NATIVE AMERICAN MAP FOR ELDER SERVICES (NAMES)

A Long Term Care Planning Tool Kit

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INTRODUCTION

"Long term care differs from other types of health care in that the goal of long-term care is not to cure an illness, but allows an individual to attain and maintain an optimal level of functioning" (U.S. Senate Special Committee on Aging – February 2000).

Long term care is generally defined as ongoing health and social services provided for individuals who need assistance on a continuing basis because of physical or mental disability. Services can be provided in an institution, the home or the community and may include informal services provided by family or friends as well as formal services provided by professionals or agencies.

American Indian and Alaska Native elders in Indian Country have fewer options for long term care services when compared with other seniors. According to the National Indian Council on Aging in 2002 there were only 12 tribal nursing homes nationwide and 90 percent of reservation long term care is provided by families. In addition, Indian Health Service, a primary health provider for American Indians and Alaska Natives, does not consider long term care to be part of its funding mission.

In 2002, the National Resource Center on Native American Aging (NRCNAA), located within the Center for Rural Health, University of North Dakota School of Medicine and Health Sciences, received a grant from the Office of Rural Health Policy to develop a long term care planning tool kit. The purpose of the tool kit is to describe long term care services that will assist American Indian and Alaska Native groups with planning, developing, and implementing long term care services in their communities.

As part of the grant and to begin the process of developing the tool kit, NRCNAA developed a chart that presents the spectrum of long term care (see Figure 1). The measure of functionality that was used for the chart was adapted by Dr. Richard Ludtke of the NRCNAA from a model originally developed for the U.S. Department of Health and Human Services.

The level of disability is defined in terms of levels of functional limitations in the population. Nearly all definitions of functional limitations use information about activities of daily living (ADLs) and instrumental activities of daily living (IADLs). ADLs include eating, walking, toileting, dressing, bathing and getting in and out of bed. These activities are considered fundamental to survival. IADLs reflect activities required for independent living, but are less severe than ADLs. IADLs include cooking, shopping, managing money, using a phone, doing light or heavy housework and getting outside the home.

The measure of functionality combines ADLs and IADLs into four functional limitation levels of little or none, moderate, moderately severe, and severe. The four levels are then matched with service goals, services that best meet the goals, and personnel that would be required to carry out the services. Although the chart is clear in its categorization of functional limitations of elders and the corresponding service for which people would qualify, it should be noted that there is some hesitancy about placing elders into categories due to differences in individual resources

such as access to care, finances, informal family caregiving, and people's acceptance of formal services.

The functional limitation levels help us produce an estimate of the numbers of people who would be screened as eligible for services at differing levels of formal care. For example, people would require a severe level of functional limitation to become eligible for skilled nursing care. Clearly, only a small percentage of those technically eligible for institutional care actually end up choosing such care as the needs end up being provided for by family caregivers augmented by home- and community-based services.

By using the chart and the results of the NRCNAA, or similar, needs assessment, tribes can gain insight into which long term care program or facility will best suit their community and their elders. We suggest tribes first inventory the long term care services they currently provide, use the results from their needs assessment and the chart to determine what services their community should be providing, and then use the tool kit as a resource to learn more about long term care options for their elder community.

About The Tool Kit

Two of the tool kit chapters correspond to the functional limitation chart categories. Chapter Three is on health promotion and preventive care services which correspond to the 'little or none' category. Chapter Four is on home- and community-based services, which corresponds to the 'moderate' category. Chapters Three and Four also contain an example of a best practices program that corresponds to that respective chapter. It is hoped that these descriptions will provide you with an idea or basis from which to develop your own program.

Other chapters in the toolkit address needs assessments and community mobilization. Closing out the tool kit is a list of funding and general resources. These resources can be used in assisting tribes as they plan long term care services.

The intention of this tool kit is not to be all inclusive of the long term spectrum but rather a starting point in developing long term care infrastructure and services within your community. Each chapter may stand alone; however, the chapters are not meant to be mutually exclusive, but rather complement one another

Figure 1

FUNCTIONAL LIMITATION LEVELS APPLIED TO SERVICES AND PERSONNEL

Level of Functional Limitation	**Service goals**	**Services for which people at each level would become eligible**	**Personnel required**
Little or none (0 ADL, up to 1 IADL)	Health promotion, preventive care, maintaining vitality	No caregiver services required, health promotion/prevention	Health educators, physical trainers, therapists
Moderate (1 ADL or 2 or more IADLs) This category represents entry level functional limitations and requires assistance usually consistent with remaining in one's home.	Supportive services to aid persons in remaining in own homes. Train and support informal providers and buffer them with respite and contact services for a range of possible tasks.	Informal care – w/supports Chronic disease management Home- & community-based: • Day/night care* • Durable medical equipment* • Home health care* • Homemaker services* • Physical therapy • Occupational therapy • Medication assistance* • Speech therapy • Mental health services • Transportation services* • Nutritional services* • Personal care* • Respite care* *Requires local providers	Family and friends Trainers for informal caregivers Facility staff – LPN/CNA Home- and community-based staff – RN, LPN, CNA, PT, OT Cleaning and chore assts. PT, PT aides, tele-health OT, OT aides, tele-health Medication aide Speech therapist Psychologist, Psychiatrist, Psych. Social Worker Van driver Dietician, aide Trained attendants Trained respite providers or institutional site
Moderately severe (2 ADLs) This level of care represents an increase in frailty. People with two ADL limitations are often candidates for assisted living or institutional care designed to provide care for people with moderate needs for assistance.	The goal for this level of care is to provide housekeeping and meals along with a modest level of oversight. People may contract for additional services from agencies providing home- and community-based services which are then provided in their assisted living	In addition to the above services individuals become eligible for: Congregate care Basic care facilities Assisted living	Institutional staff as required by state regulations. All of the home- and community-based staff in the above list may also apply at this level.

	apartment.		
Severe (3 or more ADLs) With three or more ADL limitations, this level includes prime candidates for skilled nursing care. They represent care needs with relatively high levels of acuity.	Skilled nursing care is the most fully institutional and is reserved for those with medical needs at higher levels of acuity that may necessitate a level of care best met by access to 24 hour-a-day professional care.	In addition to the above services individuals become eligible for: Skilled nursing care	Institutional staff as required by state regulations.
End of life care as special category	End of life care occurs at all points on the above continuum of functioning, but is likely to be concentrated at the higher levels of limitation. At this point, palliative care is sought with a goal of optimizing physical and emotional comfort, but not providing curative care.	In addition to the above services individuals become eligible for: Hospice care	Hospice volunteers and coordinator. Educators for informal caregivers (family and friends).

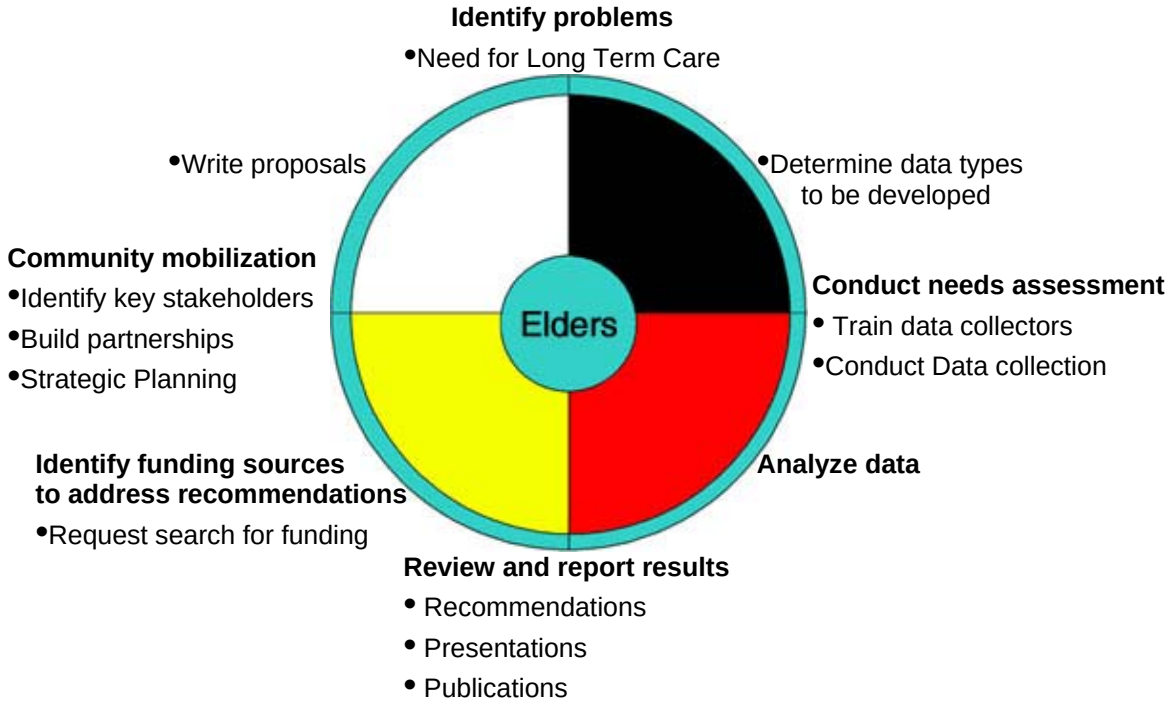
CHAPTER I

NEEDS ASSESSMENT

The medicine wheel has been used by many as a model to show a holistic view of a topic. The circle has no beginning or ending, so it assists us in visualizing that we are going to end up wherever we started. The Medicine Wheel represents not only the circle of life, but also the seven directions. These include the four directions (N,E,S,W), mother earth, the Creator, and finally, ourselves at the center. Everything is related within this viewpoint, so when something happens in one of the directions, the balance of the rest of the wheel is affected. In regards to our elders, the circle suggests stages are occurring throughout our lives and we must adapt accordingly.

