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PERCEPTIONS OF DISABILITIES AMONG NATIVE AMERICANS WITHIN THE
STATE OF UTAH

by

Erica Ficklin

A thesis submitted in partial fulfillment
of the requirements for the degree

of

MASTER OF SCIENCE

in

Psychology

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2020

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ABSTRACT

Perceptions of Disabilities Among Native Americans within the State of Utah

by

Erica Ficklin, Master of Science

Utah State University, 2020

Major Advisor: Dr. Melissa Tehee

Department: Psychology

According to the U.S. Census, about 24 percent of the Native American population is diagnosed with a disability, compared with 19 percent of the general population. Despite this disparity, little research exists on disabilities in this population 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, the authors held sharing circles throughout the state of Utah to listen and amplify the voices of the Native communities. In these sharing circles, participants were asked how they define “disability”, what they thought of current services, and how they thought the needs of Native persons with disabilities should be addressed. The authors used thematic coding on the transcripts and identified four major themes: a culturally based definition of “Disability”, barriers to services, belonging, and needed actions. These themes give light to 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.

(56 pages)

PUBLIC ABSTRACT

Perceptions of Disabilities Among Native Americans within the State of Utah

Erica Ficklin

Native Americans are diagnosed with disabilities at a significantly higher rate than the general American population. Due to cultural differences, other factors are likely impacting this difference in diagnosis rates. One possible factor is that Native Americans may have a different definition for ‘disability’ than the general American population. This study aimed to identify whether there is a difference in the definition for ‘disability’ and to learn about the current services available and what changes should be made to better serve Native Americans with disabilities. Native American participants were asked to share their experiences and thoughts about disabilities in sharing circles. Four major themes were identified following these sharing circles. These themes included a culturally based definition of “disability”, barriers to services, acceptance, and needed action. 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.

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Erica Ficklin

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CHAPTER I

INTRODUCTION

Native Americans routinely have been identified as an at-risk population for disabilities (Goins et al., 2007). Native Americans are significantly more likely to be diagnosed with a disability than members of the general population. There is currently no research regarding the perceptions and understanding of disabilities among this community. The Western definition of disability and the Native American definition may differ from the general population due to cultural differences. As such, disparate prevalence rates likely do not align with the conception of disabilities from a Native American perspective. This mismatch may impede Native American youth from accessing and receiving culturally appropriate services for disabilities. By developing a better knowledge base of the cultural perceptions of disabilities and available services, we can work to redefine quality care for Native Americans with disabilities.

The researcher utilized a qualitative approach to investigate the perception and understanding of disabilities within the Native American communities in Utah. This study aimed to develop a better understanding of how disabilities affect the lives of Native American children, both inside and outside primary and secondary school settings. Another goal was to give space to the voices of Native communities in Utah to articulate the main issues surrounding disabilities in their community, as well as how society views individuals with disabilities. Findings from this study fill a gap in the literature and may guide future research in how to approach services and interventions in a culturally informed manner.

Introduction to the Author

Listening to people's stories and helping my community are a couple of my biggest motivators in life, and they are the reasons why I decided to pursue an education in graduate school. I wanted my thesis to have meaning and to use my privilege as a graduate student to amplify the voices of the Native communities in Utah surrounding important topics related to disabilities. I grew up with someone who has a learning disability and I love her dearly. Learning disabilities come with their own challenges, and I was so proud of her for her resilience—she worked hard and pushed herself daily. Some days were worse than others. I cannot describe the heartbreak I felt when she came home and told me a teacher had told her she was “too stupid for college”. My sister, strong as she is, did not listen. She went to college with a tenacity few students can claim to have. She proved that teacher wrong—she is a capable, knowledgeable, award-winning nurse.

Our Native students should never be told that they are less than or made to feel like they cannot succeed in school. No Native person with a disability should have to feel like they are not respected or receiving equitable, quality care. I was blessed to hear so much wisdom from the Native communities of Utah, and I pray that I am honoring them by sharing their stories. Please show these individuals the respect they deserve by hearing their words and acknowledging the truth in them. I hope that they stick with you and give you insight into what you can do to better the lives of Native persons with disabilities. Above all, my greatest hope is that these voices will be heard and that they will ignite change in how we provide services to Native persons with disabilities.

CHAPTER II

REVIEW OF THE LITERATURE

The goal of this literature review is to familiarize the readers with the current information available regarding disabilities among Native American communities. This information will help researchers to form the basis of our understanding regarding the information about disabilities among Native Americans in Utah. Currently, there is no research about how Native communities perceive and define disabilities. Thus, the literature review aims to give the readers some background information about current statistics of disabilities in Native American communities and how disabilities affect day-to-day life.

Individuals with disabilities of all classifications and Native Americans are members of marginalized groups (Bialka, Brown, Morro, & Hanna, 2017). Persons with disabilities have pervasive difficulties finding employment (Schur, 2002). In addition, there may be inadequate services provided to transitioning high school students with disabilities into higher education (Janiga & Costenbader, 2002). Native Americans experience racism, discrimination, and stigma (Belcourt-Ditloff & Stewert, 2000). J.T. Toubbeh gave a speech at the National Conference on Indians with Disabilities (as cited by Ma, Coyle, Wares, & Cornell, 1999) in which he shared that Native Americans of all ages are six times more likely to be diagnosed with a disability than that of the general population. Natives with disabilities have dual marginalized identities, leading to a need to consider the intersectionality of these identities. This topic will be further discussed later in this paper. 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).

