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EXPLORING THE IDENTIFICATION OF AMERICAN INDIAN CHILDREN WITH AUTISM SPECTRUM DISODER THROUGH THE STORY OF A PARENT

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EXPLORING THE IDENTIFICATION OF AMERICAN INDIAN CHILDREN WITH AUTISM SPECTRUM DISODER THROUGH THE STORY OF A PARENT

By

Christopher P. Cooper

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DEDICATION

This dissertation is dedicated to Pablo, who helped me keep the faith and keep pushing through every pivot of this dissertation. I know how important this research was to you and your family.

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I would like to acknowledge several people for their help towards the completion of this dissertation. First and foremost, thank you to my wife, Claudia, who patiently supported me through the program. Second, to my mom, Elizbeth Cooper Trujillo who was available to answer questions that helped my self-reflection throughout the process. I would also like to thank the G-Unit (Pablo, Sima, Jenny, Leha, Tina, Tau, and Mong) for the laughs, the tears, the lunches, and texts to keep all of us supported and graduating.

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EXPLORING THE IDENTIFICATION OF AMERICAN INDIAN CHILDREN WITH AUTISM SPECTRUM DISODER THROUGH THE STORY OF A PARENT

Abstract

By Christopher P. Cooper

University of the Pacific
2021

American Indian and Alaska Native children are diagnosed with Autism Spectrum Disorder at later ages than Non-Hispanic White children. Other than being included in prevalence studies, in the last thirty years, there has been less than a handful of studies that have looked specifically at Autism Spectrum Disorder within the AI/AN community. No studies looked at the assessment experience of parents.

This exploratory study used Indigenous Storytelling Methodology to hear an AI/AN parent's initial developmental concerns about their child and their experience with the Autism Spectrum Disorder diagnosis process. The system of assessment created a frustrating experience, and the parent believed the child made eye contact, but found out later that there was really a lack of sustained eye contact. This research creates a base to start looking at Autism Spectrum Disorder symptoms to use for better outreach in the community and informs Tribal Health Clinics and Early Childhood Programs to better help guide parents through the Autism Spectrum Disorder assessment process.

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LIST OF ABBREVIATIONS

ADDMN	Autism and Developmental Disabilities Monitoring Network
ASQ-3	Ages and Stages Questionnaire 3rd Edition
AI/AN	American Indian and Alaska Native
APA	American Psychiatric Association
ASD	Autism Spectrum Disorder
CBPR	Community Based Participatory Research
COVID-19	Corona Virus Disease 2019
CDC	Center for Disease Control and Prevention
CRIHB	California Rural Indian Health Board, Incorporated
DSM-V	Diagnostic Statistical Manual 5th Edition
HIPAA	Health Insurance Portability and Accountability Act
IDEA	Individuals with Disabilities Education Act
IRB	Institutional Review Board
M-CHAT	Modified Checklist for Autism for Toddlers
M-CHAT-R	Modified Checklist for Autism for Toddlers Revised
M-CHAT-R/F	Modified Checklist for Autism for Toddlers Revised with Follow-up
PHI	Personal Health Information
SWYC	Survey of Wellbeing of Young Children
USPSTF	United States Preventative Services Task Force

CHAPTER 1: INTRODUCTION

This is not a typical dissertation, it is unique. As a Native scholar working with American Indians and Alaska Natives (AI/AN), it important that I introduce myself first, where I come from, and my beliefs to establish context and positionality (Sarche, 2019). Yá’át’ééh shik’éí dóó shidine’é. Shí éí Christopher Cooper Trujillo y Sandoval y Quintana y de Herrera yinishyé. Ákót’éego diné nishłį́. Ahéhee’. That was in Diné, allow me to introduce myself in English. Hello my family, my people, and friends. My name is Christopher Cooper Trujillo y Sandoval y Quintana, y de Herrera. In that way I am a Diné. Diné is more commonly known by their U.S. government name, Navajo. Thank you. I currently live in the Sacramento area, but am originally from Eastern Washington. My mom’s family’s homeland is New Mexico, my dad is Irish and Romanian. I see the world through the lens of an American Indian, Latino, and Western viewpoints. Chapter 3 will give a more thorough description, as it will be important to this research.

Dissertation as an Iterative Process- Background of the Problem

This dissertation started as a small project in Education 293D: Lean Start-Up in Social Entrepreneurship. In class, I sought to find a solution to the problem of only 13% to 50% of all eligible children for special education services being found before kindergarten entry (Glasscoe & Marks, 2011; Rosenberg, Robinson, Shaw, & Ellison, 2012). Informal research conducted by interviewing parents of preschoolers at a local Toys ‘R’ Us showed that most parents searched Google or WebMD if they had a concern about their child’s development. Less than half respondents stated that they would talk to the child’s doctor about a concern. Almost all parents said they would use a mobile application (app) to screen their child’s development if one was available.

Issues With Iterating a Child Development Application

Several iterations of the screening app were done by testing mock-ups of pages and features with groups of potential users. However, there was one problem, an actual child development screening tool was needed for the app. Child developmental screens are highly proprietary and expensive (Brooke's Publishing, 2018; Pearsons, 2018; Whitesell, Sarche, Trucksess, and the Tribal Early Childhood Research Center SWYC Community of Learning, 2015). The *Survey of Wellbeing of Young Children* (SWYC) is a free screen that was developed with funding from Centers for Disease Control and Prevention (CDC) (Sheldrick & Perrin, 2013). However, a feasibility study among American Indian or Alaska Native (AI/AN) focus groups noted that parents and community members felt that answers to some of the questions could lead to child welfare removing children from families (Whitesell et al., 2015). This meant that a child development screen for the app would need to be developed.

Adding Autism Spectrum Disorder to the application idea. The informal research and a prototype of the app was shown at the University of the Pacific Innovation Summit was presented. Potential end-users gave feedback that the screen also needed to include a screen for Autism Spectrum Disorder (ASD). Those that mentioned the ASD screen were Latina/o and have autistic children. They wished a mobile application existed earlier that found their children at an earlier age when intervention may have been more helpful. This meant that the screen for the app needs to include an embedded autism screen. There is currently not a reliable and valid child development screen that includes an embedded autism screen.

How do I develop a screen. A review of existing dissertations show that dissertations tend to focus on testing the psychometrics of existing screens with different ethnic groups or adapting them in foreign languages and to other countries. These types of dissertations typically take place at the university where the child development screen was developed the screen being used in the dissertation. I did not find dissertations that talked about developing a new screen. As mentioned earlier, existing screens are proprietary (Brook's Publishing, 2018; Pearsons, 2018, Whitesell et al., 2015). The creators of these screens do not write about how they created the screen, but release Users Guides that talk about the psychometrics, reliability and validity of the screen as well as how to use the screen (Squires, Twombly, Bricker, & Potter, 1995; Squires, Potter, & Bricker, 1995).

The first iteration- too big. The first iteration of this dissertation was to identify developmental milestones in the communication, social, fine motor, gross motor, and cognitive domains with autism symptoms in the communication and social domains. The milestones would be written with measurements as a questionnaire and parents with children ages three (3) to five (5) would be asked to complete the questionnaire. Differential analysis would be conducted to check for bias by gender, race, education, and socio-economic status. I was told that this type of research would take three to five years and is typically the kind of study that a university would ask CDC for large funding to conduct with a research group.

The second iteration- lack of cultural and qualitative research. The second iteration of this dissertation was to use a structured literature review and expert interviews to identify the milestones in the communication, social, fine motor, gross motor and cognitive domains. During the defense of the proposal, I was asked to trim the topic down further and tighten up the methodology. I originally chose a structured literature review, because I had been advised early on that meta-analysis of the literature review is not typically allowed as a dissertation. At the proposal defense meeting, it was agreed to focus on symptoms of autism using the literature and expert interviews.

For four (4) months, I worked on changing my research questions and tightening the methodology. The questions changed to what are the primary, secondary, and emerging symptoms of autism in children ages two (2) through five (5), and what symptoms had cultural considerations. In discussion with my chair, my methodology focused on meta-synthesis and expert interviews. Meta-synthesis involves analyzing the theories, methods, and results of qualitative studies and synthesizing that analyses into new theories and ideas (Paterson, Thorne, Canam, & Jillings, 2001; Zimmer, 2006). I developed keywords and worked with the librarian for Benerd School of Education to identify database Search Engines. Exclusion and inclusion criteria were developed. Chapters One through Three were re-written to reflect the narrowing of the dissertation topic.

Due to advances in technology, in 1991, researchers began using home videos of autistic children from when they were younger to look for symptoms in the toddler and preschool years (Adrien, Faure, Perrot, Hameury, Garreau, Barthelemy, & Sauvage, 1991). Use of video in research is often a qualitative methodology (Bogdan & Bilken, 1997; Silverman, 2016). This led to the belief that there may be qualitative studies to use for a meta-synthesis. However, in doing the literature search, there were only quantitative studies. Studies that were qualitative were simply commentaries, summarizing the quantitative studies.

I consulted with my chair, and a plan was made to expand the parameters of the literature search to look at a larger swath of autism studies and glean information from those studies. It was also decided to look at studies that included biomarkers for autism. Biomarkers research is quantitative with a couple of commentaries of the existing research. In opening the parameters, topics were wide range but stayed at the overall domain level. For example, one study talked about parents' thoughts on communication of their autistic children, but the study stayed focused on communication and did not discuss any communication skills.

