

**Tribal Guide for Elder Care:  
A Primer on Long-Term Care Services & Financing  
For Indian Elders**

**Produced for the Retirement Research Foundation  
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## **INTRODUCTION**

Long-term care in Indian country brings into play a different set of assumptions than may be true for mainstream American communities. Respect for Indian elders, while romanticized by media portrayals of Indian culture, nevertheless remains a core value of most American Indian/Alaska Native communities. Bruce Finke, M.D., director of the Indian Health Service Elder Health Care Initiative, observes several prevailing tribal attitudes that characterize Indian communities. These include strong family support for care in the home, community recognition of the importance of the caregiver role, recognition of the importance of the elder in the life of the community, widespread community commitment to elder care, and a holistic understanding of health (physical, mental, and social well-being).

Formal long-term care services have not been firmly established in Indian country. Although modest provisions exist in the pending reauthorization of the Indian Health Care Improvement Act<sup>2</sup>, funding has never been available – either to the Indian Health Service (IHS) or to Tribes – for the implementation of significant long-term care services or initiatives. Nearly half a century after the IHS began providing health care for Indians, long-term care services (and access to the federal funding streams that would provide them) remain, for the most part, fragmented and difficult and to access.

In planning for elders' long-term care needs, Tribes face two central problems. First, "long-term care" is not one standard package of services. Nursing home care is a long-term care service – and so can be a home-delivered meal, a van ride to a doctor's office, an installation of a grab bar in an elder's bathroom, and many other services. To choose an appropriate or workable package of long-term care services, or just an individual long-term care service, a Tribe should consider setting priorities and deciding which type(s) of long-term care services will be the most useful, cost-effective, and appropriate.

The second problem is related to the first. Funding for long-term care services is limited, fragmented, and difficult to access without considerable knowledge of available funding sources. Some long-term care services may be available through the IHS, but most are not. Funding may be available through a state Medicaid program, or through opportunities provided under the federal Older Americans Act, but each of these programs has significant limitations.

These problems are significant, but not insurmountable. A major part of the solution is to be familiar with the relevant programs and rules – which is the purpose of this guide. The guide provides the reader with a comprehensive introduction to the most important and common services and funding sources, along with an explanation of the most significant rules.

Long-term care is too important to be left to chance. This guide can assist Tribes and their tribal members in making long-term care services available to elders who need them.

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<sup>2</sup> S. 556, The Indian Health Care Improvement Act Reauthorization of 2003 in the U.S. Senate and H.R. 2440, The Indian Health Care Improvement Act Amendments of 2003 in the U.S. House of Representatives.

## **INDIAN HEALTH CARE**

### **Indian Health Service**

#### ***Introduction***

The Indian Health Service delivers health care services directly through IHS-administered hospitals and clinics, and also through facilities that have a contract with IHS. IHS services may include hospital and medical care, dental care, and public health nursing and preventive care (*e.g.*, vaccinations), but do not include nursing home care. IHS does not provide the same services in each area served; service availability depends on funding, the existence of alternative service resources, and other factors. IHS services are provided without charge to eligible Indians.

Although IHS does not provide a defined package of long-term care, the IHS-funded services include many that should be considered as long-term care services. The degree to which IHS resources are used to provide long-term care services is very much dependent on local priorities and capacity. In any case, however, IHS is not currently authorized to provide custodial care or housing, and hence does not provide nursing home care. IHS can, and in some cases does, provide some time-limited transitional care (swing bed care provided in a hospital) and rehabilitation services that are traditionally provided in nursing homes.

The reality is that IHS health care services often are inadequate to meet a tribal community's need. As explained above, the federal law does not require a particular level of IHS services. Rather, the federal law sets general guidelines, and the availability of services depends in large part on each year's federal budget. Because of inadequate appropriations in the federal budget, IHS health care services generally are recognized to fall short of what is needed.

#### ***Community Health Representative Program***

The innovative IHS "Community Health Representative" (CHR) program, one of the first Indian health programs to engage tribal members in their own health care, provides a vital link for Indian long-term care. Training Indians to provide health and health-related services within Indian communities, the CHR program began as a culturally sensitive way to provide home health care and a variety of curative, preventive, and rehabilitative services. Today, CHR programs assume numerous different roles with Tribes. When necessary, in non-emergency situations, CHRs can provide transportation for Indians who otherwise would lack the means to travel to a hospital or a clinic, or act as a go-between when patients and health care providers are having difficulty communicating with each other. As tribal employees funded by IHS, CHRs educate Indian communities on health promotion and disease prevention.

Some CHR work focuses on health systems, rather than individual patients. CHRs act to improve tribal connections with government agencies, and work to recruit and retain health care providers for the tribal community.

## *Contract Health Services*

Contract health service is the mechanism by which IHS and tribal facilities purchase services that cannot be provided directly by IHS/tribal programs. The program was designed to care for those dependent on IHS-funded care and, as a result, eligibility generally is limited to those living on or near their home reservation or community, as well as students or dependents who may be away at school. Contract health service funds are limited and priority is given to life-threatening and urgent need.

### *Diabetes Care*

The Balanced Budget Act of 1997<sup>3</sup> provided \$150 million to the IHS over a five-year period (fiscal years 1998-2002) to establish grants for the “prevention and treatment” of diabetes in Indian communities. Eligible recipients of these grants included IHS programs, Tribes and tribal organizations, and urban Indian organizations. The funding was distributed to more than 300 grant recipients through a process that included extensive tribal consultation, the development of a formula to distribute funds to eligible programs, and a formal grant application process. Today, the programs continue to use this funding to design activities according to local priorities and needs.

In the Consolidated Appropriations Act of 2001<sup>4</sup>, Congress appropriated additional funding for the Special Diabetes Program for Indians. This appropriation included an additional \$70 million in FY 2001, \$70 million in FY 2002, and \$100 million in FY 2003. In 2002, Congress amended the Public Health Service Act<sup>5</sup> to extend the Special Diabetes Program for Indians through 2008 and increase the amount of funding to \$150 million per year.

The mission of the IHS National Diabetes Program is to develop, document, and sustain a public health effort to prevent and control diabetes in Indian communities. The program’s network consists of a national program office in Albuquerque, New Mexico, Area Diabetes Consultants in each IHS area, 19 Model Diabetes Programs in 23 sites, and local diabetes programs in more than 300 Indian communities. As the nation’s most comprehensive rural system for diabetes care, the program combines both clinical and public health approaches. In summary, the IHS National Diabetes Program:

- Provides comprehensive diabetes surveillance;
- Provides research translation through training and technical assistance;
- Conducts quality assurance and improvement activities in clinical and community programs;

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<sup>3</sup> Public Law 105-33.

<sup>4</sup> Public Law 106-554.

<sup>5</sup> Public Law 107-360.

- Provides technical support to IHS, tribal, and urban Indian programs; and
- Develops, field tests, and distributes Indian diabetes education print and audio-visual materials to participating programs.

