be said, that although faced with few resources, American Indian families do seem to have less difficulty in providing care to elders.139 The traditional value of respecting elders runs deep in the fabric of Native culture. In reservation settings, caregivers and elders share the many challenges in daily life. Together they face barriers to transportation, access to health care, adequate housing, and sufficient finances. Caregivers also face stresses in family relationships, and difficulties with behavioral health issues. Caregivers need the support of community-based services including: nutrition, home-maker, chore, respite, personal care, and home health services.139

In the midst of these challenges, caregivers continue to provide an irreplaceable service, so every effort should be made to provide support for them. Traditionally, Native American families have a strong commitment to the care of every generation. Native elders have given their lifetimes for the younger generation, and this often translates into the ongoing care of their children and grandchildren. In return, American Indian families are traditionally committed to providing for their elders:

> “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” 140, p.65
LTSS and HCBS Planning in Rural Tribal Communities

Community people do know what is most needed within their communities, and it is important to ask them for their input as Long Term Services and Supports (LTSS) are planned within each Tribal Nation. It is clear that the need for LTSS exists. It is recommended that Tribes seriously pursue the development of community-based LTSS programs in their local communities, and especially find ways to use Home & Community-Based Services (HCBS) programming through State Medicaid Waivers.

Having established local programs in Tribal communities will go a long way towards strengthening the ability for elders to age in place. Local resources need to be assessed, gaps identified, and the process begun to work with state and county departments to access available resources for Tribal elders.

It is possible to build a community-based program for LTSS. But, it does take the support and direction of Tribal leadership, followed by an in-depth planning phase that is informed by local stakeholders throughout the community. There are programs and funds available through each state to assist with the provision of community-based LTSS, especially through Medicaid. These resources can be successfully accessed once a Tribe decides to prioritize the building of a local LTSS network. Continued collaboration with Tribal, IHS, county, and state resource programs will eventually lead to the creation of the necessary infrastructure for strong community-based LTSS programs in rural Tribal Nations.

One Example of Problem-Solving through Community Input

If caregivers are asked, their needs can be identified, and their advice can be followed. Through community conversations, many problem areas can be identified and possible solutions can be offered. For example, at one community meeting in the Great Plains region, the importance of respite care came up. An elder stated that respite services can be difficult to find, especially for elders with
dementia. There was the concern that people who are confused with dementia may not understand a change of caregiver, and it may become even more difficult to take care of them when the usual caregiver is gone.

A solution suggested by other elders was to try to always use the same respite caregiver who was someone the elder knew and who seemed to make the elder feel comfortable. Then, it was also recommended to try out short periods of respite time at first, and then to work up to longer periods, so the usual caregiver could take regular breaks. Importantly at this meeting, the elders did not think it would be a good idea if the caregiver did not take a break.

Beyond the helpful suggestions from other elders in providing support for the caregiver who needed respite, there was another important outcome of this “community conversation”. The discussion created an awareness of a need for respite support for caregivers. The consensus of the community members made it clear that respite should not be “optional”. From meetings like this one, needs are identified and directions for building a Tribal LTSS network do emerge.

**Planning for Elder Programs in Rural Tribal Communities**

**Recommendation: Bring Community Shareholders Together**

Overall, it is recommended that Tribes who would like to proactively plan for HCBS for their elderly population begin by bringing together the shareholders in the community. Bringing together stakeholders who are committed to the care of elders and who want to prepare for future generations is a powerful strategy. A “synergy” is created when ideas and discussion are shared among people who care and who have a “stake” in a specific situation. Ideas will multiply! A “talking circle” among shareholders is an inexpensive and effective strategy for planning locally, and is recommended as the first step to take.

**Recommendation: Access National and Local Data that is Relevant & Available**

The National Resource Center on Native American Aging in the Center for Rural Health (located within the University of North Dakota) was opened in 1994. It is
one of three nationally designated centers for serving needs Native elders (the other two are in Alaska and Hawaii). The commitment to assisting Native elders can be seen in the NRCNAA Mission and Vision statements: *Mission: To identify and increase awareness of evolving Native elder health and social issues. Vision: To empower Native people to develop community based solutions.*

As part of the “mission” to “identify and increase awareness of evolving Native elder health and social issues”, the NRCNAA has collaboratively conducted surveys with literally hundreds of American Indian Nations and thousands of Native elders. The purpose of these surveys has been to find out directly from Tribal elders what they perceive as their most important needs. The survey process is often done in partnership with many of the Elderly Nutrition Programs throughout Indian Country (under Title VI of the Older Americans Act).