Re-assessing through the lens of empowerment. During this time, I began to think about my research design and methodology. Perhaps, I was taking the wrong approach. In every iteration, I had defined the expert as psychologists, home visiting nurses, school psychologists, early childhood teachers, and other professionals that worked with young children over several years. I went back to explore the research and the previous theoretical frameworks. The initial theoretical frameworks were Equity of Access and Empowerment. Equity of Access Framework is a health care model that assumes equal access, equal utilization, and equal outcomes, which is used to identify barriers to access (Aday & Anderson, 1981; Goddard & Smith, 2001; Oliver & Mossialos, 2004). Empowerment Framework refers to the ability to change one's reality (Freire, 1971; Rappaport, 1981; Rappaport, Swift, & Hess, 1985). The process of empowerment allows people to have better access to resources to improve their lives (Zimmerman, 1995). These frameworks were used to argue for the need to create a culturally relevant early childhood screening mobile app for parents to use as way to increase access to screening and give parents control of when to refer their children for more formal assessment if there were potential delays.

I chose to go back and review some of the autism readings through different frames of empowerment theory. In its most basic definition, empowerment is about creating self-determination in people (Freire, 1971; Rappaport, 1981; Rappaport et al., 1984; Rappaport 1987). Empowerment connects the well-being of the individual with the larger social environment (Perkins & Zimmerman, 1995). The thought of empowerment leads us to look for solutions to problems (Rappaport, 1987). Freire talks about the oppressor keeping one group in a monistic viewpoint, otherwise known as the oppressed (Freire, 1971), however he left it to the investigator to define the oppressed and the oppressor (Au, 2007; Tuck & Yang, 2012). In re-examining the literature, I chose to define the oppressor as the academic research community, and the oppressed as the communities of color in the research. I wanted to see how the research connected the well-being of the child to the larger social environment of the community (Perkins & Zimmerman, 1995). Finally, how would my looking at the literature through this framework, cause me to exercise self-determination of looking at autism within my own personal communities (Freire, 1971; Rappaport, 1981; Rappaport et al., 1984; Rappaport 1987).

There is lack of empowerment issues around autism. In genetics research around autism and minority cultures, there is an argument over whether the research is amounting to eugenics (Chown & Bearden, 2017; Nadesan, 2010; Ne'eman, 2010). A history exists of forced sterilizations of AI/AN women as part of eugenics ideals and used to enforce white superiority of people of color (Rutecki, 2011; Torpy, 2000). Although there are recommendations to develop culturally relevant screens, the research will at the same time recommend educating families to the major symptoms of autism in the dominant culture (Tek & Landa, 2013). These recommendations do not truly change how autism is looked at in those communities or if the culture defines major symptoms differently.

These issues led me to re-focus my dissertation. Although my dissertation was trying to find the intersection of culture and autism symptoms, it was still designed with a Western methodology and still trying to fit autism into a dominant culture. I decided to flip the script on the current research. Parents are the best experts of their own child's development (Glascoe, Altemeier, & MacLean, 1989; Glascoe & Dowrkin, 1995; Glascoe, MacLean, & Stone, 1991). The experts were not the professionals as the original design called for, but the parents of children with autism in the culture. Research should focus not trying to fit children from other cultures into the dominant cultures view of autism but should find what symptoms caused concerns by the parent.

I looked internally to find the most appropriate methodology, which to me seemed based on cultural traditional ways of knowledge and traditional Indigenous views of child development. This dissertation has been re-focused to meet with American Indian parents and learn about autism from their viewpoint using Indigenous Methodologies.

What Is Autism

Autism Spectrum Disorder (ASD) is “persistent deficits in social communication and social interaction across multiple contexts” (p. 47) according the Diagnostic Statistical Manual-5 (DSM-V) (American Psychiatric Association [APA], 2013). The severity of ASD is based on repetitive, restricted behavior patterns and the social communication impairments. The deficits cannot be due to global developmental delay or an intellectual disability (APA, 2013). In 2013, the APA merged the four different autism diagnoses, Autistic Disorder, Asperger’s Syndrome, Pervasive Developmental Delay-No Otherwise Specified, and Childhood Disintegrative Disorder together into ASD (McPartland & Dawson, 2014; McPartland, Law, & Dawson 2016). This research will refer to it all as autism.

Autism can be diagnosed in toddlers and preschoolers (Andersson, Gillberg, & Miniscalco, 2012; Van Wijngaarden-Cremers, Van Eeten, Groen, Van Deurzen, Oosterling, & Van der Gaag, 2013). With early autism diagnosis, early intervention has been shown to work to increase intelligence quotient (IQ) with young children (Dawson, Rogers, Munson, Smith, Winter, Greenson, Donaldson, Varley, 2016; Lovaas, 1987). Early intervention can also lead to long-term language and other cognitive skills improvement (Lovaas, 1987; Warren, McPheeters, Sathe, Foss-Feig, Glasser, & Veenstra-VanderWeele, 2011).

The Importance of Screening for Autism

The Individuals with Disabilities Education Act (IDEA) requires screening of children ages birth through five-years-old for developmental concerns as well as providing services for those children with concerns (Adams & Tapia, 2013; Aron & Loprest, 2012). Both the Autism and Development Disabilities Monitoring Network (ADDMN) and Healthy People 2020 advocate for increasing the number of children screened for ASD in early childhood (Christensen, Braun, Baio, J., Bilder, D., Charles, J., Constantino, J. N., Daniels, J., Durkin, M.S., Fitzgerald, R. T., Kurzius-Spencer, M., Lee, L. C., Pettygrove, S., Robinson, C., Schulz, E., Wells, C., Wingate, M., Zahorodny, W., & Yeargin-Allsopp., 2018, Healthy People, 2019). Estimates show ASD prevalence increasing in four-year-old children from 13.4 per 1,000 in 2010 to 17.0 per 1,000 in 2014 (Christensen, Maenner, Bilder, Constantino, Daniels, Durkin, Fitzgerald, Kurzius-Spencer, Pettygrove, Robinson, Shenouda, White, Zahorodny, Pazol, & Dietz, 2019). The APA did change the criteria for an autism diagnosis in 2013 (McPartland & Dawson, 2014; McPartland, Law, & Dawson 2016), it is not known if this increase was due to that change.

Autism screening tools. Despite screening efforts, there is no universal screening in the United States for autism, (Siu & United States Preventative Services Task Force [USPSTF], 2016). The USPSTF recommends two autism screens, the Modified Checklist for Autism for Toddlers-Revised (M-CHAT-R) and the Modified Checklist for Autism for Toddlers Revised with Follow Up (M-CHAT-R/F) which have both been modified for children between the ages of 18 months through 30 months (Siu & USPSTF, 2016). The M-CHAT-R has been used with preschool age children (36 months through 60 months) and shows promise, but it has not been validated for that age group. The Modified Checklist for Autism in Toddlers (M-CHAT) has shown a culture bias (Albores-Gallo, Roldan-Ceballos, Villareal-Valdes, Betanzos-Cruz, Santos-

Sanchez, Martines-Jaimes, Lemus-Espinosa, & Hilton, 2012; Zhang, Wheeler, & Richey, 2006) and requires significant adaptations besides language when being validated in other countries (Albores-Gallo et al., 2012). A review of the literature shows no independent research to show that the culture bias from the M-CHAT has been resolved on the M-CHAT-R and M-CHAT-R/F.

Currently, there are no comprehensive child development screens with a built-in autism screen. The creators of the Ages and Stages Questionnaire-3rd Edition (ASQ-3) built an autism screen into the ASQ-3, but it has not been validated yet (Squires, Twombly, Bricker & Potter, 2009). One study has shown promise in using the ASQ-3 as an autism screen, but the sample size was small, and it did not explore for any differences in screening based on race or socio-economic status (Hardy, Haisley, Manning, & Fein, 2015).

Racial disparities in identification of autism. There are racial disparities in the identification and diagnoses of autism. A study in 2011 noted that although the Risk Index for autism across all races increased each year from 1998-2006, it increased the least for Latina/o and AI/AN students, and it was less than half the total Risk Index increase for Non-Hispanic White students by 2006 (Travers, Tincani, & Krezmien, 2011). In the same study, the Risk Index for African-American children was higher than Non-Hispanic White children in 1998, however, by 2000, the Risk Index for African-American children dropped below Non-Hispanic White children, and by 2008, was about two-thirds the Risk Index of Non-Hispanic White children (Travers et al., 2011). Latino and African-American children are more likely to be diagnosed with severe form of ASD later in childhood rather than in early childhood (Fountain, King, & Berman, 2011; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Mandell, Wiggins, Carpenter, DiGuiseppi, Durkins, Giarelli, Morrier, Nicholas, Pinto-Martin, Shattuck, Thomas, Yeargin-Allsopp, &Kirby, 2009; Pederson, Pettygrove, Meaney, Mancilla, Goschall, Kessler, Grebbe, & Cunniff, 2012). In autism screening, doctors self-reported they felt it was easier to diagnose White children with autism than African-American and Latina/o children (Zuckerman, Mattox, Donelan, Batbayar, Baghaee, & Bethell, 2013). The doctors also self-reported that they felt White parents had a better understanding of autism, than African-American and Latina/o parents (Zuckerman et al., 2013). This study does not mention implicit bias, nor was it set up to measure implicit bias. A scan of the literature does not show implicit bias as a part of the racial barrier to screening. The same study showed if there was a Latino working in the office, screening rates increased for African-American and Latina/o children (Zuckerman, 2013).