In conducting needs assessments, we used the medicine wheel to describe the stages by which needs assessments and planning for long term care services are related and how each activity is a part of a series of activities that lead to a well thought out plan of action (read the circle clockwise). We have placed the elders at the center of the circle, because this is our focus.

Community Based Research Model



Developing long term care services is complex and requires a significant amount of planning in order to be successful. Generally, the first step to planning is identifying the problem. The problem may be high levels of chronic disease, inadequate access to health care, lack of transportation, or any issue important to your elders. In most cases, communities have a wide range of issues with varying degrees of needs and resources, which makes it hard to determine what should be the highest priority. These issues are especially important when resources are limited and when one is uncertain how to best address the needs of one's community.

A needs assessment assists in collecting information to identify disparities by comparing your community with the state, other tribes, or national populations. In this regard, the general population is used as the benchmark to determine if your community falls above or below acceptable standards. Once information is reviewed and disparities are identified, the community is better able to prioritize their needs and direct resources to address the needs of their community by exploring planning and advocacy opportunities.

COMMUNITY NEEDS ASSESSMENT

A community needs assessment is a process where the extent of needs and available services to address those needs are identified. Generally, information collected from these efforts is used as the basis for the development of new programs, facilities and services, but the information can also be used to modify current projects to address changing needs of the population.

For example, the recent increase in life expectancy among Indian elders is now producing rapid growth in that segment of our population. As this occurs, changes will be required to respond to the needs for assistance and care for elders that were not as large of a problem in the past. As the size of the population of elders grows, their needs need to be identified and decisions made as to how these needs can most effectively be addressed by tribal and state agencies.

Conducting a community needs assessment should help you focus on three major goals:

- identifying important issues for your community
- locating options for responding to the issues
- assessing the options and charting action plans

Survey Methods

The most commonly used method for community needs assessments is a survey. The following presents a brief description of survey methods, a brief discussion of the advantages of survey methods and description of the process employed in the NRCNAA project.

Surveys can provide accurate descriptions of your people based either on a complete head count or a representative sample of the people from your community. A variety of methods for collecting survey data include: 1) self administered, mailed questionnaires; 2) self administered questionnaires that are delivered and picked up or gathered at meetings; 3) face-to-face interviews; and 4) telephone interviews. Interviews require more time, effort and training, but produce the best response rates. These allow for more complete responses permitting probes that encourage people to answer the question.

The recommended strategy for data collection with the elderly is face-to-face interviews. With an interviewer reading the questions and recording the answers, elders are assisted in reading and filling out the survey. For Native elders, language barriers could also be an issue, so a translator may be needed.

If you elect to use survey methods, the following are considered critical steps:

Instrument Design - If you design a unique, new questionnaire it is important to exercise care in framing the questions. Use simple language, keep the questions short, avoid requiring recall from previous questions, make questions specific rather than general, offer exhaustive response alternatives, and include a no opinion option. Question order should be examined to ensure a logical flow to the questions to ensure the flow is from general to specific in terms of content. It is important that you consult a standard reference such as Backstrom and Hursch (1981) for checklists against which to evaluate your questions.

Sampling - In many cases, elder populations are small enough to allow you to ask all of them to be surveyed. If your population of elders is large, a properly selected representative sample can estimate characteristics of a population while using only a small fraction of the population. In order to draw a sample with reasonable assurances of adequacy you must have a complete list of the population to be sampled and a method that will ensure a representative selection of respondents.

The size of a sample depends on the level of accuracy you require, with larger samples yielding the greatest precision. We recommend a sample size that will yield results at the 95 percent confidence level, which means you can be 95 percent sure that your results did not appear by chance.

Sampling Lists - To draw a sample of elders in your community, you need a complete list of them. We often use directories such as telephone directories for lists of people in the population, and then draw a systematic random sample in which every nth (e.g. 10th or 15th etc.) name is drawn. If you use this approach you must have a random start and know what proportion you need to draw. This is accomplished by drawing a random number for a starting point and using every nth residence thereafter where "n" is determined by the fraction you need. Thus if you wanted to use 25 percent of your population, you would randomly select a number between 1 and 4 and then select every 4^{th} name thereafter. (e.g. If you start with # 2, would take the 6^{th}, 10^{th}, 14^{th}, 18^{th} and so forth.) This provides a representative sample.

If there is any reason to suspect that the directory is not a current or complete listing of the population, then you must seek an alternative list. For example, using telephone directories may be a problem as many might not have telephones or the number may be unlisted. The goal is to have as complete a list as possible of everyone within the target population.

Data Collection – Data collection must be both systematic and coordinated. You must carefully select the data collection method. Mail, telephone or face-to-face interviews are all good data collection strategies. Face-to-face interviews are most likely to yield excellent response rates

and more complete responses. NRCNAA recommends face-to-face interviews for data collection with the elderly as this avoids problems and makes the experience more positive.

Telephone interviews also yield high response rates and are quite cost efficient, but are dependent on current and accurate directories and nearly universal possession of telephones. Telephone interviews should seek people at varying times of the week and day and interview times should be scheduled when necessary.

If you conduct a mail survey, you will need a cover letter to explain the purpose of the survey, its sponsors and make an appeal for cooperation. A cover letter should always be included with the questionnaire. A systematic follow-up is needed in order to prod people to respond and improve the rate of response. This can be done either by mail or telephone and may require mailing a second questionnaire to the respondent. Follow-up should begin after the returns have tapered off - usually a couple of weeks after the initial mailing.

Detailed records must be kept to avoid repeatedly contacting the same people and to be able to assess your response rate.

Analysis - Survey results are computerized and analyzed using statistical programs. For participants in the NRCNAA process, data entry, creation of a data base, and statistical analysis are provided. The results also provide U.S. general population and Native elder comparisons.

Those choosing to conduct their own community needs assessments might consider contracting with a consultant for this analysis. A consultant can assist you in developing a system for coding the data that is compatible with statistical software and equipment. Because of the flexibility of survey data, it is also possible to go back to the data several times while exploring issues. Normally, a consultant will anticipate many of the questions you might have and can offer suggestions on useful observations about the patterns that emerge for your elders. Frequency distributions and cross tabulations are normally sufficient to derive the essential findings from this type of a survey.

<u>Survey advantages</u>

The following lists some advantages to using the survey method for conducting needs assessments:

- You can be assured of a representative cross section of the community.
- Surveys allow for broad participation.
- Standardized questions from state or national studies allow you to compare your results with national norms or with norms established for all Native American elders.
- Detailed information about behavior, attitudes, beliefs, attributes and opinions can be recorded.
- Cross tabulation (creating tables that compare people in different categories such as gender) can help profile problems and assist in targeting programs.
- Surveys are lower in cost and consume less time than other alternatives.
- They permit you to reach people who are geographically spread out.

- Surveys afford a great deal of flexibility in terms of portability and allow for re-analysis as one can revisit the data to explore different issues.

The NRCNAA Process

NRCNAA uses a standardized process where all communities use the same survey instrument and sampling methodology for data collection. The process allows NRCNAA to assist tribes with community information on health status, long term care need, health risks, and service use while building a national Native elder data file.

At the onset, each tribe seeking to participate is asked to secure a resolution from their tribal councils authorizing the survey. The protocols for the survey are provided in a draft resolution which explains what NRCNAA provides and what is expected from the tribes. The main points from the resolution are that the data belongs to the tribe with local personnel responsible for interviewing their elders. In exchange, we ask permission to include their data in an aggregate national file to be used for analyses, presentations, and publications at the state, regional, and national levels. Confidentiality of the tribes is protected as individual tribes are not identified in any of the larger analysis or presentations.

Training is conducted at the regional or national meetings to assist in developing good interviewing skills and to assist in understanding sampling methodology. Sufficient quantities of the survey are provided to the tribes participating by NRCNAA through funding from the Administration on Aging.

Analysis of the data is accomplished by scanning the surveys and inputting the data into a statistical software program. When this process is complete, the data is checked for accuracy and mistakes are corrected. Because survey questions were used from national studies, comparison data is already available for the U.S. general population and when enough tribes have been entered in the national file, a national Native elder comparison is generated, thus allowing tribes to compare their elders not only to the general population, but also the rest of the Native elders in the nation. A comparison report is then put together for the tribe and returned to the tribal council and tribal contact person as a community call to action.

Additional Methods for Assessing Community Needs

Key Informants

A key informant approach utilizes people who are most likely to be knowledgeable about the community as a source for information. This usually involves a questionnaire with broad open-ended questions and involves a very limited number of interviews. Key informants are commonly found among community leaders and people in key positions. The people are selected because they are expected to know the community and its elders and to be able to represent the needs of this population. The results from the key informant interviews may be more suggestive than conclusive, but can provide a good basis for resolving problems.

