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Perceptions of Disabilities Among Native Americans Within the State of Utah

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Perceptions of disabilities among Native Americans within the state of Utah

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ABSTRACT
Currently, little research exists on disabilities among Native American communities and no research exists on how Native Americans perceive disabilities, services currently available, and unmet needs. Understanding these key areas is essential to providing efficacious and culturally relevant care. To address this gap in the literature, we used Indigenous research methodology through sharing circles throughout the state of Utah to listen and amplify the voices of the Native communities. Participants shared how they conceptualize “disability,” what they thought of current services, and how they thought the needs of Native persons with disabilities should be addressed. Four major themes emerged in the data: a culturally-based conceptualization of “disability,” barriers to services, belonging, and needed actions. These themes highlight the cultural strengths among Native communities surrounding disabilities and bring attention to systematic change needed to better address the needs of Native Americans with disabilities.

POINTS OF INTEREST

- Native Americans are diagnosed with disabilities more than the general American population. Cultural understandings, including the definition of “disability,” may influence diagnosis rates.
- This study aimed to get a more complete picture of how Native Americans understand disabilities and what services would be helpful for those with disabilities in their communities.
- Native American participants shared their experiences and thoughts about disabilities in sharing circles to discuss important topics in a cultural way.

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• Four major themes were identified following these sharing circles, including a culturally-based definition of “disability,” barriers to services, belonging, and needed actions. These themes highlight the cultural strengths among Native communities surrounding disabilities and bring attention to what changes could be made to better serve the needs of Native Americans with disabilities.

Introduction

Individuals with disabilities of all classifications and Native Americans are members of marginalized groups (Bialka et al., 2017). Persons with disabilities have pervasive difficulties finding employment (Darcy et al., 2016). In addition, there may be inadequate services provided to transitioning high school students with disabilities into higher education (Kendall, 2016). Native Americans experience racism, discrimination, and stigma (Roberts & Rizzo, 2021). J.T. Toubbeh gave a speech at the National Conference on Indians with Disabilities (as cited by Ma et al., 1999) in which he shared that Native Americans of all ages are six times more likely to be diagnosed with a disability than the general population. Natives with disabilities have dual marginalized identities, leading to a need to consider the intersectionality of these identities. Prevalence rates show that some of the most common disability classifications among school-aged Native Americans are emotional disturbances and learning disabilities (National Council on Disability, 2003). As a note, throughout the text, the authors will alternate between using the terms “Natives” and “Native Americans” to refer to the Indigenous peoples of what is now known as North America. These terms fit with the first author’s method for self-identification.

Current definitions of disabilities

The Individuals with Disabilities Education Act (IDEA) is a national U.S. legislative act that asserts children with disabilities’ fundamental right to appropriate education by providing access to services and aids (20 U.S.C. § 1400 (2004)). IDEA defines thirteen categories of disabilities that children may receive services for (20 U.S.C. § 1400 (2004)). Children rely on IDEA for access to services in school. While these definitions are a good place to start, they can be an issue for children with misdiagnosed or unnoticed disabilities. In these situations, children face impediments to an enriching education without aid.

There are other legal definitions for disability, as well, such as in Section 504 of the Rehabilitation Act of 1973 (45 CFR Part 84) and the Americans with Disabilities Act (ADA; 42 U.S.C. § 12101 et seq. (1990)). According to Section 504, a disability is a physical, cognitive, or mental health condition that significantly impacts functioning; most, but not all, children who fall
under an IDEA classification also meet criteria under Section 504. The ADA favors a more broad definition of disability in that it is defined as a “physical or mental impairment that substantially limits one or more life activities…a record of such impairment; or being regarded as having such impairment” (42 U.S.C. § 12101 (1990)). The ADA protects civil rights of persons with disabilities and is focused more on accessibility to the built environment than providing services in the education system. The ADA does not make schools responsible for free and appropriate education, this is why we focus on the definitions from IDEA and Section 504, which do require schools to provide equitable services and access to education.

In addition to providing children with services, the IDEA gives rights to the parents and guardians of children with disabilities. Parents or guardians are required to be a member of the team in their child’s evaluation and for the formation of the child’s individualized education program (IEP). This right enables parents/guardians to be active advocates for their child. If an IEP does not properly fit their child, or if the school is not providing these services appropriately, the parents/guardians can then intervene and ensure that their child is receiving adequate care. However, it is important to note that parents and guardians may not be aware of their ability to advocate for their child, nor be familiar with their rights; parent and guardian intervention can be difficult to achieve due to this lack of awareness. Thus, it is essential that parents and guardians are aware of these rights in order to assert them.