### ***Medicare and Medicaid Payments to IHS Facilities***

An IHS hospital can receive reimbursement under Medicare Part A, whether the hospital is operated directly by IHS, or is operated by a Tribe or Tribal organization. The hospital must comply with applicable Medicare law.<sup>6</sup> Any payments made by Medicare or Medicaid are not considered in determining a Tribe's allocation of IHS services or funding.<sup>7</sup>

Since 2000, IHS hospitals and clinics have been eligible to receive payment under Medicare Part B for the services of doctors and other practitioners, such as nurse-midwives, clinical social workers, clinical psychologists, registered dietitians, and physical and occupational therapists.<sup>8</sup> Under 2003 Medicare legislation<sup>9</sup> – the legislation known primarily for adding limited prescription medication to Medicare coverage – IHS hospitals and clinics will be able to bill Medicare for all Part B services, during the five years from January 1, 2005, through December 31, 2009.<sup>10</sup> Undoubtedly Tribes and others will lobby Congress during those five years to make Part B coverage permanent.

If an IHS hospital is entitled to Medicaid payment, that payment is placed by IHS in a special fund for the improvement of IHS facilities. In order to assure that any redistribution of funds is not too drastic, it is required that payment be made so that at least 80 percent of the money is spent in the IHS service unit that originally was entitled to receive the Medicaid reimbursement.<sup>11</sup> Special funds are not available to a hospital or clinic that has chosen (as discussed below) to contract or compact with IHS, and that as a result bills Medicare and Medicaid directly rather than through IHS.

Any Medicaid reimbursement received by an IHS provider consists entirely of federal money, with no state financial participation.<sup>12</sup> The same is true for reimbursement to a Tribe under a contract or compact with IHS (see below), or reimbursement to a provider who is providing care under a contract with IHS to a patient referred by IHS.<sup>13</sup>

Reimbursement from the Medicare and Medicaid programs has become a critical funding

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<sup>6</sup> 42 U.S.C. § 1395qq(a).

<sup>7</sup> 25 U.S.C. § 1641(a) (Medicare), § 1642(b) (Medicaid).

<sup>8</sup> 42 U.S.C. § 1395qq(e); *see* 42 U.S.C. § 1395u(b)(18)(C) (listing professions included under term “practitioner” in section 1395qq(e)(2)(B)).

<sup>9</sup> Public Law 108-173.

<sup>10</sup> 42 U.S.C. § 1395qq(e)(1)(A); *see* Pub. L. No. 108-173, § 630 (2003) (creating five-year trial period for billing under Medicare Part B).

<sup>11</sup> 25 U.S.C. § 1642(a).

<sup>12</sup> 42 U.S.C. § 1396d(b).

<sup>13</sup> *North Dakota ex rel. Olson v. CMS*, 286 F. Supp. 2d 1080 (D. N.D. 2003); *Ellenbecker v. CMS*, 2003 U.S. Dist. LEXIS 25691 (C.D. S.D. 2003).

source for IHS and tribal health care sites, since IHS funding is inadequate to meet tribal needs.

## Contracting and Compacting with IHS

Tribes have three options for receiving IHS-funded health care:

- 1) Receiving health care directly from IHS;
- 2) Contracting with IHS for health services; or
- 3) Compacting with IHS for the funding and control to be transferred to the tribal government, which arranges for health care to be provided.

A Tribe, by resolution, may request that the federal government enter into a **contract** for certain health care services to be administered and provided by the Tribe, rather than by IHS. These contracts are commonly known as “638 contracts,” because the relevant law – the Indian Self-Determination Act – was originally enacted in 1975 by Public Law 93-638.<sup>14</sup> Under a 638 contract, a Tribe steps into the shoes of IHS and provides the health care services that otherwise would have been provided by IHS. In many cases, IHS maintains a significant level of oversight.

A Tribe instead may choose to **compact** with the federal government to take complete control over the money that otherwise would have been spent by IHS. Compared to a contract, a compact gives a Tribe much greater control over the health care services (and other services) that will be provided. A compact is essentially a block grant between the federal government and the Tribe. The federal government provides the money – roughly the equivalent of what otherwise would have been spent by IHS – and the Tribe uses that money in providing health care.

Contracting or compacting Tribes may bill Medicare or Medicaid directly for services provided through a tribal hospital or clinic. If services are within the permissible scope of services for a hospital or clinic, Medicaid payment made under these circumstances is made entirely by the federal government, with no financial participation by the state.<sup>15</sup> This point should be emphasized to state officials; once they understand that the state is not liable, they will be more likely to authorize the services.

A direct-billing Tribe must use the received payment first for bringing the hospital or clinic into compliance with federal standards and then, if any money is remaining, to improve the health care services available to tribal members.<sup>16</sup>

A critical feature of the contract/compact process is that IHS cannot contract for a service which IHS does not ordinarily provide. For example, because the IHS does not provide nursing

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<sup>14</sup> 25 U.S.C. § 450f(a).

<sup>15</sup> 25 U.S.C. § 1645(a); 42 U.S.C. § 1396d(b); *see In re South Dakota Dep’t of Soc. Servs.*, HHS Departmental Appeals Board, Appellate Division, Docket No. A-01-98, Decision No. 1847 (2002).

<sup>16</sup> 25 U.S.C. § 1645(b)(1).

home care, the IHS cannot contract with Tribes for nursing home care. This rule limits a Tribe's flexibility under the contract/compact process.

## **Tribal Members' Eligibility for Medicare and Medicaid**

### ***Introduction***

"Medicare" and "Medicaid" sound alike and, as a result, each program often is confused with the other. Each requires that a beneficiary be either at least 65 years old or disabled, but there are at least two important distinctions between Medicare and Medicaid eligibility rules.

- Medicare eligibility is based on the work history of the individual or the individual's spouse, but Medicaid eligibility is based on financial need.
- Because Medicaid is designed for individuals in financial need, Medicaid provides for on-going long-term care, either in a nursing home or (to a more limited extent) at home. Medicare, by contrast, focuses more on acute or short-term care, and provides more limited coverage for long-term care.

Another important distinction is that Medicare is a federal program and, as a result, Medicare rules are the same no matter where the Medicare beneficiary lives. Medicaid, on the other hand, is a program run by the each individual state under general rules set by the federal government. Medicaid services and eligibility rules differ significantly from state to state. This is true even in those instances when the Medicaid payment consists of 100% federal money (which, as discussed above, occurs when Medicaid payment is made to an IHS provider).

### ***Medicare***

Part A of Medicare covers care in a hospital or nursing home; Part B covers doctor services, medical equipment, and other health care services and items. Home health care can be covered under either Part A or B. Medicare coverage for home health services and for nursing home care is discussed in more detail later in this guide.

An elder's eligibility for Medicare Part A is based on the work history of the elder or the elder's spouse. In the most common type of eligibility, the elder is at least 65 years old, and either the elder or the spouse has a work history that creates an entitlement to Social Security benefits. An elder also is eligible for Medicare Part A if the elder has been receiving Social Security disability benefits or railroad retirement disability benefits for at least 24 months. If the elder's disability is due to kidney failure, the 24-month waiting period is waived. Under all of these scenarios, Part A coverage is provided without a monthly premium.