Focus Groups

The use of focus groups involves assembling small groups (up to 10 persons) in order to engage in a free and open conversation. The focus is provided to the group by presenting them with a limited number of well thought-out and well-sequenced questions. While focus groups may generate a great deal of information and new ideas, they are somewhat lacking in terms of documenting the importance of any particular need or idea. However, used in combination with another technique that yields more standardized data such as a survey, focus groups can make an excellent contribution. Focus groups can also be used to triangulate the data received through the needs assessment process assuring that elders have adequate voice in planning long term care options.

Community Forum

The community forum allows for broad participation in a single meeting and provides an appearance of inclusiveness for all interested parties to attend and participate. A community forum can usually be conducted in the same manner as a focus group, but on a larger scale.

An additional benefit to conducting a focus groups or community forums is the opportunity to learn more about other projects and to build or expand networks within one's community. It's very possible that services are being duplicated in the community and by combining resources the community may be able to reach more people with less effort. Possible stakeholders to consider for invitation to the focus group or community forum would be Title VI (Nutrition and Family Caregiver programs), senior citizen organizations, Community Health Representatives, tribal health directors, Indian Health Service directors, and any other organizations providing service to the elderly.

CONCLUSION

The assessment of the community's elders' needs is an important task that should precede establishing a plan of action. A temptation is nearly always present to skip the rigors of systematic data collection and move immediately into action. The preceding material suggests a variety of ways to systematically assess one's local community needs and to establish well founded priorities for its elders. Each method has its own peculiar strengths and weaknesses, but each offers a significant improvement over making such decisions on the basis of personal agendas or perceived needs rather than real needs as reported by community elders or key informants.

CHAPTER II

COMMUNITY MOBILIZATION

Over the years it has become clear that individual health is closely linked to community health. Community health is profoundly affected by the collective beliefs, attitudes and behaviors of everyone who lives in the community (Healthy People 2010).

Community mobilization is the act of bringing community members and organizations together to raise people's consciousness of a problem and developing solutions/policies to address the problem. Mobilizing the community in planning, developing, and implementing long term care services for the elderly benefits the elder and the community as the community can take ownership in providing for their elders.

The following are some areas to consider when mobilizing a community. You may go through some of these steps only once, but the majority of these steps may be repeated at each step of your project. Each of these steps should be viewed as its own separate activity as well as an activity step in the overall plan to mobilize the community.

Defining the community

Before you can mobilize a community to plan or implement a program, you need to define what you mean by 'community.' Defining a community can give you the information to determine who you are going to serve through the program you wish to develop, guide you in deciding where to look for support, what resources are readily available and which ones you will need to pursue or develop, and who can serve as possible partners.

Communities may be defined by geographic boundaries, political boundaries, or demographic characteristics. Communities may also be defined as any group of people living together or having close interaction and common interests. A community may be composed of a few families or consist of multiple families of various ethnic backgrounds.

In Indian Country, a community may be defined by reservation boundaries or by land base. These are then internally divided into districts or segments which can become communities in their own right. In Alaska, communities are called villages. Sometimes the reservation or village community extends out to those tribal members that are living in or near towns located close to the reservation. Urban Indian communities can either be an area where Native Americans, Alaska Natives, or Native Hawaiians live or a location where these groups congregate.

Gaining commitments and support

Projects are often not successful because of lack of commitment and support from key community leaders. Any project development and implementation will require a series of decisions made by key people in the community. Gaining commitments and support from these

key people can strengthen your project by providing you with the assistance and resources necessary to plan and implement the project.

Key decision makers for your community could be Tribal government officials, financial managers, tribal planners, program managers, or project coordinators. Other key people can be champions of the elderly, elderly leaders, and people who either serve as advocates for the elders or whose support is essential before progress can be made. These people can be located by simply asking service providers or the elders.

Identifying needs

Knowledge of the community's problems, people, and programs is important information to know before you start a project. A needs assessment will help you to identify gaps between the current health status of elders and the desired health status, determine which issues are priority by identifying high risk areas, help select the best resources for the activity, and provide a baseline for evaluation purposes. In addition, the process of completing a needs assessment for the community often provides the first opportunity for citizen involvement in the project.

Coordination of resources

Coordination of resources involves the continuous and active involvement of the people and resources that you will need for your project. By doing an assessment you can identify the people and resources within and beyond your community that can assist you with your project.

Working with a variety of people and resources can occasionally lead to discontent at times. People will bring their own values, priorities, ideas, agendas, vested interests, and needs to the project. You should try to maximize people's strengths to achieve the kind of consensus that is essential to the planning process. Achieving a consensus requires time and patience, but with adequate discussion and a patient leader, people tend to find this level of agreement and this serves as a good starting point for action.

Communication

Good communication can assist you in keeping community members involved. The general public, specific groups and organizations, and selected individuals need to be informed and educated about your program efforts at most every step of the project. The information you communicate will help to alleviate confusion, doubt, and in some cases barriers as to the process and goal of your program.

Partnerships/Collaborations

Build partnerships and/or collaborations at every step of the process. They can help gain commitment and support from key stakeholders, identify and coordinate resources, and communicate the significance of the project to others.

Partners/collaborators may include, but are not limited to, tribal governments, program managers, health care providers, social service providers, academic institutions, governmental agencies, and community-based organizations. Communities with similar programs or goals, those who will be the recipients or consumers, and those who will be providing or delivering the service should also be considered for partnership, or at least consulted, preferably in the early planning stages. Including these people develops, for them, a sense of ownership, provides you with additional people power, and gives you a broader group with which to brainstorm and explore strategies.

Evaluation

Evaluation should be regularly undertaken in order to assess what seems to be working, what is not working and to identify barriers to success. Two types of evaluation need to be considered. First – **process evaluation** is essential. This involves simply raising questions regularly to identify problems or mistakes and to remedy them before they can damage your project. Ask what went wrong, why and what can be done to correct the problem. This will improve the flow of activity and prevent you from pursuing unproductive paths. Second, **outcome evaluation** is conducted to document success or failure. This is normally done at the conclusion of a project and seeks documentation for success or failure that relate directly to the goals of your project. These usually employ direct measures of success related to the measurable objectives you formulate as goals for your project. For example, you may have a goal of providing a 20 percent increase in the number of health screenings for cancer among your elder population. Using this as a measurable goal, you would locate data to document the numbers of screenings conducted in the years before and after the beginning of your project.

CONCLUSION

Community mobilization is not an easy job and it can require special skills, knowledge, and experience. Mistakes can, and probably will, happen along the way, especially if you are working with a larger community. Some of the more common mistakes to be aware of are inadequate time for planning or overlapping with someone else's project. Process evaluation can be of great help in determining if and what mistakes are being made.

Barriers should be considered when working with the various organizations involved in the community project. There may be concern that one organization is getting special treatment over other organizations or there could be an issue of organizational control. There could be an issue of lack of trust among the organizations or simply a lack of interest by the organizations or individuals in the project. These issues could become part of the communication that tries to build a consensus on goals and means.

One other point to consider is that traditions and current practices may exist in communities, especially tribal communities. Be sensitive to the local culture. Not everyone believes the same way, so do not generalize to all members of the community, even when they belong to the same tribe. In addition, every tribe is different so try to avoid generalizing from one tribe to another.

The most effective way to deal with traditions and current practices is to be aware of them and incorporate their influence on the planning process. Many of the community traditions will emerge in discussions, and current practices often can be identified through observation. You may also want to consider enlisting the help of a local person who is highly regarded for her/his traditions and current practices in your interactions with the community.

Community mobilization can provide a way that everyone in the community has a chance to participate in decisions and actions that can affect their lives and the lives of others. It is not an easy task to take on, but the benefits can be great and well worth the effort.

CHAPTER III

HEALTH PROMOTION AND PREVENTIVE CARE SERVICES

For tribes that have conducted the national NRCNAA needs assessment the majority of their elders have fallen into the 'little or none' functional limitation category. The category of 'little or none' means that the elder has no ADLs and up to one IADL's and still retains most of their functionality. If, based on the results of your needs assessment, the majority of your elders fall into the 'little or none' category, it is recommended that you consider providing health promotion and preventive care services to your elders. Health promotion and preventive care services can help the elder in maintaining functional capacity, thereby keeping them in their home longer, and maintaining a higher quality of life.

The purpose of this chapter is to provide the basic information to assist you in the planning of health promotion and preventive care service programs to the elderly. Although we do not address health education in this chapter, we do believe it is an important part of gaining your desired health promotion outcomes.

HEALTH PROMOTION

Health promotion provides the strategies to assist the elder in carrying out healthy living. It is the process of intervening to foster awareness, influence attitudes, and identify alternatives so that elders can make informed choices and change their behavior in order to achieve optimum health. Health promotion could be providing health education and information to individuals or communities that are intended to promote healthier lifestyles or it could be advocating increased awareness of personal and community health, changing attitudes so that changes in behavior are possible.

Physical activity, good dietary practices, tobacco abstinence, and stress management are all important in gaining and maintaining a healthy life. Elders should be made aware that it is never too soon or too late to start living healthy.

Exercise

Exercise is consistently identified as one of the most significant health interventions in the lives of the elderly and is an important way to build the elder's health reserves and to help prevent a wide range of health problems.

There are basically four types of exercise that are important to maintaining a healthy lifestyle for the elderly. These exercises can be done individually, but are best when done in conjunction with each other.

