



# Ethics at the Intersection

Discussing End of Life Choices With American Indian and Alaska Native Patients

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# Disclosure statement

I have nothing to disclose.





# Objectives

1. Examine the principles of clinical ethics from the perspective of American Indians and Alaska Natives.
2. Recognize that applying clinical ethics to end of life care begins long before discussions on advance care planning.
3. Identify approaches to discussing advance care planning with American Indian and Alaska Native patients.





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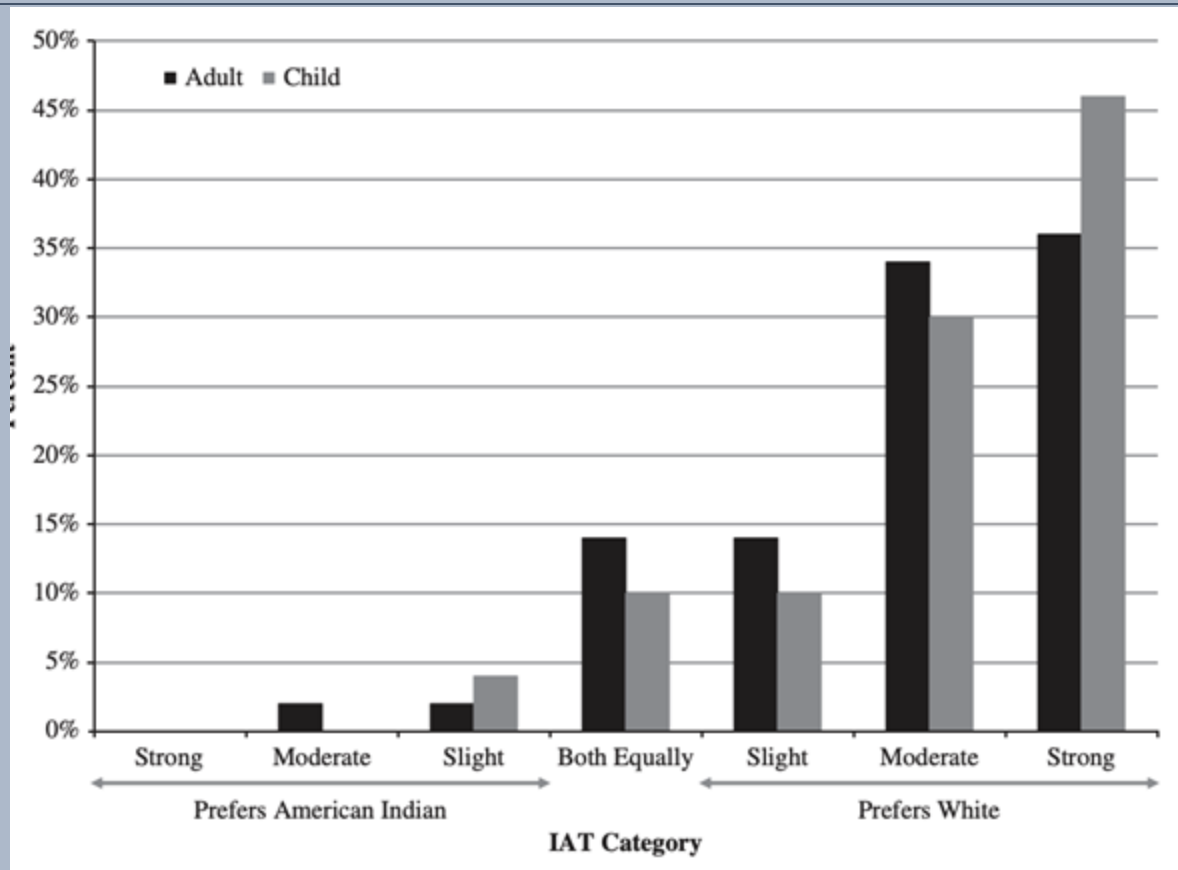
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Source: Puumala, S. E., Burgess, K. M., Kharbanda, A. B., Zook, H. G., Castille, D. M., Pickner, W. J., & Payne, N. R. (2016). The Role of Bias by Emergency Department Providers in Care for American Indian Children.



