



FAMILY VOICES®
... keeping families at the center of children's health care

Cultural Agility

when cultural competence means
planning to change your plans



National Genetics Education
and Family Support Center

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Maria Isabel Frangenberg
September 25, 2019



National Genetics Education and Family Support Center (Family Center)

Made up of:



Funded by HRSA/HHS to:

- Help families develop skills to partner with professionals and improve systems of care
- Assist RGNs in partnering with families & family-led orgs
- Assist with outreach to diverse & medically underserved families
- Provide Education & Support

Agenda

- Introductions
- Cultural humility (20 min)
- Break
- Capacity building (15 min)
- Break
- Group activity (30 min)
- Adaptability (25 min)
- Break
- Shared leadership (20 min)
- Conclusion



INTERSECTIONALITY



CULTURAL HUMILITY



The Law: Executive Order 13166

On August 11, 2000, the President signed Executive Order 13166, **"Improving Access to Services for Persons with Limited English Proficiency"** ([PDF](#)). The Executive Order requires Federal agencies to examine the services they provide, identify any need for services to those with limited English proficiency (LEP), and develop and implement a system to provide those services so LEP persons can have meaningful access to them. It is expected that agency plans will provide for such meaningful access consistent with, and without unduly burdening, the fundamental mission of the agency. The Executive Order also requires that the Federal agencies work to ensure that recipients of Federal financial assistance provide meaningful access to their LEP applicants and beneficiaries.

The National CLAS Standards

(Culturally and Linguistically Appropriate Standards)

Principal Standard

“Provide effective, equitable, understandable and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy and other communication needs.”

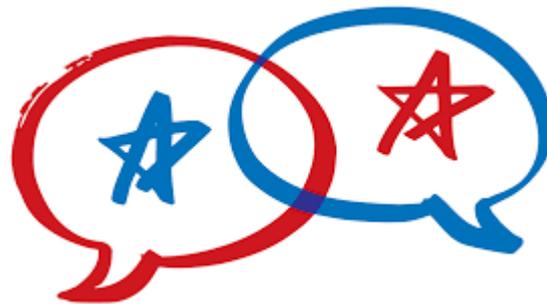
Other Standards in the following areas:

- Governance, Leadership and Workforce
- Communication and Language Assistance
- Engagement, Continuous Improvement and Accountability

<https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=53>

How do we do this?

- ***The Technical Challenges*** are defined as those that can be solved by the knowledge of experts
- ***The Adaptive Challenges*** *can only be addressed through changes in people's priorities, beliefs, habits and loyalties*



Source: *Perspectives on Change, by Ronald Heifetz*

What is Cultural Competence?

Cultural competence is a developmental process that evolves over an extended period of time. Individuals, organizations, and systems are at various levels of awareness, knowledge, and skills along the cultural competence continuum.



Source: <https://nccc.georgetown.edu/documents/NCCC-Climate-Checklist.pdf>

Latin America



Hispanic Countries



What is Linguistic Competence?

“The capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse groups including persons of limited English proficiency, those who have low literacy skills or are not literate, individuals with disabilities, and those who are deaf or hard of hearing.”

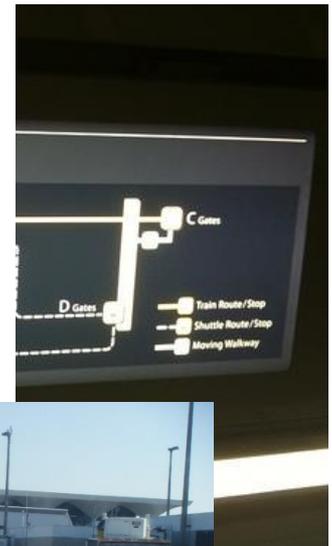
Source:<https://nccc.georgetown.edu/documents/NCCC-Climate-Checklist.pdf>

Thinking about DISGUST...

Small group discussion (5-7 minutes)

- **What are some things that are disgusting?**
- **How do you know what is disgusting?**

Until that Fateful Day



and the fruit of love

Cultural Humility

Is the belief that providers, teachers and legislative officials optimally allow each patient, student, family or constituent to inform them as to the important aspects of their own personal culture, so that they can form a *mutually respectful and humble partnership*, working toward the individual's well-being.



CAPACITY BUILDING



Targeting capacity building

Who needs to build capacity?