Medicare Part B coverage is available to any elder eligible for Part A. Part B coverage requires payment of a monthly premium – the Part B monthly premium is \$78.20 in 2005, and

will increase year by year.

## ***Medicaid***

### *General Eligibility Rules*

Unlike Medicare, Medicaid is **not** concerned with the work history of an elder or an elder's spouse. Rather, Medicaid eligibility depends on the elder's financial need.

Medicaid is available only to an elder who is at least 65 years old or is disabled. An elder who receives Supplemental Security Income (SSI) is eligible for Medicaid automatically. Otherwise, an elder can be eligible for Medicaid when his or her available savings fall below approximately \$2,000 (the exact amount varies from state to state; remember Medicaid eligibility rules can differ significantly from state to state). The value of the home is not counted against this savings limit. Also not counted are a necessary automobile, clothing, household goods, a burial plot, and other important items.

Unless SSI-eligible, an elder generally is required to pay a monthly deductible before Medicaid will cover the elder's medical expenses. The deductible is calculated based on the elder's income, and generally will allow the elder to retain monthly income of approximately \$500 to \$900, depending on the state.

In summary, the Medicaid program is designed to provide safety-net coverage for individuals who are aged (at least 65 years old) or disabled. Financial eligibility is extremely limited, although (fortunately) certain important items like a home or a necessary automobile are not counted against resource limits.

Eligibility standards are eased somewhat for married couples, in recognition that two cannot live quite as cheaply as one. The savings limitation is raised somewhat – likely to \$3,000 or \$4,000, depending on the state – and the amount of monthly income to be retained is raised to the neighborhood of \$600 to \$1,100 monthly, also depending on the state.

### *Medicaid Eligibility for Nursing Home Residents*

If an unmarried elder resides in a nursing home, Medicaid eligibility standards become very restrictive. The state Medicaid program generally requires that the elder pay virtually all of his or her monthly income to the nursing home, based on the reasoning that the elder receives room, board and necessary health care in the nursing home. The monthly amount retained by the resident commonly is no more than \$40 or \$50, depending on the state. In some states, eligibility is denied to anyone with a monthly income of approximately \$2,000 or higher.

If an elder is married, however, Medicaid eligibility standards become more generous

when the elder moves into a nursing home, because Medicaid rules take into account the fact that the resident's savings and income may be needed by the spouse living at home. As is discussed in this guide's section on nursing home care, a couple may be able to retain approximately between \$20,000 and \$90,000 of savings, and between \$1,600 to \$2,300 of monthly income, depending on the state.

### *Claims for Repayment Following Elder's Death*

It should be noted that Medicaid to a certain extent can be considered a loan rather than a gift, because a state Medicaid program has the right to seek repayment following the death of the elder and the elder's spouse (if any). When repayment is sought it is taken from the elder's property, and the elder's home is not protected. The elder's estate has a debt to the Medicaid program, and that debt must be paid before any of the elder's property is passed on to the elder's heirs (the children or grandchildren, most likely).

The Medicaid program's claim always is limited to the amount of the elder's property or the amount paid by the Medicaid program for the elder's health care, whichever is less. An elder may be able to reduce a Medicaid program's claim by holding or transferring property in certain ways, based on advice from an attorney knowledgeable in Medicaid laws.

A Medicaid program must waive its claim if the elder's property otherwise would go to a child under age 18, or to a disabled individual. Also, a Medicaid program may waive a claim if that claim would cause hardship to the individual who otherwise would receive the elder's property. For example, a Medicaid program's claim might be waived if the claim would force the eviction of a family member from the elder's house.

A Medicaid program cannot enforce a claim against tribal land, or against income derived from tribal land. Also, a Medicaid program cannot enforce a claim against items that have a unique spiritual or cultural significance in the Indian community.<sup>17</sup>

## **LONG-TERM CARE SERVICES**

### **Home Health Care**

#### ***Medicare Coverage for Home Health***

Medicare is the most common public funding source for home health care. The Medicare home health care benefit generally requires a need for skilled nursing care, or physical or speech therapy.

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<sup>17</sup> State Medicaid Manual § 3810(A)(7).

Services are only provided for those individuals who are considered “homebound,” based on the reasoning that elders who are *not* homebound could travel to a hospital or clinic for routine health care. An elder is considered “homebound” if leaving the home is a very difficult process. In determining whether an elder qualifies as “homebound,” the elder is not penalized for leaving home to receive health care treatment or to attend an adult day care program. Also, attending religious services does not limit an elder’s ability to be considered homebound.

Medicare will not cover permanent, daily skilled nursing care. Generally nursing care must be needed six days a week or less. If nursing care is needed every day, Medicare will only pay if the daily nursing care will be needed for only a limited time-period – three or four weeks, for example.

Nursing care is considered “skilled” if a nursing service requires the expertise of a licensed nurse. For example, treatment of a wound or administration of an injection, are skilled nursing services that qualify for Medicare reimbursement. On the other hand, bathing an elder, or helping an elder get dressed, are services that do not qualify for Medicare reimbursement.

Therapy services also must be “skilled” in order to qualify for Medicare reimbursement. The expertise of a licensed physical therapist or certified speech therapist must be required. If an elder requires skilled nursing services or skilled therapy, the Medicare home health benefit also may be able to provide the part-time assistance of a home health aide, as appropriate given the elder’s care plan. Also, the Medicare home health benefit may provide medical supplies (such as catheters) or durable medical equipment (such as walkers), if the supplies or equipment also are part of the care plan.

All home health aides must complete a training and competency evaluation program. The training must include at least 75 hours, including at least 16 hours of supervised practical training.

Physical therapists must be licensed, and have at least two years of experience. Speech therapists must be certified in speech pathology or audiology by the American Speech-Language-Hearing Association.

### ***Medicaid Coverage for Home Health***

The Medicaid program pays for home health care, but the Medicaid home health benefit is used much less frequently than the Medicare home health benefit. The reason is that, under federal law, a Medicaid program can cover home health care only for elders who have a medical or physical condition that otherwise would require nursing home care. By contrast, as explained above, Medicare home health care benefits do not depend on the beneficiary needing nursing home services. A Medicare program can cover home health care if a beneficiary is homebound and needs skilled nursing or therapy services.

## Personal Care Services

### *Medicaid Payment for Personal Care Services*

Examples of “personal care services” are assistance provided to elders in bathing, dressing, eating, cooking, or cleaning. Personal care services in general are less medical than home health care. Personal care services usually are provided by individuals with relatively little training, at least in comparison to the years of training required of nurses and therapists.

The Medicare program provides almost no personal care. The exception is the home health aide service that can be provided as part of the Medicare home health care benefit, as a complement to the skilled nursing or therapy services that are the primary component of the Medicare home health benefit.

Much more frequently, personal care services are provided through the Medicaid program. A Medicaid program may provide (or depending on the state, may not) personal care services in one of two ways: through a Home and Community-Based Services Waiver, or through personal care services made available through the Medicaid program’s standard package of services.