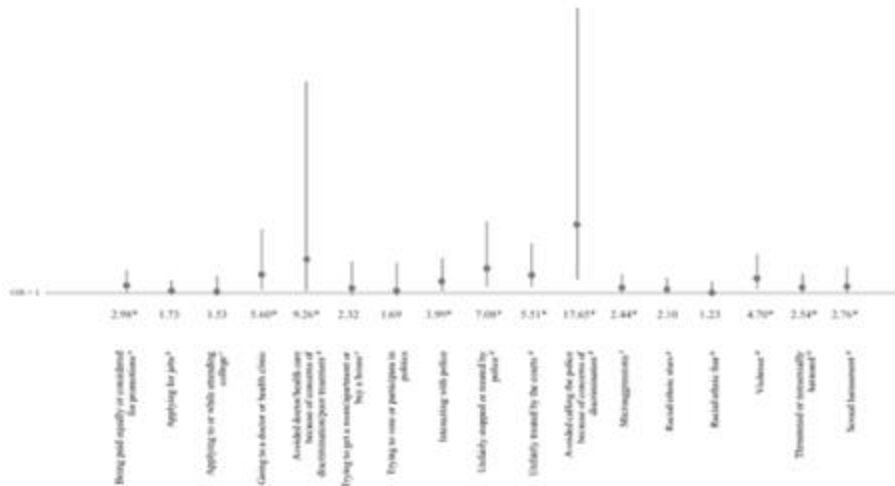


President Joe Biden delivers remarks at the Gila Crossing Community School, Friday, October 25, 2024, in Laveen Village, Arizona. (Photo by Oliver Contreras/White House)

### Discrimination in the United States: Experiences of Native Americans

Avoided doctor/health care because of concerns of discrimination/poor treatment <sup>d</sup>

Avoided calling the police because of concerns of discrimination <sup>d</sup>



Source: Findling, M. G., Casey, L. S., Fryberg, S. A., Hafner, S., Blendon, R. J., Benson, J. M., Sayde, J. M., & Miller, C. (2019). Discrimination in the United States: Experiences of Native Americans.

Health Services Research, Volume: 54, Issue: 52, Pages: 1431-1441, First published: 27 October 2019, DOI: (10.1111/1475-6773.13224)







# Code of Indian Offenses



# Culture is a protective factor





768 × 512

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Volume 42 | Issue 5

Article 11

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2016

## From Dysfunction and Polarization to Legislation: Native American Religious Freedom Rights and Minnesota Autopsy Law

Gail T. Kulick

Tadd M. Johnson

Rebecca St. George

Emily Segar-Johnson

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# Autonomy as a factor of health

“There is more to Poverty than low income and poor material conditions .....Lack of social participation and inadequate control over your life, in the sense of not being able to lead the life you want to lead, will lead to chronic stress, which in turn increases risk of a number of diseases, heart disease among them.”

Marmot (2004, 68-75)



# Clinical Ethical Standards

Autonomy, Beneficence, Non-maleficence, and Justice



# Weaving Pathways

## Pilot Description

Identify and address barriers to healthcare directive completion and discussions about end-of-life choices with Native American patients.

