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# Societal Factors in the Identification of Developmental Disabilities within a Native American Community

by

Diane Keister

#### A thesis

submitted in partial fulfillment

of the requirements for the degree of

Master of Science in the Department of Psychology

Idaho State University

Spring 2022

The members of the committee appointed to examine the thesis of DIANE KEISTER find it satisfactory and recommend that it be accepted.	
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To the Graduate Faculty:

November 5, 2019

Diane Keister Psychology MS 8112

RE: Study Number IRB-FY2019-235 : Societal Factors in the Identification of Developmental Disabilities within a Native American Community

Dear Ms. Keister:

Thank you for your responses to a full-board review of the study listed above. Your responses are eligible for expedited review under FDA and DHHS (OHRP) regulations. This is to confirm that I have approved your application.

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Sincerely,

Ralph Baergen, PhD, MPH, CIP Human Subjects Chair

### TABLE OF CONTENTS

List of Figures	vi
List of Tables	vii
Abstract	viii
Introduction	1
Prevalence of Developmental Disabilities	1
Prevalence within Native American Populations	3
Beliefs about Developmental Disabilities	6
Treatment-Seeking and Beliefs	6
Native American Beliefs	8
Measurement of Beliefs	11
Knowledge of Developmental Disabilities	11
Measurement of Knowledge	13
Acculturation	14
Impact on Knowledge	14
Impact on Beliefs	14
Measurement of Acculturation	15
Purpose	15
Methods	18
Participants	18
Materials	19

Surveys.	19
Procedure	22
Hypotheses and Analyses	24
Hypotheses	24
Analyses	25
Results	26
Discussion	36
Implications and Limitations	38
Appendix A	51
Appendix B	53
Appendix C	57
Appendix D	61
Addendum	66

# List of Figures

Figure 1 Financial Need Histogram
Figure 2 Log10 of Financial Need Histogram
Figure 3 Years of Education Histogram
Figure 4 Square Root of Years of Education Histogram31
Figure 5 P-P Plot of the Residuals for All Predictor Variables and Knowledge of Developmental
Disabilities
Figure 6 P-P Plot of the Residuals for All Predictor Variables and Beliefs of Developmental
Disabilities
Figure 7 Scatterplot of the Residuals for All Predictor Variables and Knowledge of
Developmental Disabilities
Figure 8 Scatterplot of the Residuals for All Predictor Variables and Beliefs of Developmental
Disabilities

## List of Tables

Table 1 Hypotheses	24
Table 2 Descriptive Statistics	29
Table 3 Correlation Table for All Variables	34
Table 4 Multiple Regression T-Test Values	35

Societal Factors in the Identification of Developmental Disabilities within a Native American

Community

Thesis Abstract – Idaho State University (2022)

Native Americans are a seldom researched population with divergent prevalence rates of some

developmental disabilities when compared to Whites and some racial and ethnic minorities.

These differing prevalence rates are thought to be due to several reasons including distinctive

tribal beliefs and limited knowledge of developmental disabilities. However, these beliefs differ

across tribes and the knowledge of developmental disabilities has not been investigated in a

Native American population. The current study addresses the present literature gap by utilizing

several surveys to collect data from residents of a local tribal community. The surveys were

administered to 24 members of the tribal community measuring acculturation, knowledge of and

beliefs about developmental disabilities, and demographic information. The data collected was

analyzed through correlations and two multiple linear regressions. No statistically significant

results were found with the current available data. Limitations and future directions of the

current study are discussed.

Key Words: developmental disabilities, Native Americans, knowledge, beliefs

viii

#### Introduction

#### **Prevalence of Developmental Disabilities**

Developmental disabilities are defined as a group of conditions that result in developmental deficits in physical, learning, language, and/or behavioral domains (Center for Disease Control and Prevention [CDC], 2018). Developmental disabilities occur amongst all races and ethnicities although researchers have found inconsistent prevalence rates amongst groups (Zablotsky et al., 2017). The variability in prevalence rates is likely due to the diverse array of conditions that are encompassed under the broad label of developmental disabilities in combination with cultural factors relevant to racial and ethnic minorities. This diagnostic racial and ethnic disparity has several possible explanations that include a more limited access to health care and insurance coverage as well as language barriers (Boyle et al., 2011). Due to these possible explanations, not only obtaining an accurate diagnosis of a developmental disability is more difficult, but then receiving treatment for these conditions is also more difficult. Thus, the prevalence rate of a developmental disability within a population would be lower than expected.

Conversely, it has also been found that prevalence rates of intellectual disabilities tend to be higher in minority populations relative to non-minority populations (Leonard & Wen, 2002). Intellectual disabilities are a form of developmental disabilities that are characterized by deficits in intellectual and adaptive functioning in conceptual, social, and practical domains (American Psychiatric Association, 2013). These contradictions among the research suggests that there are likely to be other covariates affecting the differences in the literature. It has been documented that socioeconomic status (as defined as one's income, education, and occupation [Bradley & Corwyn, 2002]) influences the prevalence rates of developmental disabilities. Typically, developmental disabilities are diagnosed at a higher rate in children with caregivers of low

socioeconomic status (Drews et al., 1995; Durkin et al., 2017). Additionally, according to the American Psychological Association (APA; n.d.), low socioeconomic status tends to correlate with racial and ethnic status, suggesting an increased likelihood of being diagnosed with a developmental disability for individuals who are both a racial or ethnic minority and from a low socioeconomic status. Possible reasons that have been proposed for these higher prevalence rates include lower educational attainment, particularly maternal educational attainment (Croen et al., 2001; Decouflé & Boyle, 1995), as well as living in racially segregated and disadvantaged communities (Breslau et al., 2001). Both of which are characteristics of low socioeconomic status as well as communities of color (APA, n.d.). These possible reasons potentially contribute to the higher rate of developmental disabilities within these communities due to lower qualities of the school systems and fewer community economic resources (Breslau et al., 2001) as well as greater exposure to environmental toxins and a higher likelihood of exposure to trauma due to illness or injury (Fujiura & Yamaki, 1997).

Autism Spectrum Disorder (ASD), a form of developmental disability, affects an individual's social functioning and communication and is characterized by restrictive and repetitive behaviors (American Psychiatric Association, 2013). Upon investigating the epidemiology of ASD, it was found to be equally distributed across all races, ethnicities, and socioeconomic statuses (Fombonne, 2003). While there is evidence suggesting the prevalence rates of ASD to be equivalent across all races, the actual reported prevalence rates have been found to differ across races. More specifically, racial and ethnic minorities typically have a lower prevalence rate of ASD than non-minorities (Baio et al., 2018; CDC, 2016; Tek & Landa, 2012). It is suggested that this is due to a lack of knowledge and education and less access to healthcare resources within minority communities leading to fewer diagnoses (Tek & Landa, 2012). While

there is evidence of differing prevalence rates, it has been found that socioeconomic status plays a role in these differences in prevalence rates although all ethnicities are likely affected similarly (Durkin et al., 2017). This finding suggests that ASD is frequently underreported in racial and ethnic minorities from a lower socioeconomic status, who have a higher financial need. Taken together, these findings indicate that there is the possibility of having true prevalence rates that are unbiased across races and ethnicities when adequate resources and access to healthcare are provided.

Prevalence within Native American Populations. Within the research that examines the prevalence rates of racial minorities with developmental disabilities, a very limited number of studies have examined Native Americans as their own racial category. Typically, this population is grouped within an "Other" category with other races such as Pacific Islander, Native Hawaiian, or Native Alaskan. This is most likely due to the smaller population size of Native Americans relative to other minorities as well as the complexities of their culture and traditions. Additionally, the subject of broad developmental disabilities has not been an area of focus within Native American populations. Therefore, in order to discuss previous literature on this topic, it must be concentrated to specific forms of developmental disabilities.

Despite this lack of information on this population, it is assumed that Native Americans, like other racial and ethnic groups, will have true prevalence rates of ASD that are equivalent to other races and ethnicities when controlling for access to resources. However, there is evidence from the relatively few studies that examined Native Americans directly, that this population tends to be diagnosed less frequently with ASD than other racial minorities (Travers et al., 2013). Similarly, intellectual disabilities have been documented at the lowest rate in racial minority children classified as "Other" which, in this study, included American Indians, Alaska Natives,

Pacific Islanders or Native Hawaiians, other race or multiracial, and race or ethnicity not stated (Mandell et al., 2009). While there is evidence that Native Americans are being diagnosed with developmental disabilities less frequently, there needs to be further investigation into causes behind this diagnostic disparity. Possible reasons that have been suggested as to why these lower prevalence rates exist within the Native American community include isolated geographic location, tribal beliefs about disabilities that are distinctive to Native American communities, poverty, and the influence of longstanding and extensive political and economic oppression experienced by Native American communities (Tincani et al., 2009). In addition to these possible explanations, Utley & Obiakor (2001) also speculated limited access to healthcare as another reason for lower prevalence rates within this community (as cited in Tincani et al., 2009).