**Rationale for Utah focus**

There are currently 573 federally recognized Native American tribes in the U.S. (National Congress of American Indians, 2022). Due to this large number, Native communities are inherently diverse and have different cultural values, traditions, and languages. In order to respect this diversity among tribal groups, we conducted this study within the state of Utah, the ancestral lands of many tribes, including the Northwestern Band of the Shoshone Nation, Confederated Tribes of Goshute, Skull Valley Band of Goshute, Ute Mountain Ute, Ute Indian Tribe of the Uintah and Ouray Reservation, San Juan Southern Paiute, Paiute Indian Tribe of Utah, and the Navajo Nation. The number of tribes in Utah allows for a balance of honoring tribal diversity and the unique perspectives of each of these tribes. The authors sought to include the perspectives of as many of the tribes of Utah as possible. This study has representation from five nations. Native communities in other regions may have different perspectives about disabilities and services, so the results from this study may not accurately reflect the views of all Native Americans. The inclusion of members of different tribes living in the state has enhanced the rigor of our results. The reason for our decision to focus on Utah is that the researchers live within the state, making the area accessible to us. At the heart of our decision to focus on Native peoples within the state
of Utah is that Utah is where the researchers work and reside and is where we can make the most impact and create lasting, reciprocal relationships.

**Learning and culture**

The education system in the United States is based on Western cultural ideals of success through independence, which do not align with Native American cultural values (Garrett, 1995), which include connectedness and interdependence (Fryberg, et al., 2013). Native American educational values focus on relationships and kinship as a primary source of knowledge (Larkin-Gilmore et al., 2021). This kinship extends to valuing place and what connections to the land and creatures can teach us (Larkin-Gilmore et al., 2021, Medin & Bang, 2014). This cultural mismatch in education values has led to a long history of systematic inequality and racism in our school systems that resulted in physical, cultural, and spiritual traumas during the Indian boarding school era, resulting in historical trauma (Kirmayer et al., 2014; Blume et al., 2019), which continues to impact the lives of Native students today. Nationally, the high school dropout rate among Native American students was 9.6% in 2019, compared to 5.1% among the general population (National Center for Education Statistics, 2021). In Utah, this number rises to 21%, compared to 11% of all students (Utah State Board of Education, 2018). These numbers show the results of centuries of systematic discrimination and oppression. This systematic racism has resulted in increased barriers to academic success for Native students.

A difference in learning approaches is one component of this systematic racism. U.S. school systems value and teach assertiveness (Fryberg et al., 2013). Those unfamiliar with Native worldviews often interpret reserved, observant Native American children as uninterested, unengaged, or not as intelligent because they are not interacting in the expected ways. However, learning approaches differ across cultures, and these children are engaging in a culturally appropriate manner (Fryberg et al., 2013; Garrett, 1995), by showing respect to the teacher and classmates through listening rather than speaking up. This misconception may contribute to the education system's over-representation of Native American students in special education programs (Faircloth, 2006), and further suggests a difference of how Native communities view disabilities compared to the general population.

**Prevalence and disparities of disabilities among Native Americans**

Native Americans are disproportionately diagnosed with disabilities (Rabang, et al., 2023), including within the school setting (Blume et al., 2019; Executive Office of the President, 2014; Whitford, 2017). The prevalence of disabilities
among Native Americans of all ages fluctuates from 22 to 27 percent (National Council on Disability, 2003), approximately double the prevalence for the general population, which is about 12.7 percent (United States Census Bureau, 2020). Prevalence of disability increases with age but the same pattern emerges when comparing disability prevalence for those up to age 65 (the current average life-expectancy for Native Americans; Goldman & Andrasfy, 2022) of approximately 45% for Native Americans compared to 26% of US adults generally (Courtney-Long et al., 2017). Native children are overrepresented in special education programs in the United States (National Center for Learning Disabilities, 2020). Native Americans also are more likely to experience a number of health disparities, such as inadequate access to healthcare, limited health insurance coverage, and poorer overall physical and mental health (Utah Department of Health, 2016). Furthermore, Native American youth experience heightened risk factors for health disparities, such as adverse childhood experiences, residing in food deserts, decreased access to quality healthcare, distrust of the medical system, and suicidal ideation (Herne et al., 2014; Jernigan et al., 2017; O’Keefe et al., 2014; Warne et al., 2017).