Answers to one of the survey questions (from the results of Cycle III of the NRCNAA surveys) indicated that overall, Native elders seemed very interested in using the following Home & Community-Based Services (HCBS) if they were made available:

- Adult day care
- Caregiver program
- Emergency response systems
- Financial assistance
- Home repair
- Home modification
- Legal assistance
- Home delivered meals
- Help with personal care (bathing, dressing, etc.)
- Assisted living facilities
- Senior Center programs
- Transportation
• Volunteer services

When planning for local elder programming, Tribes can easily access and utilize the NRCNAA survey data that is specific to their respective Tribes. The survey results can provide clear directions for future community LTSS planning. This information, when combined with input from community talking circles, can make it possible to plan LTSS that “fit” the needs of specific Tribes. Below is an example of how a Tribe did use this approach to successfully write for an LTSS planning and training grant a few years ago.

**Example and Template for Planning Grant**
One Tribal Nation in the Great Plains region used their NRCNAA survey data, followed up by a meeting with elders and community providers. From that meeting, they developed a “wish list to fill the gaps” in available services and local resources. From that “wish list”, a grant application was developed to apply for funding to plan for the needs that were identified which would help them to build stronger HCBS programming.

As a resource to assist Tribes with the grant application process for LTSS planning, Appendix C provides an example of a *draft* narrative for a grant application. This draft of a grant narrative may be useful to other rural American Indian Tribes as an example or “template” of what might be done with input from community elders and providers. (As mentioned previously, each Tribal Nation does have unique circumstances, and will be best served by assessing their own communities for the kinds of resources they know are needed. The “template” below in Appendix C is offered only as an example of a planning approach).
Summary Session 3.5

It is important to recognize, support, and appreciate the most important resource to American Indian elders, that is, their families and community members who serve as dedicated caregivers. The future of elder generations will depend on their continued strength and commitment.

However, it is also important for caregivers to “address their stress”. The relief of stress for each person can be achieved in different ways, so it is an important task of caregivers 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, it is possible to find a way that will work best to maintain strength for the caregiving journey. 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”.

On the “journey”, it is often helpful to enlist help from an “outside perspective”, for example, talking things over with a health care provider, social worker, spiritual advisor, counselor or a trusted friend. It is also helpful (and actually necessary) for caregivers to have their own learning and training needs met. This can be done in various ways through health care systems and Tribal colleges, as well as by self-learning through internet resources, caregiver support groups, and collaborations with local health care providers.

In order to build the increased capacity for community-based care of elders that will be needed, communities do need to identify their resources and their “resource gaps”. Shareholder meetings, supplemented with local and national survey data from various sources, can “jumpstart” the process of planning for Tribal-specific and locally relevant LTSS. Harnessing the “synergy” of dedicated community members, including caregivers and elders, can set the direction for improved community-based LTSS for elders in American Indian reservation settings for current and future generations.
SESSION 4.1
Elder Abuse Awareness
SESSION 4.1 ELDER ABUSE AWARENESS

PURPOSE

- Understand the risk to Native elders for elder abuse
- Understand the need for Tribes to create strong elder abuse prevention programming which integrates cultural strengths

OBJECTIVES

At the end of the session, participants will:

1. Identify the types of abuse that an elder can be at risk for
2. Identify signs that abuse may be happening to an elder
3. Identify risk factors for elder abuse
4. Identify interventions needed to address elder abuse

LEARNING OPPORTUNITIES

- Talking Circle focused on cultural values and traditions honoring elders
- Identify local resources to enlist in the protection of elders and prevention of elder abuse
- Create a draft of a proposal to establish a Tribal Elder Protection Code through a Community initiative
“Some Ideas to Think About”

The “idea” of elder abuse is very difficult to even think about, because the “traditional status of elders in American Indian and Alaska Native cultures is one of honor and respect.” But elder abuse is a harsh reality in contemporary life on the reservation. As with any form of abuse, goals must be targeted to prevention. The violation of respect that is inherent within any form of abuse is particularly difficult for Native elders to cope with, especially since respect is one of the deeply embedded traditional values of American Indian culture.