Current Definitions of Disabilities

The Individuals with Disabilities Education Act (IDEA) is a national U.S. legislation that asserts children with disabilities' fundamental right to appropriate education by providing access to services and aids. Through IDEA, eligible children in primary and secondary schools may receive an Individualized Education Program (IEP) that will provide the children with the services they need in order to progress in school. Some examples of services include specialized instruction, speech and occupational therapy, accommodations for tests and note taking, and assistive technology. These services are eligible to children whose disabilities are among the thirteen disabilities identified in the IDEA law and children who have a 504 plan. If a child does not, then these special education services are not available to them. While this is understandable to children who do not need them in order to have an enriching education, it can be an issue for children with misdiagnosed or unnoticed disabilities. In these situations, the child faces impediments without aid.

In addition to providing children with services, the IDEA gives rights to the parents and guardians of children with disabilities. Parents are required to be a member of the team in their child's evaluation and for the formation of the child's IEP. This right enables parents/guardians to be an active advocate 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 parent intervention can be difficult to achieve due to a lack of awareness about their own and their children's rights. Thus, it is essential

that parents and guardians are aware of these rights in order to assert them. Parents and guardians may not be aware of their ability to advocate for their child, nor be familiar with their rights.

Nationally, the Individuals with Disabilities Education Act identifies thirteen disabilities for which a child can receive services. These disabilities include specific learning disabilities (SLD), Autism Spectrum Disorder (ASD), emotional disturbances, speech or language impairments, visual impairments, deafness, hearing impairments, deaf-blindness, orthopedic impairments, intellectual disabilities, traumatic brain injuries, other health impairments, and multiple disabilities. Children diagnosed with a disability in one of these domains are eligible for services through IDEA.

Emotional disturbances are defined by IDEA (2004) as:

“...a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child’s educational performance: (A) An inability to learn that cannot be explained by intellectual, sensory, or health factors, (B) An inability to build or maintain satisfactory interpersonal relationships with peers and teachers, (C) Inappropriate types of behavior or feelings under normal circumstances, (D) A general pervasive mood of unhappiness or depression, (E) A tendency to develop physical symptoms or fears associated with personal or school problems”. (Sec. 300.8)

IDEA (2004) defines Autism as:

“a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance.” (Sec. 300.8)

IDEA (2004) defines specific learning disabilities as:

“...a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written and impact a child’s ability to excel in areas such as reading and writing, listening, and calculating math. The disorders included: perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. Disorders not included: a learning problem that is primarily the result of visual, hearing, or motor disabilities, of mental retardation, of emotional disturbance, or of environmental, cultural, or economic disadvantage.” (Sec. 300.8)

Different disabilities impact children’s lives in different ways. For example, learning impairments affect a child’s ability to engage in school, such as ADHD or serious illness. Furthermore, ASD may affect a child’s behavior and ability to interact with others socially. Speech and language impairments also impact a child’s ability to communicate and covers difficulties like stuttering and articulation. Visual impairments, hearing impairments, deafness, and deaf-blindness cover issues with vision and hearing that impact a child’s ability to learn through verbal or written language. Orthopedic impairments include any form of physical disability. Intellectual disabilities and traumatic brain injuries both impact the child’s brain and development. IDs and TBIs may result in communication and learning difficulties. The multiple disabilities diagnosis applies to any child with more than one disability covered by IDEA.

Rationale for Utah Focus

There are currently 573 federally recognized tribes in the U.S. (National Conference of State Legislatures, 2018). 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 our current study within the state of Utah. 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 reason for our decision to focus on Utah is that the researchers live within the state, making the area accessible to us. The inclusion of members of different tribes living in the state has hopefully increased the truthfulness and validity of our results. At the heart of this decision was that the state of Utah was where we could make the most impact and create lasting, reciprocal relationships.

Of all students with disabilities in Utah, 50.1% had a specific learning disability. The Utah State Board of Education defines learning disabilities as: “a disorder of the psychological processes involved in understanding or using language that may affect an individual’s ability to listen, think, speak, read, write, spell, or do mathematical calculations” (p .46, 2016). In the 2017-2018 school year, the school system identified over 47,551 children from the general population with a specific learning disability within the state of Utah (U.S. Department of Education, 2020). Of these children, 1,426 were Native American (U.S. Department of Education, 2020). Native Americans throughout the country are twice as likely to be diagnosed with a learning disability than the general population (Graham & Eadens, 2017). There are numerous disparate outcomes for Native American youth with learning disabilities, including lower rates of academic achievement, employment, and independent living when compared with Native American youth without learning disabilities (Ramasamy, Duffy, & Camp, 2000).