It is important once again to recognize that individual states have a great deal of flexibility in developing the state’s Medicaid program. A state’s Medicaid program may provide personal care services through both methods, through only one method, or may not provide personal care services at all.

#### *Personal Care Services Funded Through a Home and Community-Based Services (HCBS) Waiver*

In most states, Medicaid-funded personal care services are available only to those elders who receive care through a Home and Community-Based Services (HCBS) waiver. The term “waiver” is used because, for home and community-based services, the federal government has waived the general requirement that all Medicaid services be available equally to any eligible individual within the state. Because this rule has been waived, the state Medicaid program can choose to offer home and community-based services only to a limited number of eligible persons. States commonly set an enrollment limit on home and community-based services, and waiting lists are common.

An HCBS waiver is meant to keep elders out of nursing homes to the extent possible. Accordingly, HCBS waiver services are available only to those elders whose medical or physical condition otherwise would have required nursing home care. In general, the services provided through the HCBS waiver must be no more expensive than what nursing home care would have cost for that same elder. Both the elder and the Medicaid program win: the elder is able to receive care at home, rather than a nursing home, and the Medicaid program pays less than it would have paid if the elder had been in a nursing home.

In addition to personal care, an HCBS waiver program also can provide adult day health care, case management, private duty nursing, family training, minor home modifications such as installing grab bars, and other services. The availability of all of these services varies from state to state.

*Personal Care Services Funded Through a Medicaid Program's Standard Package of Services*

In relatively few states, eligibility for HCBS waiver services is not required for receipt of personal care services. In these states, it is not necessary that an elder have a medical need for nursing home services, and the state must provide personal care services to all eligible Medicaid beneficiaries, without any waiting list. In many cases, however, the state Medicaid program will not authorize the number of hours of personal care services that the elder feels that he or she needs.

Personal care services can be provided through an agency (similar to how home health services are provided by a home health agency), but increasingly personal care services are provided by individuals unaffiliated with an agency. In some states, Medicaid can pay for personal care services provided in an assisted living facility. In most states, the training requirements for personal care workers are relatively minimal.

At a state's option, a Medicaid program can pay family members for personal care services. Under no circumstances, however, can an elder's spouse receive payment from Medicaid for provision of personal care services, because the spouse is considered legally obligated to provide necessary services.

Personal care services can be extremely useful in Indian country. Use of personal care services may allow an elder to remain safely at home. Also, employment as a personal care worker (may be referred to as "personal care assistant," "personal care aide," and similar titles in states) may be an attractive option for the elder's children or grandchildren, or for others in the tribal community. No previous experience is required to serve as a personal care aide.

On the other hand, it should be remembered that personal care services are often funded through HCBS waivers, which require that the elder have a medical need for nursing home care. For waiver-funded services to serve the elder appropriately, it is important that he or she have access to adequate medical back-up.

A Tribe may wish to request that tribal elders be exempted from any waiting list for HCBS waiver services. HCBS waiver services often are particularly important in a tribal community, given that the nearest nursing home may be many miles away. Also, HCBS waiver expenditures in a tribal community often will be limited (good news to a Medicaid program trying to save money) because relatively few health care providers are available to provide

services under the waiver. More good news for the state, as discussed above, is the fact that HCBS waiver expenditures in a tribal community will consist entirely of federal money, with no state financial participation.

A Tribe also may wish to have a waiver developed specifically for Indian country. Such a waiver might emphasize diabetes-related services or other services that are especially relevant to an Indian population.

### ***Personal Care Services for Veterans***

Under certain circumstances, the Department of Veterans Affairs may pay for personal care assistance for a veteran, or for the surviving spouse of a deceased veteran. This assistance is called “aid and attendance.”

The veteran must have served during wartime, but is not required to have seen combat action. The veteran must have received a discharge that was not dishonorable. The veteran must be “permanently and totally disabled” from a condition or incident unrelated to the veteran’s military services. (If an elder’s disability is service-related, other V.A. programs provide help.) Also, the veteran or spouse must show that the aid and attendance of another person is needed in order to live safely.

A payment for aid and attendance is available only to veterans or spouses with limited savings and incomes, based on the standards of the Department of Veterans Affairs. The amount paid will be increased to the extent that the veteran or spouse has made unreimbursed payments for medical expenses, including the expense of medications, in-home health care, nursing home care, assisted living care, or health care insurance.

### **Hospice Care**

Hospice care is designed for elders who are likely to die within the next six months. Hospice care focuses less on treatment of illness, and more on the elder’s comfort and emotional health.

Most hospice care is paid by Medicare Part A, and provided through Medicare-certified hospice agencies. Medicare-funded hospice care can include nursing care, home health aide and homemaker services, medical supplies, and medications. Also, Medicare may pay for temporary care of an elder in a nursing home, in order to provide an at-home caregiver with a respite from the stress of caring for the elder.

For hospice care to be provided, Medicare requires a doctor’s certification that the elder is expected to die within six months. If the elder in fact does not die within the six months, hospice care can be continued indefinitely, as long as the doctor continues to certify that the elder is not expected to live much longer.

By choosing the hospice service package, an elder gives up services related to the treatment of the terminal illness. For example, if cancer is expected to lead to the elder's death within six months, the elder's decision to receive hospice services means that the elder will not be able to receive Medicare funding for attempts to eliminate the cancer.

To be certified for Medicare reimbursement, a hospice agency must employ at least one nurse and one social worker, must employ or have a contract with at least one doctor, and must meet numerous other requirements. An agency can be certified by Medicare to be both a hospice agency and a home health agency, as long as the agency meets all relevant requirements.

Although hospice care is often thought of as something that is provided at home or in a specific hospice facility, hospice care also can be provided in an assisted living facility or a nursing home. When hospice care is provided in either type of facility, the hospice care should not replace anything that the facility otherwise is obligated to do. Instead, the hospice agency should provide services that supplement and improve the facility services.

Although hospice services can be extremely helpful, the decision to choose hospice care can be very difficult for an elder and the elder's family. The decision is obviously influenced greatly by an elder's culture and religious beliefs.

The availability of hospice services can be limited by the relatively stringent requirements put on hospice agencies by the Medicare program. Many tribal communities suffer from a shortage of nurses and other medical professionals, and as a result may not be able to support a Medicare-certified hospice agency.

## **Adult Day Care (Adult Day Health Care)**

Adult day care or adult day services are community-based programs to care for functionally and/or cognitively impaired adults for part of the day. They provide a variety of social, health, and other related support services. Most adult day care centers are established in a senior center, assisted living facility, nursing home, or other freestanding center.

There are several types of adult day care. **Adult day social care** offers meals and social activities, recreation, transportation to and from the elder's home, and some health-related services. **Adult day health care** provides more intensive health care, medical services or therapeutic services for clients with severe medical problems. There are also **adult day dementia care** centers that provide social and health services just for clients with Alzheimer's disease or other types of dementia.