Cultural bias in screening. As noted above, the M-CHAT may be biasedhas shown a culture bias (Albores-Gallo, Roldan-Ceballos, Villareal-Valdes, Betanzos-Cruz, Santos-Sanchez, Martines-Jaimes, Lemus-Espinosa, & Hilton, 2012; Zhang, Wheeler, & Richey, 2006) and requires significant adaptations for use in other languages and cultures (Albores-Gallo et al., 2012). Both the M-CHAT and M-CHAT-R/F contain questions about pointing with the finger and eye contact and (Robins, 2019), but for many Latin American and Asian Countries and AIAN, pointing and making eye contact are not socially acceptable behaviors (Albores-Gallo et al., 2012, Morris, 1994; Zhang et al., 2006). There has been no independent research to verify that the M-CHAT-R and M-CHAT-R/F have solved the bias issue. The ASQ-3 has not been checked for bias in its autism screening. There is a need for culturally relevant screening for ASD.

Description of the Research Problem

From 1998 through 2006, AI/AN children had the lowest Risk Index of all races for autism (Travers et al., 2011). AI/AN children with autism were underrepresented in special education programs in 1998 (Donovan & Cross, 2002). For children ages three through five years of age, AI/AN children were the only underrepresented racial group (Morrier & Hess, 2010). Western research methods focus on educating parents about autism symptoms that are culturally inappropriate (Tek & Landa, 2013). There are limited studies that look at autism through an Indigenous world view, and no studies that ask parents what they view as the symptoms, and what they do not view as the symptoms of autism.

Purpose of the Study

The purpose of this research is to look at autism through an Indigenous world view, so educators and doctors can better screen and assess AI/AN children for autism.

Research Questions

This study addresses the following questions:

1. What developmental characteristics initially gave AI/AN parents' concerns about their autistics child's development?
2. Were the developmental concerns part of the recognized symptoms of autism as identified by the Mayo Clinic, or a different symptom.
3. How was the autism referral and assessment experience for parents.

Significance of the Study

This exploratory study seeks to study autism from the view of the forgotten experts, AI/AN parents. Most research recommendations have been to focus on educating AI/AN parents about the indicators of autism such as lack of eye contact or pointing at items that are considered cultural taboos versus what the community views as the indicators. Other than prevalence studies, there have been little studies into autism among the AI/AN population.

Decolonizing and Indigenizing the Research

This study seeks to decolonize autism research among the AI/AN population and indigenize academic research. Decolonizing is moving away from Western ways of learning and knowledge and moving towards using AI/AN traditional ways of knowing and research methods (Cull, Biin, Simcoe, Erickson, Hancock, McKeown, Pidegeon, & Vedan, 2018; Smith 2013). It is moving away from a system that maintains it power by saying we must educate the culture that these cultural issues are indicators of autism to this is how the population defines indicators of autism and using storytelling methodology to explore the answers. It switches the experts from academia to the population itself.

Indigenization is the process of creating space to allow for AI/AN culture, processes, intent, and traditional ways of knowing (Cull et al., 2018). By working with me to approve this dissertation, the dissertation committee and Benerd School of Education have opened themselves and the dissertation process up to the indigenization process. It creates a precedence for future Native scholars at University of the Pacific to use Indigenous methodologies.

Theoretical Framework

This dissertation is based on Indigenous epistemology. This means that the theoretical frameworks used are Indigenous based. The two main frameworks are Indigenous ways of knowing and Indigenous child development theory. For the purposes of this research, decolonizing theory is included as a means of promoting Indigenous knowledge.

Indigenous Ways of Knowing and Decolonizing Theory

In research, there is always a power dynamic between the researcher and the participants, with the power residing with the researcher (Ben-Ari & Enosh, 2013; Denzin, 2001; Goffman, 1959; Smith, 2013). Academic research is based in Western power, thought, and science as a part of colonizing Indigenous people (Hart, 2010; Kovach, 2010; Smith, 2013). Academia cataloged and categorized the Indigenous people and their culture from a Western viewpoint and Western sciences and methods (Smith, 2013). This was based on a false assumption by academia that Indigenous people did not have the ability or knowledge to do their own research or catalog their own culture (Smith, 2013).

Decolonizing theory is changing the paradigm of Western research. Decolonizing is the idea of stripping away the Western research methods and categorizing of Indigenous knowledge, culture, and thought (Botha, 2011; Denzin & Lincoln, 2008; Smith, 2013) The theory is based on Indigenous people being able to do research in their own communities, using their own methodologies (Botha, 2011; Smith, 2013). It looks at problems and research through the Indigenous lenses of culture, Indigenous knowledge, community, concepts of time, levels of consciousness, spirituality, context, and positionality (Denzin, Lincoln, & Smith, 2008; Smith, 2013).

The traditional ways of knowing are attempting to bring back the knowledge that was blocked by Western knowledge and imposition of the dominant culture (Castellano, 2000; Dei, Hall, & Rosenberg, 2000). The Indigenous worldview shapes Indigenous knowledge (De la Torre, 2004; Hart, 2010). De la Torre (2004) defines knowledge as the worldviews, traditions, and customs enacted by an Indigenous nation. Castellano (2006) breaks Indigenous knowledge down to four categories; 1). Holistic; 2). Personal; 3.) Oral; and, 4). Experiential. Maurial (1999) adds local as a knowledge category. Indigenous knowledges are linked together by the spiritual which ties everything back to Creator (McKenzie & Morrissette, 2003). Indigenous knowledge is also circular compare to western knowledge being linear because it is all interconnected (Maurial, 1999). This dissertation is looking at autism through the lens of Indigenous knowledge.

Indigenous Child Development Theory

Although boarding schools disrupted Tribal family practices and traditions for generations (Giago, 2006), there have been attempts at creating a Tribal framework of child development. Child development is viewed as a healthy child and that health encompasses spiritual, mental, and physical components, with culture binding everything together

(Ledesma,1998). Children are given autonomy to explore their environment and learn (Connors & Donnellan, 1993; Friesen & Friesen, 2002). The parents, extended family, and community help to raise the child and give guidance.

The spiritual plays a strong role in child development. From perinatal development and forward, children are considered sacred and a gift from Creator to raise (EagleWoman & Rice, 2016; Light and Martin, 1985). During this time, is when spiritual beliefs and attitudes are taught (Bia, 2011; Light & Martin, 1985).

Children are encouraged to develop at their own pace and are not held to the same developmental milestones as Western Culture (Connors, 1992). Among the Diné, if a child has a delay, it may be considered a unique trait of the child versus a developmental condition (Connors & Donnellan, 1993). For many Tribe, disabilities are not stigmatizing and may be considered special or spiritual messengers (Patterson, 1997).

Limitations of the Research

This study has some limitations. There are 574 federally recognized Tribe in the United States. Each has its own culture, language, and traditional ways of knowing. This means that the study is not generalizable to the general public. As a researcher, I see research through the lens of the three cultures that I was raised in, so it is possible, that I may have missed some cultural context, even though I tried to safeguard against that.

Another limitation is acculturation and assimilation. At its most basic level, acculturation is the changes and processes that happen between two cultures meeting over time (Redfield, Linton, & Herskovitz, 1936). In acculturation, eventually, one culture picks up the cultural patterns of the other dominant culture, and this leads to that culture assimilating or becoming a part of the dominant culture (Alba & Nee, 1997; Gordon, 1964). This study does not take acculturation and assimilation into consideration. This study explores what autism looks like to the participants of American Indians and Alaska Natives from various Tribe, and not whether the participant is traditional or acculturated and assimilated.

Description of the Study

This is an exploratory qualitative study. It is Community Based Participatory Research (CBPR) and utilizes an advisory committee of AI/AN parents that have experience with early intervention and early childhood special education services to help guide the formulation of the questions, research methods, and appropriateness of the research. Besides Institutional Review Board (IRB) approval from University of the Pacific, the study was also approved by a Tribal IRB through the California Rural Indian Health Board, Inc (CRIHB). The study uses storytelling, which is an Indigenous methodology, to answer the research questions. Participants are AI/AN parents with at least one child that has been diagnosed with autism.

Definition of Key Terms

The following terms will be used throughout this study.

American Indian/Alaska Native are people whose origins are from the original Indigenous people of the Americas (U.S. Census Bureau, 2010). There is not a set legal definition of American Indian or Alaska Native although Congress, Bureau of Indian Affairs, and the Courts have tried to establish legal definitions (Wilkins & Stark, 2017). The Bureau of Indian Affairs defines American Indian/Alaska Native as any member by blood degree of a federally recognized tribe (Bureau of Indian Affairs, 2017), however that definition excludes people from Tribe whose recognition was terminated by the U.S. government, Native Hawaiians, and descendants of Indigenous peoples of Puerto Rico (Wilkins et al, 2017). For the purpose of this study, the definition if anyone that self identifies as descending from the original people of North America. Some AI/AN tribe's peoples are on both sides of the United States border along with Mexico and Canada.