1. Aerobics – walking at a rapid rate, jogging, swimming, biking, square dancing, pow-wow dancing, aerobic dance, cross country skiing, and running.
2. Strengthening – lifting small or light weights on a consistent basis.
3. Flexibility – stretches to neck, shoulders, back, stomach, and hips (i.e., yoga, tai chi).

4. Balance – maintaining good posture. Too often the importance of balance comes after an elderly person has fallen.

Prior to starting any exercise program, it is essential to consult with the elder's primary care provider, determine an elder's capacity to exercise, and to develop an appropriate exercise program that will meet the needs of the elder. Remember, even performing activities of daily living can be a form of exercise for some elderly people.

Nutrition

Eating the right foods and the right amounts of foods can help you live a longer, healthier life. A varied, well-balanced diet not only will help you maintain your overall health and protect against disease, but also will give you more energy and make you feel better. Research indicates that many illnesses – such as diabetes, heart disease, and high blood pressure – can be prevented or controlled by eating right.

Nutrition assessment and recommendations should be individually determined and include the elder's perception of obstacles to improving nutrition. These perceptions can include the ability to pay for food; ability to shop for food; ability and willingness to prepare food; and ability to eat food.

Tobacco Abstinence

Tobacco use is the single most preventable cause of death and disease in the United States today. Tobacco use increases the risk for lung and other cancers and for cardiovascular and respiratory diseases. The American Cancer Society estimates that cigarette smoking is responsible for one of every five deaths in the United States, or more than 430,000 deaths per year.

Addictive smoking should be differentiated from ceremonial smoking. In Indian country, it is important to remember the role tobacco plays in ceremonial, religious, and medicinal usage for Native Americans.

Stress Management

Stress is what you experience when you believe you cannot cope effectively with a threatening situation. Your muscle area is a prime target for stress. Many forms of headache, chest pain, and back pain are among the more common conditions that result from stress induced muscle tension. Stress can play a role in circulatory diseases such as coronary heart disease, sudden cardiac death, and strokes. The gastrointestinal system can be affected and you may experience constipation, diarrhea, gas, bloating, and weight loss.

Stress is not necessarily all bad. Stress can be positive in the kind that adds to the enjoyment and satisfaction of our lives. Everyone handles stress differently. How an elder views stress and how they deal with it is what makes the difference.

Developing or expanding a program to incorporate just these four areas, exercise, nutrition, tobacco abstinence, and stress management is a big job. Securing the needed resources, material and personnel, enlisting the support of the community, and recruiting the participants for the program could become a challenge. However, the potential benefits in having healthier elders, as well as a healthier community, can be well worth the effort.

PREVENTIVE CARE SERVICES

Maintaining good health care for any existing medical conditions and regular preventive care are very important to staying healthy as you grow older. Preventive care might include a test or it might be advice from your doctor. It can be offered in the traditional doctor's office settings, or in other places such as clients' homes, workplaces, senior housing, senior centers, churches, adult day centers, hospitals, and long term care facilities. Preventive care services can be offered just about anywhere elders congregate.

There are two categories that preventive care services come under. Primary prevention consists of stopping the disease or problem before it begins. Secondary prevention includes screening for a hidden disease.

Primary Prevention

Immunizations – changes in the immune systems of the elderly place them at greater risk for infectious disease. Immunizations can provide additional protection. Some immunizations to consider are:

- *Hepatitis B* – All authorities recommend that those at risk for Hepatitis B be immunized regardless of age.
- *Influenza* – A viral respiratory illness, influenza continues to be a major cause of morbidity and mortality in the elderly. The influenza vaccine should be offered annually to all clients 65 years and older. Medicare covers the cost of vaccination.
- *Pneumococcal* – Most major medical authorities agree that all persons aged 65 years and older should receive the pneumonia vaccine at least once. Routine re-vaccination is not recommended but may be appropriate to consider in individuals at highest risk for morbidity and mortality from pneumococcal disease (persons who are over 75 years of age, have severe chronic disease, or are immuno-compromised) who were vaccinated more than 5 years earlier. Medicare has covered the cost of the pneumonia vaccination since 1993.
- *Tetanus and diphtheria* – A primary series of three tetanus-diphtheria (Td) vaccinations should be given to adults who have never been immunized. Once the series has been received, a routine Td booster vaccine should be provided every 10 years. Medicare does not currently cover the cost of the vaccine for routine immunization.

Dental care, preventive medications, and vitamins and mineral supplements are some other primary preventive care areas.

Secondary Prevention

Blood pressure – older adults with even mild hypertension are at elevated risk for coronary heart disease, stroke, peripheral vascular disease, renal disease, and retinopathy. Early detection and treatment is the key to preventing end-organ disease. Most authorities agree that blood pressure in adults should be measured every one to two years. However, because the risk of hypertension increases with age, it is prudent to measure blood pressure in the elderly at each visit.

Body measurement – The American Academy of Family Physicians and the U.S. Preventive Services Task Force recommends periodic measurement of height and weight at a frequency established by the health care provider. Elders who are overweight or obese should be counseled about associated health risks and encouraged to lose weight slowly through diet and exercise. Non-dieting individuals who have a recent weight loss of 10 or more pounds in the past 6 months require a further evaluation to identify and treat causative factors.

Cancer Screening – There are different types of cancer and each have their own recommendations for screening.

- *Breasts* – Breast cancer is the most common type of cancer and the second leading cause of cancer death in women after lung cancer. Increasing age is the most influential risk factor. The American Cancer Society (ACS) recommends that women conduct monthly breast self-examinations, annual clinical breast examination for women 40 years and older; and annual mammography for women 50 years and older. Medicare will cover the cost of a screening mammogram annually.
- *Cervical, Uterine, and Ovaries* – The Pap smear test affords detection of cervical cancer at its earliest stages. Medicare covers the cost of the screening Pap smear once every three years. ACS recommends that women age 40 years and older should also have an annual pelvic exam.
- *Testes* – the ACS recommends annual clinical examination of the testes.
- *Prostate* – Among American men, prostate cancer is the most common cancer after skin cancer and has the second highest cancer mortality rate (ACS). The risk of prostate cancer increases with age, with over 80 percent of all prostate cancers occurring in men over age 65 years. ACS recommends that men aged 40 years and over should have a digital rectal exam annually (for colorectal and prostate cancer screening). Men aged 50 years and over should also have an annual prostate-specific antigen blood test. Men 50 years of age and over should receive counseling about the known benefits, limitations, and risks associated with prostate cancer screening and treatment.
- *Oral Cavity and Pharyngeal* – The incidence of oral cavity and pharyngeal cancer increases after age 40 years and is twice as likely in men as in women. The ACS advises a yearly oral examination. Instruct elders to check their oral cavity in the mirror on a regular basis and report any white or red patches, sores, or lumps that fail to resolve.
- *Skin* – Skin cancer is the most prevalent type of cancer in the United States, occurring most frequently in the elderly. Early detection is important as almost all skin cancers are curable if diagnosed and treated early. ACS recommends that individuals ages 40 years and over practice skin self-examination monthly and have a clinical skin examination annually.

- *Colon and rectrum* – ACS states that, in the United States, cancer of the colon and rectrum is the fourth most common form of cancer and is the second leading cause of cancer deaths in adults. In average-risk individuals, ACS recommends annual performance of a digital rectal exam after age 40 years and a fecal occult blood test after age 50 years. In addition, a flexible sigmoidoscopy examination is advised every three to five years after age 50 years. Individuals with a family history of colorectal cancer or other risk factors may require colonoscopy and commencement of screening at an earlier age. Medicare will pay for one screening of the fecal occult blood test annually and one flexible sigmoidoscopy every four years for individuals over age 50 years.

Cholesterol – Elevated serum cholesterol is a known risk factor for coronary heart disease (CHD). For primary prevention, it is advised that all adults without evidence of CHD should have a screening measurement of total cholesterol and HDL cholesterol at least once every five years. When borderline or high-risk cholesterol is detected in clients without CHD, primary prevention is focused on education to reduce all CHD risk factors.

Functional Status – The American College of Physicians recommends that functional assessment be done in patients over 75 years of age in the acute-care setting as a part of discharge planning. The American Academy of Family Physicians and the U.S. Preventive Services Task Force do not recommend routine screening but encourages the health care provider to periodically assess the functional status of older clients. Functional assessment is particularly important for people who must care for themselves or others during illness or crisis.

Hearing – Hearing impairment is prevalent in older adults. The U.S. Preventive Services Task Force recommends screening older clients for hearing impairment by periodically questioning them about their hearing. Persons who perceive their hearing loss to be a problem are more likely to have further testing and accept the need for a hearing aid. It is a good idea to have your hearing checked once a year.

Vision – Visual disorders can pose potentially serious problems among older people, increasing the risk of falls, car accidents, and other types of injuries. Early detection and treatment of vision problems helps prevent further vision loss, and in most cases can lead to improved vision and quality of life. Vision screening for asymptomatic older adults should be performed every one to two years.

Anemia – the American College of Obstetricians and Gynecologists recommends an anemia screening for women over 65 years of age and older.

Plasma Glucose – can be used to identify diabetes mellitus. Periodic screening should occur for those with the following risk factors: obesity; first-degree relative with diabetes mellitus; Native American, Hispanic, or African-American heritage; previously identified impaired glucose tolerance; hypertension, hyperlipidemia or hypercholesterolemia; and gestational diabetes.