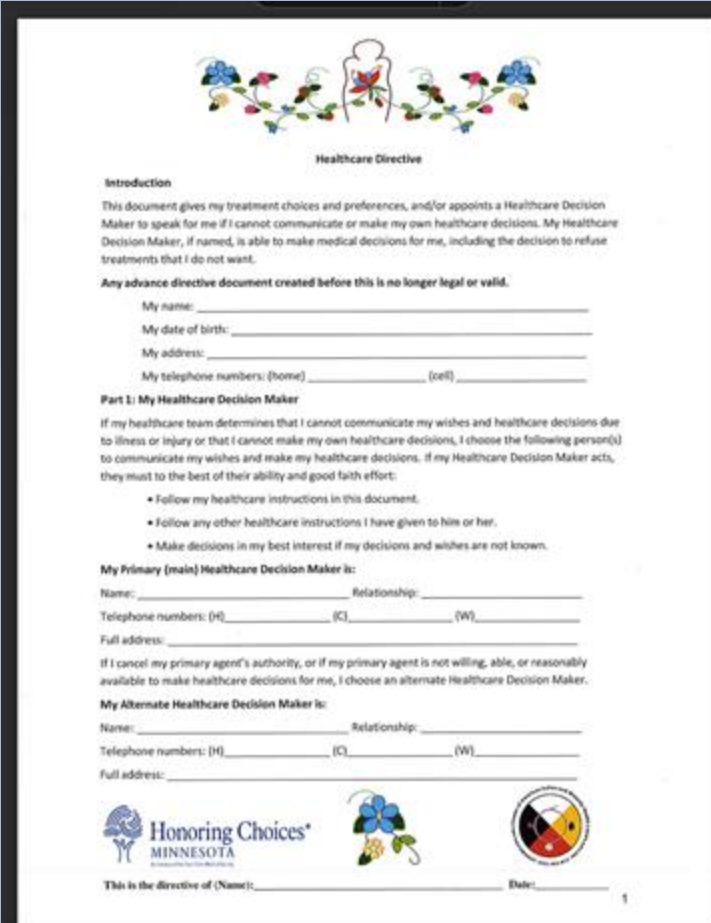
## Rationale


The literature highlights that there exists a relative paucity of completed healthcare directives nationally, even fewer exist within minority populations. Therefore, a large portion of the U.S. population is vulnerable to subpar EOL care and at risk for misalignment between wishes and patient experience.

## Impact

Follow-up evaluation in one tribal clinic showed that the number of healthcare directives and/or individuals with advanced care documents on file had increased by 18%.

Mangan Golden, Ginearosa Carbone, Sharon Day, Kathy Litcherman, Kristin Parendo, Charlie Bouverette, Charles Neher, Lynn Betzold, Mary Owen



  
Healthcare Directive

**Introduction**  
This document gives my treatment choices and preferences, and/or appoints a Healthcare Decision Maker to speak for me if I cannot communicate or make my own healthcare decisions. My Healthcare Decision Maker, if named, is able to make medical decisions for me, including the decision to refuse treatments that I do not want.

**Any advance directive document created before this is no longer legal or valid.**

My name: \_\_\_\_\_  
My date of birth: \_\_\_\_\_  
My address: \_\_\_\_\_  
My telephone numbers: (home) \_\_\_\_\_ (cell) \_\_\_\_\_




**Part I: My Healthcare Decision Maker**  
If my healthcare team determines that I cannot communicate my wishes and healthcare decisions due to illness or injury or that I cannot make my own healthcare decisions, I choose the following person(s) to communicate my wishes and make my healthcare decisions. If my Healthcare Decision Maker acts, they must to the best of their ability and good faith effort:

- Follow my healthcare instructions in this document.
- Follow any other healthcare instructions I have given to him or her.
- Make decisions in my best interest if my decisions and wishes are not known.

**My Primary (main) Healthcare Decision Maker is:**  
Name: \_\_\_\_\_ Relationship: \_\_\_\_\_  
Telephone numbers: (H) \_\_\_\_\_ (C) \_\_\_\_\_ (W) \_\_\_\_\_  
Full address: \_\_\_\_\_

If I cancel my primary agent's authority, or if my primary agent is not willing, able, or reasonably available to make healthcare decisions for me, I choose an alternate Healthcare Decision Maker.

**My Alternate Healthcare Decision Maker is:**  
Name: \_\_\_\_\_ Relationship: \_\_\_\_\_  
Telephone numbers: (H) \_\_\_\_\_ (C) \_\_\_\_\_ (W) \_\_\_\_\_  
Full address: \_\_\_\_\_

This is the directive of (Name): \_\_\_\_\_ Date: \_\_\_\_\_





End of life discussions begin long before end of life



TABLE 1. TECHNIQUES THAT FACILITATE NATIVE AMERICAN  
END-OF-LIFE DISCUSSIONS

- All patients/families are asked how they wish to receive information, how they make decisions, and who needs to be present.
- All patients/families queried if they would prefer a translator.
- Care provider often speaks in third person.
- Reassure that no harm is intended from the discussion.
- State that palliative care team and other providers “hope for the best.”
- Attention to appropriate eye/hand contact.
- Allow patient/family to control tempo of discussions.
- Encourage comfort with silence.
- Schedule family meetings at convenience of family.
- Support consultation with traditional healers.
- Provide sufficient time for decision making.

Source: Confronting Myths:  
The Native American Experience in an Academic  
Inpatient Palliative Care Consultation program.  
Marr, L., Neale, D., Wolfe, V., & Kitzes, J. (2012).