Autism is "persistent deficits in social communication and social interaction across multiple contexts" (p. 47) according the Diagnostic Statistical Manual-5 (American Psychiatric Association [APA], 2013). The severity of ASD is based on repetitive, restricted behavior patterns and the social communication impairments. The deficits cannot be due to global developmental delay or an intellectual disability (APA, 2013). For the purposes of this paper, any diagnosis that falls under the umbrella of ASD is referred to as autism.

Decolonize is moving research away from Western methods and epistemologies and using Indigenous traditional ways of knowing and Indigenous research methods (Cull et al., 2018; Smith, 2013).

Indigenous does not have a definition, but it does have two distinguishing characteristics. Indigenous are people that have "an ancient relationship with a defined territory and ethnic distinctiveness" (Curie, 2003). AI/AN are the Indigenous people of the United States. The term Indigenous maybe interchanged for AI/AN. Indigenous will be used to discuss epistemology and methodology.

Summary

Autism has a low prevalence rate among AI/AN young children (Travers et al, 2011). Autism screening tools have several questions about eye contact with people and pointing at people, which are not done in many AI/AN cultures (Albores-Gallo et al., 2012, Morris, 1994; Zhang et al., 2006). Western research says that educational outreach should focus on educating AI/AN parents about the symptoms of autism that are not culturally done (Tek & Landa, 2013). There is limited research about autism within AI/AN communities. Instead of relying on Western methods to determine how best to reach out about autism symptoms, this study seeks to use storytelling methodology to determine what autism symptoms caused initial concerns for AI/AN parents with autistic children.

CHAPTER 2: LITERATURE REVIEW

Autism is an illness with differing levels of severity that effects social communication and social interactions (APA, 2013). The risk and prevalence have increased across all races over the last 20 years (Christensen et al., 2018; Christensen et al., 2019, Travers et al., 2011). The prevalence of autism among AI/AN is low (Travers et al., 2019), although the reason is unknown. Some of the Western defined symptoms of autism include a lack of eye contact and pointing with a finger (Albores-Gallo et al., 2012, Morris, 1994; Zhang et al., 2006). These are not considered symptoms in many AI/AN cultures, as eye contact and pointing with a finger are considered cultural taboos (Albores-Gallo et al., 2012, Morris, 1994; Zhang et al., 2006). There have been few studies about autism within the AI/AN community.

This is a community based participatory study to learn about autism identifiers from the perspective of AI/AN parents using Indigenous methodologies. This literature review will start by looking at the foundational frameworks of traditional Indigenous knowledge, the suppression of that knowledge, and finally, the decolonization of that knowledge. The review will then move to reviewing Indigenous child development thoughts and ideas.

Following theories, the literature review will move into the research on the etiology of autism, and perspectives on children with special needs and autism among AI/AN. Finally, it will end with a look at the unique AI/AN population in California.

Indigenous Knowledge and Wisdom

Prior to Columbus coming to the Americas, the Indigenous people of the continents had their own ways of knowledge, wisdom, and science. The Mayans had a complex math and astronomy system including algorithms (Joseph, 2010; Lara-Alecio, Irby, & Morales-Aldana, 1998; Saturno, Stuart, Aveni, & Rossi, 2012). The Incas had a binary code system (Ascher, 2005; Ascher & Ascher, 1972; Ascher & Ascher, 1981). The Iroquis practiced a form of democracy (Barreiro, 1988; Grinde & Johansen, 1991; Grinde & Johansen, 1996). The Mexica (Aztecs) had a free public education and higher education system in place (Gonzalez, 2017; Padilla & De Snyder, 1988). The botanical knowledge and healing traditions of American Indians had a great influence on modern western medicine (Moerman, 1979; Portman & Garrett, 2006). North America was simply known as Turtle Island by the people who lived here, as an outline of Canada, the United States of America, and Mexico looks like a turtle (Dei, 2013; Dumbrill & Green, 2008, Snyder, 1994).

Western research requires a definition of Indigenous knowledge, as defining is one way that Western knowledge categorizes and compares (Battiste & Youngblood Henderson, 2000). With thousands of Indigenous groups, it is not possible to give a definition to Indigenous knowledge (Hart, 2010; Smith, 2013). Smith (2013) argues that it is unethical to define due to so many groups with their own cultures, knowledges, and belief systems. Defining Indigenous knowledge is inappropriate, because by defining it, researchers are trying to compare knowledges, and no methodology exists for that (Battiste & Youngblood Henderson, 2000).

Indigenous Worldviews

Although there is no formal definition for Indigenous knowledge, Indigenous knowledge can be described as the deep-rooted knowledge, customs, traditions, and worldviews of Indigenous nations (De La Torre, 2004; Hart, 2010). Hart (2010) believes that Indigenous worldviews can be used to describe Indigenous knowledge and an epistemology. There are several commonalities among Indigenous worldviews (Gill, 2002; Hart 2010, Rice 2005). Indigenous worldviews are relational between the spiritual, community, and individual (Battiste & Youngblood Henderson, 2000; Graham, 2002; Gross, 2003; Hart 2010; Simpson, 2000; Weaver, 2001). There are seven specific commonalities between Indigenous worldviews; 1)

Knowledge is cyclical, holistic, and relational between entities, the non-living and the living; 2) The importance of the relationship between the people and the spiritual; 3) The human is of least importance; 4) The truth is dependent on an individual's experience, so there are many truths; 5) Sacredness of the land; 6) Everything is equal; and, 7) Everything lives (Battiste & Youngblood Henderson, 2000; Hart, 2010; LaFrance & Nichols, 2009; Simpson, 2000). Knowledge is a living entity that crosses realities (LaFrance & Nichols, 2009). It connects the ancestors, the spiritual, and the physical (Battiste & Youngblood Henderson, 2000; LaFrance & Nichols 2009; Smith, 2013).

There are also characteristics of Indigenous knowledge. It is oral, holistic, and local (Battiste & Youngblood Henderson, 2000; Castellano, 2000; Hart, 2010; Maurial, 1990). Castellano (2000) also says the characteristics are experiential, personal, and transmitted through anecdotal and metaphorical language.

Pushing Indigenous Knowledge Out of Academia

Indigenous knowledge was pushed aside by colonization, academia, and the government of the United States. With the conquest and colonization of Indigenous peoples came new education and knowledge systems (Gonzalez, 2017; Smith, 2013). Spain brought in education through religious education by the Catholic Church and the establishment of Universities influenced by the Enlightenment (Gonzalez, 2017). Eventually, Indigenous children were left out of the education system (Gonzalez, 2017). Smith (2013) goes further in giving examples of how the system changed to exclude Indigenous knowledge. Part of the reasons that Smith (2013) gives are: 1) Britain brought over its own law system that decides what is admissible, and in the university systems decides what is valid and reliable; 2) What is objective, subjective, and neutral to determine the framework and outcome of the research; 3) A premium on written knowledge versus oral knowledge, which leaves out the wisdom and knowledge of elders in

Indigenous communities; 4) the decision of who is the expert and who speaks for who in disseminating the knowledge; 5) the idea of time and location is related to history and determines how long observation is; 6) views of science that allow who determines and arranges the facts; and, 7) views about human nature, the individual, and personal responsibility. Smith (2013) argues that this allowed colonists with their supremacy viewpoints to not acknowledge that Indigenous people were as smart as them, leading to ignoring and pushing aside Indigenous knowledge and science. This system also allows research to continue to keep its Western dominant view.

An example of Smith's argument can be seen in the article by the same Gonzalez (2017) that mentioned Mexica education in the introductory paragraph of this section. The article is looking at the history of education in Mexico and is part of a larger book on education in Africa, the Caribbean, and Central America. In one paragraph, Gonzalez (2017) talks about the Calmecac and how it was used to educate Mexica children. She mentions how it was a free public education system, and it was used so children could grow up to help change their social position (Gonzalez, 2017). In the next paragraph, Gonzalez (2017) speaks of the Spanish conquest, and how the Spaniards changed education. Gonzalez (2017, p. 89) writes that education changed to "formal knowledge, including reading, writing, and arithmetic." In just that sentence, her own subjectivity and objectivity, and ideas of what is valid and reliable, has allowed her to completely dismiss the Mexica way of education and knowledge. Spain had more formal knowledge than the Indigenous people. By writing "reading, writing, and arithmetic", Gonzalez placed importance on the textual knowledge versus that oral nature of education. In one sentence the whole previous paragraph and idea of Indigenous education and knowledge was dismissed and made to be inferior.

Academia stifled Indigenous knowledge in other ways. Anthropology and ethnography were used to research Tribal communities from a Western perspective and to categorize the information without any input from the people it was studying (Kovach, 2010; Smith, 2013). To control Indigenous knowledge, areas of studies became ethnobotany and other ethno- types of studies, which implied that Indigenous knowledge was a lesser knowledge (Kovach, 2010; Smith, 2013), even though there is no methodology to compare knowledges (Battiste & Youngblood Henderson, 2000). Indigenous worldviews were not taught, because philosophers believed that Indigenous knowledge was disjointed because there was no critical thought or sequencing as based in Eurocentric, Western views (Gill, 2002). Indigenous students are forced to assimilate to Western viewpoints at college and ignore the wisdom and knowledge that they have learned (Hart, 2010; Kovach, 2010). Even in this dissertation, it has been suggested by other academics, outside of the dissertation committee, that Marxist viewpoint with its Critical Race Theory, should be used as the theoretical background versus Indigenous knowledge and Indigenous child development. However, Marxist theory was still developed in Europe and is just another Western viewpoint to examine Indigenous knowledge that existed before Western viewpoints came to America. It only shifts the type of Western viewpoint to examine and categorize the research and is not an Indigenous worldview.