Adult day health care services can be funded through Medicaid, if the state has included those services in an HCBS waiver, and the elder is eligible for HCBS waiver services. As discussed immediately below, an adult day health care center also may be the central location for

the provision of PACE program services.

Adult day programs may present challenges in Indian country, given the rural environment of many tribal communities. When elders may live 20, 30, or more miles from the adult day care center, providing transportation to and from the day care center is a significant task.

## **PACE Programs**

“PACE” stands for “**P**rogram of **A**ll-Inclusive **C**are for the **E**lderly.” The PACE model is noteworthy for at least two reasons: a PACE program provides a comprehensive package of services, and PACE can combine Medicare and Medicaid. PACE programs are meant to prevent or delay nursing home admissions and, for that reason, are eligible only to those elders who otherwise would be appropriate medically for admission to a nursing home.

Most PACE enrollees are eligible for both Medicare and Medicaid. When an elder eligible for both signs up for a PACE program, the PACE program begins receiving a certain flat amount each month from the state and federal governments. In return for that flat amount, the PACE program is obligated to provide or pay for all the elder’s health care, including doctor services, hospital services, and nursing home services.

Most PACE programs are built around an adult day health care center. Elders visit the adult day health care center every weekday or several times a week, and, during those visits are able to have frequent contact with the PACE program’s doctors and nurses. A team of health care professionals within the PACE program develops an individualized treatment plan for each enrollee.

Despite the enormous appeal of the PACE model, there are very few operating PACE programs at this time, because programs have had trouble recruiting enough eligible enrollees to make the model economically feasible. The problem is especially difficult in rural communities, given the small populations and elders’ difficulties in traveling to adult day care centers. As this guide is written, some Tribes are investigating the feasibility of PACE in tribal communities. The Cherokee Nation in Oklahoma is in the early development stages of establishing a PACE program.

## **Other Services and Items**

### ***Medical Equipment***

An elder’s ability to remain healthy and at home often depends upon the availability of medical equipment. Both Medicare and Medicaid are able to pay for important items of medical equipment that can be used in the home. Medicare Part B, for example, can pay for hospital beds, wheelchairs, walkers, canes, and bedside toilets, as well as many other items.

A tribal organization may wish to inquire into the possibility of becoming a Medicare- or Medicaid-certified provider of medical equipment. Both the elder and the tribal organization win: the elder receives the necessary equipment, and the tribal organization can bring additional income into the tribal community.

### ***Transportation***

Two key federal agencies help fund programs to transport older Americans to essential community services every day. These are the Administration on Aging's Older Americans Act (OAA) Title III program and the Department of Transportation's Section 5310 Transportation for the Elderly and Persons with Disabilities program and its Section 5311 rural transportation service program.

The Older Americans Act (discussed later) provides approximately \$80 million in funding for transportation to facilitate access to its Title III supportive services or nutrition services provided by area agencies on aging. Smaller amounts are spent on transportation through the Title VI (services for American Indian, Alaska Natives and Native Hawaiians) program, and through the Title V senior employment program.

In addition, there are smaller transportation assistance programs under the Social Security Act, including Medicare (primarily emergency ambulance transportation) and state Medicaid (transportation to and from medical appointments). The Centers for Medicare and Medicaid Services requires states to include transportation services in their annual state medical assistance plans.

#### *Section 5310 (Elderly and Disabled) Transportation*

The Transportation for the Elderly and Persons with Disabilities program, known as "Section 5310,"<sup>18</sup> is authorized under the Transportation Equity Act for the 21<sup>st</sup> Century (TEA-21) and operated by the Federal Transit Administration (FTA). For fiscal year 2004, FTA had \$98 million for this program. Funds are used to provide transportation services to meet the special needs of the elderly and persons with disabilities. The money is allocated by a formula based on the number of elderly and individuals with disabilities in each state. The program is administered through the states, which make specific funding decisions.

States apply for funds on behalf of local private non-profit agencies and certain public agencies. The state agency ensures that the local applicants and project activities are eligible and in compliance with federal requirements, that private not-for-profit transportation providers have an opportunity to participate where feasible, and that the program provides for coordination of

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<sup>18</sup> 49 U.S.C. § 5310.

federally assisted transportation services. Each state has its own regulations and procedures for distributing Section 5310 resources to local partners or “subrecipients.”

At the local level, the funds are used for capital projects, mostly to purchase vehicles, but also for acquisition of transportation services under contract, and lease or other arrangements. There is a requirement for 20 percent in matching funds.

### *Section 5311 (Rural and Small Urban Area) Transportation*

The Section 5311<sup>19</sup> program provides formula funding to states to support public transportation in areas of less than 50,000 population. For fiscal year 2004, FTA had \$219 million for this program. The money is distributed in proportion to each state’s non-urbanized population to state and local governments, non-profit organizations (including Indian Tribes and groups), and public transit operators. This program provides assistance for capital, operating, and administrative expenditures by state and local agencies, nonprofit organizations, and operators of transportation systems to provide public transportation services in rural and small urban areas. Elders comprise an estimated 36 percent of the ridership in nonurbanized areas. This is nearly three times their proportion of the rural population.

In their annual program plan, states must provide for fair and equitable distribution of funds within the states, including Indian reservations, and must provide for maximum feasible coordination with transportation services assisted by other federal sources. Transportation funding for community services stems from the Federal Transportation Act (Section 5310/elderly and disabled transportation services and Section 5311/rural transportation services), Medicare medical transportation, and the Older Americans Act.

## **Care Provided in Long-Term Care Facilities**

### *Nursing Home Care*

Payment under Medicare Part A or Medicaid is available for nursing home, including care in a nursing home operated by a Tribe or tribal organization.<sup>20</sup>

The Medicare program, however, pays for relatively little nursing home care. The Medicare program can pay only if the nursing home admission occurred after a hospital stay of at least three days. Also, Medicare pays for a maximum of 100 days of nursing home care. Only the first 20 days are paid in full; days 21 through 100 require a **daily** co-payment of \$114 (in 2005). This daily co-payment will increase in years to come.

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<sup>19</sup> 49 U.S.C. § 5311.

<sup>20</sup> 42 U.S.C. § 1395qq(a) (Medicare); § 1396j(a) (Medicaid).

The biggest restriction is the fact that Medicare can pay for nursing home care only if the elder requires skilled nursing services on a daily basis, or skilled therapy at least five days a week. A “skilled” nursing service is one that requires the expertise of a licensed nurse. Examples of skilled nursing services include injections and assistance with tube feeding. Routine “custodial” care does not qualify for Medicare reimbursement – Medicare will not cover nursing home expenses if a resident only needs (for example) assistance with bathing, dressing, using the toilet, and/or moving from bed to wheelchair and back again.

In summary, Medicare reimbursement for nursing home care is intended to pay only for transitional care occurring after a hospital stay. Medicare is *not* designed in any way to pay for ongoing nursing home care for chronic conditions.