In Utah, 2.7% of all students with disabilities had an emotional disability

(National Center for Learning Disabilities, 2017). The Utah State Board of Education defines emotional disabilities as “an inability to learn that cannot be explained by intellectual, sensory, or health factors...” (p. 38, 2016). The two classifications of emotional disabilities are externalizing behavioral problems focused outside of the student, and internalizing behavior problems focused with-in the student (Utah State Board of Education, 2016). Anxiety and depression can be considered internalizing emotional disabilities in school-age children (IDEA 2004). The rates of anxiety and depression have been shown to be high among Native American youth (Anderson & Mayes, 2010), indicating a need to investigate emotional disabilities in Native American children.

Learning and Culture

The United States based its education system on Western cultural ideals of success and potential, which do not align with Native American cultural values (Garrett, 1995). This cultural mismatch in education values has resulted in a long history of systematic racism in our school systems that has resulted in trauma during the boarding school era and historical trauma (Kirmayer, Gone, & Moses, 2014; Blume et al., 2019), which continues to impact the lives of Native students to the detriment of their experiences in education. Nationally, the status of the high school dropout rate among Native American students was 13.2% in 2015, compared to 5.9% among the general population (National Center for Education Statistics, 2017), which may be a result of a difference in learning and teaching styles. In Utah, this number rises to 21%, compared to 11% of all students (Utah State Board of Education, 2018). Those unfamiliar with Native worldviews often interpret reserved Native American children as uninterested or

unengaged in the content. However, learning styles differ across cultures, and these children are engaging in a culturally appropriate manner (Garrett, 1995), as these students are likely showing respect to the teacher and classmates through listening rather than speaking up. This misconception may contribute to the education system's overrepresentation 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

The prevalence of disabilities among Native Americans of all ages fluctuates from 22 to 27 percent according to National censuses (National Council on Disability, 2003). These rates are higher than the estimates for the general population, which is about 19 percent (United States Census Bureau, 2012). Native children are also overrepresented in special education programs, which is notable when considering the heightened risks that face children with disabilities. The discrepancy between diagnosed disabilities among Americans in general and Native Americans in particular could indicate inconsistent or inappropriate methods for diagnosing Native persons with disabilities, or these inflated numbers could be due to other risk factors that contribute to health disparities, such as poverty, lack of access to quality schools, or health concerns (CDC, 2018). Native Americans 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, 2009). Furthermore, Native American youth experience heightened risk factors for health disparities, such as poverty and suicidal ideation.

Definitions of Disability and Their Implications

Current studies assessing disabilities in Native Americans have utilized the definitions and measures set forth by the majority population (Saravanabhavan & Marshall, 1994; Ramasamy, Duffy, & Camp, 2006; Monteau, 2016). A misdiagnosis can impact the way a child views his 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 definition 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.

Diagnosis

Receiving a late diagnosis or not receiving a diagnosis when a disability is present can inhibit a child's ability to access services, which could greatly benefit their academic endeavors. Likewise, an individual that receives an incorrect diagnosis could have negative implications for their life. This lack of resources could also heavily contribute to Native children with other types of disabilities not receiving a proper diagnosis at an adequate age, if at all. Not receiving a diagnosis early in life or not receiving a diagnosis at all excludes Native children from an IEP and other disability resources that could help them succeed in academic settings and improve quality of life. An incorrect or non-existent diagnosis can severely impact a person's sense of self throughout the lifespan.

If a school team recommends a child to be assessed for and diagnosed with a disability due to prejudice rather than a true presence of a disability, that child is likely experiencing discrimination in the school setting as well. Alternatively, as discussed earlier, racism could lead to the incorrect diagnosis of a disability due to Native stereotypes. Taking the effects of discrimination on children's lives into account, the importance of accurately diagnosing disabilities among Native children becomes apparent. If this continues, misdiagnosis will further perpetuate the discrimination that Natives have been experiencing for centuries. Considering the compounding risk factors for Native youth, including bullying and an incorrect diagnosis, the importance of better methods for identifying disabilities among Native Americans becomes clear.

Autism Spectrum Disorder. Receiving services early for children with ASD enables children to learn better communication skills and betters the child's overall development (Autism Spectrum Disorder Foundation, 2018). Although clinicians are trained to be able to identify ASD in children as young as two years old, psychologists and medical professionals are not diagnosing minority children until they are several years older (Mendell et al., 2009). Psychologists and medical professionals diagnose Native children with Autism Spectrum Disorder (ASD) at a significantly older age than members of the majority group (Mendell et al., 2009).

Externalizing disorders. Medical professionals and psychologists may overdiagnose Native children with externalizing disabilities, such as ADHD and Oppositional Defiant Disorder. Society commonly describes children with these diagnoses as "ill-behaved," "lazy," or "the bad child." These phrases are

almost identical to the phrases used when describing Native American stereotypes. These stereotypes typically label Natives as “lazy,” “poor,” “uneducated,” and “savage” (Blume, Tehee, & Galliher, 2018). Considering this, it is highly likely that medical professionals and psychologists are diagnosing Native children with externalizing disorders because the stereotypes for these disorders and Native Americans as a whole align with each other. Potentially, prejudice and racism form the base for the overdiagnosis of Native children with externalizing disorders, and these labels have become a new systemic method of discriminating against Native American children. Part of the issue may come from the fact that the Western education system is not in line with Native cultural values, as discussed previously. Native children are not behaving in the classroom in the same way as other children, which may lead teachers to believe that the child is misbehaving or not paying attention when the reverse may be true.