- Us
- Them
- All of us, together

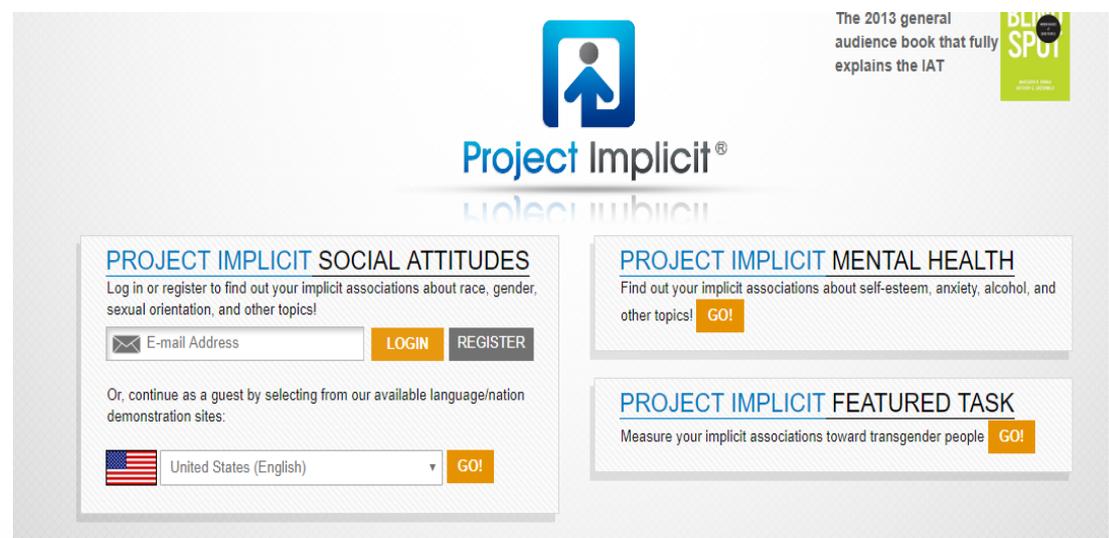
Thinking about COMPETENCE...

Small group discussion (5-7 minutes)

- **What skills does everyone need to have?**
- **How do you know what skills everyone needs to have?**

Racism education

- Racism today
 - The enduring impact of “historical” racism
- Replacing color blind with color aware
 - Anti-oppression training
 - Implicit bias
 - Race privilege
 - Intersectionality
 - Critical theory
 - CELEBRATING our diversity



The screenshot shows the Project Implicit website interface. At the top right, there is a promotional banner for a book titled "BLIND SPOT" with the text "The 2013 general audience book that fully explains the IAT". The Project Implicit logo, featuring a stylized blue figure with an upward arrow, is centered at the top. Below the logo, the text "Project Implicit®" is displayed. The main content area is divided into three sections:

- PROJECT IMPLICIT SOCIAL ATTITUDES**: Includes the text "Log in or register to find out your implicit associations about race, gender, sexual orientation, and other topics!". It features an "E-mail Address" input field, "LOGIN" and "REGISTER" buttons, and a section for guest users: "Or, continue as a guest by selecting from our available language/nation demonstration sites:" with a dropdown menu showing "United States (English)" and a "GO!" button.
- PROJECT IMPLICIT MENTAL HEALTH**: Includes the text "Find out your implicit associations about self-esteem, anxiety, alcohol, and other topics!" and a "GO!" button.
- PROJECT IMPLICIT FEATURED TASK**: Includes the text "Measure your implicit associations toward transgender people" and a "GO!" button.

Establishing Trust: Cultural Liaisons

- Cultural liaison as a cultural guide-
Assisting in developing educational materials that will help families to navigate the systems that they encounter, while empowering them to make changes
- Educate providers about the needs of the families in your state to empower them to serve diverse communities in a culturally responsive manner.

Source: NNCC – Cultural Divide in Healthcare

Cultural Liaisons are not interpreters

- A cultural liaison can be an advocate, though not always
- Understand cultural norms and educate both parties to promote more effective and responsive interactions
- A liaison checks for understanding, communicates freely and respectfully with the family and provider
- Built trust with both parties allows for communication BEYOND interpretation

Lessons learned

- Listen, ask and observe
- Seek to understand rather than to be understood
- Not all people from the same ethnic, linguistic and racial groups are the same- address my own biases
- I'm not an expert on "my" people
- Behold humility, strive for humility, work in humility

The way it made me feel
was smart because I was
asking good questions
and giving good answers.

ACTIVITY

Do you want to build a tower?



What Happened?