In contrast to the prevalence rates of intellectual disabilities and ASD, another developmental disability that is particularly prevalent and impactful within the Native American community is Fetal Alcohol Spectrum Disorder (FASD). According to Indian Health Services (2007), FASD is an umbrella term used to categorize several disorders that are developed through alcohol use of the mother during pregnancy and is characterized by possibly lifelong physical, mental, behavioral and/or learning disabilities. FASD and alcohol abuse in general are health concerns that greatly affect Native American tribal communities at a disproportionate rate relative to non-Native American communities (Indian Health Services, 2007). Native Americans have some of the highest prevalence rates of FASD relative to all other racial and ethnic groups (CDC, 2002; Indian Health Services, 2007; May & Gossage, 2001). The reported prevalence rate among some Native American tribes is about 1.5 to 2.5 per 1,000 individuals compared to non-Native American population's prevalence rates which range from .2 to 1 per 1,000 individuals

(CDC, 2002; May & Gossage, 2001). Possible reasons surrounding this health disparity are believed to be the long history of trauma the Native American community has endured (Center for Substance Abuse Prevention, 1994) as well has the high levels of poverty within the Native American community and limited access to adequate healthcare (Indian Health Services, 2007).

It is also common to have diagnostic comorbidities within developmental disabilities. FASD, for example, has many common co-occurring disorders including intellectual disability which occurs at 23 times the expected rate in individuals with FASD (Popova et al., 2019; Weyrauch et al., 2017). According to Polyak and colleagues (2015), comorbidities, such as intellectual disability, can confound the prevalence rates of ASD, leading to inaccurate and biased prevalence rates due to the presence of symptoms of intellectual disability. Therefore, certain diagnoses can be obscured by others that are comorbid, leading to an inaccurate prevalence rate.

In summary, Native Americans are affected by the underdiagnosis of developmental disabilities, such as intellectual disabilities and ASD, and high rates of other developmental disabilities such as FASD. While the prevalence rates may differ depending on the type of developmental disability as well as any existing comorbid condition, there are commonly identified possible reasons for these prevalence rates. These reasons include high poverty rates, the vast history of trauma and oppression faced by Native Americans, and limited access to healthcare which could be due to isolated geographic location. To support these proposed explanations, it has been reported that Native Americans are more likely to live in poverty than other Americans with 25.7% living below the poverty level relative to 12.4% of all Americans (Indian Health Services, 2014) and that 22.6% of Native Americans do not have health insurance coverage (Office of Minority Health, 2018). Though not directly studied in a Native American

sample, low educational attainment has been found to be a possible reason for lower prevalence rates for racial and ethnic minorities (Croen et al., 2001; Decouflé & Boyle, 1995). Relating this to Native Americans, it has been stated that in this population there is a lower level of educational attainment relative to non-Hispanic Whites, with 82% of Native Americans achieving a high school degree relative to 92% of non-Hispanic Whites (Office of Minority Health, 2018).

#### **Beliefs about Developmental Disabilities**

Treatment-Seeking and Beliefs. While racial and ethnic minority status can affect geographic location and socioeconomic status, it can also influence beliefs about disabilities (Mandell & Novak, 2005), all of which can affect treatment-seeking attitudes and behavior of the individuals (Danseco, 1997; Mandell & Novak, 2005). The beliefs held about the treatment of disabilities occur from the beliefs held about the nature or cause of the disability, which is typically either from a biomedical perspective, a sociocultural perspective, or a combination of the two viewpoints (Danseco, 1997).

A biomedical perspective looks at and relies upon the biological basis, such as environmental and genetic factors, to explain the nature and causes of a disability. According to Danseco (1997), a belief of biomedical causes may lead a caregiver of a child with disabilities to seek out a medical professional's advice. However, even while following a medical professional's prescribed treatment, individuals of a racial/ethnic minority would typically also employ cultural practices that are more in line with a sociocultural perspective (Danseco, 1997). If individuals subscribe to this perspective, they are more likely to take their child to a medical professional if their child displays early signs of a developmental disability. This would lead to

an increased diagnostic rate of developmental disabilities within a population that endorses a biomedical perspective.

A sociocultural perspective looks at more traditional and culturally-based causes of a disability. This belief may lead a caregiver to seek out more traditional methods of treatment that are in line with their culture. This can sometimes result in the caregiver either not obtaining treatment or not seeking out treatment from a professional within the mainstream medical field and instead relying on treatment consistent with their cultural beliefs. Additionally, when addressing a child's disabilities, a caregiver will more heavily rely on their culture and its surrounding beliefs (Pachter & Harwood, 1996). These beliefs will then extend to the treatment-seeking behaviors of the caregiver (Mandell & Novak, 2005; Ravindran & Myers, 2011). If these cultural beliefs center around developmental disabilities not being a concern or something to be treated, or the beliefs hold developmental disabilities as being stigmatized, then it follows that there would most likely be a reduction in treatment-seeking attitudes and behaviors, and, therefore, a lower diagnostic rate within that culture. It has also been found that older adults who are racial and ethnic minorities are more likely to be affected by their culture's beliefs than younger individuals (Jang et al., 2009).

Typically, however, beliefs are commonly combined, and caregivers will rely on a mix of the two perspectives (Danseco, 1997). By merging these outlooks, caregivers will utilize practices that are both relevant to their cultural and conventional practices. This is also the case for racial and ethnic minorities that live in a diverse society--they tend to hold the sociocultural perspective's beliefs more frequently but will also employ the use of a biomedical perspective and seek out both of these beliefs and practices (Danseco, 1997). This combination of perspectives could lead to a caregiver seeking out both medical professionals as well as treatment

consistent with their culture for a child with developmental disabilities. This could also suggest that if one treatment is more readily available, such as a culture located in an isolated geographic location, that the caregiver may prioritize culturally consistent treatments due to ease of accessibility to this treatment method. This suggests that those in isolated geographic locations may be subject to a lower diagnostic rate of developmental disabilities due to a lack of accessibility, and, therefore, possibly preference for treatment seeking from medical professionals. Due to the majority of individuals having viewpoints that combine these two perspectives, even those living in isolated geographic locations, the perspectives provide a possible lens to interpret the findings through rather than an additional variable that should be measured.

Native American Beliefs. Native Americans have been described by Red Horse (1997) as being engrained in their established attitudes, knowledge, and beliefs that are deep-rooted in cultural traditions and differ greatly from the typical American middle class. These traditional beliefs can lead to differing treatment-seeking attitudes, which can lead to differing diagnostic prevalence rates compared to non-Native American populations. Related to disabilities specifically, it has been stated that disabilities do not exist without the influence of culture (Coleridge, 2000). In fact, the Navajo Nation did not have a word for disabilities within their language until they were acculturated by the American influence (Kapp, 2011). This is most likely due to the beliefs of Native Americans surrounding disabilities. However, there has been limited research conducted on the general beliefs of Native Americans surrounding developmental disabilities. Red Horse (1997) detailed that Native Americans do not view individuals who would be defined as having disabilities by American culture and language as having deficiencies but as having special strengths and are, therefore, thought of with respect by tribal members. Due to this respect and

that Native Americans are less likely to hide a person with disabilities compared to other cultures (McCallion et al., 1997). While there is limited evidence to compare beliefs across tribes, these views of strengths and attitudes of respect seems to be consistent across most tribes that have participated in research. However, it has only been found by the study conducted by McCallion and colleagues (1997) that Native Americans are less likely to hide a person with disabilities.

There has been additional research conducted within the Navajo Nation specifically. According to Navajo beliefs, a person with disabilities is thought of as a part of diversity that is associated with strength and difficulties (Wilson, 2015). As stated in a qualitative study completed by Medina and colleagues (1998), the traditional beliefs of this tribe are that individuals with disabilities are teachers for the rest of the community and are there to convey special lessons and offer unique gifts to the tribal community. Due to these traditional beliefs, treatment for the disability could hinder or interfere with the message or gift of the individual with disabilities (Ravindran & Myers, 2011). This belief then has the potential to lead to a reduction in the treatment-seeking attitudes of this tribe. Kapp (2011) advances this idea by stating that, in the Navajo Nation, after individuals who are deemed to have a condition partake in a ceremony that incorporates them with the universe, they will receive full acceptance and appreciation by the rest of the tribe and will no longer be affected by their condition. In fact, Navajo culture makes a great amount of effort to include individuals with autism within society as much as it is feasible to do so (Kapp, 2011).

While the Navajo Nation may hold traditional views about individuals with disabilities being teachers with lessons for the tribe, the study by Medina et al. (1998) revealed that there are also traditional Navajo beliefs that held more negative implications surrounding disabilities.

These traditional beliefs asserted that disabilities were the consequences of parental breaking of taboos, a representation of disharmony and imbalance, and that the individuals with disabilities themselves were taboo and rarely seen in public (Medina et al., 1998). These traditional beliefs found in the study conducted by Medina et al. may lead to stigmatization, a reliance upon traditional cultural practices, or a hesitancy of treating the disability due to cultural values. These consequences of the traditional beliefs may result in a reduction of treatment-seeking attitudes for the differing reasons listed. This reduction in treatment-seeking attitudes can result in the underdiagnosis of developmental disabilities and, therefore, lower prevalence rates within Native American populations (Bernier et al., 2010; Travers et al., 2013) The study conducted by Medina et al. (1998) also offered contemporary beliefs about disabilities from the Navajo Nation that more closely resemble more conventional and mainstream beliefs. These contemporary beliefs are that disabilities are caused by social and environmental influences (Medina et al., 1998). These beliefs shift the blame and stigma away from both the individuals with disabilities and their caregivers. This may lead towards an attitude surrounding developmental disabilities that does not cause a reduction in treatment-seeking behaviors due to the reduced stigma relative to the traditional beliefs uncovered in the same study.