This topic of abuse is of direct relevance to caregivers. Caregivers by virtue of their caregiving role are thrust into the role of “protector”. They may be the only people close enough to an elder to observe signs that may indicate abuse is occurring or to recognize that the elder is at risk of being abused.

The caregiver may also be the only one who can assist the elder to address the abusive situation. The topic is also important to caregivers, since unrelenting stress and burden on caregivers can place them at risk for becoming abusive. And, in fact, studies have demonstrated that living with a caregiver or friend may increase the risk for elder abuse.

Session 4.1 will discuss: ways that elders may be abused, signs that abuse may be occurring, risk factors for elder abuse, and the challenge to implementing prevention and intervention strategies to stop abuse of Native elders.

Identification of Elder Abuse

It may be helpful to define the meaning of elder abuse. A working definition from the National Legal Resources Center within the Administration for Community Living (ACL) is stated immediately below.
The term (elder abuse) is used generically to include physical and sexual abuse, financial exploitation, psychological or emotional abuse, neglect by others, abandonment, and - sometimes- self-neglect. Elder abuse is committed by family members, friends, fiduciaries (including guardians and conservators), paid and volunteer caregivers, and others in a relationship of trust to the victim.143

By 2030, Native elders aged 65 and older will become 15% of the American Indian/Alaskan Native (AI/AN) population. This is more than double the number AI/AN elders in 2010. Consequently, it can be expected that elder abuse statistics will also increase if left unchecked.144 Below are some signs that can be observed in each category of abuse. Having knowledge of these signs can help a caregiver (or family member or friend or health care provider) to recognize when an elder needs help and protection.145

**Physical Abuse Signs**

- Unexplained falls and/or bruises, welts, scars, especially if symmetrically on both sides of the body (like wrists)
- Broken bones, sprains, dislocations
- Report of medication overdose or failure to take medications regularly
- Broken eyeglasses or frames
- Signs that restraints were used, such as rope marks
- Refusal to allow the elder to visit with someone else, isolating the elder

**Emotional Abuse Signs**

- Threatening, making fun of, or controlling the elder’s behavior
- Behavior of the elder that seems like dementia
**Sexual Abuse Signs**

- Bruising around breasts or genital area
- Unexplained genital infections or STDs
- Unexplained vaginal or rectal bleeding or underwear that is torn, stained or bloody

**Neglect Abuse Signs**

- Unusual weight loss, malnutrition, dehydration
- Problems such as bedsores that are appearing, not being treated
- Sanitation problems in the home such as dirt, bugs, soiled clothes/bedding
- Lack of hygiene and bathing
- Not wearing clothes for the weather, such as no jacket in cold weather
- Unsafe living conditions, such as having no water or heat, or fire safety issues
- Being left alone in a public place without help or food or water or a way to get to a restroom

**Financial Abuse Signs**

- Large sums of money withdrawn from an elder’s bank account
- Sudden changes in the elder’s financial situation, such as having no funds, for example, soon after receiving a social security check
• Items or money missing from the elder’s home

• Suspicious changes in legal documents such as wills or power of attorney or titles to cars or insurance policies

• Additions of people who have been allowed to sign a co-signature on documents like checks

• Unpaid bills or lack of medical care even when the elder should have enough income to pay for them

• Signs of financial activity that the elder could not have done, such as withdrawing money an ATM machine when the elder is homebound

• Unnecessary services, goods, or subscriptions in the home that the elder does not even use, or sales receipts for things the elder did not sell or buy

What Places an Elder More at Risk for Elder Abuse?

