Disability in Indian Country:
A proposal to use the ICF and a Disability Disparity Model to Highlight the Needs of American Indian Children

June 27, 2016
NCAI Data Partners Conference
Spokane, WA
Objectives

1. Describe the International Classification of Function, Disability and Health (ICF)
2. Identify potential sources of disparity in disability for Native Americans with TBI
3. Discuss methods for upcoming research project
Outline

• Introduction
• What is Rehabilitation Medicine?
• The ICF
• Disability Disparities Model
• Project in development
About me

- Member of the Confederated Tribes of Warm Springs
About me

• Goal of being a physician since the age of 4
• April 27, 1996
  • Sister with C1 spinal cord injury
  • Inpatient rehabilitation for two months
  • Personal exposure to many fields of medicine
Physical Medicine and Rehabilitation

• Nerve, muscle, bone and brain experts who treat injury or illness to **restore function as part of a multidisciplinary team**
• Approach considers the whole person and not just one disease or organ system
• Develop a **comprehensive** program for helping a person and their family put the pieces of their life back together after injury or illness
Outline

• Introduction
• What is Rehabilitation Medicine?
  • (and what is a physiatrist’s role in TBI?)
• The ICF
• Disability Disparities Model
• Project in development
The International Classification of Functioning, Disability, and Health (ICF)

- Biopsychosocial Model
- Classification system
- Conceptual Framework
- Disability is social construct
- Interaction between many dimensions of a person and his or her environment
The International Classification of Functioning, Disability, and Health (ICF)

Body function and structures – Spinal Cord Injury

- Paralysis
- Insensate skin
- Bowel and bladder changes
- Low blood pressure
- Temperature dysregulation
Persons with Spinal Cord Injury may have differences in:
- Mobility
- Dressing
- Toileting

Capacity – level of activity in ideal setting
Performance – level of activity in person’s environment (WHO 2002)

Activity level mediates participation in children with CP (Bjornson 2013)
What does that mean?
- A “set of organized activities directed toward a personally or socially meaningful goal” (Coster and Khetani 2008)
- The construct will vary between individuals and among cultures (Stevelink 2013, Pichette 1999)

Participation contributes to quality of life and is the end goal of rehabilitation programs. (Dahan-Oliel 2012, Coster 2012)
The International Classification of Functioning, Disability, and Health (ICF)

Context – Personal and Environmental Factors

- **Personal Factors** – background of a person’s life and living
  - Age, gender, educational background, employment history, socioeconomic status
  - Choices and goals

- **Environmental Factors** – physical, social, attitudinal environment in which people live and conduct their lives
  - Rural – Urban
  - Built environment (paved roads, sidewalks, ramps)
  - Support system (family, community)
  - Social norms around function and roles
  - Institutions (health care, law, etc)
The ICF and Native Americans

My hypotheses

- No specificity for American Indians at the Body Functions & Structure or Activity level
- Unique American Indian experience of disability within the areas of Participation, Personal and Environmental Factors
  - Culturally-mediated nuances
  - Social Determinants of Health
Outline

- Introduction
- What is Rehabilitation Medicine?
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“A differential experience based primarily on cultural orientation that results in higher incidence of disability, and/or lower participation levels in the formal helping system, and/or fewer successful individual outcomes when compared to majority culture groups”
Disability Disparities

Factors accounting for higher incidence:
- Genetic factors
- Lifestyle, behavior choices

Group perspective on disability:
- Etiology
- Progression
- Effective Intervention

Access to services, Utilization:
- Role of SES
- Group’s help-seeking tradition
- Complex system entry

Practitioner or service system conscious or unconscious bias:
- Nature and quality of service experience
- Treatment alliance
- Cultural expectations
- Service quantity, quality

Impact of services on individual outcome:
- Outcomes: Aligned with culture
- Appropriate measures

Disability disparities – Is there a higher incidence of disability among AI/ANs?