**Conceptualizations of disability and their implications**

Current studies assessing disabilities in Native Americans have utilized the definitions and measures set forth by the majority population (Monteau, 2016; Ramasamy et al., 2000; Saravanabhavan & Marshall, 1994). A misdiagnosis can impact the way a child views him- or herself and negatively affect their self-esteem (Schur, 2002). It is essential to take culture into account when assessing for disabilities to ensure that the diagnosis is not coming from a place of prejudice. The negative impacts an incorrect diagnosis can have on a child’s life accentuates the need for a culturally-based and appropriate conceptualization for disability. Due to the considerable cultural differences between the definition of health and values in education (Faircloth, 2006), it is essential to develop a greater understanding of how disabilities are defined and perceived among Native American populations. Culturally-competent care is associated with trust in healthcare providers, adherence to healthcare treatment, and overall improved health (Alizadeh & Chavan, 2016). Given that knowledge is a key component of cultural competence (Tehee et al., 2020), having an understanding of how disabilities are perceived among Native communities is essential to culturally-competent care.

**Accessing services**

Overrepresentation of Native children diagnosed with disabilities and placed in special education programs may be amplified as we/they may also have greater difficulty accessing services than other populations (Cromer et al., 2019). An
important consideration is the quality of services available to Native Americans with disabilities. For some time, Native Americans with disabilities have expressed unmet needs for medical and mental health services and difficulty accessing available services (Cromer et al., 2019; Saravanabhavan & Marshall, 1994). Because many members of Native American communities live in rural areas, transportation is often another barrier to accessing services.

Cultural competence is imperative to providing quality healthcare (Ngo-Metzger et al., 2006). Patients that have healthcare that they do not perceive as culturally competent are more likely to report discrimination experiences and distrust of the medical system (Ngo-Metzger et al., 2006). As such, it is essential that medical care providers be culturally competent to lessen disparities commonly experienced by minority members, such as discrimination by staff and providers (Institute of Medicine Committee on Understanding and Eliminating Racial and Ethnic Disparities in Heath Care, 2003). However, it is impossible to know what culturally competent care means for Native Americans with disabilities if we do not ask. Learning directly from Native Americans about how best to provide medical care is an essential step on the road to equal health care.

**Detrimental outcomes**

Native Americans with disabilities have been reported to have poor health outcomes within the state of Utah compared with the general population (Utah Indian Health Advisory Board & Utah Department of Health Office of Health Disparities, 2016). These negative outcomes display the need for a better understanding of disabilities among Native communities. The influence of these services and interventions on a child’s social and academic lives is immeasurable. Children with disabilities are more likely to experience bullying than other children (stopbullying.gov, 2018). The Indian Health Service has stood against the bullying of Native children due to culture by embracing Native values in their “Stand Up, Stand Strong” campaign (Indian Health Services, 2012). As is, Native children are already at a heightened risk for bullying simply because of their racial identity. The mismatch between cultural understandings of disability places Native children at an increased risk for bullying and all the adverse outcomes that stem from it, including mental health issues that may persist into adulthood, lower academic attendance, lower GPAs, increased dropout rates, increased health problems, and higher suicide risk (stopbullying.gov, 2018).

As previously stated, Native students are overrepresented in special education programs, which is a form of discrimination. It is essential to take into consideration the impact that discrimination can have during children’s lives. A child that experiences discrimination is at a higher risk of mental health issues like depression, anxiety, and overall negative
affect (Blume et al., 2019). Furthermore, children who perceive discrim-
inination are more likely to have poor self-esteem and less life satisfaction
(Blume et al., 2019).

Research design and methodology

The current study aimed to develop a culturally-based conceptualization
of what a “disability” is for Native Americans living in Utah. We invited
Native Americans age 18 and older to participate in sharing circles, an
Indigenous research method similar to focus groups (Lavallé, 2009). We
held these sharing circles throughout the state of Utah. We audio recorded
the sharing circles and transcribed the recordings. We used thematic anal-
ysis to find major themes that came up during the sharing circles. These
themes formed a culturally-based conceptualization of what a “disability”
is for this population. This culturally-based conceptualization can help to
ensure that Natives are diagnosed with disabilities in accordance with our/
their cultural values. In addition, this conceptualization is less susceptible
to racial prejudice because it was generated directly from Native community
members.

Participants

We recruited 26 participants from within the state of Utah. All participants were
over 18 years old and self-identified as Native American. The participants’ ages
ranged from 18 to 64 years. The average age was 31.2 years with a standard
deviation of 5.632 years. Participants identified as being a member of five tribal
groups, which will not be identified to protect the privacy and confidentiality
of these nations. Although not all are tribes native to Utah, all participants
lived in Utah. Participants had a variety of experiences with disabilities; some
participants had disabilities themselves, some had family members with dis-
abilities, and others were not close to anyone with a disability, resulting in a
range of perspectives on the concept. The researchers contacted multiple orga-
nizations within the state to locate potential participants. These nine organiza-
tions are Utah State University Extension at Blanding, Utah State University
Extension at Vernal, the Title VI Coordinators (American Indian Education through
the Utah State Board of Education), the Native American Student Council at
Utah State University, and the Native American Student Mentorship Program.
These organizations connected us with participants and gave us opportunities
to meet with community members for sharing circles. Each organization was
of pivotal importance in the recruitment process.