A sparse amount of research has been conducted with Native Americans surrounding developmental disabilities, and, to date, the study piloted by Medina et al. (1998) is the only research available that directly examines the beliefs of Native Americans about developmental disabilities broadly. However, it is over 20 years old and consequently may not represent current views of Native Americans. Also, the cultural beliefs of a single Native American tribe are specific only to that tribe. It cannot be assumed that the beliefs of the Navajo Nation are the beliefs of every Native American tribe, similar to how one culture would not generalize to all

other cultures (Rogers-Adkinson et al., 2003). There are 573 federally recognized tribes within the United States alone (Bureau of Indian Affairs, 2018) and each hold their own distinct values and identities. Therefore, while these findings allow for speculations of beliefs from a single Native American tribe, they are only presumptions that need evidence to be proved accurate or inaccurate for a particular tribe.

Measurement of Beliefs. In order to measure beliefs of developmental disabilities, several methods have been utilized previously. Within the limited literature on Native Americans, beliefs have been assessed through qualitative interviews, focus groups, or narrative accounts. To date, no studies were found that used quantitative methods to assess beliefs about developmental disabilities. Outside of Native American populations, numerous studies have assessed these beliefs through quantitative measures, such as surveys. However, no research studies have assessed these beliefs broadly about developmental disabilities. The only assessments of beliefs of developmental disabilities found came from state organized surveys about public attitudes of developmental disabilities (Connecticut Council on Developmental Disabilities, 2007; Market Response International, 2012). Instead, more frequently, developmental disabilities have been partitioned into specific developmental disabilities such as intellectual disabilities and ASD. Several measures have been created that measure attitudes and beliefs of these specific disabilities (De Boer et al., 2012; Scior, 2011).

#### **Knowledge of Developmental Disabilities**

There has been limited research to date on the knowledge of developmental disabilities within the general public, and no previous literature could be found that directly researched this knowledge within Native American populations. In order to discuss the knowledge of developmental disabilities of a lay public, the broad category of developmental disabilities must

be reduced to specific developmental disabilities due to the limited scope of the research that has been previously conducted.

Regarding intellectual disabilities in particular, a review conducted by Scior (2011) found that there were only eight studies that directly examined the general public's knowledge of intellectual disabilities and even fewer studies within the United States. Results from one study suggested that the general public had a limited understanding of intellectual disabilities (Gordon et al., 2004). Within other countries and cultures, there was found to be a general lack of knowledge and awareness of intellectual disabilities with the lay public (Scior, 2011). Within Israelis, those with Western origins tended to have a higher knowledge of intellectual disabilities than those of Eastern origins (Aminidav & Weller, 1995). In Ethiopia and Japan, it was discovered that neither population had abundant knowledge of intellectual disabilities, including how common intellectual disabilities are (Alem et al., 1999; Tachibana, 2006; Tachibana & Watanabe, 2003). In India, it was found that the proportion of individuals asked to identify severe intellectual disability through a vignette was varied, with successful identification at about half in a sample of parents and community health workers (Madhavan et al., 1990) and one in 34 in a sample of individuals living in slums of New Delhi (Ojha et al., 1993). Furthermore, in a study conducted by Scior and Furnham (2011), it was found that 24% of individuals from a sample consisting of the general public of various ethnicities in the United Kingdom and Asia were able to correctly identify mild intellectual disability. Within this study, it was reported that individuals of African and Asian ethnicities had a lower likelihood of identifying intellectual disabilities than white British individuals (Scior, 2011). Taken together, from the limited research on the subject there is evidence that, though the amount of knowledge surrounding intellectual abilities may differ across cultures, it is generally low within the lay public. A greater

level of knowledge has been indicated to reduce misconceptions about intellectual disabilities and improve attitudes towards intellectual disabilities (McManus et al., 2010; Scior, 2011).

Specifically, with ASD, there is a diverse level of awareness and knowledge globally, with a heightened awareness in Western countries (Harrison et al., 2017). However, within Western countries, minority populations experience lower levels of ASD knowledge due to certain barriers that they face including lower levels of educational attainment and fewer sources of ASD specific knowledge (Magaña et al., 2013; Mercadante et al., 2009; Zuckerman et al., 2013) resulting in fewer opportunities for advancement in ASD knowledge. This lower level of knowledge could result in the lower prevalence of ASD within racial and ethnic minorities within the United States (Mandell et al., 2009). Therefore, it is then theorized that increasing ASD knowledge would aid in reducing the diagnostic disparities of ASD (Harrison et al., 2017).

Concerning the findings of knowledge surrounding intellectual disabilities and ASD, though this may not be representative of all findings of developmental disabilities, it is suggested that there likely is a low level of knowledge of developmental disabilities within the general public. This low level of knowledge seems to be particularly prevalent within racial and ethnic minorities, suggesting a possible explanation for lower levels of diagnosis of developmental disabilities for racial and ethnic minorities.

Measurement of Knowledge. While there have been no studies to date that have measured public knowledge of developmental disabilities, several studies have been conducted that measure knowledge of specific developmental disabilities. Previous studies have analyzed attitudes towards intellectual disabilities through surveys, including adapted and author-created surveys, vignettes, phone interviews, and open-ended questionnaires (Scior, 2011). The most common form of measurement of knowledge about this population was through surveys. Studies

that have analyzed knowledge of ASD have primarily utilized surveys to collect this information but have also employed the use of vignettes and semi-structured interviews (Harrison et al., 2017). Taken together, the most commonly used method to assess knowledge of specific developmental disabilities has been surveys.

#### Acculturation

Acculturation is described as the process by which an individual assimilates to the mainstream culture surrounding them and grows distant to their original culture (Yoon et al., 2013). In addition to how a person identifies them self, culture has been found to impact both knowledge of developmental disabilities and beliefs about developmental disabilities.

Impact on Knowledge. The level of acculturation of an individual has been shown to impact their knowledge of developmental disabilities. Previous literature has found that higher levels of acculturation, or assimilating to the dominant culture, has been linked to higher levels of educational attainment in racially and ethnically diverse samples (Chen, 2009; Marin et al., 1992; Ouarasse & Vijver, 2005; Suinn et al., 1992). Lower levels of educational attainment have been connected to lower amounts of knowledge about developmental disabilities (Croen et al., 2001; Decouflé & Boyle, 1995; Magaña et al., 2013; Mercadante et al., 2009; Zuckerman et al., 2013). Therefore, lower levels of acculturation are likely associated with lower levels of knowledge about developmental disabilities. However, no studies could be found that directly tie acculturation to knowledge of developmental disabilities.

**Impact on Beliefs.** Acculturation has also been found to have an effect on an individual's beliefs of developmental disabilities. Previous literature has found that in racially and ethnically diverse samples, higher levels of acculturation have been linked to more positive and contemporary beliefs about developmental disabilities (Choi & Lam, 2001; Zaromatidis et al., 1999). While

these studies were conducted with individuals who immigrated to the United States, it is possible that this effect would still be present within individuals who are not immigrants.

Measurement of Acculturation. Previously, acculturation has been primarily measured through the use of surveys. However, some interviews have also been conducted in order to understand acculturation (Wallace et al., 2010). Acculturation measures have been used for research within many different cultures and have also been specifically adapted or developed for use within specific cultures. It has also been used to understand many different topics, such as how cultural identity influences substance abuse (Center for Substance Abuse Treatment, 2014). It has also been conceptualized in a number of different ways, including on a continuum as well as through complex multidimensional models (Skinner, 2001). Acculturation measures have also been found to measure several conceptual structures, such as acculturation conditions, acculturation orientations, acculturation outcomes, acculturation attitudes, and acculturation behaviors (Celenk & Van de Vijver, 2011).

#### **Purpose**

While there is limited research that has been conducted with Native Americans on the topic of developmental disabilities, the previous research suggests that lack of knowledge and holding traditional beliefs about developmental disabilities are two of several possible causes for the underdiagnosis of developmental disabilities within this population. However, there is no research that links other factors hypothesized for relating to Native Americans' knowledge and beliefs surrounding developmental disabilities, such as acculturation, financial need, level of education, and age. The current study aims at investigating the relationship between the beliefs and knowledge of Native Americans about developmental disabilities and these possible factors that have been identified that could help explain such relationship. This study hopes to answer

the question: Do the knowledge or beliefs about developmental disabilities differ according to level of education or financial need, age, or level of acculturation within this tribal community? As this is a topic of research that has not been widely examined and has not been directly researched in the past 20 years, this proposed study will address this gap in the literature as well as add to the available literature on Native Americans. The study employs the assistance and support of a northwestern Native American tribal community through the implementation of community-based participatory research in order to investigate the relationship between the identified relating variables and Native Americans' beliefs and knowledge of developmental disabilities. To date, no research has been conducted with this tribe on the topic of developmental disabilities. In the process of updating and increasing the literature on this topic, we aim to develop an intervention to spread awareness of developmental disabilities for this community. It is suspected that higher knowledge and more contemporary beliefs about developmental disabilities will relate to individuals who are younger, more highly educated, of lower financial need, and more are acculturated.