Bone Mineral Density – Osteoporosis occurs when bone is broken down faster than it is replaced. Bone loss exceeds bone replacement after menopause in women. Measurement of

bone mineral density can determine whether osteoporosis is present. Older women should receive counseling on safety measures to reduce the risk of falls with subsequent fractures.

No single set of preventive services is appropriate for all individuals in all settings. However, there are guidelines offered by federal agencies (Centers for Disease Control and Prevention), professional organizations (American Academy of Family Physicians), and national voluntary associations (American Cancer Society).

Payment for the preventive services varies depending on the insurance coverage. Collaborating with other programs, agencies, or groups to promote immunization clinics, screening events, and health promotion programs can significantly reduce your cost and time effort, as well as improve the health of the community.

CONCLUSION

In most Native cultures the elder is revered and well respected, but unfortunately in Indian Country they have a shorter life span and are at a higher risk for chronic disease. Providing health promotion activities and preventive care services to the elderly can assist in increasing an elder's healthy behaviors, thereby increasing their chance for a healthier lifestyle and possible increased longevity.

Remember that there is no foolproof way in which to select the right combination of health promotion and preventive care interventions that will ensure the most effective results. What works for one elder, or one community, may not work for another.

HEALTH PROMOTION AND PREVENTIVE CARE SERVICES:
BEST PRACTICES

Wisdom Steps

In 1998, an American Indian Community Forum was held in Minnesota to decide what to do about meeting the health needs of elders when population estimates projects four times as many elders in the year 2030. Projections from the state showing less available funding for increased number of needed services resulted in the decision to develop a preventive health model program. The intended outcome was to have more elders living healthier lifestyles requiring less costly services. Out of this forum "Wisdom Steps" was born.

Wisdom Steps was organized as a partnership between American Indian communities in Minnesota and the Minnesota Board on Aging. Wisdom Steps is governed by a Board of Directors which is made up of a representative from each of Minnesota's eleven reservations and from the cities of Duluth, Minneapolis, and St. Paul. An Advisory Council made up of interested community members and others working with American Indian communities work with the board.

Wisdom Steps developed a logo to provide for recognition, consistency, and ownership. The logo consists of a pair of worn, tipped, moccasins surrounded by symbols from the Dakota and Ojibwe tribes. The moccasins identify with the American Indian community and the worn and tipped represent the wisdom of the elderly.

One of the first things Wisdom Steps did was to conduct a needs assessment. Wisdom Steps formed a partnership with the National Resource Center on Native American Aging (NRCNAA) to find out what elders could tell us about their health. The survey, "Identifying Our Needs: A Survey of Elders" was conducted in each interested community and the results were used for planning Wisdom Steps activities.

Elders are encouraged to participate in three preventive health activities:

- Health Screenings - Elders are encouraged to practice good preventive health by visiting their physicians and setting personal health goals. Elders are encouraged to have annual screenings for blood pressure, blood glucose, cholesterol, and weight. Elders are also encouraged to consider other preventive health screenings.
- Health Education – Elders are encouraged to attend education programs that support their health goal, and to watch and learn how and why preventive health is important.
- Healthy Living Activities – Elders are encouraged to practice good health by walking or joining in preventive health promotions that encourage routine exercise.

These preventive health activities correspond to the little or none category of the functional limitations chart developed by NRCNAA. Based on the needs assessment results, the majority of Minnesota's American Indian elderly fell into this category.

A model project was developed for each of the preventive health activities. Health screenings contain "Medicine Talk" where communication is encouraged between elders and pharmacists.

"Medicare in American Indian Community" is the model project for health education. The project includes a Medicare information packet which includes simple definitions and answers about what it is, who can get it and how to access it. "We Walk, Many Together" focuses on healthy living activities and encourages elders to set an exercise goal for themselves that is achievable.

Wisdom Steps hosts a gathering each year to celebrate and honor elders for practicing good preventive health. A simple incentive plan encourages the elder's participation. Elders must complete two of the three activities listed below to qualify for a pin, charm, or certificate:

- Health Screenings - Elders must complete the four required screenings of blood pressure, blood glucose, cholesterol, and weight and complete one other preventive health screening.
- Health Education - Elders must attend a reservation/urban/regional health fair.
- Healthy Living Activity – Elders must participate in an organized walk or routine exercise of their choice.

Elders that complete the incentive plan are recognized at the gathering. Educational sessions, elder assessment data, elder service exhibits, model project updates, health screenings, and a health walk are also part of the conference. Every three years, Wisdom Steps hosts an "Honoring Our Elders Pow-wow", which recognizes Tribal and urban Indian leaders and social service agencies for their support.

For more information on the Wisdom Steps program, please contact:

Mary Snobl
Minnesota Board on Aging Indian Elder Desk
444 Lafayette Road
St. Paul, MN 55155-3843
Telephone: (651) 297-5458

Or visit their website at http://www.wisdomsteps.com.

CHAPTER IV

HOME- AND COMMUNITY-BASED SERVICES

Many elders prefer to live independently in their own homes for as long as possible. In many tribes/villages, keeping the elder at home is part of the culture. In addition to the physical and mental benefits for the elder and their family when the elder remains at home, there can also be a significant financial savings if the care required is not too complicated or too frequent to require outside help.

Home- and community-based services can assist in providing the services needed to keep the elder in their home. Home- and community-based services refer to assistance with the elder's activities of daily living in their home or in a non-institutional community setting.

If, based on your needs assessment, the category labeled "moderate" in the chart on functional limitations contains a relatively large proportion of your elders, this should direct you to paying particular attention to home- and community-based services as these are designed to meet the needs of people not in or eligible for institutional care and ultimately help retain people in their home settings even as they experience increased frailty. Results from the NRCNAA national needs assessment show that approximately 20 percent of the Native elders surveyed across the nation fell into this category.

Many different types of home- and community-based services have been developed for elders and their caregivers. These services can include medical, social, and support services and involve many different service providers. Some of these services have been listed below. Because some of the services can be done in the home, the community or in both home and community no distinction has been given as to which service belongs in which setting. Please remember that this is not an all-inclusive list, but rather a starting point.

Case Management

Case management services are aimed at providing a single access point into the service system. Case management is usually performed by a social worker or a registered nurse, which begins by assessing the physical, environmental, financial, cognitive and functional level of the elder. The next step is the determination of the services needed to enhance the current support system and maintain the elder in his or her environment. Care is then arranged with appropriate providers by locating, developing, arranging and coordinating services, monitoring the provision of those services on a regular basis, as well as changes in the elder's condition, and, adjusting the service plan as needed. Case managers may also advocate on behalf of the elder with health care providers and other agencies.

Adult Day Care

Adult Day Care affords the elder the comforts of home and at the same time gives families the respite they need. This care is usually reasonably priced and may even be subsidized by certain

local resources. Offered in community centers and through some senior programs, Adult Day Care provides social, recreational, meals, and sometimes transportation services.

Durable Medical Equipment

Durable medical equipment includes devices, controls, or appliances specified in the plan of care that enable the elder to increase their ability to perform activities of daily living. This equipment can be used over and over again; is ordinarily used for medical purposes; and is generally not useful to a person who isn't sick, injured or disabled.

Examples of durable medical equipment include equipment to help the elder move around: canes, crutches, walkers and wheelchairs. It also includes equipment needed to care for the elder at home: bed pans, heat lamps or pads, hospital beds, special toilet seats and machines that help make breathing easier.

Prior approval for the equipment may be needed in order to have the cost covered by a specific program.

Home Health Care

Home health care is a formal, regulated program of care delivered by a variety of health care professionals in the elder's home. An elder must be homebound to receive home health care services. Homebound implies that the elder is unable to leave home or that leaving home requires a considerable and taxing effort.

Home health care includes skilled nursing care such as providing therapy treatments or administering medication; home health aide services such as checking temperature and blood pressure; personal care such as help with bathing, dressing, walking, exercise; and physical, occupational, respiratory, or speech therapy. The skill level of the home health provider is dependent on the task to be performed; many duties can be performed by a home health aide, others require a registered nurse.

Chore Services

Chore services are non-continuous household maintenance tasks such as heavy cleaning, minor repairs, and yard work that are intended to increase the safety of the elder living at the residence. Chore services are available to elders who are physically unable to perform tasks or are unable to secure assistance from family or friends nor have the means to pay privately.

Homemaker Services

Homemaker service is extended to elders who are unable to perform day-to-day household duties and have no one available to assist them. Services may include light housekeeping, shopping, meal preparation, personal care (bathing, toileting, eating, dressing, hair care, exercise, oral hygiene), and laundry service.

Physical Therapy

Physical therapy is a vital part of the total care for elders who have problems of temporary or permanent disability. A medical referral is often made post-operatively, following stroke, and following injury or illness.

The main goal of physical therapy is to restore physical function. This can involve treating pain, range of motion, strength, posture, balance, endurance, control, and sensation.

Physical therapy services are provided by a physical therapist. A physical therapist is specially trained and educated at a college and must be licensed in the state in which he or she practices.

Occupational Therapy

Occupational therapy is a health care profession that is concerned with restoring useful physical functionality following disabling accidents and sickness. The goal of occupational therapy is to assist the elder in achieving the maximum level of independent function.