- Was there a division of labor early on?
- How did the power distribution happen in your team?
- Did everyone participate?
- Was there ONE prevailing plan?
- Are you proud?



ADAPTABILITY



What's in a smile?

Vastly different perceptions of smiling people across cultures

- A Russian proverb says “smiling with no reason is a sign of stupidity”.
- The Norwegian government humorously explains nuances of Norwegian culture by indicating that when a stranger on the street smiles at Norwegians, they may assume that the stranger is insane (EURES 2010).
- There's a correlation between corruption and the perception of a smiling adult.
- Yet, smiling is generally perceived as a prosocial behavior.

Source: Be Careful Where You Smile: Culture Shapes Judgments of Intelligence and Honesty of Smiling Individuals
Kuba Krysz et al. J Nonverbal Behav (2016) 40:101–116 DOI 10.1007/s10919-015-0226-4

Do you know your biases?



Project Implicit®

The 2013 general audience book that fully explains the IAT



PROJECT IMPLICIT SOCIAL ATTITUDES

Log in or register to find out your implicit associations about race, gender, sexual orientation, and other topics!

 E-mail Address

LOGIN

REGISTER

Or, continue as a guest by selecting from our available language/nation demonstration sites:



United States (English) ▼

GO!

PROJECT IMPLICIT MENTAL HEALTH

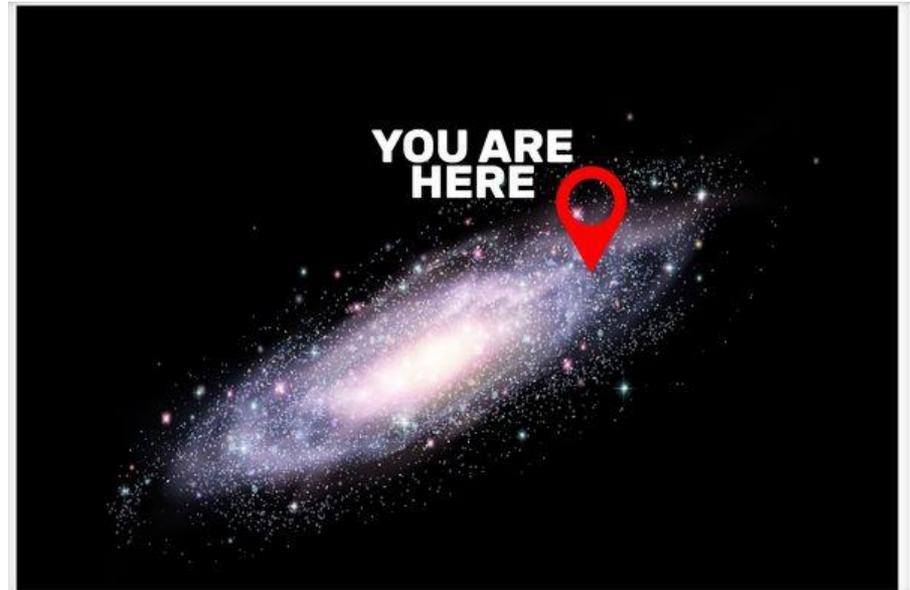
Find out your implicit associations about self-esteem, anxiety, alcohol, and other topics! **GO!**

PROJECT IMPLICIT FEATURED TASK

Measure your implicit associations toward transgender people **GO!**

Where does this leave us?

- Work culture vs. work ethic
- Sense of time and timing
- Establishing trust
- Relinquishing control



Work Culture vs. Work Ethic

"the best-laid plans of mice and men oft go astray."

- How do we think of the way others work when they work differently?



Sense of timing

- Lead times for different cultures vary widely



Establishing Trust

- Establishing mutual trust should be an intentional process.
- Consider all the dimensions of how we relate to one another
- Who, in your organization, has a clear understanding of those dimensions?
- Above all, respect engenders trust

Relinquishing control

- Will the tower fall?
- Will it be the tallest?
- Will we get the recognition we have worked so hard for?
- Will we get the data?
- Data
- DATA

THERE ISN'T ENOUGH ROOM IN
YOUR MIND FOR BOTH WORRY
AND FAITH. YOU MUST DECIDE
WHICH ONE WILL LIVE THERE.

Thinking about AUDIENCE...