In addition to the data obtained from the sharing circles, we utilized a
demographic questionnaire with questions regarding age, education level,
gender, tribal affiliation, living situation, whether the individual knows
someone with a disability, and their relationship with that person. Data from the demographic questionnaire was used solely to describe the aggregated participant sample and is not disaggregated in order to protect the participants’ and tribes’ confidentiality.

**Grounded theory Methods**

The researchers used grounded theory methodology (Charmaz, 2006) to understand how disabilities are perceived among the Native American community in the state of Utah. Utilizing methods from grounded theory allowed us to develop themes of the perceptions of disabilities based on the information provided by participants in the sharing circles. Grounded theory is a reflexive and continuous research approach that continuously analyzes the data for themes and concepts that can form the basis for a theory (Glesne, 2016). Researchers using this methodology seek out new data for comparison with the previously collected data in order to refine the theory to the greatest extent possible (Glesne, 2016). The reflexive nature of this approach enhances the trustworthiness of the results of the study. In this study, the researchers worked to develop the theory by asking questions about perceptions of disabilities in sharing circles. Following each sharing circle, the researchers further developed and refined the theory of disability. Once we reached saturation and were no longer gaining new information, we discontinued sharing circles and compiled the data for thematic analysis.

**Indigenous research Methods**

This study utilized Indigenous research methodology to address the research question in a culturally-appropriate manner. Sharing circles are an Indigenous research method (Lavallé, 2009) that gives space to a group of people to share their thoughts and stories about a given topic. Sharing circles are similar to talking circles, which is a traditional way to communicate and ensure that everyone’s voice is heard. In sharing circles, all participants’ time and opinions are respected. While one person is sharing, the rest of the group listens. This ensures that everyone’s experiences and thoughts are heard and valued (Carr et al., 2020; Drawson et al., 2017).

In an effort to collect data in a culturally-appropriate manner, we utilized sharing circles as our primary data collection method. The researchers felt that this method gave voice to each participant regarding the topic. We developed seven questions for the sharing circles, along with follow-up questions that were asked if needed. The ideal number of participants per sharing circle is 6-8 participants. Due to recruitment approaches and chance, this number ranged from 1 to 14 participants per sharing circle, with a total of six sharing circles in five different locations around the state of Utah. The
researchers advertised for sharing circles ahead of time through electronic flyers and discussion at organization meetings. Because of this, we did not have control over how many participants attended each sharing circle. We continued to recruit participants until theoretical saturation occurred, that is, when no new information was gathered in the sharing circles (Oktay, 2012). At the ending of the sharing circles, the first author provided a list of available disability services in the state of Utah to the participants, along with a $20 gift card as compensation for their time and perspectives.

**Analysis**

The researchers transcribed the audio recordings from the sharing circle sessions. Transcripts were analyzed from the sharing circle using thematic coding in order to identify major themes and ideas. Thematic coding is commonly used in grounded theory in order to identify the theory and the point of saturation (Oktay, 2012). Three coders, including the first author, who is Native, and two other co-author coders, one of whom identified as Native and who were both committed to serving Native communities, independently analyzed the transcripts. Prior to disseminating findings, the first author sought community feedback by presenting the findings to participants. The participants were asked to give feedback on the themes to ensure that the results were trustworthy. Feedback from the discussion has been incorporated into our findings.

**Positionality**

The primary researcher is a Native American female doctoral student. I, Erica Ficklin, am a member of two federally-recognized tribes, the Tlingit and Oglala Lakota tribes. The second author and my mentor, Dr. Melissa Tehee, is a member of the Cherokee Nation. We both deeply value our communities and seek to honor the perspectives of the tribal communities with whom we worked. This goal led us to use Indigenous research methodology throughout the project, which is also culturally-consistent for us. Our coauthors comprise Native and non-Native researchers with expertise in disability advocacy, qualitative research, and cultural competence.

I, Erica, was initially asked to be a part of this project when I was offered a fellowship through the center for disabilities at my university. Through this fellowship, I learned much about the field of disabilities and how researchers and practitioners currently talk about issues regarding disabilities. I knew a little about disabilities because of my sister’s experience. She grew up with a disability that impacted her ability to learn and focus. Throughout her education, she experienced multiple situations in which she was told to limit her goals for her life because of her disability. Rather than listen to these
authority figures at the time, she pursued her goals, believed in herself, and ultimately succeeded in a strenuous medical program. I feel that watching my sister’s experience helped in the way I listened to people’s stories and interpreted them—rather than learning more about the government’s definitions of disabilities, I was able to pay greater attention to people’s experiences with them. I hope that I have represented those stories well in this document and honored the experiences of those who shared them with me.