Services

Native Americans are disproportionately diagnosed with disabilities and this problem may be amplified as they may also have greater difficulty accessing services than other populations (Ma, Coyle, Wares, & Cornell, 1999). 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 (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 provide quality healthcare (Hays 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 (Hays et al., 2006). As such, it is essential to have medical care providers be culturally competent to lessen disparities, commonly experienced by minority members, such as discrimination by staff and providers (The National Academies of Sciences, Engineering, and Medicine, 2017). 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.

Outcomes

Native Americans with disabilities have been reported to have poor health outcomes within the state of Utah compared with the general population (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.

Bullying. 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 it 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. Bullying has been linked to a number of negative outcomes, such as 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). That individual could then grow up enduring bullying and a sense of isolation from their peers due to the requirement to be in special education.

Mental health outcomes. 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 perceives discrimination is at a higher risk of experiencing negative aspects of psychological well-being (Blume, Tehee, & Galliher, 2009). Children who perceive discrimination are more likely to experience mental health issues like depression, anxiety, and overall negative affect (Blume, Tehee, & Galliher, 2009). Furthermore, children who perceive discrimination are more likely to have poor self-esteem and less life satisfaction (Blume, Tehee, & Galliher, 2009). This experience could lead a child to believe that he or she is unintelligent or unable to perform well in school, resulting in a poor sense of self-efficacy. Poor self-esteem could lead to the development of depression and substance abuse disorders. In addition, that person may be more likely to experience suicidal ideation.

Current Study

The current study aimed to develop a culturally based definition 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 comparable to focus groups (Lavallé, 2009). We held these sharing circles throughout the state of Utah. We audio recorded the sharing circles and transcribed them. We used thematic analysis to

find major themes that came up during the sharing circles. These themes formed a culturally based definition of what a “disability” is for this population. This culturally based definition will help to ensure that Natives are diagnosed with disabilities in accordance with cultural values. In addition, this definition was less susceptible to racial prejudice because it came from Native community members.

CHAPTER III

METHOD

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. 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 disabilities, and others were not close to anyone with a disability, resulting in a range of perspectives on the concept. The researchers contacted multiple organizations within the state to locate potential participants. These organizations included 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.

Research Design and Methodology

The researchers used qualitative research methodology to understand how

disabilities are perceived among the Native American community in the state of Utah. The study used particular methods from grounded theory to better understand Native American definitions and experiences of youth with disabilities. 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.

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. These 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.

Sharing circles and interviews are common methods for the grounded theory methodology (Glesne, 2016). 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 this topic. We developed seven questions for the sharing circles, along with follow-up questions that were asked if needed (see Appendix A). 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. The researchers advertised for sharing circles ahead of time. Because of this, we did not have control over how many participants attended each sharing circle. We continued to recruit participants until saturation occurred, when no new information was being gathered in the sharing circles (Saunders et al., 2017).

Throughout data collection, we transcribed the information from the sharing circles. This continuous process allowed us to begin to form ideas about the themes and concepts regarding disabilities and to compare new data to the data we had previously collected and allowed us to ensure data saturation. This iterative process guided our data analysis, leading to more comprehensive themes found in the transcripts. Thematic coding (discussed further in the analytic plan) is a conventional data analysis method for grounded theory and other approaches in qualitative analysis (Glesne, 2016).

Demographics

In addition to the data obtained from the sharing circles, we utilized a demographic questionnaire (see Appendix B). This questionnaire included 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 participant sample and is not connected to transcripts or other analyses in order to protect the participants' and tribes' confidentiality.

Procedure

Sharing circles were the primary method of data collection, each lasting approximately two hours, with 60 - 90 minutes dedicated to the interview

questions. I audio recorded all sharing circles. I read the informed consent aloud with the participants and provided paper copies to ensure all participants were fully aware of the study procedures before starting. The sharing circles were structured using a total of seven over-arching questions regarding disabilities (*see Appendix A*) and began with an icebreaker question to ease tension and begin to create cohesion in the group. In order to avoid priming the participants, I did not immediately use the term “disabilities”. There was a break in the middle of the sharing circle and snacks were provided for the participants. Translation services were available but were not needed for any of the participants at the sharing circles. Participants filled out the demographic survey at the end of the sharing circle. In order to inform participants of available services in the state of Utah, I provided a list of these services to the participants at the end of the sharing circles along with a \$20 gift card as remuneration.

Analytic Plan

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. The researchers began the transcription process by reviewing a few initial portions of the transcripts to develop ideas about possible themes. We then proceeded to analyze the rest of the transcripts using the preliminary ideas as a guide. Three coders, which included myself and two other coders, independently analyzed the transcripts and differences in coding were discussed to increase reliability and trustworthiness of the study. After each coder had completed their individual analysis, the three coders met to discuss their analysis. The primary researcher suggested names for themes that emerged from the collective coding. These themes were discussed

and adjusted so all three coders were in agreement. Prior to disseminating findings, the researcher 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 this document.