Individual exercise (5-7 minutes)

- **Who do you serve?**
- **Do they know you serve them?**
- **Who should you serve?**
- **Who can you serve?**

Working within systems

- Planning
- Budgeting
- Implementation



Planning

- Plan and PROCESS for adapting as you go
 - “The draft recruitment flier is shown in Exhibit A; The Community Oversight Board will review this flier for language and cultural appropriateness and assist us in developing variants targeted for specific sub-communities within the community.”
- Establish buffer zones against the unexpected
 - Avoid tight schedules
 - Build in quality improvement, such as Plan-Do-Study-Act

Budgeting

- Allocate funds for community engagement
 - For example, stipends for Oversight Committee.
- Allocate funds for capacity building
- Identify funds that can be reallocated
- If budget is tight, re-evaluate scope
 - PRIVILEGE cultural agility

Implementation

- Identify adaptive and technical challenges
- Develop a toolkit of methods
 - WAY easier to change tools in the middle if you already have it in your toolkit!
 - An adaptable approach to technical challenges
- Structure vs openness
 - A balancing act with no set solution
 - Core vision, values, goals are essential



Shared Leadership



Thinking about FAILURE...

In small groups, take 5-7 minutes to talk about a time when your outreach effort to a new underserved population fell on its face.

- What happened? Did you know what happened?**
- Did you go back and try it again?**
- Are you still re-grouping?**
- What do you think will happen if things continue as they are?**

On Best Practices

- Best Practices are co-developed in accordance with specific regional and population needs
- A high level of specific community involvement ensures a higher likelihood of success
- Developing relationships with specific community leaders and offering them an equal seat at the table will lend inclusive solutions to outreach and education.

[Poster Title] Lorem ipsum dolor sit amet, consectetur adipiscing elit maecenas porttitor congue massa fusce

LOGO

[Replace the following names and titles with those of the actual contributors: Dorena Paschke, PhD1; David Alexander, PhD2; Jeff Hay, RN, BSN, MHA3, and Pilar Pinilla, MD4
1[Add affiliation for first contributor], 2[Add affiliation for second contributor], 3[Add affiliation for third contributor], 4[Add affiliation for fourth contributor]

Abstract

- Type the abstract here. To remove bullet points, just click the Bullets button on the Home tab.

Background

- Add title if necessary. Click the B button on the home tab to add bold formatting.
 - Background item
 - Background item
 - Background item

Objectives

- List objectives here
- Objective 1
- Objective 2
- Objective 3

Methods

- List methods and descriptions here
- Method 1
- Method 2
- Method 3

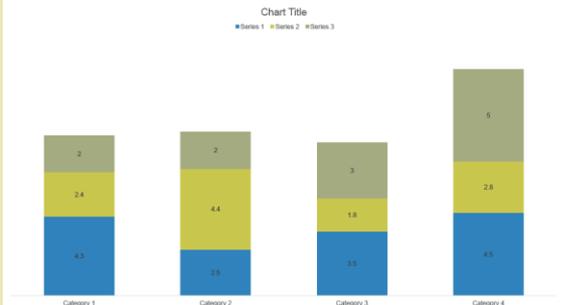
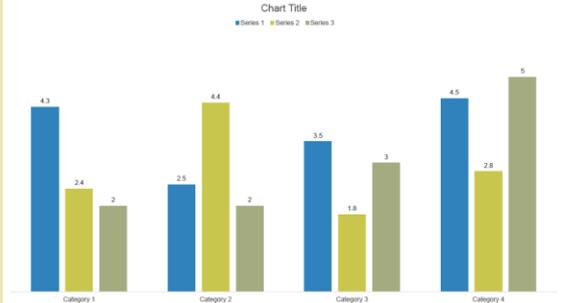
	Heading	Heading	Heading
Item	122	233	345
Item	759	856	290
Item	228	134	238
Item	954	875	976
Item	324	325	301
Item	199	137	186

- Type additional information or methods here.

Results

- Result 1
- Result 2
- Result 3

Results



Conclusions

- Conclusion 1
- Conclusion 2
- Conclusion 3

Lessons Learned from the Radiation Exposure Compensation Act

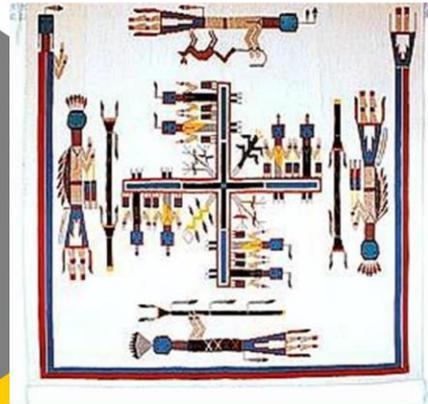


Long before the United States became interested in uranium, German researchers observed that 75% of deaths among uranium miners were caused by lung disease.¹