Government Attempts to Eradicate Indigenous Knowledge

In addition to colonialism and academia stifling the Indigenous knowledge, the government of the United States tried to eradicate Indigenous knowledge. Indigenous knowledge is based on the sacredness of the land and the people’s relationship with the land (Battiste & Youngblood Henderson, 2000; Hart, 2010; LaFrance & Nichols, 2009), the government passed the Indian Removal Act of 1830 and the Dawes Act to remove and relocate AI/AN from their ancestral homelands (Black, 2015; Bowes, 2016). The Indian Relocation Act of 1956 encourages AI/AN to move to urban areas of the West Coast (Jaimes, 1992). By disconnecting people to the land, an attempt was made to create a loss of Indigenous knowledge.

Denying religious ceremonies. Spirituality is a key characteristic of Indigenous knowledge, as there is a deep relationship between the spiritual, the people, and multiple realities (Battiste & Youngblood Henderson, 2000; Hart, 2010; LaFrance & Nichols, 2009; Simpson, 2000; Smith, 2013). Until the passing of the Indian Religious Freedom Act, the government routinely infringed upon, banned, or tried to eradicate in many instances the practice of AI/AN religious ceremonies and beliefs (Michaelsen, 1984; Suagee, 1982).

The use of boarding schools to erase Indigenous knowledge. The last major way that the government tried to eradicate Indigenous knowledge was through boarding schools. Boarding schools were operated by Christian churches and the government from 1870-1935 (Adams, 1995; Cooper, 1999; Davis, 2001). Some refer to this era of the boarding schools as the last major war against AI/AN people (Davis, 2001). During this time, AI/AN children were forcibly removed from their homes and reservations and placed in boarding schools, where their hair was cut, their language and culture was forbidden, new concepts of time, space, and land were taught to them, as well as English and Western culture (Adams, 1995; Cooper; 1999; Davis, 2001). Ceremony and songs were forbidden (Adams, 1995; Cooper, 1999). To speak a Tribal language, engage in your culture, or practice ceremony was met with harsh punishment (Adams, 1995; Cooper, 1999; Davis, 2001). Boarding schools forced AI/AN children to assimilate into the American culture, and lose their Indian identity and culture (Adams, 1995; Cooper, 1999; Davis, 2001). Many children died at the boarding schools or were sent home to die (Adams, 1995; Cooper, 1999). The result of the boarding schools was almost the extinction of Tribal languages, traditions, and culture (Adams, 1995; Cooper, 1999; Davis, 2001), which are integral parts in descriptions of Indigenous knowledge (De La Torre, 2004; Hart, 2010).

The Importance of Indigenous Knowledge and Methodologies in Research

When studying the AI/AN community, Indigenous knowledge and methodologies should be used (Hart, 2010; Kovach, 2010, Smith, 2013). Although AI/AN may have a mixture of Indigenous viewpoints and Western viewpoints (Adams, 1995; Davis, 2001), these viewpoints differ in concepts and realities (Battiste & Youngblood Henderson, 2000; Hart, 2010; LaFrance & Nichols, 2009; Simpson, 2000). To truly understand an answer given in research, there must be an understanding of the answer from the perspective of the person giving the answers, because there are many truths based on the person's experiences, and their relationship with the spiritual, community, and self (Battiste & Youngblood Henderson, 2000; Hart, 2010; LaFrance & Nichols, 2009; Simpson, 2000). There must be an understanding of the frameworks of what is being studied within the culture (Kovach, 2010; Smith 2013).

Indigenization Process

Given that academia in one of the parties that has used research to maintain Western viewpoints, and discourage Indigenous knowledge, academia must go through the Indigenization process. Academia needs to be open to Indigenous students using Indigenous knowledge and methodologies in their research (Cull et al., 2018; Kovach, 2010; Smith, 2013). This means creating a space for students to explore these areas (Cull et al, 2018, Hart, 2010; Kovach, 2010; Smith, 2013). During my interview to the doctoral program at University of the Pacific, I was asked what kind of research I wanted to do. My answer was that I wanted to do something that involved Indigenous methodologies or evaluation frameworks and adding to the traditional knowledge base. I was not discouraged from this during the interview process or during any point throughout the doctoral program. Throughout the process, myself and other students were allowed to talk about Indigenous frameworks, worldviews, and decolonization of data. I was allowed to use Indigenous Evaluation Framework for the Evaluation class while working with a small AI/AN educational organization. The framework has been shared with several cohorts. By allowing this space, the Benerd School of Education in Sacramento is going through the Indigenization process.

Decolonization Process

Besides the Indigenization process, there is also the decolonization process. Research in Indigenous communities is traditionally based on Western viewpoints and looking at Indigenous culture and issues through a Western lens (Hart, 2010; Kovach, 2010, Smith, 2013). This was because of the academic view that Indigenous knowledge lacked critical thinking and was not sequential (Gill, 2002; Hart, 2010), therefore, Indigenous knowledge was inferior (Gill, 2002; Hart, 2010; Smith, 2013). To bring Indigenous knowledge to the forefront, the research process must be decolonized (Kovach, 2010; Smith, 2013). To decolonize is to strip away the Western methodologies, viewpoints, and lenses that have been used to study Indigenous peoples (Botha, 2011; Denzin & Lincoln, 2008; Smith, 2013). Instead, Indigenous methodology is used to categorize Indigenous knowledge, wisdom, culture, and insights around a research subject (Botha, 2011; Kovach, 2010; Smith, 2013).

Indigenous Child Development

The literature and research on Indigenous child development theory is scarce (Sarche & Whitesell, 2012). Boarding schools disrupted Indigenous family practices and traditions (Campbell & Campbell, 2006; Giago, 2006; Sarche & Whitesell, 2012). However, what is known about Indigenous child development follows the Indigenous worldviews as previously discussed (EagleWoman & Rice, 2016; Ledesma, 1998; Sarche, Tafoya, Croy, & Hill, 2016;

Sarche & Whitesell, 2012). Healthy child development is spiritual, physical, mental, community, and cultural aspects (Ledesma, 1998).

The Spiritual Aspect of Child Development

Indigenous child development is rooted in the spiritual (EagleWoman & Rice, 2016; Light & Martin, 1985; Sarche et al., 2016; Sarche & Whitesell, 2012). Starting in perinatal development through the early childhood years, children are considered sacred, as Creator gave children to parents to raise (Bia, 2011; EagleWoman & Rice; 2016, Light & Martin, 1985; Sarche et al., 2016). Wakanyeja is the Lakota word for child, which translates to sacred little one (EagleWoman & Rice, 2016; Sarche et al, 2016). As a part of this sacredness, children are taught religious and spiritual practices (Bia, 2011; Light & Martin, 1985). Diné boys may participate in the Fire Dance at age four (Bia, 2011). Children are a sacred gift filled with beauty and purity, and thus must be kept safe and protected as such (Sarche et al., 2016). Different Tribe had different ways of protecting young children (Sarche et al., 2016; Light & Martin, 1985).

Language and Culture

Besides raising their children as sacred gifts, parents were responsible for other aspects of the child's upbringing. Parents taught the tribe's language and culture to the child. Children exercise autonomy in exploring their environment and learning from the environment (Connors & Donnellan, 1993; Friesen & Friesen, 2002). Cheyenne parents did not harshly discipline young children (Light & Martin; Llewellyn & Hoebel, 1967). Cheyenne believed that children could be trained for their roles as adults in the early months, and were given toys that helped them develop skills for those roles (Light & Martin, 1985; Llewellyn & Hoebel, 1967). Cheyenne children were taught self-regulation and deference by learning to respect elders early, and be quiet when an elder spoke (Light & Martin, 1985; Llewellyn & Hoebel, 1967).

Socializing Children

Hopi parents used kachina dolls to socialize their children and teach social skills as well as the culture (Light & Martin, 1985; Schlegel, 1973; Sekaquaptewa, Capps. & Tonsing 1976). Kachina dolls are representations of the Kachinas which are the supernatural, which are represented by masked men at dances (Schlegel, 1973). Kachinas know a child's thoughts and actions, so if a child was good they are rewarded with a toy or gift, if they were bad, the child must behave through the dance to be rewarded at the end (Schlegel, 1973). A child could also be threatened that if they did not behave, the Kachina would not bring them anything (Schlegel, 1973). Mothers and fathers also sing to the children at an early age that teach culture (Schlegel, 1973). Besides songs and lullabies from their parents, at dances, children will also hear the katsinas (Glowacka & Sekaquaptewa, 2009; Schlegel, 1973). Katsinas are songs that teach a person how to be Hopi and to live morally (Glowacka & Sekaquaptewa, 2009).