Positionality

The primary researcher is a Native American female doctoral student. I was initially asked to be a part of this project when I was offered the Native American Leadership Fellowship through the Center for People with Disabilities at Utah State 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, but that had been the extent of my knowledge in this area. I feel that this 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.

In order to minimize researcher bias that may influence study procedures and data analysis, the researcher identified and discussed potential biases and expectations with the research team prior to beginning data collection and analysis. She aimed to remain cognizant that this knowledge may lead to an expectation of certain themes during data analysis. To prevent this bias from impacting the study results, the researchers worked to challenge findings during the discussion of identified themes.

CHAPTER IV

RESULTS

Thematic analysis of the transcripts revealed four major themes regarding how disabilities are perceived and experienced among Native communities in Utah. These included an overall definition of a disability – disability status is subjective and dependent on whether the individual needs extra help when compared with peers; belonging– the impact its presence has on the overall wellbeing of the person with a disability and sense of belonging in the community, among peers, and in academic or employment settings; barriers to accessing services; and needed action – ways that the needs of and services for Native people of disabilities should be met or adapted. The four major themes identified in the sharing circles are interconnected—one cannot be completely understood without the other. 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.

Definition

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



Figure 1. Four Interconnected Themes of Perceptions of Disabilities.

Another participant expanded on this definition 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, several of these types of disabilities that participants discussed are recognized as disabilities among the majority culture in the United States, as well. Conditions that impact ability to learn were a common

subject discussed in the sharing circles. One participant mentioned her sister's dyslexia and its impact on her schooling. "My sister's dyslexic. I know that always made it hard for her to read. She'll scramble the letters."

Another participant discussed her son's Attention Deficit Hyperactivity Disorder (ADHD) and how this added to academic stress.

...The hardest thing for him was sitting in a classroom with average kids. The fear of someone calling on him to say, "Hey can you read that there? Can you read that paragraph?" ... He said, "Mom, I have to count, because it's like fifteen kids, one, two, three, fifteen paragraphs. I would try to re-read. I wasn't even paying [attention] to anything they were saying up here because I was trying to read that one paragraph to make sure I knew all the words. If not, I'd have to sound it out." I could see that. Of course, it would come up to his turn and if it got jumbled, "Oh, that was too short for you. Read another one." He'd be like, "Ahh!" Or if he was called out, "What's the answer?" He'd be like, "I don't even know what you're doing in math. You're so far ahead of me."

The participant's son's experience shows the stress that comes from feeling left behind and how this stress kept him from feeling like he could succeed in class. Rather than having the opportunity to focus and learn, he had to adapt to classroom pressure by mentally preparing for reading his paragraph aloud.

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.

The participants discussed medical conditions that require significant care for the individual and how they could be considered disabilities. Medical conditions that were mentioned included cancer, arthritis, diabetes, and autoimmune disorders, to name a few. Other health conditions, such as premature birth, were also considered disabilities. "Because newborns, too, they're on some kind of support for breathing or heart or lungs or oxygen. That's a disability, because you see little babies that come in that are premie that are on oxygen."

Ability to communicate with others was frequently discussed. One participant expressed how difficulty socializing impacts many areas of life. "...Someone that is socially... Unable to socialize. How would they be able to go to a store? To even walk into a store? To interact with people they don't know?" Another participant shared how socializing is a source of distress for her nephew with autism.

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 communicating can become overwhelming and interfere with quality of life.

Mental health problems and whether or not they could be considered disabilities 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." Negative impacts on work and school performance and everyday tasks were also discussed. "And that can cause you distractions at work or at school, just any everyday activity." This sentiment was further iterated by another participant, who stated, "...There are obstacles and challenges you have to go through, just like anyone else, but it's more difficult for them because they're going through stuff."

However, other participants felt that mental health problems are not disabilities. One participant mentioned that anxiety is fairly common among college students, and resilience could negate the detriments of the mental health concern.

Anxiety... I wouldn't really consider that a disability. I know people in college have anxiety. I think it just all depends on how much that strength is within that

person to overcome it.

Another individual shared that although she considers mental health concerns disabilities, other people may not agree. “I think people might not... Other people might not see it as a disability because they don’t see it...” The notion that the invisibility of mental health concerns would lead people to not consider them disabilities was mentioned by several participants. “I feel like maybe the older generation wouldn’t consider mental health a disability since it’s not something you can actually see.” Other participants thought that people might think the commonness of mental health concerns in today’s population means that they should not be considered disabilities. “I don’t think other people would see it as a disability because it’s common among many people.”

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.

The 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.

The mother also noted a couple non-Native parents of children on the opposing team who did not appreciate her son's accommodations. However, she continued to support her son and stick up for him by cheering for her son.

The parents [said], "If he wants to play in these regular leagues, then he needs to be treated like them." And I'm just sitting there and I had a friend sitting there next to me. ... They [said], "Yeah, he should've been out. That could've been a double-play right there." ... I was just kind of quiet, and then in the final [inning] I'm like, "Come on! Your mama loves you! Let's go!" And they're like, "Oh, crud."

His mother had to listen to other parents complaining about her child's playing, but she

refused to let it affect her son's fun. She continued to support him and stuck up for him by cheering for him in front of the other parents.