It is unknown how prevalent elder abuse is in Indian Country. It is assumed that elder abuse prevalence is rising, but most elder abuse is not reported. There are no large national research studies to draw from and very few Tribal studies that can help to accurately document the extent of the abuse of Native elders. This makes it difficult to understand what causes elder abuse, or to know what kinds of interventions or preventive strategies would work best to stop it.\textsuperscript{141}

Prosecution of elder abuse as a criminal offense is rather new (except for violent assaults or major theft/fraud), since abuse has usually been treated as a social service problem.\textsuperscript{141} Although it is not possible to know exactly who will become a victim of elder abuse, some situations have been identified as posing more risk for elders.
Situations that seem to make *elders more vulnerable to abuse* include: 145, 146, 147

- Social isolation, that is, not having a social network
- Poor mental health (such as depression)
- Dementia
- History of domestic violence in a home
- History of the elder as an abusive parent or spouse
- Strained relationships and frequent arguments with caregivers
- Intense caregiving needs, such as for a major illness or disability
- Use of verbal or physical aggression toward others

It is difficult to think about caregivers being abusers, since caregivers are often spouses, adult children or adult grandchildren of the abuse victims. However, from the previous discussion in Sessions 3.4 and 3.5, it is possible to see that the risk for abuse by a caregiver may increase over time, as coping skills become depleted and demands for caregiving tasks continue to increase. It is possible that a very well-meaning caregiver can just physically, mentally, and emotionally “wear out”. This makes it even more essential for caregivers to practice the strategy of “ask for and accept help”.

Situations that seem to make *caregivers more likely to become abusive* include:

- Stressors such as financial or health issues
- Caregiver burn-out
- Lack of respite services
- Depression
- Ineffective coping skills
- Alcohol or substance abuse
- Lack of training for caregiving tasks
- Other caregiving and/or work responsibilities

**Common Forms of Abusive Practices**

As stated above, very little formal study of elder abuse and its prevention has been done, and especially in Indian Country where only a handful of studies have ever been reported. However, accounts by Indian elders, families, and Tribes indicate that it is a serious and complex problem that will have no simple solution any time soon. From the limited information that is available, it seems that the main type of abuse of elders in Indian Country involves exploitation.

Exploitation means using or taking an elders’ resources (money or car or property) without permission or not paying back a loan. It may mean moving in with an elder and not helping the elder to pay expenses. Exploitation can also mean taking advantage of elders in other ways, such as leaving young grandchildren for extended periods with an elder who is too frail or does not have the resources to take care of children.

The other two types of abuse that seem to be most common are neglect and physical abuse. Neglect may include having no visitors, being left in the home without food, being left at home when community gatherings are going on, not helping an elder who is unable to care for self, or not getting medical treatment for an elder.

Types of emotional abuse may be more frequent, depending on how emotional abuse is defined. For example, emotional abuse may include yelling or saying
disrespectful things to an elder, threatening elderly parents or grandparents, using alcohol in the elder’s home, or ignoring elders when they speak.\textsuperscript{147} There can also be a form of abuse that falls under a category of “spiritual abuse”, such as when ceremonial items may be taken from the elder’s home and sold, or when an elder wishes to attend spiritual ceremonies and is denied the opportunity.\textsuperscript{147}

**Interventions to Prevent and Stop Elder Abuse**

**Tribal Codes**

Addressing elder abuse will require a combination of legal, Tribal, and social service interventions\textsuperscript{148} and the prevention of abuse will need to be addressed by each Tribal community in its own way. Some Tribes have created Elder Protection Codes, however, the implementation of the Codes is variable.\textsuperscript{141} There is not one approach that will resolve the issue of abuse, but it does seem clear that any effective resolution of the problem will need to reflect the culture, values, support and commitment from each Tribe.

For example, some elders do not wish to press criminal charges against a family member, although they do want the “disrespectful behavior” to stop. So, some Tribes take a “peace-making” approach or a “restorative justice” approach to remediating abuse situations rather than using the criminal justice system.\textsuperscript{141}

A useful tool is available for helping Tribes to develop their elder abuse codes and to plan for how they will implement them. The National Indian Council on Aging (NICOA) has provided a document titled “Using Your Tribal Values to Develop an Elder Protection Code: A Step by Step Guide for Communities”. The approach of integrating Traditional values does invite an in-depth community investment in the prevention of elder abuse.\textsuperscript{149}

**Federal Resources in Raising Awareness of Elder Abuse**

At a federal level, the Administration on Aging (AOA) supports the National Center on Elder Abuse (NCEA)\textsuperscript{150} and in 2011 awarded two new grants, including
one for the establishment of the National Indigenous Elder Justice Initiative (NIEJI) at the University of North Dakota. This AOA/NCEA award to fund NIEJI is the first dedicated to elder abuse in Indian Country. The NIEJI program is specifically focusing on the need for developing culturally relevant information and education materials for Tribal communities to address elder abuse in Indian Country.151

**Education for Health Care Providers**

Anyone who has responsibility for provision of health care services in the clinic, hospital, or community setting can (and should) be trained to routinely observe for the common signs of elder abuse as outlined above. It may be a health care provider who will pick up on something that an elder says or who will see a sign of possible physical abuse or neglect during an assessment. For example, malnutrition/weight loss may be noted while routinely taking a weight or bruises may be noted while taking a blood pressure.