Despite mining contracts that required protection for workers' health, uranium mine employees in the Dinetah were not warned of long-term health consequences. Haulers routinely stored loads of uranium at home overnight. Family members as well as workers handled uranium ore and dusty clothing without precautions.^{2,3}

Decades later, the U.S. government attempted to redress these wrongs with the Radiation Exposure Compensation Act (RECA), giving lump-sum payments to individuals who met specified thresholds, e.g., diagnosis with certain health conditions.⁴ This approach overlooked damages that fell outside the thresholds, such as direct health effects on spouses of workers.⁵

Problems



RECA and related programs are the result of an impressive fifty-year tradition of advocacy originating within the Dinetah.^{1,2,5}

Despite ongoing expansions, RECA still does not cover:

- ☛ Workers in poor health who fail to meet thresholds;
- ☛ Family and community members exposed to uranium;
- ☛ Emotional and physical consequences of ongoing real and perceived uranium threats;
- ☛ Cost to communities in increased healthcare demand.

RECA is characterized by a focus on the individual that overlooks harms to families and communities, and by a goal of fair compensation rather than of healing the harm. As such, it is not only culturally inappropriate within the context of the Dinetah, but also ineffective in an absolute sense that transcends cultural context.

Conclusions

RECA Compensation Categories as of 2012⁴

Uranium miners, millers, and ore transporters	\$100,000
"Onsite participants" at atmospheric nuclear weapons tests	\$75,000
Individuals who lived downwind of the Nevada Test Site ("downwinders")	\$50,000
☛ Survivors may claim compensation when the qualifying individual is deceased.	
☛ Compensable health conditions vary by category.	
☛ The Energy Employees Occupational Illness Compensation Program (EEOICP) may provide an additional or alternate source of compensation.	

The Diné did not trust outsiders, and for many years refused to open the Dinetah to mining. During World War II, out of loyalty to the United States, the Diné allowed mines to open and supplied vanadium and uranium for the war effort. The first uranium mines were opened shrouded in the secrecy of the Manhattan Project.³

Researchers working for the U.S. government determined that radon, a gas emitted by uranium, was the cause of uranium-mining-related health problems. They explored venting mines as a means of protecting workers; these investigations continued for years amidst internal debates over whether workers should be told.¹

By the time miners were informed of the dangers of radon gas, many had already died of lung disease. Widows in the Dinetah began to organize and advocate.¹

Beginnings



Once mine ventilation proved effective in reducing lung disease associated with uranium mining, the U.S. government began to inform workers of health hazards associated with mining and handling uranium. Local laws were passed to require ventilation of uranium mines.¹

Between 1962 and 1990, a number of civil lawsuits were filed against the U.S. government on behalf of workers. These suits were not permitted to go ahead, but in 1990 RECA was passed in lieu of litigation.⁴ The legislation was subsequently updated to add new eligibilities (e.g., above-ground workers) and eliminate stumbling blocks (e.g., for surviving spouses whose marriages were not legally documented).⁵

As of April 2012, the U.S. government has distributed almost \$1.7 billion to individuals as part of RECA.⁴