Factors accounting for higher incidence

- Genetic factors
- Lifestyle, behavior choices

Cultural traditions, biogenetics, response to oppression

Prevalence of disability among non-institutionalized working-age people (21-64)

Prevalence Rates: Race (%)

Erickson et al. 2010
Disability Status Report United States.
Disability disparities – incidence

Factors accounting for higher incidence
- Genetic factors
- Lifestyle, behavior choices

Cultural traditions, biogenetics, response to oppression

Current Project
• Northwest Portland Area Indian Health Board / Portland Area IHS
• Identifying records with diagnostic codes associated with disability in children
  • Prevalence of disability among AI/AN children in Portland Area (WA/OR/ID)
  • Etiology of disability (traumatic, congenital, etc.)
  • Type of disability (physical, cognitive, etc.)
  • Diagnoses (Cerebral Palsy, brain injury, etc.)
Disability disparities – worldview

- Are there differences between the Native and Western worldview about disability?
- What are the intertribal differences in perspective on disability?
- Do Natives believe Western rehabilitation services are beneficial?
Disability disparities – service access

Are there differences in access to inpatient rehabilitation services for Natives?

- Differences in worldview, values
- Access to services, Utilization
- Role of SES
- Group’s help-seeking tradition
- Complex system entry
Disability disparities – service access

- Are there differences in access to inpatient rehabilitation services for Natives?
- Proposed barriers to accessing rehabilitation services
  - Availability
  - Transportation
  - Other contextual factors? (link to the ICF)
Disability disparities – quality of rehabilitation service

- Do Natives have equal rehabilitation experiences?

Practitioner or service system conscious or unconscious bias

Nature and quality of service experience

- Treatment alliance
- Cultural expectations
- Service quantity, quality
Disability disparities – quality of rehabilitation service

- Do Natives have equal rehabilitation experiences?
  - Among children who had loss of consciousness >24 hours after TBI, Native children had less improvement in motor function during inpatient rehabilitation.

Practitioner or service system conscious or unconscious bias

Nature and quality of service experience

- Treatment alliance
- Cultural expectations
- Service quantity, quality
Disability disparities – outcome measures

Practitioner or service system conscious or unconscious bias

Impact of services on individual outcome

Outcomes:
- Aligned with culture
- Appropriate measures

- To my knowledge, there are not outcome measures related to disability or rehabilitation outcomes that have been specifically validated with Natives

- Importance of eliciting patient and family goals, understanding the context of a family
Etuaptmumk – Two-Eyed Seeing

- Formally shared by Mi’kmaw elders in 2004
- “Learning to see from one eye with the strengths of Indigenous knowledges and ways of knowing, and from the other eye with the strengths of Western knowledges and ways of knowing ... and learning to use both these eyes together, for the benefit of all”

“Requires a “weaving back and forth” between knowledges, and this will draw upon abilities to meaningfully and respectfully engage in an informed manner in collaborative settings”

- Co-learning
  - Reciprocity – learning from each other
  - Collectivity – learning together
  - Creativity – seeing linkages between knowledges
  - Weaving capacity – going between the cultures’ actions, values, knowledges


Next steps - Understanding the Experience and Priorities of AI/AN Children with Disabilities and Their Families

- In-depth interviews
  - AI/AN youth (age 11-24) with disabilities
  - Parents/caregivers of AI/AN children/youth (birth to 24) with disability
    - Washington, Oregon, Idaho
- Questions to elicit experience of health, activity, participation, health/rehabilitation service utilization, intersection with culture
  - Framework analysis using ICF and disability disparities model
- Identify priorities of consumers/communities in order to develop culturally-relevant interventions
Next steps

Challenges

• Relatively low incidence (but high impact on family and community)

• Intertribal differences

• Eliciting perspectives of people who do not utilize tertiary care centers

Proposed Solutions

• Recruit from multiple communities

• Work with communities from similar cultural groups

• Recruit at community level, not just from rehab hospital
Questions or Suggestions?
1. Beaudin, PG. *A Contemporary Socio-cultural Exploration of Health and Healing: Perspectives from members of the Oneida Nation of the Thames (Onyota’a:ka)*. London, Ontario, Canada: Rehabilitation Sciences, University of Western Ontario; 2010.