Conversations with an elder inquiring about family members or about how “day to day” care is going at home may bring out areas of concern that can be addressed. For example, a health care provider or outreach worker can ask about medications not being refilled or how difficult it has been to get to the grocery store, or if there is money to buy groceries, or if the elder has had any falls since the last clinic visit, or if the elder has been able to go to a District meeting, or how many people are currently living with the elder in their home, or if the elder has had a chance to attend social events or spiritual gatherings.

There may be cues related to abuse that will emerge from caring conversations that can be further explored through non-intrusive questions like these. If there is a “cue” that does emerge, there may be hesitation on the elder’s part to speak of “abuse”. However, since respect is a tradition that Tribal people understand and value, it may be more acceptable to pose further questions asking if someone is not “respecting” the elder. Using the language of “respect vs disrespect” can make it easier for elders to discuss abuse in these terms.152
Community Interventions as Prevention for Elder Abuse

Beyond the policy and legal work that is needed to raise awareness and codify the prevention of elder abuse, it is also important to focus on the development of community-based support programs to assist elders and their caregivers. Many of the types of supports that elders and their caregivers need have been discussed in Sessions 3.4 and 3.5 above. A focused effort to build the infrastructure for LTSS within local communities holds the potential to “de-fuse” some of the situations that trigger elder abuse through the provision of adequate support and services for elders, caregivers, and families.

Drawing from the large data sources of the National Resource Center on Native American Aging (NRCNAA) 18,062 surveys were analyzed. The results of the analysis indicated that there are a number of services that elders are not currently accessing, but that they would access if they were available. Less than 1% of elders used programs that have the potential to prevent elder abuse, but 13% said they would use them if they were available. Particular services that elders stated they would have an interest in using include: financial assistance, legal assistance, transportation, caregivers, home-delivered meals, personal care, home health, and home modification services.

This analysis by the NRCNAA can be very helpful in assisting Tribal communities to work towards the creation of a Long Term Services and Supports (LTSS) network. The advantage of the NRCNAA data is that priorities have been identified as valuable by the elders themselves. LTSS programs necessarily will depend on the collaboration of a wide community network. Strong collaboration to develop LTSS would make it easier to engage all “helpers” in the community as elder advocates.

A strong local LTSS program would also provide additional “eyes and ears” to prevent elder abuse in the community through Tribal health program outreach workers (CHR, Suicide Prevention, Substance Abuse Prevention, Diabetes
Outreach, Elderly Nutrition) IHS providers, law enforcement officials, housing officials, social workers, and family caregivers. The opportunities for assessing early signs of elder abuse would be multiplied by increasing the number of LTSS care providers visiting homes on a regular basis. Early recognition of elders at risk can lead to early interventions for the prevention of abuse. LTSS programs would also provide the types of services and supports for elders and caregivers to decrease stressors that lead to elder abuse. The provision of care and respect to Native elders is a sacred trust that must be honored.
Summary Session 4.1

The problem of elder abuse in Tribal communities is very complex and will require ongoing collaboration among all community sectors including: Tribal Leadership, Tribal Justice Departments, Law Enforcement, health care providers, community health workers, families and community members. The development of community-based LTSS programs may provide a vehicle to “de-fuse” triggers for elder abuse caused by stress overload in caregiving situations, through the provision of needed services for elders and families.