Actions



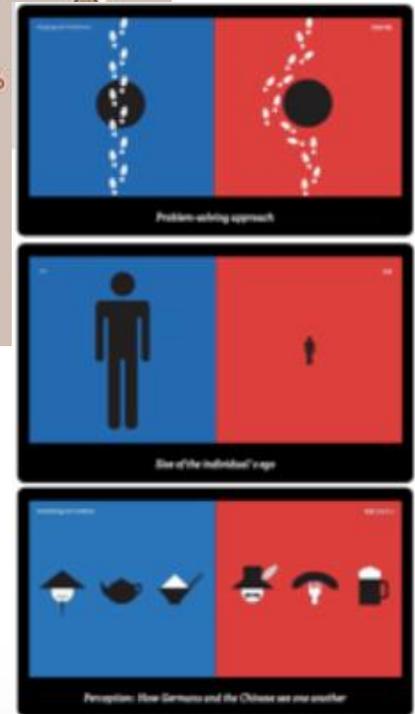
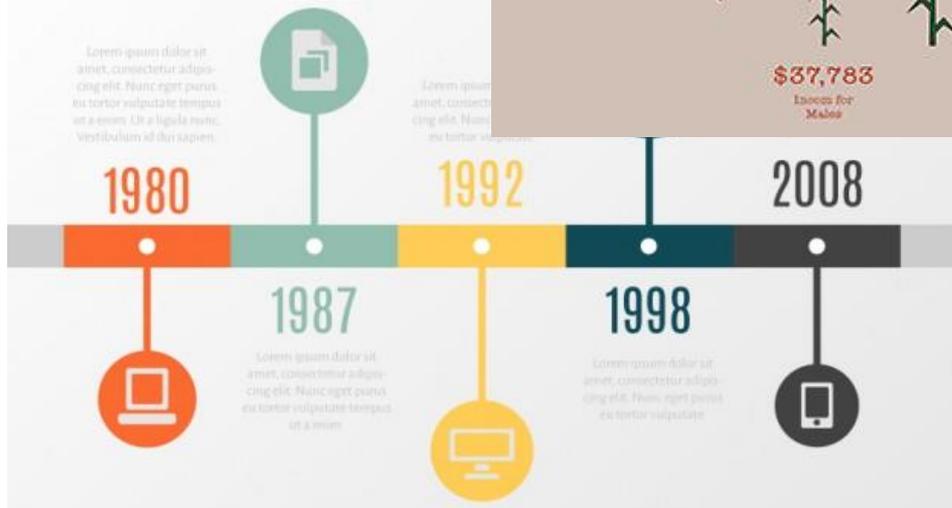
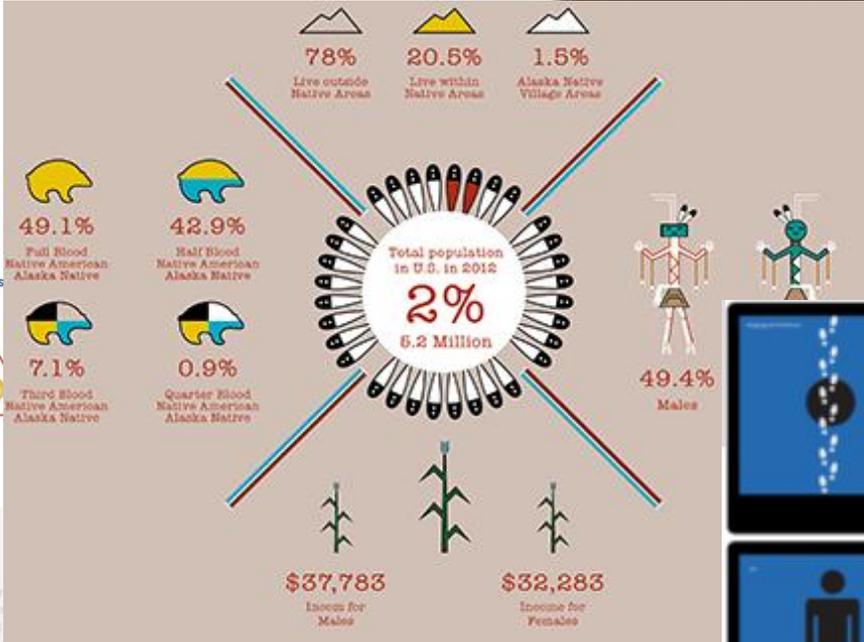
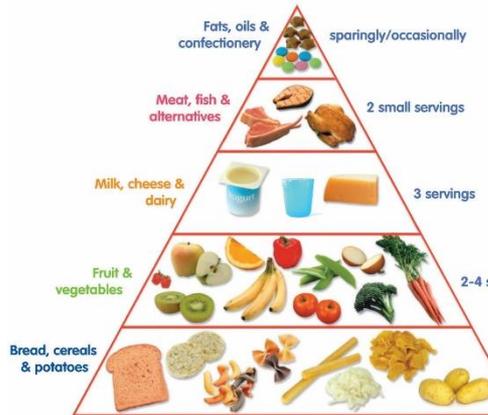
Images

Cove, AZ mine, from <http://www.miningartifacts.org/Arizona-Mines.html>
RECA map, from <http://www.justice.gov/civil/common/reca.html>
Nightway textile, from <http://culturedart.blogspot.com/2010/11/nightway-chant-nightway-logs-navajo.html>
Yellowcake uranium, from <http://coloradoindependent.com/3222/uranium-mining-whats-thirst-for-drinking-water>