Another participant described bullying she witnessed. She explained that other children would bully children with disabilities, but her mother, the 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".

Several participants described how people with disabilities were treated as equals in the community, without noticing their differences. One participant mentioned that he did not notice his daughter had a disability until it was discussed at the sharing circle. Her disability was considered just another part of her identity, rather than viewed as something negative.

I guess my daughter is missing an ear. She was born without one ear. We've been going through the hospital, getting it fixed, but still... It's hard, yeah. But, I never... To this day, I don't think of it like a disability. It looks normal to me, doesn't faze me. I talk to her and everything just like a normal person. I didn't even think about it until we brought it up now.

Another participant shared how people with disabilities were completely integrated into the social system at her high school. She mentioned that a person with a disability was the quarterback for her high school football team.

He was there my freshman year. He was varsity. So, when I went to join the team, he was there, and I was like “wow”. It really changed my perspective and many others. So, I think that after that, the people that I grew up with in high school, they all changed their mindset.

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.

Barriers to Services

When discussing the perceptions of disabilities among Native communities, it is important to discuss the services available to persons with disabilities. 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 a lack of internet access. One participant described the difficulty getting in to be seen at the hospital.

I think getting medical help, like professional help on the rez, that's also really harder 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 people have to wait to see a doctor in an emergency situation highlights the added challenges people have 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. She shared her perceptions on the process with her son and why she thinks other parents have not had their children diagnosed. She also mentioned a fear of the potential stigma associated with having a disability.

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 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.

Another mother related her experience when she was trying to get services for her daughter.

So, you've got those stumbling blocks that are working against you because you're trying to provide for your child and then making sure that they are up with the rest of their peers. But then, according to these rules and regulations, you're not. So, they section you into a certain category. Then, that makes you really discouraged. The parent gets discouraged as well as the student.

The experiences the parents shared about their difficulty receiving services is heartbreaking and leads to a feeling of hopelessness, which is not something that parents

should have to experience when advocating for their child.

Still other parents described the frustration they felt, even after jumping through hoops to get their children services. One mother expressed agitation at the accommodations her son received, after years of advocating for him to receive these services, that did not allow him to learn material that would be appropriate for him.

So, we took him, and we homeschooled him. ... He has a disability. He can't...

Well, he can read, but he can't do math. They wanted him to do... He's in tenth grade. They wanted him to do tenth-grade math. He doesn't even know how to

add. Then we had the specialist guy come out and test him. "Oh yeah, he does

have a disability. He doesn't know a lot of things." But the thing is, in the state of

Utah, they cannot have him work in a level that he's in even though he's in tenth

grade. He has to do tenth grade math and he doesn't even know what he's doing.

So, how can you have your child do online work at a tenth-grade level math when

he doesn't even have first grade [math skills]. He doesn't even know adding or

subtracting and they wanted him to do that. That's impossible!

Her frustration is valid and further points to a need to better support Native students with disabilities in their education.

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, or 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 blind.

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.

One individual described the work her mother did with students in Native communities and her dedication to helping them personally.

She got to talk to more people because [she was] Native. She got a lot further with

the parents than rather somebody else who would go out there and speak. They would work with her and work with her child. She got a lot of them graduated through school. She got tutors for them. She did what she had to do to get them graduated. She would help them herself work through problems or something that. She would get extra help for them to graduate. So, yeah, she did help a lot of the tribal people out there. But, it's that trust, I think.

Her mother's ability to support Native students shows the difference that trust can make when serving Native communities.

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.

CHAPTER V

DISCUSSION AND SIGNIFICANCE

The purpose of this study was to identify a culturally based definition of “disability”, to learn about 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 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 Services, and Needed Action.

The American government has legal definitions for disabilities which arose from Western culture’s schema for what a disability is. Because such concepts are inherently culturally-based, this definition is not necessarily appropriate for all cultures within the United States, particularly Native cultures. The participants in the sharing circles each had their own experiences with disabilities. 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. The participants lived in very different areas of the state, and yet there were still striking similarities in what they wanted to share. The participants felt that disability itself was subjective and determined by the individual’s view of whether it was a disability and something they needed help with. Many noted that they did not view their family members as having disabilities or that they had situations that they considered disabilities that the state did not. This definition suggests the importance of talking to people about how they are feeling about their current situation and whether they could benefit from services and supports for

disabilities. The results from this study indicate that Native peoples within the state of Utah perceive the definition of “disability” to be subjective. This definition differs significantly from the objective legal definition set forth by the American government. In practice, this subjective definition could mean that providers should respect Native Americans’ choice of whether to be classified as having a disability. There are a number of settings in which respecting this subjective definition 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, and autonomy. 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 (Hays et al., 2016).

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 as Needed Action. 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. 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. 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. 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.