Recipients of occupational therapy may include persons suffering from strokes, cerebral palsy, spinal cord injuries, arthritis, head injuries, amputations, burns, hand injuries, and people with visual, auditory and speech problems.

Medication Assistance

Medication assistance is helping an elder, who is capable of self-administration, to use or ingest, store and monitor medications.

Medication assistance can also be assisting elders in the purchase of prescription drugs. A number of states have programs that provide this assistance. The programs are usually aimed at elders who have low or modest incomes and who do not qualify for Medicaid.

Speech Therapy

Speech therapy is the treatment of communication disabilities and swallowing disorders. Speech therapists treat disorders resulting from disease, trauma, congenital anomaly or prior therapeutic process.

Mental Health

Mental disorders are experienced by nearly 20 percent of elders who are 55 years and older. These mental disorders are not part of the normal aging process. Some of the most common disorders are anxiety, severe cognitive impairment, and mood disorders.

The federal government augments state and local funding to provide community-based mental health services to elders with serious mental health illness. Medicare will only cover 50 percent of mental health services.

Transportation Services

Transportation is one of the more common needs for elders. The availability of adequate transportation enables older persons to live independently in their communities, helps to prevent isolation and the possible need for long term care placement.

Transportation services vary from community to community. Some types of transportation that may be available for the elderly are individual door-to-door service, fixed route with scheduled services, or ridesharing with volunteer drivers. In some communities the Area Agency on Aging arrange, monitor, and support programs that provide transportation for the elderly. Even if your local agency doesn't provide transportation services directly, they might be able to give assistance in locating resources for obtaining transportation services.

Nutritional Services

Good nutrition is crucial to maintaining an older person's health and overall well-being. The most well-known nutritional support is the Home-Delivered Meals program, often called Meals-On-Wheels. Operated through Title III-C(1) and Title VI of the Older Americans Act these services seek to assure the provision of one nutritionally complete meal per day to elderly and disable persons who are unable to prepare meals themselves or travel to a central site. Most programs utilize volunteers for the daily delivery process although there are several localities which have provided microwave ovens and weekly deliveries of frozen meals.

Seniors may also receive congregate meals in group settings at community centers, churches and senior centers. Usually these meals are provided on a Monday through Friday basis and the participants are offered additional activities such as recreational and educational programs.

Personal Care

Personal care services include assistance with mobility, eating, medication management, skin care, household services, toileting, meal preparation, hygiene, and minor maintenance of assistive devices. The personal care attendant may be a family member (except a spouse), friend or neighbor or the person needing support may elect to have an attendant assigned to them.

The personal care program is an optional Medicaid benefit by which states may choose to provide beneficiaries with assistance with daily living activities.

Respite Care

Respite refers to short term, temporary care provided to the elderly. Respite care services are used by the caregiver of an elderly who requires around the clock care. The caregiver can utilize these services for an hour, half day, full day care, or evening hours. Respite care can be provided for a few hours or a few weeks, on a scheduled basis or in response to an emergency. Generally the respite care services offer the caregiver an opportunity to regroup and refresh him or herself.

Respite care services are usually provided in the elder's home or in another home or homelike setting. In-home respite care provides companionship, supervision and/or assistance with activities of daily living to the elder. Respite care may also be provided in a nursing home.

CONCLUSION

Not everyone using home care will need all of the services available, and not every community will provide every possible service that may be required. For home care to work well, home- and community-based programs must be found, coordinated, monitored, costs figured and changes made when necessary. All of this takes time and effort.

HOME- AND COMMUNITY-BASED SERVICES: BEST PRACTICES

Eagle Shield Senior Citizens Center

The Eagle Shield Senior Citizens Center is a program developed by the Blackfeet Tribe to provide assistance to the elderly of the Blackfeet Reservation. The Blackfeet Reservation is located in the northwestern part of Montana and encompasses approximately 1.5 million acres. In 2000, the total tribal enrollment for the Blackfeet Reservation was 14,564. Of that number, 926 were classified by the State Department of Health and Human Services as elders 60 years of age and older in need of aging services. The Eagle Shield Center is located in Browning, Montana.

Over the years, the Eagle Shield Senior Citizens Center has developed from a bare bones operation to a program that offers a wide range of senior services, from nutrition education and meal delivery to home personal assistance and social activities. The nutrition program includes meal services that are provided as congregate meals at the Eagle Shield site, home-delivered meals, and medical waiver provided meals to disabled individuals. For social activities the Center provides the elders with a place to visit, read newspapers, or just hang out. Other social activities at the Center include television viewing with videos of Blackfeet history, card and board games, space for quilting, a pool table, and an arbor and picnic tables for outdoor meals and socializing.

In addition, the Center serves as a base for community health activities such as flu shot clinics, free eye examinations for glaucoma and cataracts, educational and social gatherings held annually for cancer and dialysis patients and their families. A cardio-glide exerciser and aerobics are available for the elders should they desire to exercise. The Center operates separately from the local Community Health Representatives and Indian Health Service, but works in conjunction with them to provide health services to the elderly.

Eagle Shield Senior Citizens Center also provides access to services from other programs such as the Personal Care Attendant Program, Green Thumb Volunteers Worksite, and the Visually Impaired Program Volunteers.

The Personal Care Attendant (PCA) Program offers in-home care tasks that are medically necessary for recipients whose health conditions cause them to be functionally limited in performing activities of daily living. This program is an option with the purpose of delivering services to the elderly and/or disabled for their comfort and safety. Services can include assistance with activities of daily living and/or personal hygiene, assistance with meal preparation, and household tasks. Start up funds for the PCA program was provided by the Tribal Business Council and continues with the aid of Medicaid reimbursements.

An added benefit to the PCA program is that in a rural community that has over 70 percent unemployment, it employs and provides training for local individuals of the Blackfeet Indian Reservation. In 2001, the PCA program employed over 100 personal care attendants and maintained a pool of about 300 trained individuals.

The Green Thumb Volunteers program employs elders 55 years of age or older who qualify for the program for a maximum of four hours per day. Eagle Shield is the host agency for the Visually Impaired Program Volunteers. These volunteers are 55 years of age or older who qualify for the program and work a maximum of four hours per day. They are assigned to assist elders who are visually impaired.

The Eagle Shield Senior Citizens Center continues to progress through the building of a new center. The building was built with federal Department of Housing and Urban Development money because it includes 16 one-bedroom apartments for elders. Tribal leadership put $80,000 toward furnishings for the center.

For more information about Eagle Shield please contact Connie Bremner, Director, at (406) 338-3483 or visit their Web site at http://www.blackfeetnation.com.

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RESOURCES

This section of the tool kit contains a list of funding and general resources that are available to assist tribes in planning and implementing long term care services for their elders. The list is not intended to be an exhaustive list, but rather should be used as a starting point to obtain further information. The list is also not intended to recommend or endorse any organization or Web site.

Under the funding resources section you will find resources that are general in nature and can be applied throughout the long term care spectrum. Under both the funding and general resources sections you will find resources that are specific to each respective chapter of the tool kit and are designated as such. Some of the resources listed may not apply specifically to elders or long term care, but are included as examples, guides, or as a means to start your search for resources specific to long term care.

The resources for each section and chapter are listed alphabetically.

FUNDING RESOURCES

Funding for long term care programs or services is typically obtained through grants from private and/or public funding sources. These sources include the federal government, state and local funding agencies, and private foundations. No one funding source is more important than the other, but we suggest you consider your local resources first.

General

Public Funding

Catalog of Federal Domestic Assistance
Executive Office of the President
Office of Management and Budget
Washington, DC
http://www.cfda.gov

The Catalog is an annual listing of funding programs sponsored by the federal government. It is published annually at year-end with a mid-year update.

Federal Register
U.S. National Archives and Records Administration
Office of Federal Register
Washington, DC
http://www.access.gpo.gov/su_docs/aces/aces140.html

The Federal Register is published daily and provides information on federal assistance in the form of grants and contracts. The Register may also be available at your local library.

Federal programs that work with elderly are the Administration on Aging, Indian Health Service, USDA, HUD, Centers for Medicare & Medicaid, to name just a few.

State and local agencies

State and local governmental agencies that administer grant programs might also be useful in searching for funding information. Examples include area agencies on aging, state health departments, social services, housing, and transportation departments.

Tribes

Your local tribe and tribal government might provide either funding or resources for the long term care project.

http://www.grants.gov

This web site contains information about finding and applying for federal grant programs.

Private Funding

The Foundation Center
79 Fifth Avenue
New York, NY 10003
Phone: 212-620-4230
Toll Free: 800-424-9836
http://www.fdncenter.org

The Foundation Center operates as an independent service organization established to provide a single authoritative source of information on philanthropic giving. The Center also publishes The Foundation Directory which provides general information on the nation's top grant making programs

Grant Funding for Elderly Health Services, Fourth Edition
Health Resources Online at http://www.healthresourcesonline.com/health_grants/gfehs.htm

This book provides information on grant funds from federal agencies, charitable foundations and corporations for senior services.

Guide to U.S. Foundations, Their Trustees, Officers, and Donors.
This book can be purchased through The Foundation Center

This is an annual series that provides information on private, corporate, and community foundations.

State and Local Foundations

Many states publish foundation directories that provide information on funding provided by local givers that are often excluded from the larger, national directories. These directories might be found in your local library.