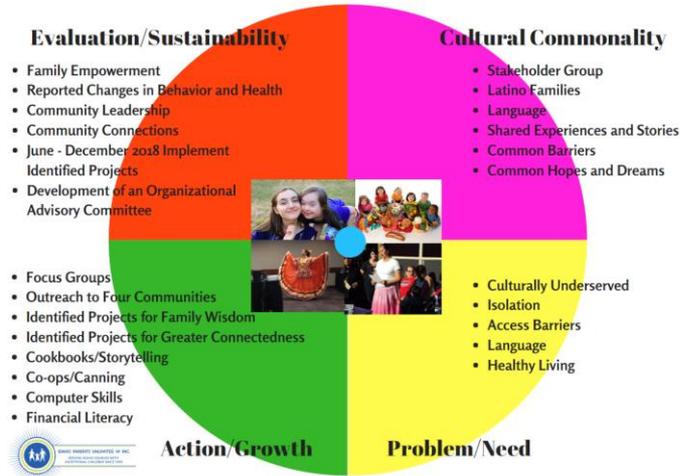
References

1. *The history of uranium mining and the Navajo people*. Brugge, Doug and Goble, Rob. 9, 2002. *American Journal of Public Health*, Vol. 92, pp. 1401-9.
2. Navajo Uranium Miner Oral History and Photography Project. *Memories Come To Us In the Rain and the Wind*. Jamaica Plain, MA: Red Sun Press, 2000.
3. Pasternak, Judy. *Yellow Dirt: an American story of a poisoned land and a people betrayed*. New York: Simon and Schuster, 2010.
4. U.S. Department of Justice. Radiation Exposure Compensation Act (RECA). [Online] [Cited: 3/23/2012]. <http://www.justice.gov/civil/common/reca.html>
5. *Psychosocial and Health Impacts of Uranium Mining and Milling on Navajo Lands*. Dawson, Susan and Madsen, Gary. 5, 2011. *Health Physics*, Vol. 101, pp. 618-25.
6. Farris, James C. *The Nightway: A history and a history of documentation of a Navajo ceremonial*. Albuquerque: University of New Mexico Press, 1990.

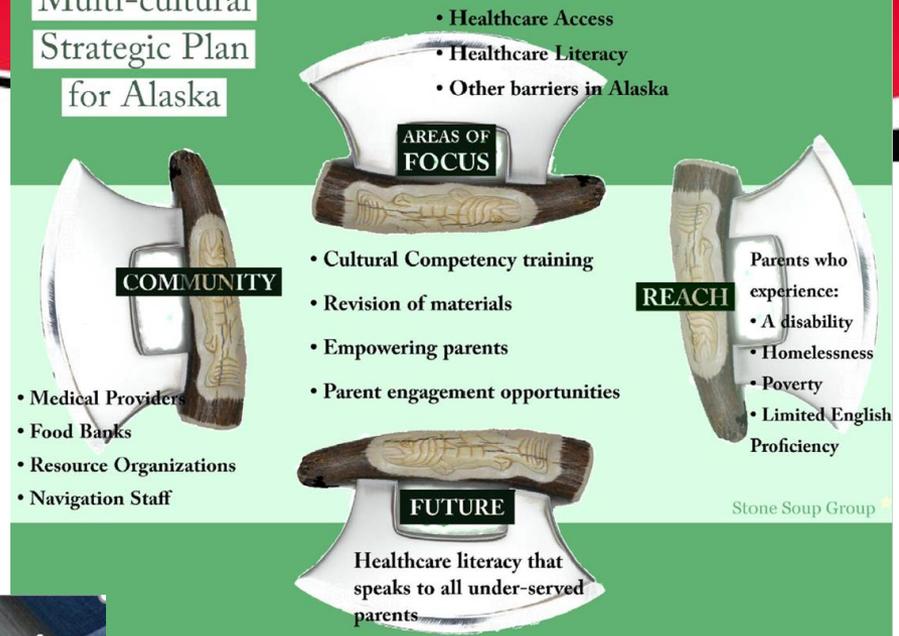
Infographics



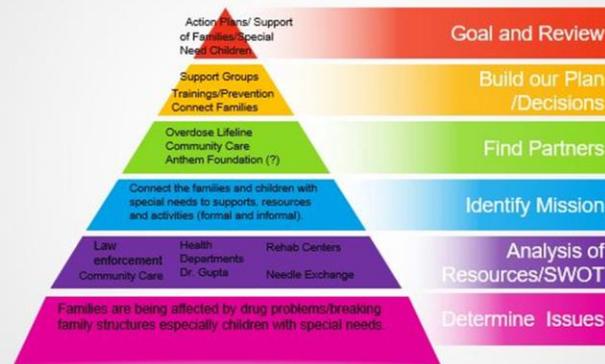
Strategic plans



Multi-cultural Strategic Plan for Alaska



WVPTI's Lifeline in WV "Opioids and Family Crisis"