References

- Anderson, E. R., & Mayes, L. C. (2010). Race/ethnicity and internalizing disorders in youth: A review. *Clinical psychology review, 30*(3), 338-348.
<https://doi.org/10.1016/j.cpr.2009.12.2008>
- Autism Spectrum Disorder Foundation. (2018). *Early Intervention Makes a Huge Difference for Autistic Children*. Retrieved from <http://myasdf.org/site/media-center/articles/early-intervention-makes-a-huge-difference-for-autistic-children/>.
- Bialka, C. S., Brown, K. S., Morro, D., & Hannah, G. (2017). On their LEVEL: How participation in a university student group shapes members' perceptions of disability. *Journal of Diversity in Higher Education, 10*(2), 117-135.
<http://dx.doi.org/10.1037/dhe0000019>
- Blackorby, J., & Wagner, M. (1997). The employment outcomes for youth with learning disabilities: A review of the findings from the National Longitudinal Transition Study of special education students. In P. J. Gerber & D. S. Brown (Eds.), *Learning disabilities and employment* (pp. 57–74). Austin, TX: PRO-ED. <https://doi.org/10.1177/001440299606200502>
- Blume, A. K., Tehee, M., & Galliher, R. V. (2019). Experiences of discrimination and prejudice among American Indian youth: Links to psychosocial functioning. In Fitzgerald H., Johnson D., Qin D., Villarruel F., & Norder J. (Eds.) *Handbook of Children and Prejudice*, (pp. 389-404). Springer, Cham.
https://doi.org/10.1007/978-3-030-12228-7_22
- Castor, M. L., Smyser, M. S., Taulii, M. M., Park, A. N., Lawson, S. A., & Forquera, R. A. (2006). A nationwide population-based study identifying health disparities

between American Indians/Alaska Natives and the general populations living in select urban counties. *American Journal of Public Health*, 96(8), 1478-1484. <https://doi.org/10.2105/ajph.2004.053942>

Centers for Disease Control and Prevention. (2018, August 17). *Health Disparities*. Adolescent and School Health.

<https://www.cdc.gov/healthyyouth/disparities/index.htm>

Chen, R. K., Brodwin, M. G., Cardoso, E., & Chan, F. (2002). Attitudes toward people with disabilities in the social context of dating and marriage: A comparison of American, Taiwanese, and Singaporean college students. *Journal of Rehabilitation*, 68(4), 5. <https://doi.org/10.1037/e504092014-002>

Davis, K., & Gavidia-Payne, S. (2009). The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities. *Journal of Intellectual and Developmental Disability*, 34(2), 153-162. <https://doi.org/10.1080/13668250902874608>

Faircloth, S. C. (2006). Early childhood education among American Indian/Alaskan Native children with disabilities: Implications for research and practice. *Rural Special Education Quarterly*, 25(1), 25-31. <https://doi.org/10.1177/875687050602500105>

Garrett, M. W. (1995). Between two worlds: Cultural discontinuity in the dropout of Native American youth. *The School Counselor*, 42(3), 186-195.

Goins, R. T., Moss, M., Buchwald, D., & Guralnik, J. M. (2007). Disability among older American Indians and Alaska Natives: An analysis of the 2000 Census public use

microdata sample. *The Gerontologist*, 47(5), 690-696. <https://doi.org/10.1093/geront/47.5.690>

Graham, D. J., & Eadens, D. W. (2017). Native Americans with Disabilities: Postsecondary Education Outcomes. *Education Leadership Review Of Doctoral Research*, 450-68.

Indian Health Services. (2012). *Stand Up, Stand Strong*. Retrieved from <https://www.ihs.gov/mspi/campaigns/>.

IDEA, 20 U.S.C. § 1400 (2004).

Janiga, S. J., & Costenbader, V. (2002). The transition from high school to postsecondary education for students with learning disabilities: A survey of college service coordinators. *Journal of learning Disabilities*, 35(5), 463-470. <https://doi.org/10.1177/00222194020350050601>

Kearney, C. A., & McKnight, T. J. (1997). Preference, choice, and persons with disabilities: A synopsis of assessments, interventions, and future directions. *Clinical Psychology Review*, 17(2), 217-238. [https://doi.org/10.1016/s0272-7358\(97\)00004-4](https://doi.org/10.1016/s0272-7358(97)00004-4)

Ma, G. X., Coyle, C. P., Wares, D., & Cornell, D. (1999). Assessment of services to American Indians with disabilities. *Journal of Rehabilitation*, 65(3), 11.

Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuseppi, C., Durkin, M. S., ... & Shattuck, P. T. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American journal of public health*, 99(3), 493-498.

- Monteau, H. (2016). *Raising Awareness About Autism in Indian Country*. Retrieved from <https://www.indianz.com/News/2016/05/06/harold-monteau-raising-awareene.asp>.
- National Center for Education Statistics. (2017). *Status Dropout Rates*. Retrieved from https://nces.ed.gov/programs/coe/indicator_coj.asp.
- National Center for Learning Disabilities. (2017). *State Snapshots*. Retrieved from <https://www.nclld.org/state-snapshots>.
- National Council on Disability. (2003) *Understanding disabilities in American Indian & Alaska Native Communities*. Retrieved from https://www.ncd.gov/rawmedia_repository/53edc4ab_c8c7_4786_8f04_35a40855075c.pdf.
- National Council of State Legislatures. (2018). *Federal and State Recognized Tribes*. Retrieved from <http://www.ncsl.org/research/state-tribal-institute/list-of-federal-and-state-recognized-tribes.aspx>.
- Ramasamy, R., Duffy, M., & Camp Jr, J. L. (2000). Transition from school to adult life: Critical issues for Native American youth with and without learning disabilities. *Career Development for Exceptional Individuals*, 23(2), 157-171. <https://doi.org/10.1177/088572880002300204>
- Rimmer, J. H., Riley, B., Wang, E., Rauworth, A., & Jurkowski, J. (2004). Physical activity participation among persons with disabilities: barriers and facilitators. *American journal of preventive medicine*, 26(5), 419-425.
- Saravanabhavan, R. C., & Marshall, C. A. (1994). The older Native American Indian with disabilities: Implications for providers of health care and human

services. *Journal of Multicultural Counseling and Development*, 22(3), 182-194. <https://doi.org/10.1002/j.2161-1912.1994.tb00464.x>