In order to begin this research study, several unique actions were taken given the nature of this topic and the community being researched. Before any survey was conducted, the participants were asked to either sign an informed consent or participate in an oral consent, depending on their preference. There are several reasons as to why documentation of informed consent were waived. The first is that this study presented no more than minimal risk to participants as it was assessing their perceptions and knowledge and some demographic information. In fact, documentation that could possibly link the participants to the study may cause more harm than not having this documentation. With the written informed consent being the only link of the participants to this study, the possibility of a breach of confidentiality causes

an increased risk of harm. By having this linking information, participants may worry that any possible negative perceptions of developmental disabilities that they have may spread within this small community which could lead to negative perceptions about themselves within this community. As this is a study within a small community, by having identifying information in a consent, it may be possible to then identify who a participant is by comparing the name provided in the consent to the de-identified demographic information, and, therefore, being able to link all other data to this participant. Another reason would be that participants from this community are from a culture where signing documents is not common and is even looked upon with suspicion. Also, this topic has been addressed by the researchers within this tribe and we received feedback that an option of oral consent would be preferable for many participants.

An influential portion of this study is the implementation of community-based participatory research (CBPR). This is a type of research method that is particularly advantageous when working with indigenous populations and emphasizes the community participating in the research as equal partners in the project (Holkup et al., 2004). Guidelines suggested by Harrison (2001) and further discussed by Holkup and colleagues (2004) outline that with CBPR researchers must:

- 1. Be flexible and willing to persevere when plans do not occur accordingly.
- 2. Be willing to collaborate and share responsibility, credit, and decisions of the research project with the community.
- 3. Be able to provide thorough consideration of ethical issues that may arise from the research.
- 4. Be able to apply the community's idea of culture into the work you are doing within that community and prepared to adapt to this culture.

In order to utilize CBPR for this research project we have connected with several key figures within tribal early intervention, primary and secondary education, as well as tribal human services. These established relationships allow us to navigate through the implementation of CBPR within this community. These community members have provided us with feedback on all aspects of this research project and allow us to interact with the community in a manner that is appropriate for their culture. We also maintained a commitment to being flexible with the research being conducted in order to tailor this study to the methods that are most appropriate for researching with this community. We have attended a tribal school board meeting in which we incorporated feedback from the school board, such as the inclusion of FASD specific items. Additionally, we met with the Tribal Business Council twice in order to gain approval for this research study. From these meetings, we incorporated feedback into the research study, such as recruiting residents of the tribal reservation instead of tribal members. See Addendum for more information about modifications.

#### Methods

#### **Participants**

Participants of this study were comprised of 24 residents of a local tribal community. Inclusion criteria included residents at least 18 years of age that had lived on the reservation for at least five years and were proficient in English. Residential status was determined via self-report, and tribal membership was collected but not included as an exclusionary criterion in order to examine the views of the broader tribal community rather than a specific tribe. Participants who did not identify as residents of the community for the previous five years or who were below the age of 18 were excluded from the study. A power analysis for a multiple linear regression ( $\alpha = 0.025$ , power = 0.80) using the G\*power statistical software (Faul et al., 2007)

indicated that approximately 48 participants were needed in total to obtain a large effect size of 0.34 with four predictors. This effect size was reported in a similar study that measured knowledge and beliefs about developmental disabilities (McManus et al., 2010). Due to the anticipation of missing data, we proposed to collect 60 participants. However, due to numerous barriers during data collection, only 24 out of 60 participants were recruited.

The participants were between 20 to 72 years old, with the mean age being 45.26 years. The sample included 18 females, 4 males, 1 non-binary participant, and 1 no response. Reported monthly income varied between \$300 to \$6666.67. A majority of the participants (17) identified as Native American/American Indian, 4 identified as Hispanic/Latinx, one participant identified as White/Caucasian and Hispanic/Latinx, one participant as Hispanic/Latinx and Native American/American Indian, and one no response. The participants' years of education ranged from 4 years to 29 years, with an average of 13.95 years. Regarding marital status, ten participants were single, five were married, four were divorced, two were in a domestic partnership, one was widowed, and two did not respond to this item. From this sample, 20 participants indicated being registered with a tribal community and living within this tribal community being researched from 5 years to 68 years, with the mean amount being 32.45 years. It should be noted that one person did not complete the demographics information and three people did not complete the latter part of the demographic questionnaire. This, combined with omitting items based on personal comfort levels, resulted in missing information about monthly income (six participants), financial stress (four participants), and years of education (4 participants).

#### **Materials**

Surveys. There were four measures that participants of this study were requested to

complete. It was approximated that it took participants about 20-30 minutes to complete all four surveys. The first was a brief, 9-item demographics questionnaire. This questionnaire asked information surrounding the participant's years of education, level of financial need, age, ethnicity, gender, and marital status (see Appendix A). Monthly household income and number of individuals within the household were collected through the demographic questionnaire as well. The level of financial need was based on the participant's income and the number of individuals (i.e., adults and children) living in their household.

Another measure utilized was the Native American Acculturation Scale (NAAS; Garrett & Pichette, 2000). The NAAS is a 20-item, multiple choice survey specific to Native Americans that results in a score which identifies an individual's acculturation level (see Appendix B). The NAAS allows participants to choose a response based on a five-point Likert scale. The responses were categorized on a scale of 1 being low acculturation and 5 being high acculturation. Therefore, the higher the score is, the less the participant is aligned with Native American culture. This measure has been validated across a sample of high school students (N = 139) resulting in good internal consistency (Cronbach's  $\alpha$  = .91; Garrett & Pichette, 2000). It has been further validated across two samples of college students (N = 489) and has been found to have good internal consistency for its subscales (Cronbach's  $\alpha$  = .77 to .85; Reynolds et al., 2012). Additionally, a confirmatory factor analysis was conducted with a Native American population which confirmed the factor structure of this measure (Reynolds et al., 2012).

A third measure utilized was a 37-item questionnaire that analyzed the participant's knowledge of autism and other developmental disabilities through a true/false scale as well as the level of confidence in their response (see Appendix C). The questionnaire was adapted specifically for this study by combining an existing 28-item questionnaire on the knowledge of

autism, A Survey of Knowledge of Autism Spectrum Disorder (ASK-ASD; Hansen & Barry, 2015), with nine author-created questions about other developmental disabilities. Hansen and Barry (2015) conducted a factor analysis for ASK-ASD which resulted in two factors: The Prognosis/Risk Factors Subscale ( $\alpha = .58$ ) and the General Features Subscale ( $\alpha = .62$ ). The Flesch-Kincaid grade level for reading was found to be 10.0 and the internal consistency ( $\alpha =$ .61) and test-retest reliability (r = .63; Hansen & Barry, 2015) were found to be adequate. As there was no questionnaire for a lay public that examined broad knowledge of developmental disabilities, the author added questions about widely recognized myths on developmental disabilities to create the adapted ASK-ASD. These additional questions were developed through the author's own knowledge about false beliefs of developmental disabilities along with the perspective of other experts in the field. These questions included broad developmental disabilities as well as intellectual disabilities, FASD, and learning disabilities. Participants can select either true or false as a response, and they can also indicate how confident they are in their response. The confidence scores will be used for future analyses; however, the true false scores were either scored as correct or incorrect. A final score was created on a scale from 0 to 1. A score of 0 is representative of the participant selecting no correct responses, while a score of 1 is equivalent to all correct responses being selected. Therefore, the closer the score is to 1, the higher number of correct responses were selected by the participant.

The last measure utilized was the Developmental Disabilities Beliefs Scale, which is an author-adapted 33-item survey that includes a five-point Likert scale to examine beliefs about developmental disabilities (see Appendix D). This survey was created by combining questions from two state surveys on this topic (Connecticut Council on Developmental Disabilities, 2007; Market Response International, 2012) as well as beliefs specific to other Native American tribes

that were identified from previous research. A score of 1 is considered a traditional belief while a score of 5 is considered a contemporary belief. Therefore, the closer the response is to 5, the more similar it is to a contemporary belief. Some items were reverse coded and have been denoted as such in Appendix D. Contemporary beliefs were identified by a group of professionals within the field of developmental disabilities as current and modern beliefs that were held about developmental disabilities. Items 7, 13, 18, 24, and 30 are beliefs that have been identified in previous literature as traditional Native American beliefs. Due to the lack of research on the topic, these items will be used for a future analysis and were excluded in the calculation of a belief score for this study.

#### **Procedure**

The primary method of recruitment of participants involved attending community events and asking individuals who attended these events if they wanted to participate in the research study. At these events, individuals were given the option of either filling out the surveys with the researcher there at that moment or being provided more information on the study. To allow for a greater sense of privacy, participants were allowed to complete the survey wherever they felt most comfortable during the events. A \$10 cash compensation was provided upon completion of the surveys.

