Executive Summary

Hospice is care designed to support people in the ending phase of a terminal illness, focusing on comfort and quality of life rather than a cure. It enables patients to live each day as fully as possible while keeping them comfortable and free of pain. Decisions about end-of-life care—including location of death, levels of care, and intervention—have become increasingly important for American Indians and Alaska Natives (AI/AN).[1] Identifying tribally operated programs that serve the end-of-life care needs of their communities offers opportunities to share and highlight successful program elements that are replicable from community to community.

Health programs funded through Indian Health Service (IHS),[2] such as those that provide hospice care, serve more than two million AI/AN people from 566 federally recognized tribes and 34 urban Indian communities. Trends indicate that AI/AN populations suffer from higher rates of death and disease than their non-Native counterparts, indicating a greater need for hospice programs in tribal communities. As health services to AI/AN communities improve, however, so does the longevity of tribal populations. Consequently, as people live longer, they are more likely to grapple with health and care issues related to chronic disease,[3] as well as an increased need for end-of-life care later in life. Hospice services that are responsive to the values, beliefs, and traditions of AI/ANs can increase the likelihood of individuals accessing these services.[4]

Currently, there are three tribally operated hospice programs in Indian Country: the Tohono O'odham Hospice (Sells, AZ), Zuni Home Health Care Agency (Zuni, NM), and Hospice of the Cherokee (Tahlequah, OK). Table I lists these programs, provides contact information, and identifies a few of the unique aspects of each program, such as funding options, interdisciplinary hospice teams, and related end-of-life services. Each program has funding certification through Medicare, Medicare-Hospice, Medicaid, or a combination of the three. Each program also has an interdisciplinary team that provides culturally sensitive supports to hospice patients and other services on the end-of-life spectrum of care, like palliative care, home health, and bereavement support. These programs, based within and operated by the tribes, are able to address the cultural needs for patients and families in need of end-of-life care.

Successful end-of-life care programs share common elements:

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[1] Finke, et al., 2004 and Robinson, et al., 2009

[2] AI/ANs have a unique relationship with the federal government based in part on treaties negotiated between sovereign Indian nations and the United States. These treaties established a unique government-to-government relationship, based upon the cession of millions of acres of land in exchange for certain promises, benefits, and reserved rights. These treaties have helped secure the federal obligation to provide health services to AI/ANs. These obligations have been fulfilled through such acts of Congress like the Snyder Act, authorized in 1921 to provide health care access to Indian people throughout the United States. The Transfer Act authorized in 1955 established the IHS under the U.S. Public Health Service to carry out this responsibility, which includes addressing the end of life care needs of Native communities.

[3] Finke, et al., 2004; Hampton, 2005; Indian Health Service, 2006; Kitzes, 2003; Arenella, et al., 2010

[4] Myers, et al., 2006

- a defined vision;
- a strategy for the use of available resources and leadership support;
- ongoing team-building and education efforts;
- targeted data collection;
- a communications strategy;
- and national, regional and local partnerships.[5]

Building culturally sensitive and sustainable palliative care and hospice programs in Indian Country must be a priority in the coming years to meet the needs of an aging AI/AN population in both rural and urban areas. In order to meet the needs of the elder population, tribal communities and health programs must firmly establish identified successful program elements. Purposeful planning and a collaborative approach to building and maintaining community-linked programs will support the further development of successful programs in more tribal communities.

[5] End Byock, et al., 2006; Finke, et al., 2004; Kitzes, 2003; Valente and Haley, 2003

Appendix A

Tribally Operated Hospice Programs

Table I. Tribally Operated Hospice Programs

Tribal Affiliation	Hospice Program and Address	Contact and Title	Certification, Year Opened	Interdisciplinary Hospice Team	Other End of Life Services
Southwestern Region					
Tohono O'odham Nation	**Tohono O'odham Hospice** Federal Rte. 15, Milepost 9 HC 01 Box 9100 Sells, AZ 85634	Dorothy Low, Administrator P: (520) 383-1893	Medicare, 2007	• Medical Doctor • Traditional Healer • Registered Nurse • Certified Nurse's Assistant • Social Worker • Volunteers	• Palliative Care • Bereavement Support
Zuni Pueblo	**Zuni Home Health Care Agency** 102 D Ave. P.O. Box 339 Zuni, NM 87327	Theresa Bowannie, Administrator P: (505) 782-5544 F: (505) 782-5546	Medicare, Medicaid, 1997	• Registered Nurse • Home Health Aides	• Home Health Care
Midwestern Region					
Cherokee Nation	**Hospice of the Cherokee** 1630 N Cedar Tahlequah, OK 74464 One Plaza South PMB 374 Tahlequah, OK 74464	Casi Jennings, Director P: (918) 458–5080	Medicare-Hospice, 2000	• Medical Doctor • Chaplains • Registered Nurses • Licensed Nurse Practitioners • Home Health Aides • Volunteers	• Bereavement Support • Home Health Care