The Medicaid program, on the other hand, will pay for any nursing home care needed by a Medicaid-eligible elder, whether the nursing home care is considered skilled care or custodial care. Medicaid coverage cannot be limited to “skilled” care because (as discussed previously, on pages 10 to 11) Medicaid-eligible elders do not have enough money to pay for nursing home care from their own money.

Because nursing home care is so expensive, Medicaid law makes special allowances for residents who have husbands or wives living at home. A single nursing home resident is eligible for Medicaid only after spending almost all savings, and most of the resident’s income has to be paid to the nursing home each month. If, on the other hand, the resident is married, Medicaid rules allow the couple to retain a significant amount of savings (depending on the state, between approximately \$20,000 and \$90,000, in addition to a home). Each month, the spouse at home is allowed to retain income in a range from approximately \$1,600 to \$2,300, depending on the state.

Operation of a nursing home is not an easy task. As explained below, nursing homes are required to employ nurses, nurse aides, and a medical director, and to be capable of handling a variety of medical conditions. Because of the expense of nursing home operations, it is difficult if not impractical to operate a nursing home unless enrollment can be expected to be in the range of at least 40 to 60 residents. Very few Tribes operate nursing homes,<sup>21</sup> and some tribal-operated nursing homes have had significant financial difficulties.

To be paid under either Medicare or Medicaid, a nursing home must comply with the federal nursing home standards. A registered nurse must be on duty at least eight hours a day, seven days a week. At all times either a registered nurse or a licensed nurse must be working at the facility. If nurses are difficult to recruit, these requirements can be waived to a certain extent by the federal government, although waiver provisions are very limited under Medicare law, given that Medicare (as explained above) only provides coverage when a resident recently left the hospital and also has a need for skilled services.

Most patient care in a nursing home is performed by nurse aides. Under federal law, each

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<sup>21</sup> Bruce Finke, M.D, Nursing Home Survey Report, Attachment A to American Indian and Alaska Native Roundtable on Long-Term Care: Final Report (2002).

nurse aide must have at least 75 hours of training, including 16 hours of supervised practical training (which, as discussed above, are the same requirements applicable to home health aides). This training must be completed within the aide's first four months of employment at the nursing home. Certification is not complete until the nurse aide passes both an examination and a demonstration of skills.

Each nursing home resident must be under the care of a doctor, and the home itself must designate a doctor as the facility's medical director. According to federal law, the medical director implements resident care policies and coordinates medical care.

### *Assisted Living*

Elders across the country – both Indians and non-Indians – increasingly are receiving care in “assisted living” facilities rather than nursing homes. At a minimum, assisted living facilities generally provide meals and assistance with routine activities such as dressing and bathing. Frequently assisted living facilities are able to assist in the storage and administration of medication. Less frequently, assisted living facilities can provide care for pressure sores and other wounds. In a small but increasing number of cases, an assisted living facility can provide services that are comparable to the services offered by a nursing home.

It is difficult to generalize about an assisted living facility. “Assisted living facility” is only one term used by states. Some states refer instead to “residential care facilities for the elderly,” “adult foster care homes,” “housing with services establishments,” “board and care homes” or other terms.

Also, “assisted living” varies from state to state and, within a state, there can be significant differences between individual assisted living facilities. In some states, all assisted living facilities must offer single-occupancy apartments; in other states, shared-occupancy (two beds to a room) is the norm. Also, states vary widely as to the type of medical conditions that can be accommodated in an assisted living facility, before a resident must be moved to a nursing home.

In most cases, health care in an assisted living facility is provided not by facility staff, but by a Medicare home health agency. As discussed previously in more detail on page 12, Medicare home health is limited to those Medicare beneficiaries who are considered “homebound.” In general, a Medicare home health agency will provide only health care – injections, for example, or dressing changes for a healing wound – and will not assist with routine activities such as dressing or bathing. Assistance with these routine activities is the responsibility of the assisted living staff.

Public financing for assisted living may or may not be available, depending on the state. In some instances, Medicaid reimbursement may be available to pay for personal care services provided in an assisted living facility. A significant number of states offer payment through a Medicaid Home and Community Based Services (HCBS) waiver, which is discussed in more

detail on pages 13 through 15. HCBS waivers, however, are limited in at least three ways: 1) HCBS waiver programs pay for services, but not for room and board; 2) HCBS waiver payment is available only for elders whose medical conditions would otherwise require care in a nursing home; and 3) most states have enrollment caps on waiver services, and waiting lists are common. In very few states, a Medicaid program will pay for personal care services in an assisted living facility without requiring a need for nursing home services, and without capping enrollment.

Finally, for those residents with very limited incomes, the federal Supplemental Security Income (SSI) program may provide some additional income, although the supplementation is likely to boost the elder's income to only a monthly total of between \$600 and \$1,000, depending on the state. An SSI income generally will be inadequate to cover assisted living expenses, unless state law requires that an assisted living facility accept an SSI rate as payment in full, or the assisted living facility is located in federally subsidized housing.

## **Older Americans Act Services**

The Older Americans Act (OAA),<sup>22</sup> created in 1965, provides funding for numerous long-term care services of value to all elders. The act represented an important step by the nation toward a lofty goal of looking after the overall well-being of senior citizens, especially those who are low-income, minority or frail. The law has been reauthorized by Congress 14 times since 1965. The OAA set out broad objectives for assuring the security of older persons; established the Administration on Aging to oversee the act; created grants for state and community programs such as meals and transportation; instituted a training and research component; launched a community service part-time employment program for low-income unemployed citizens age 55 and older; and, through amendments passed in 1992, initiated and improved programs to protect the rights and benefits of vulnerable older adults.

A special section, added in 1978 and known as "Title VI," provides grants for supportive and nutrition services just for American Indians, Alaska Natives and Native Hawaiians. However, funding for Title VI and all other OAA activities, like many federal programs, varies each year depending on choices made by Congress.

While annual funding for Title VI has remained relatively safe, it has seen only modest increases over the past few years. Generally, the amount of Title VI funding awarded to Tribes is only enough to provide some meal services, plus limited transportation to meal sites, medical appointments, and some other activities. Title VI funds are distributed directly to 243<sup>23</sup> Tribal and Native organizations representing older American Indians, Alaska Natives, and Native Hawaiians. The goal is to provide services in a manner that preserves and restores the dignity, self-respect, and cultural identities of Native Americans.

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<sup>22</sup> 42 U.S.C. § 3001 et seq.

<sup>23</sup> 241 Title VI, Part A grants (American Indian, Alaska Natives) and 2 Part B grants (Native Hawaiians), communication with AoA, August 2004.

The U.S. Administration on Aging issues the Title VI grants to qualified Tribal and Native organizations representing at least 50 individuals age 60 or older. For the federal fiscal year 2004, which runs from October 1, 2003 through September 30, 2004, Congress appropriated \$26.4 million for Title VI grants. Although this is the primary source of aging services funding for Tribes, they are eligible to participate in other OAA programs. Title III-funded area agencies on aging are obligated to ensure that Indian elders have access to OAA services funded by the agencies.