After the first community recruitment event, the COVID-19 pandemic unexpectedly occurred. This forced a halt to all in-person data collection efforts due to the unknown nature of this pandemic and the concerns of consequences of spreading and contracting the virus. As more knowledge was gained about the virus, we re-examined our methods of recruitment in an attempt to maintain participant safety. After discussions with our tribal community partners, it was decided to switch the surveys to an online format and recruitment would be completed through

flyers posted in public buildings on the reservation, word of mouth, and online advertisements. However, this method of recruitment resulted in no new participants. As concerns about the spread of COVID-19 began to decrease in early summer of 2021 with newly developed vaccines widely available and the number of confirmed COVID cases and deaths greatly reduced, we again re-examined our recruitment methods. After discussion with our tribal community partners, we began to resume in-person community events with new COVID-19 specific precautions (i.e., social distancing, personal protective equipment, and sanitization practices) on a limited basis. We were able to attend three separate events with permission of those running the events. Through these events, 15 more participants were recruited. However, over the summer 2021, a new, more spreadable variant of the COVID-19 virus began to be prevalent in this community and the surrounding areas. This resulted in increased concerns about participants' safety as even those who were vaccinated were contracting this new COVID-19 variant at high rates. We thus re-examined our recruitment efforts and decided to end recruitment for that time. Therefore, the study recruitment prematurely ended due to unforeseeable circumstances, resulting in the total of 24 participants.

#### **Hypotheses and Analyses**

#### **Hypotheses**

Table 1 *Hypotheses* 

Hypothesis 1	Participants with fewer years of education will have more traditional beliefs about developmental disabilities.
Hypothesis 2	Participants with a higher financial need will have more traditional beliefs about developmental disabilities.
Hypothesis 3	Participants with lower levels of acculturation will have more traditional beliefs about developmental disabilities.
Hypothesis 4	Older participants will have more traditional beliefs about developmental disabilities.
Hypothesis 5	Participants with more years of education will have higher levels of knowledge about developmental disabilities.
Hypothesis 6	Participants with a lower financial need will have higher levels of knowledge about developmental disabilities.
Hypothesis 7	Participants with higher levels of acculturation will have higher levels of knowledge about developmental disabilities.
Hypothesis 8	Younger participants will have higher levels of knowledge about developmental disabilities.

Hypotheses 1-8 was analyzed using two standard multiple linear regressions. In order to perform this analysis, the Statistical Package for the Social Sciences program was utilized (IBM Corporation, 2017). For Hypotheses 1-4, beliefs held about developmental disabilities was the outcome variable. This variable was measured through the Developmental Disabilities Beliefs Scale by totaling the response scores and dividing this number by the total number of questions, which results in a mean score. For ease of interpretation, this mean score was transposed into a scale of -2 to 2, with 2 being representative of a highly contemporary belief to -2 being representative of a highly traditional belief. The outcome variable for Hypotheses 5-8 was knowledge of development disabilities measured through the adapted ASK-ASD. This was measured by a resulting score from 0 to 1 which was gathered by dividing the total number of

items by the number of items correct. Higher scores are equivalent to more knowledge of developmental disabilities.

For Hypotheses 1 and 5, the predictor variable was the participants' years of education. For Hypotheses 2 and 6, the level of financial need was the predictor variable. This was calculated by dividing the reported monthly income of a participant by the reported number of people in their household. For Hypothesis 3 and 7, an acculturation score from the NAAS was the predictor variable. This score is attained by totaling the responses and dividing the total by the number of questions, creating a mean score. The mean score ranged from 1 (low acculturation) to 5 (high acculturation). Typically, any value at or below 3 served as the point at which the participant is aligned with Native American culture (Garrett & Pichette, 2000), however for this study the score remained a continuous variable. Participants' age, which was gathered by self-report on the demographics form, was the predictor variable for Hypotheses 4 and 8.

#### **Analyses**

A multiple linear regression is an analysis used to examine the causal or predictive relationship between a single outcome variable and multiple predictor variables (Allison, 2012). Through the use of this analysis, we aimed to be able to observe the relationship between the individual outcome variables (knowledge and beliefs of developmental disabilities) with age, level of financial need, acculturation, and years of education with hopes that this would allow us to discern how each predictor variable is related to the outcome variables.

Prior to conducting the multiple linear regressions, the dataset was evaluated for normality, linearity, and homoscedasticity using descriptive statistics, residual plots, and variance inflation

factor (VIF) values. As the normality or linearity assumptions were violated, the dataset was transformed depending on the severity of skewness and non-linearity.

The results of the multiple linear regressions provided correlations between each of the variables (Allison, 2012). These correlation coefficients were interpreted using descriptors of the categorization of their strength such as weak ( $r \le .35$ ), moderate (r = .36 - .67), strong (r = .68 - .89), and very strong ( $r \ge .90$ ; Taylor, 1990). However, according to Taylor (1990), a descriptive interpretation is not meaningful without an interpretation of statistical significance. Therefore, multiple t-tests were conducted to determine the significance of the individual variables as well as two F-tests, which were conducted to determine the significance of the overall models.

#### Results

Table 2 displays the descriptive statistics for the sample collected. The number of participants per variable collected ranges from 18 (financial need) to 24 (the outcome variables: beliefs and knowledge of developmental disabilities). The low response rate on the question about financial need was likely negatively impacted by the participants' comfort level of providing that information along with three participants who did not complete the back portion of the demographic form and one participant that did not complete the demographic form. The four participants who did not complete the back portion of the demographic form also resulted in missing data on the years of education variable (N = 20). The age variable was almost entirely accounted for apart from the one participant who did not complete the demographic form. The acculturation measure was filled out by all participants except two who expressed hesitancy with completing that survey to the researcher. The beliefs and knowledge surveys were completed by all participants. Pairwise deletion was used for all instances of missing data with the exception of one participant's responses on the adapted ASK-ASD. In this instance, the participant placed

question marks beside the items they left blank, indicating that they were unsure of the correct answer. In order to account for this missing data, we determined that these responses would be counted as incorrect for this participant as they were indicating that they did not know the correct answer. The participants were aged from 20 years old to 72 years old (M = 45.26, SD = 14.40) and ranged from 4 to 29 years of education (M = 13.95, SD = 4.55). There was adequate variance within the reported financial need, age, and years of education. Acculturation also had a lower range (1.90), the maximum value was 3.85 while the minimum value was 1.95, with the mean being 2.70. Given the variance being low for this variable, this information suggests that this sample did not have high levels of acculturation, had few instances of lower acculturation, and was comprised of mainly those who were in the middle levels of acculturation. Notable findings from these descriptive statistics are the restricted ranges of the outcome variables and the lack of variance on several variables (acculturation, beliefs and knowledge of developmental disabilities). Particularly of note is the lack of traditional beliefs (i.e., no value below 0 for that variable) and that no participant scored below 50% correct of the knowledge measure as well as no participant scoring above 80% correct on this measure.

When considering the skewness and kurtosis of the variables as presented in Table 2, both financial need and years of education were of concern. Financial need was both kurtoted and positively skewed (see Table 2 and Figure 1). In order to correct this, a square root transformation was completed. Upon completion of this transformation, skewness was acceptable (skewness = 1.64) and fell below the critical value of +/-1.96, but kurtosis (3.4) remained above 3 which suggests that this variable remained kurtoted. Therefore, a Log10 transformation was completed on the original variable. Results from this transformation indicated that skewness (-.03) and kurtosis (.14) were within acceptable limits (see Figure 2).

Regarding years of education, skewness was not of a concern (skewness = 1.47), but kurtosis was (kurtosis = 6.86; see Table 2 and Figure 3). A square root transformation was conducted which resulted in skewness (.01) and kurtosis (5.39) decreasing, but kurtosis remaining an issue (see Figure 4). Therefore, a Log10 transformation was conducted. This resulted in both the skewness (-1.56) and kurtosis (7.29) becoming larger than the original value. Due to this, the square root transformation was used in further analyses as it represented the best values for skewness and kurtosis. However, due to the small sample size, both skewness and kurtosis should be interpreted with caution.

Table 2

Descriptive Statistics

	N	Range	Min	Max	Observed	Observed	Mean	SD	Variance	Skewness	Kurtosis
					Min	Max					
Age	23	52	-	-	20	72	45.26	14.40	207.47	.03	64
Financial	18	6591.67	-	-	75	6666.67	1158.99	1582.64	2504741.34	2.86	9.06
Need											
Education	20	25	-	-	4	29	13.95	4.55	20.68	1.47	6.86
Acculturation	22	1.90	1	5	1.95	3.85	2.70	.53	.28	.87	.18
Beliefs	24	1.82	1	5	.07	1.89	1.13	.56	.32	45	84
Knowledge	24	.27	0	1	.51	.78	.65	.08	.01	13	78

Note. Financial need was calculated by the participant's provided monthly income divided by the number of people in their household.