LTSS development will additionally create opportunities for all sectors of the health care system and community to join together and reach out to elders on a more regular basis. Health providers in clinic, hospital, and community settings should be trained to recognize signs of abuse and the risk factors that may lead to elder abuse. If an elder needs help, anyone can find the appropriate agency responsible for assisting with an elder abuse problem in any region of the country by calling the ElderCare Locator Hotline number:

1-800-677-1116

Elders are traditionally the wisdom keepers for their people, deservedly honored and respected. Family and friends need to stay “in tune” with caregiving situations in their extended families. Regardless of the stresses and strains of caregiving or the lack of resources in a community, the abuse of a vulnerable elder cannot be ignored within a family or the wider community circle. Abuse violates the humanity of the elder and universal values of Tribal people. If abuse is suspected, it is important to “break the silence” to protect elders, as well as to find ways to return to traditional practices of respect.
SUMMARY
Native Elder Caregiver Curriculum
“NECC”
SUMMARY of the NECC 2nd Edition

The modules in this second edition of the NECC curriculum hopefully will help caregivers to have a little extra information to support 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. For elders, much is now known about maintaining functional abilities and health, especially through health promotion activities and the prevention of falls.

Also, a number of really good ideas for programs have been developing for providing long-term services and supports (LTSS) in the community setting. There is no shortage of ideas! Actually, the challenge is for American Indian and Alaskan Native elders and caregivers to learn more about potential programs, such as Home and Community-Based Services (HCBS). The next steps will include leading their communities in planning and implementing quality eldercare programming. The task remains to seek out partnerships in effectively accessing federal, state, and local resources, and then to adapt the resources to the specific needs of each Tribal Nation. Many elders wish to stay in their homes for as long as possible, and we want to honor this wish.

The work ahead to provide well for the health of our elders is sacred. The elders 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.”  

140, p.85
REFERENCES
REFERENCES FOR NECC 2nd Edition
2015


8. Vernon Lambert (Spirit Lake Dakota Elder). Personal communication.


https://www.ncoa.org/resources/hearing-loss-its-a-family-affair/


http://www.aarp.org/relationships/caregiving-resource-center/info-08-2010/elc_how_to_help_your_loved_one_with_pain.html

https://www.nrcnaa.org/well-balanced


http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3797008/

http://www.ec-online.net/Knowledge/Articles/communication.html


40. Sheftell, F. (2011). When to go to the emergency room for a headache or migraine. *ACHE: MD Education Center*. Retrieved from [http://www.achenet.org/resources/when_to_go_to_the_emergency_roomb r_for_a_headache_or_migraine/?print=y](http://www.achenet.org/resources/when_to_go_to_the_emergency_roomb r_for_a_headache_or_migraine/?print=y)


45. University of Michigan Medical School, Division of Geriatric Medicine, Department of Internal Medicine. (2003). Geriatric functional assessment. Retrieved from
http://www.med.umich.edu/lrc/coursepages/m1/HGD/GeriatricFunctionalAssess.pdf


54. John Eagle Shield (Hunkpapa Lakota Elder & “Naca” for the Standing Rock Sioux Tribe), personal communication.


92. Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion. (April 2015). Addressing chronic


Art Work Images
Inserted within the NECC Narrative and NECC PowerPoint Presentations

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APPENDIX A
Ideas for Classroom Activities
APPENDIX A

Ideas for Interactive 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.
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 maketime 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.
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
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

**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”.
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.

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

1. the participants can be placed into small groups of 3-4
2. a scenario will be given to each group of a set of symptoms that are occurring in the elder they take care of
3. 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
4. each group will act out their scenario, as the other groups “assess” what is going on
5. each group will then share their assessments of the scenarios in the other groups

Session 2.4 “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.
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.

SESSION 3.1  HEALTH PROMOTION FOR NATIVE ELDER & 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 About 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 3.1:

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.

---

**Session 3.2 Health Care System & LTSS Resources**

**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

(Sessions 3.2 and 3.3 would utilize a “combined” group activity, see below)
Session 3.3  “Navigating the System”

PURPOSE

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

For Class Activity: Sessions 3.2 and 3.3 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 “stock” their resource “recipe boxes” 😊!

Session 3.4  Caregivers: Contributions & Stressors

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 group could come up with some ideas about how to market a support group, how to find respite workers, where to go in the health care system (local, regional, county, state) to find resources to get started. The goal will be to have a plan in hand at the end of the session.

