Stakeholder Perspectives on Culturally Centered Rehabilitation Services for American Indian and Alaska Native Children With Disabilities

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Introduction

- Cultural participation is a protective health factor for American Indian and Alaska Native (AI/AN) people.
- AI/AN children with disabilities experience barriers to participating in cultural activities related to their functional impairments
- Pediatric rehabilitation services do not adequately address culturally-related functional needs for AI/AN children

Methods

Design: Descriptive qualitative analysis
Participants: Stakeholders in rehabilitation for AI/AN children: 1) AI/AN adults or parents of AI/AN children who received neuro-rehabilitation, 2) pediatric rehabilitation therapists (AI/AN or serving AI/AN children), 3) physiatrists and primary care providers serving AI/AN children, 4) leaders of AI/AN health or disability organizations.
Analysis: Contextualist constructionist epistemology. Initial codes developed from Post-Acute Care Rehabilitation Quality Framework domains with iterative expansion of the codebook. Inclusive coding by 2 investigators. Latent thematic analysis to identify themes.

Components of Culturally Centered Rehabilitation

- **Include cultural activities –** "Things like berry picking – it's a tripod pinch, so we could practice and tie berry picking in"
- **Communication about Culture -** "It's about embracing the beliefs of the people you are serving"
- **Family Empowerment –** "If you're in a system you don't have a lot of knowledge about, like our [AI/AN] families, they feel that oppression, that they're being judged. We need to help advocate for and empower families to advocate for the child."

Barriers

- **Competing Needs -** "The priority becomes immediate needs, not the greater community or cultural needs."
- **Provider unsure asking about culture -** "It makes me uncomfortable to point out differences based on culture"; It's okay to respectfully ask and not know how to respond."
- **Time -** "Really getting to know the community goes beyond what a typical workday would entail"
- **Access –** "There was certainly no [rehab clinic] to send the kids to"; "80% of my kids are on Medicaid, so access and transportation is always an issue"
- **Lack of trust/trustworthiness –** "There's the whole issue of historical trauma, broken treaties, boarding schools. Just understanding there's a reason for families to not trust outsiders"

Facilitators

- **Involving Elders/Community –** "We have the ability to think outside the box, but it should be dictated by the elders and members' visions and interests"
- **AI/AN providers –** "When there are Native [rehab providers], you know the rapport is going to be better, they're going to be understood more easily"

Table 1. Demographics

Characteristic	N=19
Female	73.7%
AI/AN	68.4%
Stakeholder Type	
Rehab Professional	42.1%
PCP or Peds Physiatrist	26.3%
Community member/Parent	31.6%
National Congress of American Indians Region	
Northwest	31.6%
Great Plains, Southern Plains, & Oklahoma	26.3%
Northeast & Southeast	15.8%
Southwest	10.5%
Alaska	10.5%
Rocky Mountain	5.3%