# Systems change

- Address institutional bias and racism
  - longitudinal trainings
  - review programs, forms, protocols
- Build relationships with community
  - consult community for recommendations and needs
  - provide needed services for community (vet med)
  - Advocate for community needs



# Proposed solutions and recommendations for overcoming barriers and supporting the development of culturally appropriate and effective hospice services.

1. **Gain support from tribal leadership, program staff, and community** on palliative and end-of-life care.
2. Create partnerships with national and local entities.
3. Embed **tribal consultation** into programs to allow for more seamless cultural integration.
4. Develop a cultural sensitivity training curriculum for new and existing health care workers.

Source: Department of Health & Human Services, Centers for Medicare & Medicaid Services. (2014). *LTSS Research: Literature Review Hospice in Indian Country*.



# Communication

- Body language
- Humility
- Ask to ask
- Polite curiosity
- Remember diversity of cultures and degrees of cultural immersion/assimilation---you must ask
- Cultural belonging can change---recheck



# Recognize and honor other cultural beliefs in clinics and hospital systems

- Incorporate local and regional Native culture into protocols and processes (smudging, prayer, singing, large numbers of people)
- Compensate Native healers—i.e. chaplains
- Tailor existing programs, documents



## Fond du Lac

**Medical Social Worker** - The Medical Social Worker assists clients with many different individual needs such as; Medical Assistance, costly prescriptions, Medicare/Social Security applications, medical equipment, Assisted Living, Long Term Care applications, and any other community resources that a client may need.



Kathy Lichterman



Jim Barney

## Mille Lacs



### NE-IA-SHING CLINIC

43500 Migizi Drive  
Onamia, MN 56359  
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320-532-4163 e



### EAST LAKE CLINIC

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218-768-3311 e



### AAZHOOOG CLINIC

45741 Grace Lake Road  
Sandstone, MN 55072  
[Get Directions](#)

320-384-0149 e

## Leech Lake

### Out Patient Clinic Teams

**Blue Team:** 218-335-3218

Mark Becker, MD, Family Practice

Mary Owen, MD, Family Practice

Melinda Haubrich, RN, Care Coordinator

**Orange Team:** 218-335-3248

Matei Teodorescu, MD, Pediatrician

Alice Lingen, MD, Pediatrician

Diane Bohn, Certified Nurse Midwife

Barb Nyberg, RN, Care Coordinator

**Green Team:** 218-335-3294

Andrea Athman-Luksik, FNP, Family Nurse Practitioner

Brad Scilley, RN, Care Coordinator

**Purple Team:** 218-335-3246

Jessica Ankney, DO, Family Practice

Stacy Cederstrom, FNP, Family Nurse Practitioner

Jana Heger, NP, Geriatric Nurse Practitioner

Jeff Krona, RN, Care Coordinator



## Facts

229 Federally Recognized Tribes (Villages)

Southcentral Foundation primary care services in Anchorage, Matanuska Susitna Valley and the Anchorage Service Unit