Session 3.5  Care for the Caregiver: Recommendations

- Understand specific ways to manage the stress of caregiving
- Understand how to access resources for caregivers for stress management, learning new caregiving skills, finding local and regional resources
- Learn of available resources for services and planning LTSS

Continuing the talking circle from Session 3.4, the caregivers can create a plan for “stress-busters” they can use and when to fit stress management into their daily routine. Another brainstorming session can help caregivers to identify what kinds of learning and training needs they have. This can be followed up by a planning session that identifies: what, who, where, and when training needs can be met, and setting a timeline to plan for arranging different kinds of training.
Session 4.1 ELDER ABUSE AWARENESS

PURPOSE

- Understand the risk to Native elders for elder abuse
- Understand the need for Tribes to create strong elder abuse prevention programming which integrates cultural strengths

This session offers another opportunity to plan with other caregivers on an important topic. The planning for having an elder abuse awareness group in their community can start with identification of services already at hand. Copies of the NICOA document “Using Your Tribal Values to Develop an Elder Protection Code” could be handed out (http://nicoa.org/wp-content/uploads/2014/05/Elder-Protection-Workbook-Final.pdf)

Elders from the community, as well as law enforcement and health care providers could be invited to this session. A special emphasis during this session would be on the “implementation” challenges to Tribal Elder Protection Codes, and how to address them.

Evaluation of the Sessions

Evaluation of the sessions should be done at the close of each training session, towards the last break before the end of the day. It is possible to offer “workshop days” one day at a time, especially if it is not feasible for some people to attend for several consecutive days. Again, this will be driven by the decision of the community requesting the training and schedules of potential trainees. The NECC lends itself to this kind of flexibility, since selected topics can be chosen for training in a workshop format, or as an “in-service”, or an entire course.
Some of the “evaluation” of the course will be done by the instructor, during the course of class activities. For example, the instructor for the course will observe the vital signs skills, and will be able to check 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.

**Sample Evaluation Questions for Each Session**

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?
APPENDIX B
Home Safety Checklist
# 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.* *(from NRCNAA.org  WELL-Balanced site)*

<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>Action:</td>
<td></td>
</tr>
<tr>
<td>Have you applied double-sided carpet tape to rugs that can slip?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Action:</td>
<td></td>
</tr>
<tr>
<td>Is your furniture arranged so you can easily walk around it?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Action:</td>
<td></td>
</tr>
<tr>
<td>Are electrical and extension cords in your walking path?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Action:</td>
<td></td>
</tr>
<tr>
<td>Can you turn on lights without having to walk through dark areas?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Action:</td>
<td></td>
</tr>
<tr>
<td>Do you use nightlights?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Action:</td>
<td></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>Action:</td>
<td></td>
</tr>
<tr>
<td>Do you keep exits and hallways clear?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Action:</td>
<td></td>
</tr>
<tr>
<td>Do you use stable chairs with armrests to help you get up?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Action:</td>
<td></td>
</tr>
<tr>
<td>Do you always watch that your pets are not underfoot?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Action:</td>
<td></td>
</tr>
</tbody>
</table>
### 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>Can you reach the handrails easily?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Are the steps even?</td>
<td>□ Yes □ No</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>Do you make repairs to worn or loose steps promptly?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Is there good lighting in the stairway?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Do you stack objects on the stairs?</td>
<td>□ Yes □ No</td>
</tr>
</tbody>
</table>

**TIPS:**

- To help avoid taking a misstep, you can paint wooden or concrete steps with a trip 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

**BATHROOM**

<table>
<thead>
<tr>
<th>YES/NO ACTION</th>
<th>Action:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are there rubber bathmats or strips in bathtubs and showers?</td>
<td></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></td>
</tr>
<tr>
<td>Have you installed grab bars in the bath tub?</td>
<td></td>
</tr>
<tr>
<td>Do you use raised toilet seats and/or handrails if you are unsteady?</td>
<td></td>
</tr>
<tr>
<td>Do you clean up water from the floor to avoid slipping?</td>
<td></td>
</tr>
<tr>
<td>Do you have a nightlight in the bathroom?</td>
<td></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>Action:</td>
<td></td>
</tr>
<tr>
<td>Do you spread sand or salt on icy walkways?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Action:</td>
<td></td>
</tr>
<tr>
<td>Do all your entrances have an outdoor light?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Action:</td>
<td></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>Action:</td>
<td></td>
</tr>
<tr>
<td>Can you reach your mailbox safely and easily?</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Action:</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX C
Draft Example of Grant Narrative
DRAFT NARRATIVE EXAMPLE for GRANT APPLICATION for ELDERS PROJECT*
*In-text reference numbers in this draft do not refer to the NECC reference list above in Appendix A on p. 204

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.