Results

Thematic analysis of the transcripts revealed four major themes regarding how disabilities are perceived and experienced among Native communities in Utah. These included 1) disability is subjective; 2) belonging; 3) barriers to accessing services; and 4) needed action. The four themes come together to represent perceptions of all aspects of disabilities (see Figure 1). The meaning and implications of the themes are further analyzed in the discussion.

Disability is subjective

The initial goal of this project was to identify a culturally-based conceptualization for “disability.” The participants who discussed disabilities in the sharing circles shared a broad conceptualization: Disability status is subjective and depends on whether someone needs help with a condition to improve their quality of life. One participant described their view of disabilities as, “I would say it’s something that you can’t do on your own that needs a second hand.” This conceptualization was shared by other sharing circle participants as well.

Another participant expanded on this conceptualization of subjectivity and highlighted the variability in disabilities and the importance of
comfort. “Just kind of someone that needs a little bit of extra help. You know, just whatever that is, if it’s learning or social. It’s a little bit more than others to feel comfortable.” Another component of disabilities that frequently came up in the sharing circles was the wide range of conditions that could be considered a disability. One participant expressed feeling overwhelmed by the sheer number of disabilities that exist, stating, “I mean, there’s a lot. There’s a lot…. I can’t even begin to think of everything.” Among this variety are several types of disabilities recognized among the majority culture in the United States, including autism, Down syndrome, attention deficit/hyperactivity disorder, and emotional disturbances. Conditions that impact ability to learn were a common subject discussed in the sharing circles. One participant mentioned her sister’s dyslexia, saying “I know that always made it hard for her to read. She’ll scramble the letters.”

Physical disabilities that impact mobility were also discussed. Vision impairment and hearing impairment were mentioned, as well as disabilities impacting range of movement. One participant discussed his grandfather’s range of mobility and the fatigue caused by the required effort.

I guess mobility would be one of them too. If you’re paralyzed it would be a disability or if you’re physically really weak. My grandpa was really weak from an early age, like his mid-fifties. He can’t really walk around that much. He has to sit down a lot and is really skinny. He just doesn’t have a lot of physical strength, so yeah, that’s on the disability list too.

His experience watching his grandfather shows how physical disabilities can greatly impact a person’s life.

Ability to communicate with others was frequently discussed. One participant expressed how difficulty socializing impacts many areas of life.

Well, I have a [nephew with autism] who lives with me…. Social skills are really, really bad. Groups of people… he just can’t handle it. It makes him so nervous and the noise, he can hear anything, and it just makes him really anxious, stressful…. The noise, he gets antsy. It makes him really anxious. You can see it in his face. He just can’t handle it.

Her nephew’s anxiety in social situations exemplifies how difficulty interacting socially can become overwhelming and interfere with quality of life.

Mental health problems and whether or not they could be considered disabilities also were discussed. Participants were fairly split on whether mental health issues could be considered disabilities. Some participants felt strongly that mental health problems are disabilities. One individual cited the control anxiety has over a person’s thoughts.

That’s probably one of the only things you ever think about. If you know the cause, then you’re thinking about the cause, but if you don’t know the cause, then you’re just thinking why am I so anxious all the time?
Another participant mentioned that mental health problems can impact relationships and public perception of the person. “It can change the way you interact with others, the way they see you when you act a certain way.”

Since these sharing circles were held, more information about Indigenous perspectives on disability has been published in the research literature. These studies have illustrated cultural knowledge of disabilities and their causes. For example, many people with disabilities have been celebrated, such as the Piki Bread Woman from the Hopi Nation (Lovern, 2021). The Piki Bread Woman had differences in her hips and back, making it difficult to travel, which she needed to do to make the piki bread. The community valued her piki bread skills, so they supported her by helping her travel without her needing to ask (Lovern, 2021). The Inka often held people with disabilities in high respect and honor (Hechler, 2021). For example, people with disabilities would have opportunities to serve leaders as knowledge keepers, assisting those in power, and as labor organizers (Hechler, 2021). Furthermore, some Indigenous communities saw disabilities and differences as a result of being out of balance connected to balance, and some understood disabilities and differences as the result of a failure to uphold one’s responsibilities to the tribe (Lovern, 2021). These differences in conceptualizations illustrate some of the various ways that different Indigenous peoples understand disabilities. However, it appears that these articles have been studies using historical artifacts and traditional stories rather than the perspectives of present-day Native peoples.