The Role of Family Members and Community

Besides the parents, other family members and the community help develop children. Among the Jacarillo Apache, the grandparents are the disciplinarians (Light & Martin, 1985; Opler, 1946). In addition to the parents, other community members helped reinforce the idea and concept of the Kachina doll to Hopi children (Light & Martin, 1985, Sekaquaptewa et al., 1976). Diné are a matriarchal society, and it is the grandmothers that help discipline the child as well as teach language and culture (Bia, 2011; Kapp, 2011). Among the Diné, the extended family outside of the parents and grandparents also help to raise the children (Kapp, 2011). In a study of American Indian Health Providers in Los Angeles, a Seneca provider told of how her grandfather taught them that they are part of their family, but also part of a larger family, the Seneca Tribe (Ledesma, 1997). Among some Tribe, the child is supported by the family, the clan, and the larger community, more commonly known as circles of care (Blyly-Strauss, 2018;

Davis, Dionne, & Fortin, 2014). For Diné, it takes four clans to raise a child (Bia, 2011). In Western civilization, family is meant to mean the immediate nuclear family (Kapp, 2009), but in Ledsma's (1997) study, family was defined more as a value and idea, family meant kin, community, tribe, and anyone that people broke bread with. All of those people had input into a child's health and development (Ledesma, 1997). Elders also have a role in child development, by keeping the language, culture, and wisdom alive, and passing it to the next generation (Bia, 2011; Kapp, 2009; Ledesma, 1997).

The Role of Location, Land, and Environment

The final part of Indigenous child development theory is the environment. The environment can be broken into two categories: 1) the location and land; and, 2) the environment around the child. In Indigenous knowledge, the land is sacred (Battiste & Youngblood Henderson, 2000; Hart, 2010; LaFrance & Nichols, 2009; Simpson, 2000), and children are taught about the land at an early age. Hopi boys begin training for farming and herding at a young age (Schlegel, 1973). Hopi girls start helping gather water and grinding corn at an early age as well (Schlegel, 1973). Hopi children are given names at their naming ceremony to tie the child to their place and their land (Glowacka & Sekaquaptewa, 2009). Diné children begin helping with farming activities at an early age, whether it is tending to the garden, or herding animals (Bia, 2009, Kapp, 2009). The children are taught to pray with corn pollen every day (Bia, 2011). Ojibwe children have a naming ceremony for a name that follows them the rest of their life and ties them to the people and its land (Blyly-Strauss, 2018: Romero-Little, 2011). Naming ceremonies are important, because it provides the child's grounding with the people, its culture, its spirituality, and the tribe's home (Red Horse, 1997; Sarche et al., 2016). The burying of the placenta ties the child to the land and its spiritual home (Molina, 2001; Sarche et alk, 2016).

The other type of environment is the overall environment around the child. Many Tribe believe in the interconnectedness of everything, from the ancestors to the future, it is all tied together (Blyly-Strauss, 2018; Sarche et al, 2016). This idea of interconnectedness is referred to as the Seventh Generation by some people. Interconnectedness is a good example of the concept of time in Indigenous knowledge. In interconnectedness, there is the connection from the ancestors all the way to today, the future with children, and all the way to seven generations past today (Bia, 2011; Blyly-Strauss, 2018; Sarche et al., 2016). Everything is connected, as the wisdom, knowledge, culture, language, and spirituality has been passed down from the ancestors, to the elders, to the parents, to the children, and to the children's children, etc. (Bia, 2011; Blyly-Strauss, 2018). It is the current generations duty to maintain it, and pass it to the next generation (Bia, 2011; Sarche et al, 2016). This means that the experiences of past generations shape the present of the current generation (Sarche et al., 2016). An example of this, is the historical trauma caused by colonization, genocide, loss of land, and the boarding schools, and how it has been passed on from generations (Blyly-Strauss, 2018; Sarche et al., 2016). Western science and the concept of epigenetics is just now starting to prove, what has always been known in Indigenous communities (Sarche et al., 2016).

An Indigenous Child Development Model

With over 500 federally recognized Tribe with differing cultures and languages, it is impossible to create one generalizable Indigenous child development model. Even in the limited research, the participants have been quick to point out to researchers, that their Tribe way is not the only way, and even within that, it may vary by family due to different experiences (Blyly-Strauss). In Ledesma's (1997) study, there were few questions about children's health and development that had more than 60% agreement, other than the basic domains that have been discussed. For the purposes of this study, I have introduced an Indigenous Child Development

Model, based on this section of the literature review (see Figure 1). In the middle is the child, surrounded by the parent, grandparents, extended family, community, elders and ancestors, and environment. Weaving throughout it is a ribbon of the spiritual, culture, and language that starts with the child and wraps around the whole model and returning to the child to demonstrate the interconnectedness.

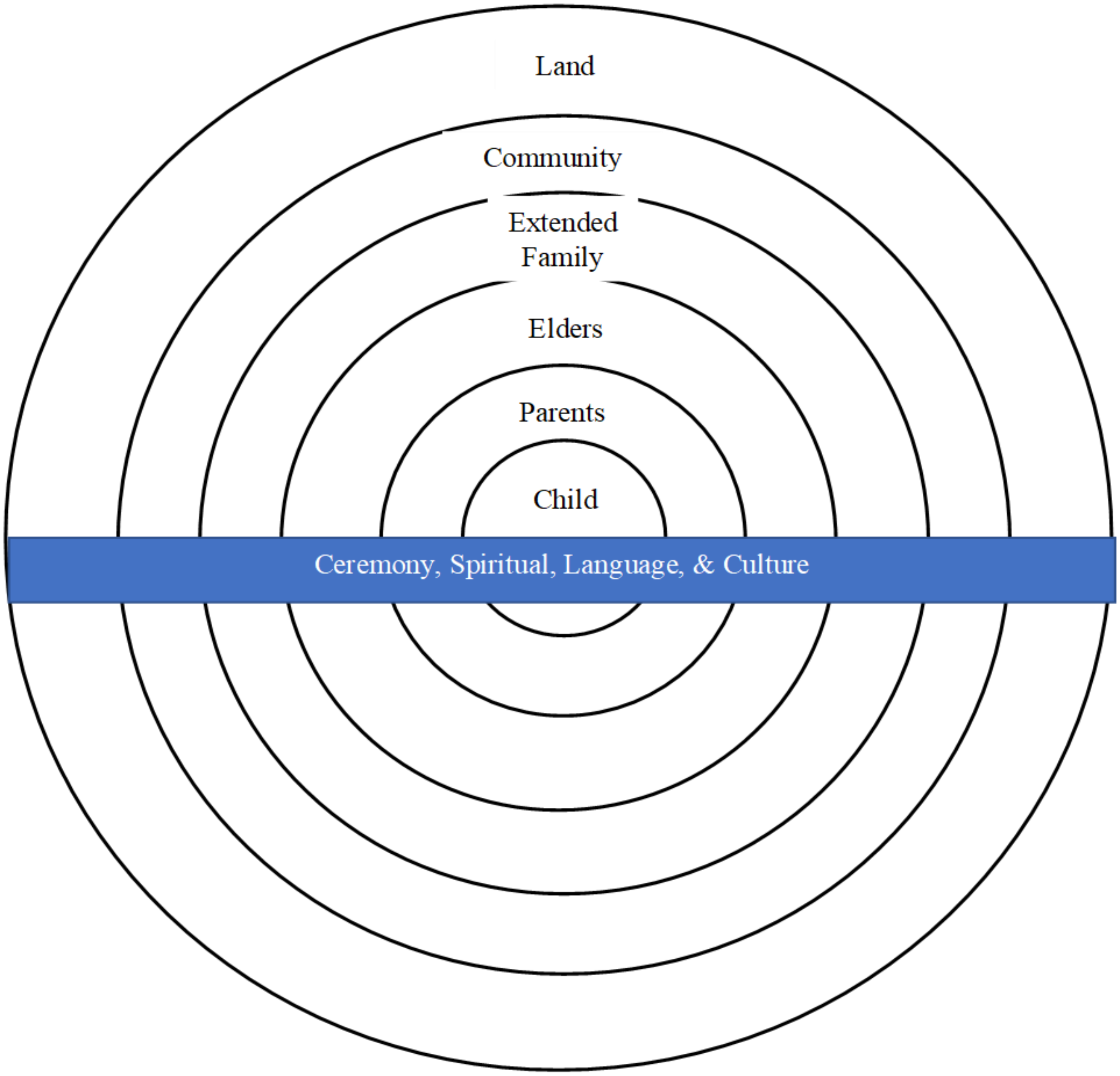

Figure 1. Cooper Indigenous Child Development Model.

Autism

Autism is “persistent deficits in social communication and social interaction across multiple contexts” (p. 47, APA, 2013). The severity of autism is based on social communication behaviors, restricted behaviors, and repetitive behaviors (APA, 2013). Intellectual disability and global development delay cannot be the cause of the deficits (APA, 2013).

Etiology of Autism

Autism was discovered by Leo Kanner in 1943 in the U.S. and by Hans Asperger in 1944 in Vienna (Baron-Cohen, 2015; Kanner, 1943). There is some argument about whether or not Kanner stole the research of Asperger (Baron-Cohen, 2015). Kanner denied stealing Asperger’s research, but, in years since then, it was discovered that the chief diagnostician that worked with Asperger left in 1938 to go to the U.S. and work with Kanner in 1938 (Baron-Cohen, 2015).