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., ... & Jinks, C. (2018). Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & Quantity*, 52(4), 1893-1907.

<https://doi.org/10.1007/s11135-017-0574-8>

Schur, L. (2002). The difference a job makes: The effects of employment among people with disabilities. *Journal of Economic Issues*, 36(2), 339-

347. <https://doi.org/10.1080/00213624.2002.11506476>

Shapiro, J. P. (1994). *No pity: People with disabilities forging a new civil rights movement*. Three Rivers Press.

stopbullying.gov. (2018). *Bullying and Youth with Disabilities and Special Health Needs*. Retrieved from <https://www.stopbullying.gov/at-risk/groups/special-needs/index.html>.

Whiting, M. (2013). Impact, meaning and need for help and support: The experience of parents caring for children with disabilities, life-limiting/life-threatening illness or technology dependence. *Journal of Child Health Care*, 17(1), 92-

108. <https://doi.org/10.1177/1367493512447089>

Willner, P. (2005). The effectiveness of psychotherapeutic interventions for people with learning disabilities: a critical overview. *Journal of Intellectual Disability Research*, 49(1), 73-85. <https://doi.org/10.1111/j.1365-2788.2005.00633.x>

U.S. Department of Education. (2020). *IDEA Section 618 Data Products: Static Tables*.

<https://www2.ed.gov/programs/osepidea/618-data/static-tables/index.html>

Utah Department of Health. (2009). *Utah Health Disparities 2009 American Indians Chronic Conditions, Reproductive Health, Injury and Lifestyle Risk*. Retrieved from http://health.utah.gov/indianh/pdfs/AmericanIndian_FINAL.pdf

Utah State Board of Education. (2016). *Special Education Rules*. Retrieved from <https://www.schools.utah.gov/file/bff61848-ae42-4265-a654-6dae5f398507>

Appendix A

Questions to Structure Sharing Circles

1. What kinds of things make it hard for students to succeed in school?
 - a. *What are some challenges for Native American children with disabilities?*
 2. What is your concept or perception of disabilities? How would you define a disability?
 - a. *Based on your experience, have you found cultural differences related to the concept/perception of disabilities between your community and the American society in general?*
 - b. *What characteristics might a person have to be considered a person with disabilities as part of your NA/AI community approach?*
 - c. *Describe any personal experience you might have had interacting with people with disabilities*
 3. What are some early signs of disabilities in children and youth?
 - a. *What are some different kinds of disabilities that you can think of?*
 4. Would you consider mental health concerns, such as anxiety and depression, to be a disability? Why or why not?
 - a. *How could anxiety and depression make school hard for children?*
 - b. *Anxiety can be described as excessive worry and stress and depression can be described as excessive feelings of sadness all day nearly every day.*
 5. How do you think the needs of Native American children with disabilities should be addressed?
 6. Where would you go for help and/or services related to disabilities?
 - a. *Would you go for information related to disabilities if needed?*
 - b. *Do you know what types of resources/services are provided?*
 - c. *Do you know about availability, costs, timing, effectiveness, and other*
-

challenges related to accessing disability services?

7. Is there anything about disabilities that I haven't asked that you would like to share?
-

Appendix B**DEMOGRAPHIC INFORMATION**

1. Please indicate your gender:

- Male
- Female
- Non-binary/third gender

2. Select one or more of the following options that best describes your race:

- Native American/American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Other (please specify) _____

3. What is your tribal affiliation? _____

4. Are you Hispanic or Latino/a

- Yes
- No

Which of the following best describes the area you live in?

- Rural
- Urban
- Reservation/Tribal Lands
- Other. _____

What is your age? _____

What is the highest level of education you completed?

- Less than a high school diploma
- High school degree or equivalent (e.g. GED)
- Some college, no degree
- Vocational/Technical Degree
- Associate degree (e.g. AA, AS)

- Bachelor's degree (e.g. BA, BS)
- Professional or Graduate degree (e.g. MD, JD, MA, PhD)

What is your current employment status?

- Employed full time (40 or more hours per week)
- Employed part time (up to 39 hours per week)
- Unemployed and currently looking for work
- Unemployed and not currently looking for work
- Student
- Retired
- Homemaker
- Self-employed
- Unable to work

What members of your family currently live in your home?

Do you know anyone that has been diagnosed with a disability?

- Yes
- No

If yes, what is your relationship with that person or persons (list as many as needed) and the type of disability if you know?