**Belonging**

Belonging—whether it be among the community, peers, family, or other relationships—can greatly impact a person’s quality of life. Belonging and its importance for members of the community with disabilities was frequently discussed throughout all sharing circles and is thus identified as a major theme. Belonging—or lack of belonging—could be considered a double-edged sword. It has a strong ability to impact a person’s sense of belonging, or, conversely, their sense of isolation. Community support and efforts to help people with disabilities feel included was brought up repeatedly. One mother shared her son’s experience on his baseball team. Her son has vision loss and a love for baseball. His coach and teammates show their support for him through adapting to his needs and making the game fun for everyone.

The coach will go out and pitch to him and the coach will say, “Hold on, can you see it?” If he says no, he’ll scoot up until he can see it…. It’s kind of neat, because some teams will count his point or his out. They usually didn’t, but now they’re starting to. They’re like, “We’re going to treat him and try to see how he can do it on the main thing.” And he’s like, “Yeah, fine, I don’t care.” … [Once] he hit the ball and it would have been really easy to catch it and throw it to second and get him out, but instead the kids looked at each other, and you could see them
looking at each other, and they threw it to first. And by chance, the guy got into first. The thing is, I see what those kids were doing. You know, it's like, “Give him a chance. Let him have fun. I can get him out, but I’m going to get the other guy because he's the bottom of the [batting] order, he's not the best.” So, right after him, it starts with the best batters. So, yeah, it’s neat.

This mother's story shows how community support can help a child feel a sense of belonging and give them the chance to have fun playing sports without worrying about being bullied for having a disability.

Another participant described bullying she witnessed. She explained that other children would bully children with disabilities, but her mother, a special education teacher, frequently stood up for them.

They get bullied. They get bullied for [their disability] so they're kind of embarrassed to go to the [special education] program that's specially made for them. And sometimes the teacher doesn't know and it's usually my mom or someone else who has to tell the teacher about it and say [to the students], “You shouldn't be as hard on them.”

Another common perception of disabilities was that they are a gift or a sign that that person has something to share with the world. Several participants mentioned that this view was a cultural teaching they had grown up with. “It comes to the fact, if there's a baby with Down syndrome in the community, those gifts... We'll see the gifts of that person eventually.”

Another participant shared what his culture taught him about disabilities, I was raised where I didn't know anything about English language or mainstream culture. So, I learned about how we thought about a person that had disability. It was viewed as, “Okay, yeah, we know this person has a disability, but there's a real good reason why he's that way or she's that way. They will be showing us something that we're not aware of. They have special gifts that we don't have, that they are given. So, because of that, we need to just watch and help.” For example, my dad, he was born with just one eye. Well, his grandfather said, “He is here to show us something that we don't see.” So, he taught him how to be a medicine man. Ever since the age of 13 on he was kind of given that authority or that right to do that. All ‘til this day, he still would help people with his singing. So, he gives service in a different way. But yet, people really highly respect him. They don't even see the disability anymore.

This view of disabilities as gifts is a cultural strength that highlights the resilience and collectivistic worldviews of Native communities.

**Barriers to accessing services**

When discussing the perceptions of disabilities among Native communities, it is important to discuss disability services. This topic was discussed in-depth, and a major theme was that many people had difficulty accessing the services that were available at all. The reasons for these difficulties were varied and ranged from transportation issues to lack of
Internet access. One participant described the difficulty of getting in to be seen at the hospital.

I think getting medical help, like professional help on the rez, that’s also really hard too. There’s only so much that hospitals can do and deal with that. There’s not enough staff. See the waiting list, it takes forever for one patient to get in. Because it usually will be one doctor for maybe 500 people and they’re just constantly running back and forth. That’s another challenge, is just finding the medical help.

Another participant discussed the long wait times people experience once they arrive at the hospital, even during emergencies. He explained these waits are in addition to the amount of time it may take to get to the hospital, which for his family was an hour drive.

My mom passed away not too long ago, and for us taking her to the emergency room, and she was in so much pain. When we got there, we had to wait another three hours just for her to get seen. Then [we waited] for them to tell us that she’s going to be admitted and everything.

The difficulty receiving emergency services underscores the long distances people have to travel in order to receive medical attention. Likewise, the amount of time waiting to see a doctor in an emergency situation highlights the added challenges in accessing medical services and a lack in needed medical care. People with disabilities, who may need medical services on a more regular basis, would have to deal with this wait and travel more frequently, which would take away time from other areas of life.

Another participant stated that the process of getting disabilities diagnosed is difficult for many Native communities.