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. 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). 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.

C. **Need for Community-based Eldercare**

Older Native people prefer to “age in place,” 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. 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.

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.” 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* 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.\(^1,9\) 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.\(^1,6\) 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.\(^2\)

   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 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 illnesses1,11, 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 NRCNAA. 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 elderscare 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.
### 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 | | | |

*HCBS refers to Home and Community-Based Services.*
### #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.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Timeline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop Project Coordinator &amp; Community Navigator position descriptions</td>
<td>By the end of the first quarter of the grant period</td>
</tr>
<tr>
<td>Advertise for Project Director &amp; Navigator positions according to policy</td>
<td>By the beginning of the second quarter of the grant period</td>
</tr>
<tr>
<td>Train Community Navigators for their job responsibilities</td>
<td>By the end of the second quarter of the grant period</td>
</tr>
<tr>
<td>PD’s developed by the end of the first quarter of the grant period</td>
<td>By the end of the third quarter of the grant period</td>
</tr>
<tr>
<td>Navigators will be hired</td>
<td>By the end of the third quarter of the grant period</td>
</tr>
<tr>
<td>Navigators will be trained &amp; fluent in “active listening”</td>
<td>By the end of the third quarter of the grant period</td>
</tr>
<tr>
<td>CN’s will begin working in the community</td>
<td>Throughout the four reservation districts</td>
</tr>
</tbody>
</table>

### #4: A plan for Elders’ Health Promotion & Caregiver Resource Center will be developed & implemented to offer educational Opportunities

<table>
<thead>
<tr>
<th>Activity</th>
<th>Timeline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work with Elder Committee to identify educational interests &amp; needs for information &amp; services</td>
<td>At least 6 presentations prepared for the project period</td>
</tr>
<tr>
<td>Develop presentations on variety of Health Promotion &amp; Caregiving topics</td>
<td>- by end of second quarter of grant period, 4 presentations will be prepared</td>
</tr>
<tr>
<td>Set up schedule for regular Health Promotion sessions</td>
<td>- by end of third quarter of grant period website will be “up and running”</td>
</tr>
<tr>
<td>Request help from Extension Services to locate &amp; invite presenters for the Health Promotion &amp; Resource Center on topics of interest to elders &amp; families, particularly nutrition</td>
<td>*evaluations of education sessions are done &amp; available for review on at least 2 education sessions</td>
</tr>
<tr>
<td>Request help from other local &amp; regional presenters, eg. I.H.S., ND State Aging Services, SDPI, Tribal Health</td>
<td>*computer locations are known &amp; accessible to at least 10 families in each</td>
</tr>
<tr>
<td>- Website developed of links to requested information and information potentially of interest to elderly &amp; their families</td>
<td>*evaluations of education sessions are done &amp; available for review on at least 2 education sessions</td>
</tr>
<tr>
<td>- Advertising of locations of</td>
<td>*computer locations are known &amp; accessible to at least 10 families in each</td>
</tr>
<tr>
<td></td>
<td>#5: Cohort of C.N.A. students will complete certification</td>
</tr>
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<td>---</td>
<td>-----------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>-develop website for elderly &amp; families to access pertinent information</td>
</tr>
<tr>
<td></td>
<td>-“elder-friendly” computers in 4 accessible locations</td>
</tr>
<tr>
<td>#5: Cohort of C.N.A. students will complete certification</td>
<td>-recruit 10 community members who are interested in C.N.A. training</td>
</tr>
<tr>
<td></td>
<td>-meet with County Social Services to determine current &amp; potential need for Quality Service Providers (QSP) for HCBS</td>
</tr>
<tr>
<td></td>
<td>-estimate of number who may qualify in the future</td>
</tr>
<tr>
<td>#6: Special “safety-focused” transportation plan for Frail Elderly people will be in place &amp; operating daily</td>
<td>-van driver will be hired &amp; trained</td>
</tr>
<tr>
<td></td>
<td>-handicapped accessible van</td>
</tr>
</tbody>
</table>