Overall the OAA – primarily through its Title III supportive and nutrition programs – reaches about 7 million older adults and their caregivers. In fiscal year 2002, the most recent year for which data is available, OAA Title III services reached 69,780 American Indian/Alaska Native elders<sup>24</sup>. In the year 2000 (the latest year for which data is available), Title VI services reached 134,333 Native elders. Clearly Title VI reaches many more American Indians/Alaska Natives than does Title III.

Title III funds that go to states and area agencies on aging support a wide array of services in addition to meals and transportation. These additional services include information and assistance, health promotion and disease prevention activities, legal assistance, case management, long-term care ombudsman services, and others. American Indians are eligible to participate in these programs, although in reality few do.

While the Title VI grant program was designed to “parallel” these Title III services and focus them just on Native American populations, the actual funding levels for Title VI falls short of this goal. However, a few states with large Indian populations (such as Arizona, New Mexico and Washington) have elected to support special Indian area agencies on aging that can receive Title III funding. There are presently 11 Indian area agencies on aging nationwide. This results in many more resources being available to Tribes covered by Indian AAAs than those in areas receiving only Title VI grants.

OAA funds help support the following programs:

#### *Congregate and Home-Delivered Meals*

Most congregate meal sites serve hot meals four to five times a week. Home-delivered meals are provided five times a week for elders who are homebound. Many of these nutrition programs offer modified diets for diabetics, or others who might be on low-fat, low-cholesterol, and low-sodium diets.

In addition to providing meals, nutrition education, screening, and counseling, Title III and Title VI nutrition programs are important for the social interaction and supportive services they offer to participants. For example, congregate meal programs give Indian elders opportunities to meet with friends, participate in recreation and other activities, and take trips to other programs.

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<sup>24</sup> AoA, State Program Reports, Table 3 (2002).

### *Supportive Services*

Supportive services grants cover many services to help an elder remain in the community, including outreach, information and assistance, homemaker and chore services, minor home repair and renovation, and transportation to meal sites, doctor's appointments, and grocery shopping, among other services.

### *Disease Prevention and Health Promotion Services*

Disease Prevention and Health Promotion grants are used to provide health promotion information and services – such as disease screenings – at various locations, including multipurpose senior centers, congregate meal sites or through home-delivered meal programs. Unfortunately, while Title III includes a specific part dedicated to disease prevention and health promotion services with its own annual appropriation, there is not a counterpart in Title VI of the OAA.

### *Family Caregiver Support*

The 2000 amendments<sup>25</sup> to the Older Americans Act, which established the National Family Caregiver Support Program, also established a Native American Caregiver Support Program (Title VI-C) to assist family members caring for Native American elders who are chronically ill or have disabilities. The program offers assistance for these family caregivers through information, support groups and respite care. It also covers services to help grandparents who are raising grandchildren. There is no requirement for matching funds and Tribes are able to decide the age at which a member of the Tribe is considered an “elder” and thus, eligible for services under the program. In fiscal year 2003, \$5.2 million in formula grants were made available to 177<sup>26</sup> tribal organizations to develop and operate family caregiver support programs. However, that amounts to relatively small individual tribal awards, ranging from \$14,180 to \$57,251 in fiscal year 2003.<sup>27</sup>

The Native American portion of the family caregiver program received \$6.3 million in funding in fiscal year 2004, while the broader caregiver program received \$152.8 million.

A June 2004 report<sup>28</sup> from the Administration on Aging indicates that about 4,230 Native American caregivers had received one or more caregiver support services under the new program. Almost all of the tribal programs provide respite service, and nearly two-thirds are providing support groups or individual counseling. Over half the programs are providing

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<sup>25</sup> Public Law 106-501, November 13, 2000.

<sup>26</sup> The number of Title VI, Part C grants in fiscal year 2004 is 175, communication with AoA, August 2004.

<sup>27</sup> AoA, The National Family Caregiver Support Program: Compassion in Action, Table: Title VI-C 2001-2003 Formula Grant Awards (2004).

<sup>28</sup> AoA, The National Family Caregiver Support Program: Compassion in Action, (2004).

caregiver training. However, Tribes have reported the following barriers to implementing the program: staffing, recruiting participants, geographic isolation, and meeting unmet needs.

### *Elder Rights*

Another important part of the OAA is Title VII, Protection of Vulnerable Older Americans, which funds long-term care ombudsman programs to help protect the rights of elders in nursing homes and other long-term care facilities. This section also provides for activities to prevent elder abuse. While the 1992 amendments to the OAA set up a special Part B to this title for funding the protection of vulnerable elders in Indian country, Congress has never provided funds for this essential program. Thus Indian country continues to be denied Title VII's valuable services.

In addition to providing support for the OAA programs listed above, the Administration on Aging also awards grants to two universities to establish National Resource Centers for Older Indians, Alaska Natives, and Native Hawaiians. The centers focus on culturally competent health care, community-based long term care, and related services. They are the National Resource Center on Native American Aging at the University of North Dakota and the new National Resource Center on American Indian, Alaska Native and Native Hawaiian Aging at the University of Alaska Anchorage. Under their federal grant, the National Resource Center at the University of North Dakota provides free assistance to Tribes to conduct comprehensive functional assessment of the long-term care needs of their elders and members with disabilities. Assessments of elders' functional needs are a key component of any serious planning for addressing the long-term care needs of elders.

### **Additional Nutrition Support Programs**

In addition to Older Americans Act nutrition services (discussed above), the U.S. Department of Agriculture (USDA) has a commodity foods program to help states supplement the diets of elderly people at least 60 years of age, pregnant women and children. These programs are operated by states and there is no specific set-aside for Tribal organizations.

The Nutrition Services Incentive Program, formerly known as the Nutrition Program for the Elderly, was recently moved from USDA to the Administration on Aging (AoA). However, the transfer to AoA did not result in significant changes to the procedures for administering the program at the state, tribal and local levels. The program provides incentives to states and Tribes for the effective delivery of nutritious meals to older adults. State Units on Aging and Indian tribal organizations funded through Title VI of the OAA may receive grants of cash and/or commodities. The allotment each year to states and Tribes is a proportional share of the annual appropriation based on the number of meals served in the prior year. Congress funded the Nutrition Services Incentive Program at \$148 million for fiscal year 2004.

Another program of note is the USDA's Seniors Farmers' Market Nutrition Program. It makes grant awards to states and Indian tribal governments to provide coupons to low-income

seniors that may be exchanged for eligible foods at farmers' markets, roadside stands and community-supported agriculture programs. The goal is to provide fresh, nutritious, unprepared, locally grown fruits, vegetables and herbs to low-income seniors, while increasing the number of farmers' markets. For 2004, USDA awarded \$16.7 million in grants to 41 states and six Indian tribal organizations.

### **Social Services Block Grant**

Social Services Block Grant discretionary funds are designed to help people of all ages, but some states use their block grant for in-home care, adult day care, adult protective services, nutrition and transportation services for seniors. However these funds are not specifically designated for tribal or native organizations. States may choose, however, to provide funds for Indians and some do. Funding for the program has been cut from \$2.8 billion to \$1.7 billion in recent years.