Kanner only described autism in young children (Baron-Cohen, 2015, Kanner, 1943), which left out adults with autism. Kanner felt that autism was rare (Kanner, 1943). Kanner blamed autism on cold or unattached parents (Baron-Cohen, 2019; Kanner, 1943). In 1967, Bettelheim re-affirmed Kanner’s description of autism as an emotional disorder (Bettelheim, 1967; Wendt, 2010), but also said that autism’s psychogenetic root was due to cold parenting (Baron-Cohen, 2015). This meant that autism was viewed as caused by a frigid, unresponsive mother (Wendt, 2010).

Although Bettleheim (1967) was pushing the frigid mother cause of autism in the Sixties, Rimland (1964) felt that autism was a neurobiological disorder versus psychogenetic disorder. In 1967, it was determined that autism was a behavior specific disorder and overall development areas were impacted by neuropathophysiological processes (Ornitz & Ritvo, 1976; Wendt, 2010). As genetics research has become more advanced, researchers have tried to find a genetic cause of autism (Lichtenstein, Carlström, Rastam, Gilberg & Anckarsäter, 2010; Malik, Kahn, Sahl, Elzamzamy, & Nazeer, 2019; Muhle, Trentacost & Rapin, 2004). Currently, there is no one known cause of autism, although environmental, non-genetic, and genetic factors contribute to autism (Autism Speaks, 2019).

Epidemiology of Autism

There is no national screening or surveillance method for ASD, but there is regional surveillance in parts of the United States known as the Autism and Developmental Disabilities Monitoring (ADDM) Network. (Baio, 2012; Christensen, Van Naarden Braun, Baio, Bilder, Charles, Constantino, Daniels, Durkin, Fitgerald, Kurzius-Spencer, Lee, Pettgrove, Robinson, Schulz, Wells. Wingate, Zahorodny, & Yeargin,Allsopp, 2018). In reviewing data from eleven ADDM regional centers that represent eleven states, the 2012 prevalence rate of autism in 8-year-old children was 14.5 per 1000 (Christensen et al., 2018). However, even among the states in that study the prevalence rate varies greatly (Chrstensen et al., 2018; Nevison, Blaxhill, & Zahorodny, 2018). California shows steady increase of autism from children born in 1931 at 0.001% to five-year-old children born in 2012 at 1.2% Nevison et al., 2018). California' study does not say how they determined autism prior to 1943, especially, since Kanner, believed autism to only be in young children and not older children of adults. Latino and African-American children are more likely to be diagnosed with a severe Autism Spectrum Disorder (ASD) later in childhood rather than in early childhood (Fountain, King, & Berman, 2011; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Mandell, Wiggins, Carpenter, DiGuiseppi, Durkins, Giarelli, Morrier, Nicholas, Pinto-Martin, Shattuck, Thomas, Yeargin-Allsopp, &Kirby, 2009; Pederson, Pettygrove, Meaney, Mancilla, Goschall, Kessler, Grebbe, & Cunniff, 2012).

Autism Screening and Assessment

There is currently not a valid and reliable child development screen that simultaneously screens for ASD (Siu & USPTFS., 2016). The third edition of the ASQ (ASQ-3) was developed with an embedded autism screen (Squires et al., 2009). The first validity and reliability study of using the ASQ-3 to screen for autism shows promise, but the sample size was small, and it did not test for cultural bias in the screen (Hardy et al., 2015).

Cultural Issues With Screening

Although there are several variations of ASD screens out there, there are only two screens that are recommended by the USPTFS, the M-CHAT-R and M-CHAT-R/F (Siu & USPTFS, 2016). The M-CHAT-R and M-CHAT-R/F are intended to screen children ages 18 months to 30 months (Khowaja, Hazzard, & Robins, 2015; Siu & USPTFS, 2016). The original M-CHAT had a cultural bias requiring significant modifications when adapting to other countries, however the culture bias remained (Albores-Gallo et al., 2012; Zhang et al., 2006). The M-CHAT-R and M-CHAT-R/F have several questions about eye contact and pointing with the finger (Robins, 2019), but for many Latin American and Asian Countries and American Indians and Alaska Natives, making eye contact and pointing are not socially acceptable behaviors (Albores-Gallo et al., 2012, Morris, 1994; Zhang et al., 2006). There is not currently a valid and reliable culturally relevant autism screening tool.

Racial Disparities in Screening and Diagnosis

Race is another issue with screening for autism at the doctor’s office. African American and Latina/o children are five times less likely than Non-Hispanic White children to be screened (Adams & Tapia, 2013; Chung et al., 2006; Rosenberg et al., 2008). As noted earlier, when screening for autism, doctors self-reported they felt it was easier to diagnose White children with autism than African American and Latina/o children (Zuckerman, et al., 2013). Doctors felt White parents had a better understanding of ASD than African American or Latina/o parents (Zuckerman et al., 2013). There is no evidence of implicit bias in this study, nor has implicit bias been studied in ASD screening. In the same study showed screening rates increased for

African American and Latina/o children if a Latina/o worked in the office, (Zuckerman, 2013). Doctors identify cultural and racial barriers as a concern for screening (Pizure-Barnekow et al., 2010; Zuckerman, 2013).

Parent Experience in Assessment Process

A majority of autism research has focused on post-diagnosis or determining possible symptoms at the earliest ages, very little research has focused on the assessment process (Buzanko, 2018; Ryan & Salisubury, 2012). A handful of studies across the world have looked at the assessment experience of parents, but almost all have been focused on the end of assessment (Buzanko, 2018). There needs to be further research into the overall assessment experience of parents (Braiden, Bothwell, & Duffy, 2010; Buzanko, 2018).

Initial concerns and source of referrals. There are varying initial concerns by parents and points of referral. Some parents had no concerns (Braiden et al., 2010; Ryan and Salisbury, 2012).   Some parents felt that their child was different since birth (Braiden et al., 2010). Some had a concern, but could not identify the concern (Braiden et al., 2010). Unfortunately, the research does not say if this was in regard to a first child or a child born after the first one. Some parents had concerns about their child by 18 months of age (Braiden et al., 2010). While Braiden et al. (2010) do not say the specific concerns, Ryan and Salisbury (2012) list delays in smiling, crawling, and babbling for infants, lack of eye contact, extreme tantrums, and anxiousness in toddlers. In one study, 75% of parents had a concern about their child's speech before diagnosis (Richards, Mossey, and Robins, 2016).

Referrals for assessment came from multiple places. One of the most common sources for a referral was the child's general practitioner (Braiden et al., 2010; Rhoades, Scarpa, & Salley, 2007; Richards et al., 2016). For parents that did not have concerns, the most common person to refer the parent to get an assessment was either the child's speech language pathologist or early childhood care provider (Braiden et al., 2010; Richards et al., 2016). Braiden et al. (2010) felt that general practitioners and early childcare providers needed to be better trained in recognizing the symptoms of autism, since they seem to be the primary referrers. However for early childcare providers, it is more than just being able to understand the symptoms, but also to know how assessment works, so the provider can guide the parent through the system (Nuner & Stevens Griffith, 2011).

Parent categories for referring child. A study in the UK saw that parents could be categorized by three types of concerns that the parents had about their children before their autism diagnosis (Ryan & Salisbury, 2012). The first was parents that had no concerns, and these parents were surprised if a professional expressed concern about their child (Ryan & Salisbury, 2012). These children tended to be diagnosed between the ages of five years and eight years (Ryan & Salisbury, 2012). The second category was passive concern; these parents had concerns but did not talk to the doctor about them (Ryan & Salisbury, 2012). Reasons for not talking to the doctor may include: 1) Not knowing how to express the concern to the doctor; 2) Doubting their concern because they were at work versus with the child often; or, 3) They were new parents and didn’t know what to say (Ryan & Salisbury, 2012). These three reasons can be summed up as not knowing how to tell the doctor about their concern. Eventually, the passive concern became an active concern (Ryan & Salisbury, 2012). These children tended to be diagnosed between the ages of four years and five years (Ryan & Salisbury, 2012). The third category is an active concern; these parents had concerns because they compared their children with siblings and peers (Ryan & Salisbury, 2012). The parents could express their concerns to the doctors starting with missed milestones and progressing towards more typical symptoms of autism (Ryan & Salisbury, 2012). Raising the concerns happened frequently from the age of nine months to three years (Ryan & Salibury, 2012). Early concerns included delays in smiling, crawling, and babbling, while concerns in toddlers included lack of eye contact, extreme tantrums, and anxiousness (Ryan & Salisbury, 2012). For parents with active concerns, the child could be referred for assessment right away, but sometimes it took between six months up to five years to refer the child, which caused a strain between the parents and doctors (Ryan & Salisbury, 2012). The reason for the delay in referring is not known. Also, if a parent already had a child with autism, the referral and diagnosis for the second child happened quickly (Ryan & Salisbury, 2012). There are limitations to this study as it is not generalizable with only twenty-four participants, the study took place in the United Kingdom where the medical programs are different from the United States, and twenty-two of the of the participants were white. Ryan and Salisbury (2012) recommend that more research be completed on parent's experience during the autism assessment.