Figure 1
Financial Need Histogram

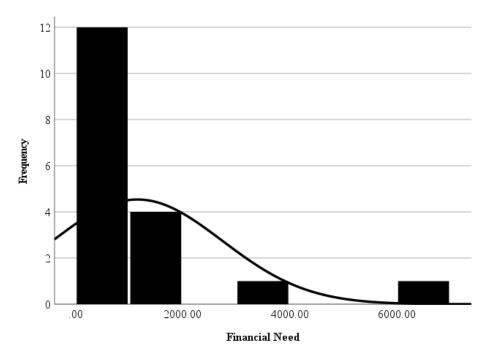


Figure 2

Log10 of Financial Need Histogram

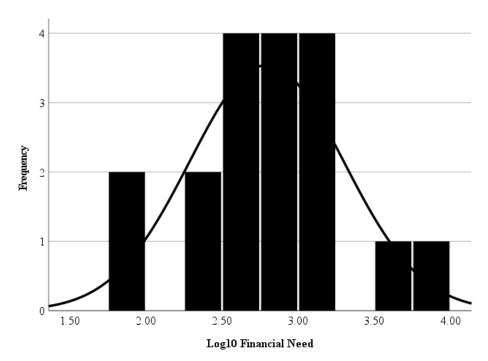


Figure 3

Years of Education Histogram

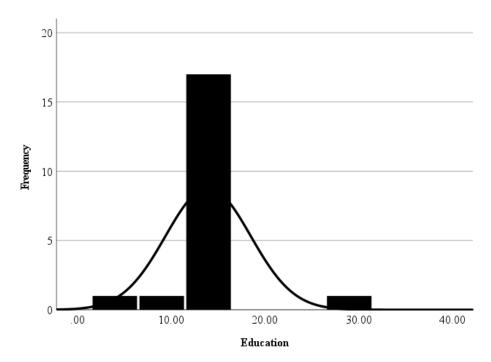
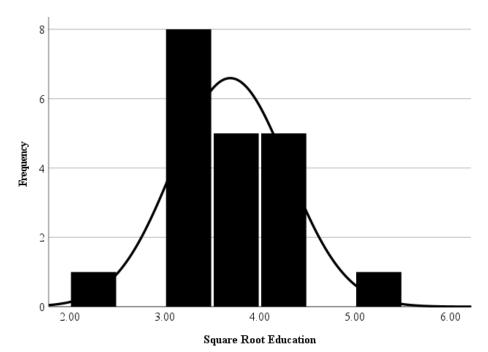


Figure 4

Square Root of Years of Education Histogram



Next, the assumptions of normality, homoscedasticity, and the absence of multicollinearity were tested. Figures 5 and 6 demonstrate that the assumption of normality is met for both outcome variables, knowledge and beliefs of developmental disabilities respectively. This suggests that the residuals were normally distributed. For the assumption of homoscedasticity, the residuals were equally distributed so the assumption is met (see Figures 7 and 8). Regarding multicollinearity, all VIF values were below 10, which suggests the absence of multicollinearity. Therefore, this final assumption was met. As all assumptions were met, analyses could proceed.

Figure 5

P-P Plot of the Residuals for All Predictor Variables and Knowledge of Developmental

Disabilities

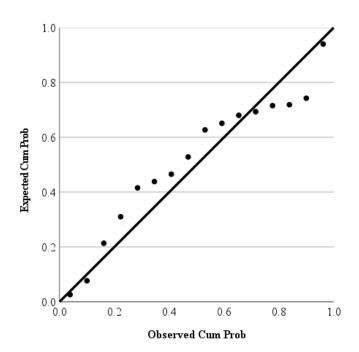


Figure 6

P-P Plot of the Residuals for All Predictor Variables and Beliefs of Developmental Disabilities

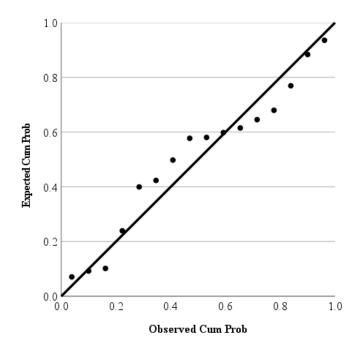


Figure 7

Scatterplot of the Residuals for All Predictor Variables and Knowledge of Developmental

Disabilities

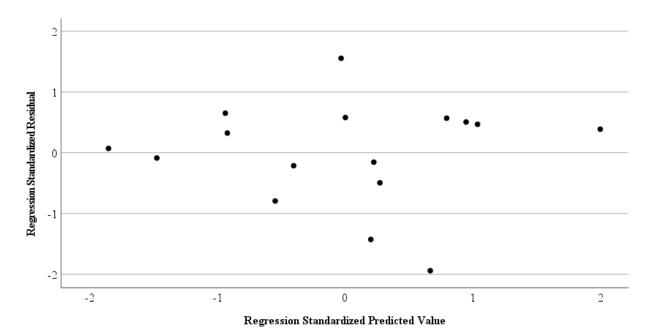
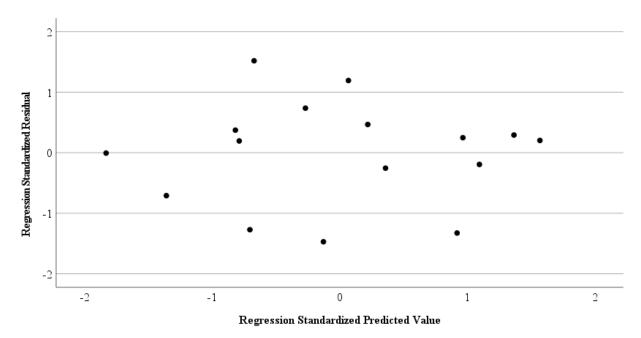


Figure 8

Scatterplot of the Residuals for All Predictor Variables and Beliefs of Developmental Disabilities



Due to the low sample size, correlations were completed between all of the variables (see Table 3). Pairwise deletion was used when running these analyses. No significant correlations were found except between the two outcome variables (r[22] = .56, p = .004) and age and financial need (r[16] = .583, p = .011).

Table 3

Correlation Table for All Variables

	Knowledge	Beliefs	Acculturation	Age	Financial Need	Education
Knowledge						
Beliefs	.560**					
Acculturation	.381	.340				
Age	.195	.116	-0.14			
Financial Need	.231	.558	.286	.583*		
Education	197	207	454	.073	.450	

<sup>\*</sup>p < .05. \*\*p < .01

To follow through with the originally planned analyses, two standard multiple regressions were conducted (see Table 4). Table 4 indicates a moderate association between knowledge

about developmental disabilities and the predictor variables (R = .44). However, the predictor variables explained 19% of the variability of the outcome variable, knowledge of developmental disabilities. The predictor variables did not statistically significantly predict the outcome variable F(4,11) = .65, p = .64. The regression model is not a good fit for the data. Table 4 displays t-values that indicate that when considering knowledge about developmental disabilities, all four predictor variables failed to contribute significantly to the prediction with no p-values even approaching statistical significance. Similarly, for the outcome variable of beliefs of developmental disabilities, Table 4 indicates a moderate association with the predictor variables (R = .46). However, the predictor variables explained 21% of the variability of the outcome variable, beliefs of developmental disabilities. Table 4 also indicates that the predictor variables did not significantly predict the outcome variable F(4,11) = .73, P = .59. Furthermore, Table 4 has t-values indicating that when considering beliefs about developmental disabilities, none of the predictor variables contributed significantly to the prediction with no p-values being <.05. Therefore, none of the hypotheses were found to be supported by the analyses.

Table 4

Multiple Regression T-Test Values

	F	df	р	R	$R^2$	t	p	β
Knowledge	.65	4, 11	.64	.44	.19			
Age						.47	.65	.001
Education						35	.73	02
Acculturation						.37	.72	.02
Financial Need						.43	.68	.04
Beliefs	.73	4, 11	.59	.46	.21			
Age						70	.50	01
Education						23	.82	10
Acculturation						.29	.78	.13
Financial Need						1.02	.33	.67

#### **Discussion**

The current study was aimed at increasing the current literature on the topic of developmental disabilities within Native American populations. It sought to (a) investigate how knowledge and beliefs of developmental disabilities change according to certain demographic factors and acculturation within a Native American community and (b) add to the current literature on the beliefs and knowledge held by Native Americans of this tribe. Previous research has suggested that the differing prevalence rates of developmental disabilities between indigenous populations and non-Hispanic Whites has several possible influential factors such as having limited knowledge of developmental disabilities and distinct beliefs about developmental disabilities within the tribal community. Additionally, knowledge and beliefs about developmental disabilities have been found to be related to a person's amount of education, age, level of acculturation and amount of financial need in previous literature.

When considering the correlational analyses that were conducted before the multiple regressions, it was noted that there were significant relationships between beliefs and knowledge of developmental disabilities. Given the low sample size and limited variance, this should be interpreted with caution. This correlation can be interpreted such that as beliefs become more contemporary, it was observed that the knowledge about developmental disabilities tends to increase within this sample. However, it should be noted that this is likely a result of the restricted variance and more data should be collected to verify this relationship.