GrantStation.com, Inc.
3677 College Road, Suite 11B
Fairbanks, AK 99709
Phone: 907-457-6601
Toll Free: 877-784-7268
http://www.grantstation.com

GrantStation quickly and easily links nonprofits to all current sources of grant money, while also teaching these organizations how to secure available funding.

Local Business and Service Organizations

Contact a local business or service organization for either funding or resources.

Other Funding

Rural Assistance Center
Center for Rural Health
UND School of Medicine and Health Sciences
PO Box 9037
Grand Forks, ND 58202
Phone: 701-777-6024
Toll Free: 800-270-189
http://www.raconline.org

The web site features an information guide on Grant/Funding Resources. Included in the Resources section is the book "Rural Health Funding Sources: A Resource Guide." The Rural Assistance Center also provides customized assistance in searching for funding opportunities.

Health Promotion and Preventive Care Services

Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244
Phone: 410-786-3000
Toll Free: 877-267-2323
http://www.cms.hhs.gov

CMS provides information about Medicare benefits, publications, and websites with information that can help you stay healthy. Medicare may also be used to pay for some preventive care services. These programs may provide funding for various home and community based services for the elderly.

Home and Community Based Services

Administration on Aging
Washington, DC 20201
Phone: 202-619-0724
http://www.aoa.gov

AoA, an agency in the U.S. Department of Health and Human Services, is one of the nation's largest providers of home and community-based care for elders and their caregivers.

Area Agencies on Aging
To find a program near you, call the toll-free Eldercare Locator at 800-677-1116.

AAAs plan, coordinate and offer services that help elders remain in their home. AAAs play a pivotal role in assessing community needs and developing programs that respond to those needs. AAAs also acts as advocates for improved services for elders and their families.

GENERAL RESOURCES

The Internet is a valuable resource as it has a variety of resources available with each of those sites linking to even more sources. We suggest developing a search plan by defining key search words for the Internet before you begin your search to save time. Other resources to consider are the public library, universities/colleges, and other resources outside of elderly programs.

Needs Assessment

National Resource Center on Native American Aging
UND Center for Rural Health
PO Box 9037
Grand Forks, ND 58202
Toll Free: 800-896-7628
http://medicine.nodak.edu/crh/nrcnaa

The Center's activities focus primarily on training, technical assistance, and research related to Native elders.

Community Mobilization

Community Tool Box
University of Kansas
http://ctb.ku.edu

The Tool Box provides over 6,000 pages of practical information to support your work in promoting community health and development. The tool box can be used as an example or guide in mobilizing the community.

Families and Work Institute
267 Fifth Ave., Floor 2
New York, NY 10016
Phone: 212-465-2044
http://www.familiesandwork.org/forums/

Has a Community Mobilization Forum program. The forum provides you with lessons learned from community mobilization efforts, tools and materials that have been developed, and ideas for developing individualized approaches that work for your community.

National Association of County & City Health Officials
MAPP Project
1100 17th Street, NW, 2nd Floor
Washington, DC 20036
Tel: 202-783-1583
http://www.naccho.org

Mobilizing for Action through Planning and Partnerships (MAPP) is a community-wide strategic planning tool for improving community health. This tool helps communities prioritize public health issues, including long term care issues, and identify resources for addressing them.

National Center for Chronic Disease Prevention and Health Promotion
Centers for Disease Control and Prevention
Mailstop K-46
4770 Buford Highway, NE
Atlanta, GA 30341
Tel: 770-488-5426
http://www.cdc.gov

CDC offers the Planned Approach to Community Health (PATCH) program. The goal of PATCH is to increase the capacity of communities to plan, implement, and evaluate comprehensive, community-based health promotion programs targeted toward priority health problems, such as long term care issues.

Ohio State University
http://www.ohioline.osu.edu/bc-fact/0010.html

Fact sheet on community mobilization.

State Offices of Rural Health

State offices collect and disseminate information; improve recruitment and retention of health professionals into rural areas; provides technical assistance to attract more federal, state, and foundation funding; and coordinates rural health interests and activities across a state.

Health Promotion and Preventive Care Services

Agency for Healthcare Research & Quality
PO Box 8547
Silver Spring, MD 20907-8547
Toll Free: 800-358-9295
http://www.ahrq.gov

Publications on elder and long-term health care, health insurance, and minority health data.

America on the Move
http://www.americaonthemove.org/

The web site provides links to information on active living, healthy eating, and weight management.

American Academy of Family Physicians
11400 Tomahawk Creek Parkway
Leawood, KS 66211-2672
Phone: 913-906-6000
Toll Free: 800-274-2237
http://familydoctor.org

Offers education and information on health care and disease prevention. Publications are free.

American Association of Retired Persons (AARP)
601 E Street, NW
Washington, DC 200049
Phone: 202-434-2277
Toll Free: 800-424-3410
http://www.aarp.org

AARP local chapters provide information and services on crime prevention, consumer protection, and income tax preparation. The AgeLine database, available on CD-ROM, contains extensive resources on issues of concern to older people. Publications are available on housing, health, exercise, retirement planning, money management, leisure, and travel.

American Cancer Society
1599 Clifton Road, NE
Atlanta, GA 30329
Phone: 404-320-3333
Toll Free: 800-227-2345
http://www.cancer.org

National Cancer Information Center (1-800-ACS-2345) – Trained cancer information specialists are available 24 hours a day, seven days a week to answer questions about cancer, link callers

with resources in their communities, and provide information on local events. American Cancer Society Web Site (http://cancer.org) – includes an interactive cancer resource center containing in-depth information on every major cancer type. Also includes a directory of medical resources, links to other sites, advocacy efforts, and special events. Publications – The Society publishes a large number of patient education brochures and pamphlets, books, and professional journals to help patients, families, and health care professionals. Community Programs & Services – community-based programs aimed at reducing the risk of cancer, detecting cancer as early as possible, ensuring proper treatment, and empowering people facing cancer to cope with the disease and maintain the highest possible quality of life.

American Diabetes Association
1701 N. Beauregard Street
Alexandria, VA 22311
Toll Free: 800-342-2382
http://www.diabetes.org

Educational materials, referrals to local chapters, information specialists.

American Legacy Foundation
2030 M Street, NW
Sixth Floor
Washington, DC 20036
Phone: 202-454-5555
http://www.americanlegacy.org

The foundation develops national programs that address the health effects of tobacco use through grants, technical training and assistance, strategic partnerships, and community outreach to populations disproportionately affected by the toll of tobacco.

American Lung Association
1740 Broadway
New York, NY 10019
Phone: 212-315-8700
Toll Free: 800-586-4872
http://www.lungusa.org

The American Lung Association offers a variety of smoking control and prevention programs targeted to specific groups.

Arthritis Foundation
PO Box 7669
Atlanta, GA 30357
Phone: 404-965-7537
Toll Free: 800-283-7800
http://www.arthritis.org

Recorded information, printed information, location of the nearest Arthritis Foundation chapter, doctor referral list.

Association of American Indian Physicians
Phone: 405-946-7072
http://www.aaip.com

AAIP members are very active in medical education, cross cultural training between western and traditional medicine, and assisting Indian communities.

Centers for Disease Control & Prevention
1600 Clifton Road
Atlanta, GA 30333
Phone: 404-639-3311
Toll Free: 800-311-3435
http://www.cdc.gov

Contact CDC for public information, health statistics, funding opportunities, and prevention guidelines.

EyeCare America
655 Beach Street
San Francisco, CA 94109-1336
Toll Free: 800-222-3937
http://www.eyecareamerica.org

The Seniors EyeCare Program (SEP) helps to ensure that all eligible seniors have access to medical eye care and promotes annual, dilated eye exams. SEP raises awareness about age-related eye disease, provides free eye care educational materials and facilitates access to eye care.

Food and Drug Administration
HFE88
5600 Fishers Lane
Rockville, MD 20857
Toll Free: 888-463-6332
http://www.fda.gov/oc/olderpersons/

FDA has numerous articles, brochures and other publications with information for older people on a wide range of health issues, including arthritis, cancer, health fraud, and nutrition. Selected publications are also in Spanish.

Healthfinder
PO Box 1133
Washington, DC 20013-1133
http://www.healthfinder.gov

A key resource for finding the best government and nonprofit health and human services information on the Internet.

Mayo Clinic-Native CIRCLE
Charlton 6; Room 282
200 First Street S.W.
Rochester, MN 55905
Phone: 877-372-1617
http://mayoresearch.mayo.edu/mayo/research/cancercenter/native.cfm

Resource center providing cancer-related materials to people involved in the education, care and treatment of American Indians and Alaska Natives.

The National Association of the Deaf
814 Thayer Avenue
Silver Spring, MD 20910-4500
http://www.nad.org

Dedicated to assuring that a comprehensive, coordinated system of services is accessible to those who are deaf or hard of hearing.

National Cancer Institute
National Institutes of Health
Public Inquiries Office
Building 31, Room 10A03
31 Center Drive MSC 2580
Bethesda, MD 20892-2580
Phone: 301-435-3848
Toll Free: 800-422-6237
http://www.nci.nih.gov

Cancer.gov, the National Cancer Institute's web site, provides accurate, up-to-date information on many types of cancer, information on clinical trials, resources for people dealing with cancer, and information for researchers and health professionals.