Intersectionality

in(t)ərsekSHə'nalədē/

noun

- the interconnected nature of social categorizations such as race, class, and gender as they apply to a given individual or group, regarded as creating overlapping and interdependent systems of discrimination or disadvantage.
- "through an awareness of intersectionality, we can better acknowledge and ground the differences among us"



RESOURCES



National Genetics Education and Family Support Center

- Family Engagement
 - Family Voices leadership training
 - Update of Advocacy ATLAS
 - Matching to family-led and disease advocacy organizations
- Education & Support
 - DiseaseInfoSearch.org
 - GenesInLife.org
 - Partnership with Genetics and Rare Disease Information Center as national call center
- Outreach & Referral
 - Referral to cultural and community-based organizations
 - Webinars and trainings on topics such as cultural humility, translation, low literacy writing, and user centered design.



A Gold Standard in Resources



Climate of the Learning Environment

Cultural and Linguistic Competence Checklist for MCH Training Programs

Resources

Limited English Proficiency (LEP)

LEP.gov

A Federal Interagency Website

[Language Identification Cards](#)

LEP Resources and Information

[Frequently Asked Questions](#)

[Executive Order 13166](#)

[Resources by Subject](#)

[Recipients of Federal Assistance](#)

[Interpretation and Translation](#)

[LEP and Title VI Videos](#)

[Demographic Data](#)

[LEP Mapping Tools](#)

LEP Compliance

[Federal Agency LEP Plans](#)

[LEP Guidance for Recipients](#)

[LEP Guidance for DOJ Recipients](#)

[File a Complaint](#)

LEP.gov

[Suggest LEP Resources](#)

[Report Broken Links on LEP.gov](#)

[Last Updated: April 27, 2017](#)

Featured Resources

- [State Courts](#)
- [Foreign Language Services Ordering Guide](#)
- [Translation and Interpretation and Procurement Services \(TIPS\) Sheets](#)
- [Training Video: Communicating Effectively with LEP Members of the Public](#)
- [Title VI Protection for LEP Individuals](#)
- [LEP.gov Mission Statement](#)

Recent Items

[Memorandum of Understanding between the United States of America and the Unified Judicial System of Pennsylvania- April 24, 2017](#)

- [Language Access Plan- March 28, 2017](#)

[Erie County of New York State Enters Agreement with HHS OCR to Ensure Availability of Language Assistance Services for Individuals with LEP \(Agreement\) \(Press Release\)](#)

[Federal District Court denies Defendant Philadelphia School District's Motion to Dismiss in IDEA, EEOA, and Title VI Language Access Lawsuit Where DOJ Filed a Statement of Interest - November 30, 2016 \(Statement of Interest PDF\)](#)

Resources



Pew Research Center *Hispanic Trends*

HOME

U.S. POLITICS

MEDIA & NEWS

SOCIAL TRENDS

RELIGION

INTERNET & TECH

SCIENCE

HISPANICS

GLOBAL

PUBLICATIONS

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INTERACTIVES

DATA AND RESOURCES

EXPERTS

Unauthorized Immigration

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INTERACTIVES | NOVEMBER 3, 2016

Unauthorized immigrant population trends for states, birth countries and regions



INTERACTIVES | NOVEMBER 3, 2016

Estimated unauthorized immigrant population, by state, 2014

OTHER TOPICS

FILTER BY YEAR

2016	2015	2014	2013
2012	2011	2010	2009
2008	2007	2006	2005
2004	2002		

Resources



GEORGETOWN UNIVERSITY

National Center
for Cultural Competence

Georgetown University Center for Child & Human Development 

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The mission of the **NCCC** is to increase the capacity of health care and mental health care programs to design, implement, and evaluate culturally and linguistically competent service delivery systems to address growing diversity, persistent disparities, and to promote health and mental health equity.



FOUNDATIONS



SELF-ASSESSMENT



DISTANCE LEARNING



RESOURCES



FAMILY VOICES[®]
... keeping families at the center of children's health care

Family Voices
PO Box 37188
Albuquerque, NM 87176
Phone (505) 872-4774
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