The current study did not find any significant relationships between the variables within the multiple regression models. However, this is likely due to the underpowered nature of this study. Additionally, within the outcome variables, we particularly noted a restricted range and limited variance within the data collected. Within the acculturation variable, there was a smaller

range than what would be ideal for a representative sample. Additionally, this variable also had low variance. Within this sample, the levels of acculturation that were collected were of middle levels of acculturation (neither high nor low acculturation). Thus, for this sample, acculturation would not contribute much to the analysis due to the lack of variance within the data collected. For the beliefs about developmental disabilities variable, we noted a restricted range and variance within this data as well. Particularly, this sample only represented contemporary beliefs of developmental disabilities. Therefore, conclusions could not be made surrounding how traditional beliefs could have affected the results and the relationships among the variables and interpretations could only be made about contemporary beliefs, further limiting the results. Similarly, the knowledge about developmental disabilities variable had a restricted range and limited variance. This affected the results in similar ways as the previously mentioned variables, restricting the results of study as the data collected impacted the ability to find relationships between variables. This is particularly salient as both beliefs and knowledge of developmental disabilities are the outcome variables within the multiple regression models which greatly impacts the findings as both models rely on these variables to identify relationships. However, it should be noted that all participants scored higher than chance on the knowledge measure, with an average being 65% correct. Thus, there is some knowledge of developmental disabilities within this sample, however the knowledge found is at a level where education about developmental disabilities may prove to be beneficial. The limited range and variance likely acted in combination with low sample size to mask any potentially significant results. The results from this study should not be viewed as proving that there is no relationship between these variables within the data that was collected. Instead, the results display that there were problems

with the data collected such as not having enough participants and limited variance within the participants responses.

## **Implications and Limitations**

The current study adds to the literature on the topic of understanding developmental disabilities within the context of an indigenous community. However, with a sample size substantially lower than what was required to have efficient power, the results are practically uninterpretable. Given this underpowered nature, conclusions should not be drawn about the relationships of any of the variables. While the quantitative analyses should not be given much significance, what can be drawn from the results of this study is the effectiveness and utility of the CBPR model even through unprecedented and highly uncertain times. Through this model of research, we were able to maintain data collection efforts, even if they were limited. The first guideline of CBPR, "be flexible and willing to persevere when plans do not occur accordingly," was a driving factor for the continuation of data collection past the start of the pandemic. We are certain that data collection would not have continued after the COVID-19 pandemic began without our community partners. Without the CBPR model as a guide and the support and counsel of our community partners, we would not have been able to collect data from the final 15 participants.

While this study has the potential to have a major impact if more data is eventually collected, there are also limitations of this study. A major limitation of this study is the small sample size. This sample size leaves the resulting data hardly interpretable. Additionally, considering the complexities of conducting research with this population compounding with an unexpected pandemic, a larger sample size is irrational to attempt to achieve under the current circumstances. Tribal communities can be understandably distrustful of people from outside of

the community entering the reservation to conduct research. In the present day, not only are outside researchers viewed with suspicion due to historical traumas, but this is also magnified by the potential spread of a deadly virus. While the number of COVID-19 cases remains high and new variants of the virus spread, it would be inadvisable to continue to attempt to collect data when there is potentiality for putting others' lives at risk. Another limitation would be the lack of ability to generalize the findings to other tribes or to indigenous people as a whole. While this limitation would be more relevant upon the collection of more data, the information collected from this study would only allow for conjectures about knowledge and beliefs of developmental disabilities from other tribes.

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# Appendix A

# **Demographic Questionnaire**

Are you registered with any tribes?	
☐ Yes ☐ No If so, which tribe(s)?	
How long have you lived in Fort Hall (in years)?	years
How old are you (in years)? years	
I identify as (select all that apply):	
☐ Asian ☐ Black/African ☐ Hispanic/Latinx ☐ Native American/American Indian ☐ Pacific Islander ☐ White/Caucasian ☐ Prefer not to answer ☐ Other:	
I identify my gender as:	
<ul> <li>□ Female</li> <li>□ Male</li> <li>□ Nonbinary</li> <li>□ Prefer not to answer</li> <li>□ Other:</li> </ul>	
How many individuals are living in your household? Do n	not include yourself.
Adults	Children

Select your marital status:
☐ Single (never married) ☐ Married ☐ In a domestic partnership ☐ Divorced ☐ Widowed
What is the approximate monthly income of your household?
\$
How often are finances a stressor for you?  Never Sometimes About half the time Often
☐ Always  How many years of education do you have?
years

#### Appendix B

#### **Native American Acculturation Scale**

Instructions: This questionnaire will collect information about your background and cultural identity. For each item, choose the *one* answer that best describes you.

- 1. What language can you speak?
  - 1. Tribal language only (e.g., Shoshone, Bannock, or another tribal language)
  - 2. Mostly tribal language, some English
  - 3. Tribal language and English about equally well (bilingual)
  - 4. Mostly English, some tribal language
  - 5. English only
- 2. What language do you prefer?
  - 1. Tribal language only (e.g., Shoshone, Bannock, or another tribal language)
  - 2. Mostly tribal language, some English
  - 3. Tribal language and English about equally well (bilingual)
  - 4. Mostly English, some tribal language
  - 5. English only
- 3. How do you identify yourself?
  - 1. Native American
  - 2. Native American and some non-Native American (e.g., White, African American, Latino, and Asian American)
  - 3. Native American and non-Native American (bicultural)
  - 4. Non-Native American and some Native American
  - 5. Non-Native American (e.g., White, African American, Latino, and Asian American)
- 4. Which identification does (did) your mother use?
  - 1. Native American
  - 2. Native American and some non-Native American (e.g., White, African American, Latino, and Asian American)
  - 3. Native American and non-Native American (bicultural)
  - 4. Non-Native American and some Native American
  - 5. Non-Native American (e.g., White, African American, Latino, and Asian American)
- 5. Which identification does (did) your father use?
  - 1. Native American
  - 2. Native American and some non-Native American (e.g., White, African American, Latino, and Asian American)
  - 3. Native American and non-Native American (bicultural)
  - 4. Non-Native American and some Native American

- 5. Non-Native American (e.g., White, African American, Latino, and Asian American)
- 6. What was the ethnic origin of friends you had as a child up to age 6?
  - 1. Only Native Americans
  - 2. Mostly Native Americans
  - 3. About equally Native Americans and non-Native Americans
  - 4. Mostly non-Native American (e.g., White, African American, Latino, and Asian American)
  - 5. Only non-Native Americans
- 7. What was the ethnic origin of friends you had as a child age 6 to 18?
  - 1. Only Native Americans
  - 2. Mostly Native Americans
  - 3. About equally Native Americans and non-Native Americans
  - 4. Mostly non-Native American (e.g., White, African American, Latino, and Asian American)
  - 5. Only non-Native Americans
- 8. Who do you associate with now in your community?
  - 1. Only Native Americans
  - 2. Mostly Native Americans
  - 3. About equally Native Americans and non-Native Americans
  - 4. Mostly non-Native American (e.g., White, African American, Latino, and Asian American)
  - 5. Only non-Native Americans
- 9. What music do you prefer?
  - 1. Native American music only (e.g., pow-wow music, traditional flute, contemporary, and chant)
  - 2. Mostly Native American music
  - 3. Equally Native American and other music
  - 4. Mostly other music (e.g., rock, pop, country, and rap)
  - 5. Other music only
- 10. What movies do you prefer?
  - 1. Native American movies only
  - 2. Mostly Native American movies
  - 3. Equally Native American and other movies
  - 4. Mostly other movies
  - 5. Other movies only
- 11. Where were you born?
  - 1. Reservation, Native American community
  - 2. Rural area, Native American community
  - 3. Urban area, Native American community

- 4. Urban or Rural area, near Native American community
- 5. Urban or Rural area, away from Native American community

### 12. Where were you raised?

- 1. Reservation, Native American community
- 2. Rural area, Native American community
- 3. Urban area, Native American community
- 4. Urban or Rural area, near Native American community
- 5. Urban or Rural area, away from Native American community

### 13. What contact have you had with Native American communities?

- 1. Raised for 1 year or more on the reservation or other Native American community
- 2. Raised for I year or less on the reservation or other Native American community
- 3. Occasional visits to the reservation or other Native American community
- 4. Occasional communications with people on reservation or other Native American community
- 5. No exposure or communications with people on reservation or other Native American community

### 14. What foods do you prefer?

- 1. Native American foods only
- 2. Mostly Native American foods and some other foods
- 3. About equally Native American foods and other foods
- 4. Mostly other foods
- 5. Other foods only

## 15. In what language do you think?

- 1. Tribal language only (e.g., Shoshone, Bannock, or another tribal language)
- 2. Mostly tribal language, some English
- 3. Tribal language and English about equally well (bilingual)
- 4. Mostly English, some tribal language
- 5. English only

#### 16. Do you

- 1. Read only a tribal language (e.g., Shoshone, Bannock, or another tribal language)
- 2. Read a tribal language better than English
- 3. Read both a tribal language and English about equally well
- 4. Read English better than a tribal language
- 5. Read only English

#### 17. Do you

- 1. Write only a tribal language (e.g., Shoshone, Bannock, or another tribal language)
- 2. Write a tribal language better than English
- 3. Write both a tribal language and English about equally well
- 4. Write English better than a tribal language
- 5. Write only English

- 18. How much pride do you have in Native American culture and heritage?
  - 1. Extremely proud
  - 2. Moderately proud
  - 3. A little pride
  - 4. No pride, but do not feel negative toward group
  - 5. No pride, but do feel negative toward group
- 19. How would you rate yourself?
  - 1. Very Native American
  - 2. Mostly Native American
  - 3. Bicultural
  - 4. Mostly non-Native American
  - 5. Very non-Native American
- 20. Do you participate in Native American traditions, ceremonies, occasions, and so on?
  - 1. All of them
  - 2. Most of them
  - 3. Some of them
  - 4. A few of them
  - 5. None at all

# Appendix C

# Adapted ASK-ASD

Please designate the following statements regarding developmental disabilities as True or False. For each answer, please indicate how certain you are of the accuracy of your response.