To get it diagnosed is even harder, because there’s a lot of steps.… When my son got it diagnosed and [we were] in the middle of nowhere it was hard because you have to bring specialists to the district, to wherever. It’s like… a lot of the parents don’t want to deal with that because we don’t know how to ask for that, as well. We don’t know how it’s all going to turn out because we don’t want our kid to be pinpointed as different.

This participant’s experience shows the barriers to getting diagnosed with a disability, which includes worries about stigma and difficulty knowing how to get diagnosed in the first place. Living in a rural area greatly increases the amount of effort parents have to give in order to have their child classified as having a disability and to receive services for that disability.

However, difficulty accessing medical services was not the only issue discussed in the sharing circles. Participants mentioned that it was hard fighting for services their children were legally entitled to receive. A parent described how she had a hard time getting the services her son was supposed to have according to his IEP.
Getting the help with disability, it’s really hard. It really is. Whether it’s at the hospital…. The hospital’s a little more willing and helpful, but if it’s with our children at the district level, it’s pretty hard unless they have a really severe handicap. It took my son, to get a stupid iPad connected to the school system, it took four years just to get it. It was only supposed to be used for the classroom so he can blow things up where he can actually see it instead of, you know… it would just be programmed to any of the smartboards or anything…. It took so long for somebody to come in and get the equipment that he needed, whether it was a stupid little magnifying thing that looked like a ruler so he could put it on, blows everything up. It took them forever to do anything until, finally, somebody from the state came down and noticed how bad he really was. Because he was being treated as, “Yeah, he’s alright. He’ll be good. He’ll be fine.” It made us look like, you know when a child cries wolf? That’s what it made me feel like. I know that he had a problem. I know that he needed the help.

Her frustration on the part of her son is poignant.

**Needed action**

In addition to discussing the current challenges people face when trying to access services for disabilities, people also had a number of ideas about how these services could be improved or what could be done differently. A common idea that was expressed in the sharing circles was for providers to build trust in Native communities. This could be done through gaining cultural competence, getting to know people, and becoming more knowledgeable about how to serve Native communities. Here is one participant’s suggestion:

I think having people, too, though, that are trained. Maybe that have some kind of cultural awareness of who Native people are. If it isn’t maybe a Native person coming to work with these people, having them go through some training so they have a little bit of cultural context for these communities, you know, that they’re working with so they’re not going in totally [lacking knowledge].

Cultural competence is a focus in many professional training programs. However, this training should continue throughout providers’ careers. Learning more about Native cultures would help providers be better able to provide quality services to Native American communities, as this participant suggested.

Another participant discussed the importance of trust when working with Native communities. One participant described this trust and the ways this can help families feel more comfortable with talking to providers.

Someone neutral and confidential with the home environment…. Sometimes they feel embarrassed for someone to come to their home. But, if they can build that trust, then I can see they would be allowed to come into the home and just work with their child. Because that’s what they want for their child is to see them be successful and if they can’t see that, then it’s like they have to find someone that’s going to be there for them.
This discussion of trust reflects the focus on relationships and holistic whole-being that is central to culturally competent care. Taking the time to build relationships with Native clients and patients shows dedication to quality care.

Another participant reflected on the need for a system-wide change and the amount of time necessary for this to be achieved. He reflected on his experiences working in the school district and the need to let the community decide what changes need to be made.

It has to be a system-wide change.... It has to be coming from the people who need that help. Right now, there's not that gathering or that group that's trying to see if there can be a system-wide change. I've never been in any other school district. I chose to stay here, and I've been trying to work with the system all this time. I had some headway with it. When you have a community, and everybody's for the change, but then you tend to stick out, like, well the rest aren't doing it, so why are you doing it? You can't do that. So, that was put back down. Then I chose to say, “Okay. You can't change it just here, you've got to change it here. How do I do that?” I chose to come to this place, which is kind of like the headquarters. So, now, I'm trying to see what can be done and what the system's doing. How can I do the same way what the system is doing, but in a different way? That is the toughest. It takes longer, you're seeing people that kind of understand things, but they're not pulled together and consistent in that pull. It takes a long time.

System wide change can, indeed, take a long time. However, it can also do a great amount of good, as this participant described. Community engagement and involvement in this change is the best way to ensure that Native Americans with disabilities are supported and receive all services they require and are legally entitled to receive.

**Discussion and significance**

The purpose of this study was to identify a culturally-based conceptualization of “disability,” to learn about Native perceptions of disabilities, the current services available to persons with disabilities, and how the needs of Native people with disabilities should be addressed. Native participants throughout the state of Utah were invited to participate in sharing circles to give insight into these topics. Transcripts from these sharing circles were analyzed using thematic analysis, which revealed four major themes, as shown in Figure 1: Disability is Subjective, Belonging, Barriers to Accessing Services, and Needed Action.