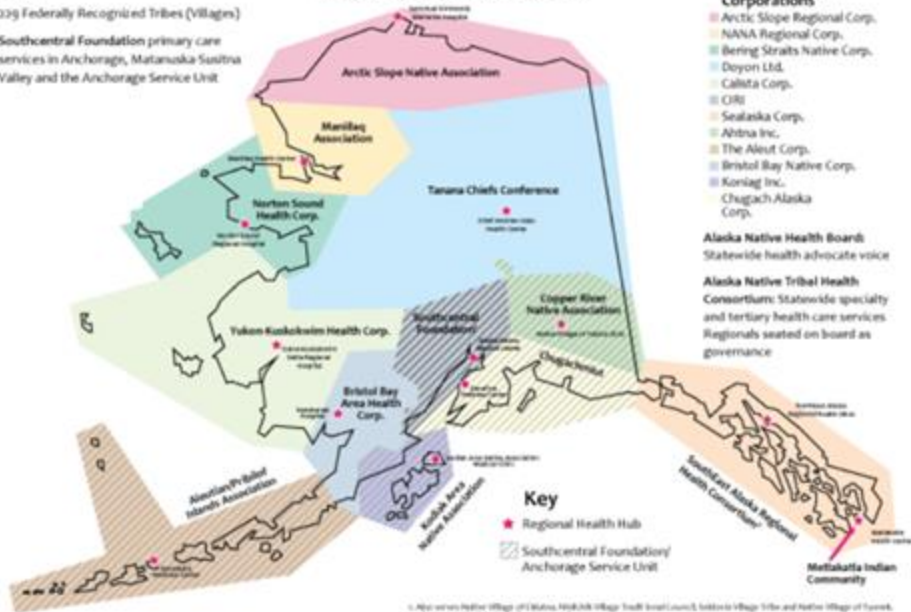
## Alaska Native Health System

### Regional Native Corporations

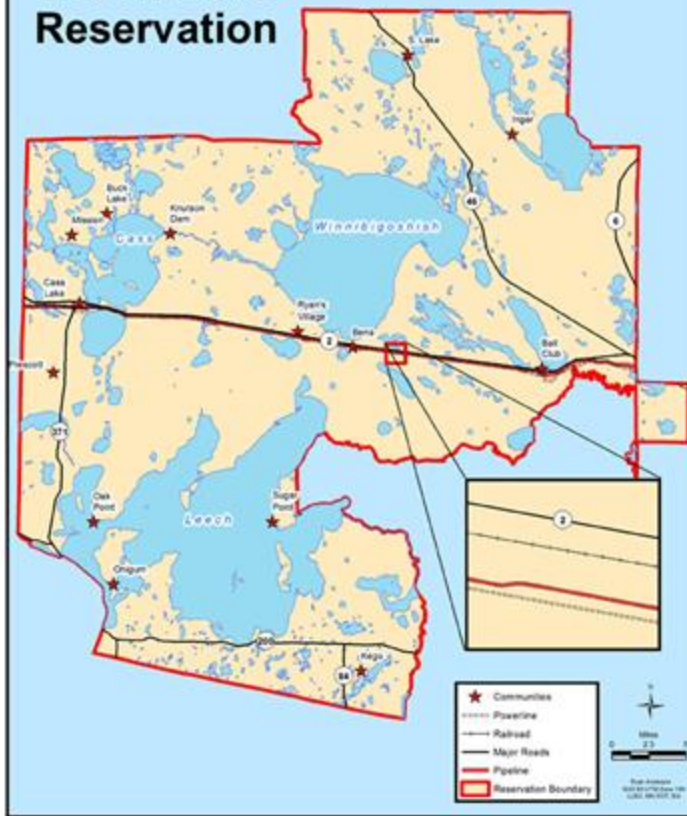
- Arctic Slope Regional Corp.
- NANA Regional Corp.
- Bering Straits Native Corp.
- Doyon Ltd.
- Calista Corp.
- CIRI
- Sealaska Corp.
- Ahtna Inc.
- The Aleut Corp.
- Bristol Bay Native Corp.
- Koniag Inc.
- Chugach Alaska Corp.

Alaska Native Health Board  
Statewide health advocate

Alaska Native Tribal Health Consortium  
Statewide specialty and tertiary health care services  
Regionals seated on board as governance



## Leech Lake Reservation





# Questions

1. Call out issues for folks with disabilities in rural areas: that much harder to access services. Shortage of providers, and shortage of services. Tribal home is where community is and traditional practices such as gathering are followed.
2. Do AIAN people generally subscribe to the same ethical values in end-of-life and other matters?
3. Do Native Americans care if their doctor is white if the doctor treats them well?
4. I was wondering if the speaker will speak on clinical ethics of mental health from American Indian & Alaskan Native perspectives.
5. Would be helpful to know how providers in different roles can be helpful (eg mental health providers, medical providers, hospice)?
6. End-of-life decision making for pediatric patients.
7. Are there major differences in beliefs among AI groups and AN around end-of-life care or are the orientation and beliefs similar?
8. Please let us know if there is anything that might be considered offensive to the patient when discussing end of life.
9. Do you have tips on getting a conversation started with older folks, that grew up knowing the westernized way?



# Questions

10. Organ donation
11. Personal need (relative needing memory care)
12. Specific aids for speech/language hearing d/o in AIAN communities



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Center of American Indian and Minority Health End of Life Toolkit: <https://med.umn.edu/caimh/resources>