		Please		Please rate your confidence in your			
			ate these	answer			
		stateme					
		true or True	False	Not at all	Confident	Very	
		True	Taise	confident	Commuent	Confident	
1.	Adults can never be diagnosed with ASD/autism.	Т	F	$\circ$			
2.	An ASD/autism diagnosis is often based on parental interviews and observations of behavior.	Т	F				
3.	If a teacher believes a student has ASD/autism, he or she can give an initial diagnosis.	Т	F				
4.	An individual can be diagnosed with both ASD/autism and intellectual disability (previously known as mental retardation).	Т	F	$\circ$			
5.	A common initial concern of ASD/autism is failure to develop language.	Т	F				
6.	There is a specific gene that can be used to identify ASD/autism.	Т	F				
7.	ASD/autism is nearly five times as likely to occur in boys as girls.	Т	F				
8.	Studies estimate that prevalence of ASD/autism in children has risen since 2008.	Т	F				

	True	False	Not at all confident	Confident	Very Confident
9. There is strong evidence for low income as a risk factor for ASD/autism.	Т	F			$\bigcirc$
10. ASD/autism is contagious.	Т	F	$\bigcirc$	$\bigcirc$	$\bigcirc$
11. Children with diets higher in sugars and processed foods show an increased risk of developing ASD/autism.	Т	F		$\circ$	$\bigcirc$
12. Most evidence suggests ASD/autism can be caused by vaccines.	Т	F	$\bigcirc$		$\bigcirc$
13. At one time, scientists believed ASD/autism was caused by lack of parental interest and motherly warmth.	Т	F		$\circ$	$\bigcirc$
14. Children with older parents have a higher risk of developing ASD/autism.	Т	F	$\bigcirc$		$\bigcirc$
15. Problems at birth (e.g., fetal distress, breech presentation) have been linked to ASD/autism.	Т	F			$\bigcirc$
16. Large-scale studies support a link between season of birth and ASD/autism.	Т	F			$\bigcirc$
17. ASD/autism can be fatal over time.	Т	F	0		
18. Early intervention can alleviate symptoms of ASD/autism and lead to improvements in IQ, language, and social behaviors.	Т	F	0	$\circ$	
19. About 75% of individuals with ASD/autism also meet criteria for obsessive-compulsive disorder.	Т	F	$\bigcirc$		

	True	False	Not at all confident	Confident	Very Confident
20. One common treatment for ASD/autism is Applied Behavior Analysis.	Т	F	0	$\bigcirc$	$\bigcirc$
21. With support, therapy, and medication, ASD/autism can be cured.	Т	F			$\bigcirc$
22. About 25% of individuals with ASD/autism remain nonverbal throughout their lives.	Т	F	0	$\circ$	$\bigcirc$
23. All individuals with ASD/autism have lower than average IQs.	Т	F			$\bigcirc$
24. An early symptom of ASD/autism is a failure to attend to facial expressions, gestures, and speech.	Т	F	0	$\bigcirc$	$\bigcirc$
25. Children with ASD/autism have patterns of play that are similar to their typically-developing peers.	Т	F		$\bigcirc$	$\bigcirc$
26. Individuals with ASD/autism have difficulty interacting socially.	Т	F		$\bigcirc$	$\bigcirc$
27. Individuals with ASD/autism rarely form intimate relationships, even with their parents.	Т	F	0		
28. Individuals with ASD/autism often engage in restrictive, repetitive behaviors (e.g., lining up cars, strictly adhering to schedules).	Т	F	0	0	

Additional items about developmental disabilities that will be mixed within the ASK-ASD measure:

	True	False	Not at all confident	Confident	Very Confident
29. Some adults with developmental disabilities can live independently.	Т	F			
30. A child with an intellectual disability benefits from school.	Т	F		$\bigcirc$	$\bigcirc$
31. You can tell some people who have a fetal alcohol spectrum disorder because they have specific facial features that indicate alcohol exposure in utero.	Т	F			
32. Children with learning disabilities are lazy and unmotivated.	Т	F			
33. Those with developmental disabilities have the same feelings as other people.	Т	F		$\circ$	
34. Individuals with intellectual disabilities have physical as well as mental disabilities.	Т	F		0	$\bigcirc$
35. All individuals with fetal alcohol spectrum disorders have intellectual disabilities.	Т	F			
36. Learning disabilities are not the same as intellectual disabilities.	Т	F			
37. Individuals with developmental disabilities cannot learn.	Т	F	$\circ$	$\bigcirc$	

## Appendix D

## **Developmental Disabilities Beliefs Scale**

Below are statements about developmental disabilities. Indicate your agreement with each statement by circling one of the numbers below each statement. A 1 indicates a strong disagreement with a statement and a 5 indicates a strong agreement with a statement.

1. People wi	th developmental	disabilities should be kept	in institutions.*	
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
2. People wi	th developmental	disabilities should be treate	ed at regular hospi	tals.
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
3. All people	with developme	ntal disabilities look differe	ent from typical pe	ople.*
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
4. People wi	th developmental	disabilities have parents w	ith developmental	disabilities.*
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
5. Some peo	ple with developr	nental disabilities can learn	to live normal liv	es.
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
	_	nental disabilities are not ca omeone else to make most o	-	
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree

7. Individuals with developmental disabilities are teachers with lessons for the community.

<sup>\*</sup>Indicates items that are reversed scored

1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
	ght education or ctive workers.	training, most people with	developmental dis	abilities could be
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
9. When socie we are all b		with developmental disabi	lities live to their h	ighest potential,
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
10. People with possible.	n developmental	disabilities should be integ	grated into normal	society as much as
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
11. People witl	n developmental	disabilities should be incl	uded in public plac	es or social events.
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
12. People with	n developmental	disabilities should be allo	wed to vote.	
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
13. People with	n developmental	disabilities have special st	rengths or gifts.	
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
14. People with pass the dri	-	disabilities should be able	to obtain a driver's	s license if they

<sup>\*</sup>Indicates items that are reversed scored

1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
-	h developmental closely monitore	disabilities should not be a ed.*	llowed to live on	their own; they
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
16. If someone	has a child with	a developmental disability	that's their proble	em.*
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
17. People with	h developmental	disabilities should be able	to marry.	
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
18. Individuals	s with developme	ental disabilities are taboo a	and should not be	seen out in public.
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
		disabilities should have equipments, and stores.	ual access to priva	ate establishments
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
	mpanies should n when they hire.	nake an effort to employ inc	dividuals with dev	relopmental
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
*Indicates ite	ms that are rever	rsed scored		

21. Most people own.*	with developmenta	l disabilities are not c	apable of making do	ecisions on their
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
	training and superv embers of their loca	ision, people with deval communities.	velopmental disabili	ties can be
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
23. Most individual community.	uals with a develop	mental disability can	learn to work and so	ocialize in their
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
24. Taboo behav	ior of the parents is	a cause of an individ	ual's developmenta	l disability.
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
25. People with o	developmental disal	pilities should have ed	qual access to places	s of worship.
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
	right with my child mental disabilities.	ren to being educated	l in the same classro	om with children
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
27. People with on as the general	-	oilities should have e	qual access to the sa	me public places
1 Strongly	2	3 Neutral	4	5 Strongly

<sup>\*</sup>Indicates items that are reversed scored

Disagree				Agree
•	•	fices, and all related meditreating individuals with c		-
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
	developmental of the developmental of the developmental of the development dev	disabilities should be able ts.	to live in their own	homes,
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
	with developmenessage for the content	ntal disabilities should no ommunity.	t be treated because	this may interfere
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
31. People with	developmental	disabilities should be allo	wed to have childre	n.
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
32. I would predisability.*	fer not to live in	a neighborhood with a pe	rson with a develop	omental
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree
	with developme unity activities.	ntal disabilities should ha	ve the opportunity t	o fully participate
1 Strongly Disagree	2	3 Neutral	4	5 Strongly Agree

<sup>\*</sup>Indicates items that are reversed scored

## Addendum

After communications with the tribal council, ownership of the data resulting from this study will be shared between the researchers at Idaho State University and the tribe. The tribal council will identify a member of the tribe who is able to comply with the Institutional Review Board's requirements for data security and confidentiality as well as understand the implications and interpretations of the data.