## **CHOICES AND DECISIONS**

A tribal leader or member reading this guide might think: "Now what?" Here are some observations and suggestions to assist Tribes in the not-easy process of planning and offering services for tribal elders.

### **Care at Home, or Care in a Long-Term Care Facility?**

Across the country – both within and outside of Indian country – elders are choosing to receive necessary care at home rather than in nursing homes or assisted living facilities. The choice of in-home care can be advantageous for everyone involved – generally, the elder and the elder's family prefer an in-home care arrangement, and the cost of in-home care is generally less than the cost of facility-based care.

Nonetheless, Tribes sometimes assume that a tribal nursing home is the answer to elders' long-term care needs. Be careful in going down this path – nursing homes are difficult and expensive to run, particularly in rural areas where there likely is a shortage both of residents and nurses. A half-full nursing home quickly can become a significant drain on tribal finances. Also, as a practical matter, a nursing home is likely not viable unless it can house at least 40 to 60 residents. If a Tribe's nursing home is to be certified to receive Medicaid or Medicare payments, the facility will need to meet federal standards related to all aspects of nursing home care, from staffing to quality of care to residents' rights.

Operation of an assisted living facility offers both advantages and disadvantages, compared to operation of a nursing home. One advantage (from a Tribe's financial and operational point of view) is that assisted living facilities are not required to meet the nursing

staffing standards and other quality of care standards that apply to nursing homes. One disadvantage is that state Medicaid funding for assisted living care is limited, as discussed earlier in this guide.

Tribes may wish to look more closely at in-home care funded by Medicaid Home and Community-Based Services waivers. Site visits with Tribes indicated that this funding too frequently was overlooked. Care can be provided at home, and the paid caregiver often can be a family member (but not a spouse) or other tribal member. Caregiver qualifications vary from state to state.

## **Respite Care**

Sometimes family members just need a break. It can be exhausting for an elder's spouse, son, or daughter (for example) to provide care seven days a week.

Respite care can be a cost-effective way for a Tribe to provide long-term care. The family member may be willing and able to provide informal (*i.e.*, unfunded) care to the elder, as long as the family member occasionally receives a respite from the rigors of caregiving. As discussed above, respite care may involve the elder's temporary admission into a long-term care facility, and respite care benefits may be available through Medicare hospice services, Medicaid HCBS waiver services, and various programs funded by the Older Americans Act.

## **End-of-Life Care**

As discussed above, the Medicare program provides a relatively generous package of hospice benefits, restricted to individuals who have been determined by a doctor to have no more than six months to live. Given their potential importance, Medicare hospice benefits have been relatively underutilized. Tribes could do elders and their family members a great service by emphasizing the availability of the Medicare hospice benefit.

For understandable reasons, it can be hard for an elder or an elder's family to acknowledge that the end of the elder's life is approaching. But there can be benefits to coming to grips with the reality of the elder's approaching death. Probably all cultures and religions recognize death as one of life's stages, and recognizing and speaking of death can give the elder a certain sense of peace. Also, the acceptance of approaching death allows family members to say what needs to be said, and to do what needs to be done.

That being said, it should be noted that it is irrelevant to the Medicare program whether the elder and the elder's family are working through issues related to the elder's terminal condition or (on the other hand) are in denial in their personal relationships about the elder's condition. In either case, the hospice benefit can be a great service to elders and families.

## **Underutilization of Medicaid Benefits**

In some cases, low-income elders avoid Medicaid because (as discussed earlier in this guide) the Medicaid program often can seek repayment from the elder's property after his or her death.

This wariness about Medicaid probably is unnecessary in many instances. As is explained above, a Medicaid program cannot collect against tribal land or against income derived from tribal land, and also cannot collect if at least one of the elder's heirs is a minor child or a disabled individual. And, in any case, a Medicaid collection never affects the elder or the elder's spouse directly. The effect is felt only by the elder's heirs – most likely the elder's children or grandchildren.

This point should not be carried too far. Without a doubt, Medicaid collections can have a significant impact on an elder's heirs. But a concern for heirs should not turn into an obsession, and an elder need not deprive himself or herself of needed health care services out of a desire to protect property for heirs.

In general, Indian elders likely do not make adequate use of Medicaid. As discussed immediately above, elders have an unnecessarily acute fear of Medicaid collections. Also, because Indians are accustomed to relying upon IHS to a certain extent, Indian elders may be less likely to apply for Medicaid, and are relatively unfamiliar with Medicaid rules and benefits. Similarly, Tribes often are unaccustomed to third-party billing (due to a longstanding reliance on IHS funding), and thus may be hesitant to pursue Medicaid funding.

The unnecessarily low use of Medicaid benefits is a problem for long-term care in Indian country. In general, IHS and Medicare do not pay for long-term care nursing home care or for other types of long-term care services. Nationwide, Medicaid is by far the largest public funder of long-term care services, so Indian elders and Tribes drastically limit their options when they fail to take full advantage of state Medicaid programs.

## **Why Is This So Complicated?**

Almost everyone involved in long-term care complains about its complexity. As is evident from the discussion above, the long-term care system is a jumbled collection of programs and funding sources. Although these complexities cannot be eliminated, use of this guide may enable a Tribe or elder to better navigate confusing rules and procedures.

Ambitious Tribes and long-term care providers have looked to create “integrated” programs that combine services and simplify eligibility determinations and funding. Probably the most complete example of integration is the PACE program (discussed earlier in this guide). In PACE, all of an elder's health care is coordinated by a team of health care professionals. The PACE program is financially responsible for virtually all of the elder's health care needs and, in

return, the PACE program receives a flat monthly amount from the Medicare and Medicaid programs for each enrolled elder.

As discussed earlier, the PACE model is not necessarily a good fit for Tribes. But in any case, individual Tribes may be able to adopt certain aspects of the PACE model, or to integrate their long-term care systems in related ways. For example, some Tribes use care coordinators who assess the needs of individuals, design plans for services, and assist individuals in getting the services they need. These coordinators are usually nurses or social workers who are skilled in determining individual need and quite knowledgeable about available services and strategies for attaining and paying for the services.

Care coordination is a process for coping with a convoluted and complex finance and eligibility system and a fragmented service delivery system, but does little or nothing to change the fundamental problems with the system. Although it is a band-aid approach to addressing the problems in our health and long-term care systems, care coordination is one of the more common processes now used to assist people in getting adequate amounts of services at the right time, and in the right place.

## **You Are Not Alone**

Long-term care planning is not easy, and there are no automatic answers. Tribes across the country are struggling with some hard realities.

This guide is a starting point so that Tribes can conduct the discussion and planning that is necessary to develop and improve long-term care services. Further information about long-term care and some technical assistance is available to Tribes by calling the National Technical Support Center for Tribal Long-Term Care which is funded by the Indian Health Service and operated by the National Indian Council on Aging. To contact Center staff, please contact NICOA at 505-292-2001 or visit <http://www.nicoa.org>.