National Center for Bicycling & Walking
1506 21st Street NW,Suite200
Washington, DC 20036
Phone: 202-463-6622
http://www.bikewalk.org

Provides specialized consulting services in the areas of long-range planning, policy development, public involvement, route selection, planning and design guidelines for bicycle and pedestrian facilities.

National Diabetes Education Program
One Diabetes Way
Bethesda, MD 20814-9692
Phone: 301-496-3583
http://ndep.nih.gov

Develops and implements ongoing diabetes awareness and education activities. Identifies, develops, and disseminates educational tools and resources for people with diabetes and those at risk, including materials that address the needs of special populations.

National Diabetes Information Clearinghouse
1 Information Way
Bethesda, MD 20892-3560
Phone: 301-654-3327
Toll Free: 800-860-8747
http://diabetes.niddk.nih.gov

NDIC services include responding to inquiries about diabetes, providing free publications about diabetes, referrals to health professionals, and maintaining a database of health education materials produced by health-related agencies of the Federal Government.

National Eye Institute
Information Office
2020 Vision Place
Bethesda, MD 20892-2510
Phone: 301-496-5248
http://www.nei.nih.gov

NEI coordinates the National Eye Health Education Program. The focus of the program is on public and professional education programs that encourage early detection and timely treatment of glaucoma and diabetic eye disease and the appropriate treatment for low vision.

National Heart, Lung, and Blood Institute
Information Center
PO Box 30105
Bethesda, MD 20824-0105
Phone: 301-592-8573
Toll Free: 800-575-9355
http://www.nhlbi.nih.gov

The Information Center provides referrals to resource organizations and information.

National Institute of Mental Health
Office of Communications
6001 Executive Blvd, Room 8184, MSC 9663
Bethesda, MD 20892-9663
Phone: 301-443-4513
Toll Free: 866-615-6464
http://www.nimh.nih.gov

Provides information on depression and its related diseases.

National Oral Health Information Clearinghouse
National Institute of Dental and Craniofacial Research
National Institutes of Health
Bethesda, MD 20892-2290
Phone: 301-496-4261
http://www.nohic.nidcr.nih.gov/

NOHIC produces and distributes patient and professional education materials including fact sheets, brochures, and information packets. NOHIC staff provide free custom or standard searches on specific special care topics in oral health.

National Osteoporosis Foundation
1232 22nd Street NW
Washington, DC 20037-1292
Toll Free: 800-223-9994
http://www.nof.org

Educational materials, information specialists.

National Women's Health Information Center
8550 Arlington Blvd. Suite 300
Fairfax, VA 22031
Toll Free: 800-994-9662
http://www.4woman.org

Coordinates women's health initiatives across the Department of Health and Human Services and to disseminate state-of-the-art information for women nationwide. Provides detailed information about the prevention, diagnosis and treatment of the illnesses and health conditions that women face.

NativeWeb
http://www.nativeweb.org

Web site that disseminates information from and about indigenous nations, peoples, and organizations around the world.

Prevent Blindness America
500 East Remington Road
Schaumburg, IL 60173
Phone: 847-843-2020
Toll Free: 800-331-2020
http://www.preventblindness.org

PBA offers many programs and services to help fight blindness and save sight through vision screenings, patient and public education programs, and information publications and videos.

Tobacco Information and Prevention Source
Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, GA 30333
Phone: 770-488-5705
Toll Free: 800-232-1311
http://www.cdc.gov/tobacco

The Office on Smoking and Health has prepared information on smoking, tobacco, and health. The OSH has a catalog of free publications.

USDA Food and Nutrition Information Center
10301 Baltimore Ave., Room 304
Department of Agriculture, NALB
Beltsville, MD 20705-2351
Phone: 301-504-5719

Nutrition information, specific publications, USDA FDA information service, FDA USDA labeling center, information specialists.

http://www.quitsmokingsupport.com

Provides free support, information, and resources to assist anyone who has the desire to quit smoking.

Home and Community Based Services

American Occupational Therapy Association
4720 Montgomery Lane
PO Box 31220
Bethesda, MD 20824-1220
Phone: 301-652-2682
http://www.aota.org

The AOTA is a professional organization of approximately 40,000 occupational therapists, occupational therapist assistants, and students of occupational therapy. May be a source to find occupational therapists in your area.

American Physical Therapy Association
1111 North Fairfax Street
Alexandria, VA 22314-1488
Phone: 703-684-2782
Toll Free: 800-999-2782
http://www.apta.org

The APTA is a national professional organization representing more than 63,000 members. Its goal is to foster advancements in practice, research, and education. May be a source to finding a physical therapist closest to your area.

American Psychological Association
Office on Aging
750 First Street, NE
Washington, DC 20002-4242
Phone: 202-336-6135
http://www.apa.org/pi/aging/

APA's Office on Aging serves as an information and referral resource for mental health professionals, elders, and the public on issues facing elders.

American Speech-Language-Hearing Association
10801 Rockville Pike
Rockville, MD 20852
Toll Free: 800-638-8255
http://www.asha.org

ASHA represents the interests of medical specialists in speech, language, and hearing science and advocates for people with communication-related disorders. ASHA produces publications and fact sheets on topics such as communication disorders and hearing aids.

Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244-1850
Phone: 410-786-3000
Toll Free: 877-267-2323
http://www.cms.hhs.gov/providers/hha/

Provides a Web page, "Home Health Information." The Home Health Web page has been developed to incorporate all Home Health specific information in one place.

Community Transportation Association of America
1341 G Street, NW, 10th Floor
Washington, DC 20005
Phone: 202-628-1480
Toll Free: 800-891-0590
http://www.ctaa.org

CTAA conducts research, provides technical assistance, offers educational programs, and serves as an advocate in order to make coordinated community transportation available, affordable and accessible.

Eldercare Locator
Toll Free: 800-677-1116
http://www.eldercare.gov

The Eldercare Locator is a national toll-free referral number funded by the Administration on Aging. The Eldercare Locator connects callers to the best state and community sources of information and assistance to address the issues, needs, or concerns of the elder and their caregivers.

ElderWeb
1305 Chadwick Drive
Normal, Illinois 61761
Phone: 309-451-3319
http://www.elderweb.com

This Web site is designed to be a research site for both professionals and family members looking for information on eldercare and long term care. It includes links to information on legal, financial, medical, and housing issues, as well as policy, research, and statistics. The site also has links to other elder care Web sites.

Family Caregiver Alliance
180 Montgomery Stree, Ste 1100
San Francisco, CA 94104
Phone: 415-434-3388
Toll Free: 800-445-8106
http://www.caregiver.org

Family Caregiver Alliance programs and services include information such as publications, fact sheets, and newsletters; caregiver workshops; professional training; and online services.

HelpingPatients.org (http://www.helpingpatients.org**)**

An interactive Web site by PhRMA that helps find patient assistance programs for which you may qualify. Patient assistance programs can help patients receive assistance in acquiring their needed medicines.

IHS Elder Care Initiative
45 Vernon Street
Northampton, MA 01060
Phone: 413-584-0790
http://www.ihs.gov/medicalprograms/eldercare

The goal of the Elder Care Initiative is to promote the development of high-quality care for American Indian and Alaska Native elders by acting as a consultation and liaison resource for IHS, tribal, and urban Indian health programs.
The core activities of the Elder Care Initiative are in information and referral, technical assistance and education, and advocacy.

National Association for Home Care
228 7th Street, SE
Washington, DC 20003
Phone: 202-547-7424
http://www.nahc.org

NAHC is the nation's largest trade association representing the interests and concerns of home care agencies, hospices, home care aide organizations, and medical equipment suppliers.

National Association of Adult Day Services
722 Grant Street, Suite L
Herndon, VA 20170
Phone: 703-435-8630
Toll Free: 800-558-5301
http://www.nadsa.org

NADSA provides its members with effective national advocacy, educational and networking opportunities, technical assistance, research and communication services. NADSA also has start-up kits for new ADS providers.

National Center on Elder Abuse
1201 15th Street, NW, Suite 350
Washington, DC 20005
Phone: 202-898-2586
http://www.elderabusecenter.org

NCEA, funded by the U.S. Administration on Aging, is a gateway to resources on elder abuse, neglect, and exploitation.

National Council on Aging
300 D Street SW, Suite 801
Washington, DC 20024
Phone: 202-479-1200
http://www.ncoa.org

NCOA is dedicated to improving the health and independence of older persons; increasing their continuing contributions to communities, society and future generations; and building caring communities. Its members include senior centers, adult day service centers, area agencies on aging, faith congregations, senior housing facilities, employment services, and other consumer organizations.

State Units on Aging

State Units on Aging are agencies designated by governors and state legislatures to administer, manage, design and advocate for benefits, programs and services for the elderly and their families.

State Departments of Human Services

These agencies can serve as a source for information on elder issues. Some agencies may have programs available for elders.

Visiting Nurse Associations of America
99 Summer Street, Suite 1700
Boston, MA 02110
Phone: 617-737-3200
http://www.vnaa.org

VNAA is an association for not-for-profit, community based home health care providers. Visiting nurses offer quality in-home medical care including physical, speech, and occupational therapy; social services; and nutritional counseling.

Please Note: We have tried to make this information as up-to-date as possible. However, since phone numbers and web sites are subject to change, some of the information may no longer be valid. If this is the case, we recommend using a computer search to find the most recent listings.