Frequently, Indigenous knowledge and conceptualizations are diminished in U.S. society. We see the continued effects of colonization in that our traditional ways of knowing are not respected or treated as valuable sources of information. Usages of Western knowledge and ways of knowing have historically been used to harm Native peoples. In the 19th century, Arch Wolfe was sentenced to prison despite a lack of evidence and then was
declared “insane” following his melancholic behavior, which was likely influenced by his separation from his culture and family (Mihesuah, 2021). Wolfe was held in the Canton Asylum for Insane Indians, in South Dakota, for nearly half his life (Mihesuah, 2021). When considered in a colonization context, Wolfe’s story is evidence of the destruction that Western ideas of disability and illness can have in Native communities. The Canton Asylum, also known as the Hiawatha Asylum for Insane Indians, used ableism through stereotypes of “violent” and “insane Indians” as another approach to displacement to support colonizers’ efforts to take land and resources from Native peoples (Burch, 2014, 2021; Joinson, 2016; Mihesuah, 2021). We need to keep in mind the history and purpose of labeling people as disabled or insane, both historically and currently, and recognize the purpose may be different for different groups of people.

The American government has legal definitions for disabilities which arose from Western culture’s schema for what a disability is (Donoghue, 2003; Switzer, 2003). Because such concepts are inherently culturally-based, this definition is not appropriate for all cultures within the United States, including Native cultures. The participants in the sharing circles each had their own experiences with disabilities, which led to the development of a subjective conceptualization for disability. What is significant about these sharing circles and the ideas they shared were the overarching ideas, problems, and strengths that participants recognized as part of their communities. Although participants lived in very different areas of the state, there were striking similarities in what they shared.

The results from this study developed a culturally-based conceptualization for disability and indicate that Native peoples within the state of Utah perceive the definition of “disability” to be subjective. This conceptualization differs significantly from the objective legal definition set forth by the American government. In practice, this subjective conceptualization could mean that providers should respect Native Americans’ choice of whether to be classified as having a disability or not. There are a number of settings in which respecting this subjective conceptualization is important, practical, and respectful. Professionals should respect a Native person’s view of whether or not they have a disability and refer to their presenting problem as that individual prefers. Doing so will show respect to Native clients’ and patients’ culture, worldview, autonomy, and self-determination. This will also enable the professional to serve their clients and patients in a more culturally-competent manner, which is an essential component of quality healthcare (Ngo-Metzger et al., 2006).

Respecting Native clients’ and patients’ language for their presenting problem can increase the overall quality of care and cultural competence of providers, which was frequently discussed by participants as “needed action.” Utilizing this language could also benefit legislators and providers in terms of reshaping the current policies for more inclusive access to
healthcare for Native persons with disabilities. The need for providers to build trust in Native communities was discussed throughout the sharing circles. Many noted the importance of cultural competence and how this could benefit providers working with Native communities (Flowers, 2005). Education on cultural competence for providers who determine and provide services for disabilities could improve Native persons with disabilities’ quality of care. Through gaining this cultural competence, providers could become more aware of the importance of building relationships with Native communities. Being available and genuine was mentioned as being highly valued. This could greatly benefit Native persons with disabilities by helping people to feel more welcome and comfortable when reaching out for services. This could also greatly help people to learn more about what services are available and what they are able to ask for. Incorporating more inclusive conceptualizations of disabilities may also shift the services available and lead to more culturally aligned services. Participants in this study shared that care for Native persons with disabilities could be greatly improved through cultural competence training. The subjective definition of disability would be an essential component of this training. Further research is needed to identify and develop an effective cultural competence training for providers, educators, and others working with Native persons with disabilities.

The theme of belonging showed the importance of community support and belonging for persons with disabilities. Repeatedly, participants discussed the ways they had advocated for their children or friends. Participants also talked about the integration of people with disabilities into the community and their inherent importance. Several noted the gifts that people with disabilities share with the community and explained that these individuals are viewed as knowledge keepers. Drawing on this strength of unity and interconnectedness is important and could benefit many Native people with disabilities.

Nearly all participants noted the difficulties they or people they know have experienced when reaching out to access services (Adakai et al., 2018). Many noted the transportation barriers and the pure physical distance between themselves and the nearest available resources. Still others reflected on the short-staffed medical facilities and the long wait times. Others talked about their lack of knowledge about how to even begin to access services. Education about how to access services and what is available could greatly benefit many Native communities in Utah. Perhaps more importantly, making these services accessible to people from Native communities is an essential component for improving the lives of Native persons with disabilities.

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