Parent user experience with assessment. A qualitative study looked at the overall assessment experience of 11 mothers in North Ireland (Braiden et al., 2010). Parents found that the diagnostic process was challenging overall (Braiden et al., 2010). Reasons for frustration may be due to seeing more than one professional, being unsure who was in charge of the diagnostic process, the paperwork being overwhelming, and the inability to remember early parts of their child's development (Braiden et al., 2010. Although most parents felt that the amount of time from referral to diagnosis was acceptable, a third of them felt the time was unreasonable (Braiden et al., 2010). Some parents felt that the concern around autism needed to be better communicated to them at the beginning of the diagnostic process (Braiden et al., 2010). Also some parents felt that they did not know how to voice their concerns. Parents with the highest satisfaction of the process were parents whose provider initially accepted the parent's suspicions of a developmental issue for the child (Braiden et al., 2010). Additional parents also felt that the assessment was not completed in a timely manner (Keenan, Dillenburger, Doherty, Byrne, and Gallagher, 2010; Wong, Yu, Keyes, & McGrew, 2017). An earlier study showed that parents felt like they were shifted around by providers in trying to get an assessment (Midence & O'Neill, 1999).

Braiden et al. (2010) felt that their sample size was very small and that more research needed to be completed to hear more varying experiences. In later research, parents expressed that parents were unadvised and uninformed during the assessment experience and dissatisfaction with the experience (Selimoglu, Ozdemir, Toret, & Ozkubat, 2013; Wong et al., 2017). The research had several stories and varying views of satisfaction, a larger sample size would allow for varying experiences to better sort themselves out (Braiden et al., 2010).

Referral for services after diagnosis. A 2007 study of 110 caregivers to children with autism, noted that in Virginia, developmental pediatricians were more likely to diagnose autism at a year younger than psychologists and neurologists. This study was completed before the change to ASD in the DSM-5, so the study saw that Autism was diagnosed at an earlier age than Asperger's Syndrome or Pervasive Development Disorder- Not Otherwise Specified [PDD-NOS] (Rhoades, Scarpa, & Salley, 2007). The DSM-5 placed all three of these disorders within the umbrella of ASD in 2013 (Autism Speaks, 2020a; Autism Speaks, 2020b). After the diagnosis, only 6% of doctors referred the family to an autism specialist, and only 34% referred families to an education specialist. Furthermore, 18% provided no information after the autism diagnosis (Rhoades et al., 2007). These children qualified for services under IDEA and only a third of them were being referred to the Local Education Agency (LEA) for services. Referrals primarily came from a development pediatrician (Rhoades et al., 2007). Approximately 20% of parents or less reported that a health provider, education specialist, or early interventionist helped them learn about autism. It was outside sources such as the internet, magazines, and parents of other autistic children learn more about autism (Rhoades et al., 2007). A limitation of this study was that 88% of the participants were Non-Hispanic White, so it was primarily the viewpoint from that culture. Only 1 participant was AI/AN and 1 other participant was Latina/o which is the most closely related cultural group to AI/AN. The research does not report their individual results.

Autism in AI/AN Communities

There is little research about autism in AI/AN communities in the U.S. Traditional Diné views do not view autism as a disability (Conners, 1992; Kapp, 2011). Child rearing practices of the Diné allow a child with autism to grow and be taken care of by their family throughout their life (Kapp, 2011). At a young age the child still helps with farming and tending to the animals, and given chores to their ability (Conners, 1992; Kapp, 2011). Also, in the Diné lifestyle there are repetitive behaviors and looking for patterns and repetitive behaviors, so an autistic child would fit into the lifestyle without being considered different (Kapp, 2011).

Indigenous communities are not as focused on developmental milestones as Western child specialists are (Bia, 2011; Conners, 1992; Kapp, 2011; Wendt, 2010). Children with disabilities may be considered spiritual or special messengers versus being stigmatized by the disability (Bia, 2011, Patterson, 1997). Within the Diné, an indicator of delay may not be seen as a delay, but a unique characteristic of the child (Connors & Donnellan, 1993; Kapp, 2011). An example of this can be found among the Diné. An important ceremony is the child's first laugh (Bia, 2011; Kapp, 2011). It doesn't matter if the laugh happened early or late or on time, it only matters that the child laughed and it is celebrated, regardless of the age it happened (Bia, 2011; Kapp, 2011; Wendt, 2010).

AI/AN children are the most underserved population of children with autism and have the lowest risk index (Donovan & Cross, 2002; Travers et al., 1998). Wendt (2010) reports that in California in 2003, the prevalence rate of autism in AI/AN was 1.3 per 10,000 compare to 3.8 to 9.1 per 10,000 for other races in California. Based on conservative estimates of the time of an overall prevalence rate of 10 per 10,000 for all races, it is estimated the number of AI/AN children with autism in California was 333, however, California reported only 44 AI/AN with autism (Wendt, 2010). However, by the time Wendt did her study in 2010, there were 89 children with autism to gather participants from.

There are differences in the studies between Conners, Kapp, and Wendt. Conners (1992) is Diné and spent two years embedded in the community studying autism only. Kapp (2011) worked with Diné people to create his research, and the approach centered more around disabilities in general. Wendt (2010) worked with AI/AN adviser and studied AI/AN in general in California, and not anyone specific tribe. Conners (1992) and Kapp (2011) both did qualitative work, while Wendt (2010) did a quantitative study and compared AI/AN with Hispanic which is the most closely related cultural group.

Wendt (2010) looked at autism from several angles. The AI/AN sample size for the study was 18. Respondents were asked which symptoms caused the person to seek help but does not report on the rank order or any other details other than to say AI/AN respondents recognized 7.5 symptoms and the list was 8 symptoms with one being other. Wendt did recommend looking at the symptoms more closely, and also looking for why there is a lower prevalence rate. In rank order of opinions about autism, half the respondents felt autism was a severe disorder, and the viewing of autism as a gift had the worst rank. The cause of autism was viewed more as a physical condition, than a spiritual condition. The top belief in treatment was therapy versus spiritual healing. It should also be noted that the sample was considered highly acculturated, and the uniqueness of the AI/AN population in California should be taken into account when looking at these results.

West Coast AI/AN Population

The West Coast consists of the states of California, Oregon, and Washington. California has a unique AI/AN population compare to many states. There are currently 574 federally recognized Tribes in United States. These three states represent one-third of the total AI/AN population in the United States (U.S. Census Bureau, 2012).

California is home to 109 of those Tribes and an additional 78 Tribes awaiting recognition (Cooper at el, 2015). The Indian Relocation Act of 1956 set up employment centers in urban areas in the Western United States to encourage AI/AN to move from their lands to urban locations. Relocation centers were set up in Los Angeles, Sacramento, San Jose, and San Francisco, leading to a large migration of AI/AN from around the United States to California (Jaimes, 1992). The overall population of AI/AN in the United States is 2.5 million, with the largest portion residing in California (Norris, Vines, & Hoeffel, 2012). More than half the AI/AN population in California lives in urban areas (Cooper et al., 2015). While California accounts for 25% of the total AI/AN population in the United States, AI/AN only account for 1.9% of the total population of California (U.S. Census Bureau, 2012).

Oregon and Washington have a smaller AI/AN population than California (US Census Bureau, 2012). During the Relocation Era, a relocation center was also established in Seattle for AI/AN to also come to Washington besides California. In Oregon, AI/AN comprise 3% of the total population (State of Oregon, 2020), and 1.8% of the total population of Washington (Washington Office of Financial Management, 2020). Oregon has nine federally recognized

Tribes, while Washington has twenty-nine Tribes (Northwest Portland Area Indian Health Board, 2020).

In studies that have involved urban American Indians, participants quickly point out that there are many differences in cultures among the urban populations and the rural populations, as well as differences between people that relocated to urban areas versus their own traditional homelands (Blyly-Strauss, 2018; Ledesma, 1997). This has made health research difficult with the population, and often unstable data.

Autism within West Coast AI/AN population. Little is known about the autism prevalence rate among AI/AN on the West Coast. Oregon and Washington do not report AI/AN as its own category in the data, and there are questions about the rates that California reports.

Although not fully addressed in her research, Wendt (2010) doubted the low autism prevalence rate for AI/AN autistic children from California or if it is not just being identified or reported. Wendt (2010) also offer five possible reasons for the low prevalence rate. The five possible reasons are: 1) The genetic variation and polymorphism of genes is not found as often in AI/AN populations; 2) there are barriers to accessing services; 3) not as many records with the state; 4) a difference in recognition of autism among AI/AN; and 5) different environmental factors to autism compared to the general population (Wendt, 2010). Autism rates in California are tracked through their regional developmental centers, and families may not register their child at those centers due to distance to the center, no center in their county, or the family moved to another region before the diagnosis (Waldman, Nicholson, Adilov, & Williams, 2008).

A scan of the literature and data for Oregon and Washington does not show the AI/AN autism prevalence rate. AI/AN are bundled together with other races as “Other”.

Summary

Autism is a condition that impacts social and communications skills in people and is marked by repetitive behaviors (APA, 2013). The prevalence rate of autism among AI/AN is lower than all other races, but the reason is not known. Western studies have hypothesized that this may be due to parents not being concerned about the symptoms or unaware of the symptoms. Western recommendations have been to train AI/AN parents about the symptoms that are not considered concerns culturally, such as eye contact and finger pointing. However, other reasons potentially exist for lower prevalence rates. There is not culturally relevant screen for autism, and doctors are more comfortable talking with white parents about autism compared to other races as they are viewed as more educated.

The research about autism among AI/AN is very limited. Two studies are among one tribe, while another study is among a highly acculturated population among several Tribe. Two studies are also from the framework of Indigenous knowledge and Indigenous child development. More research needs to be done in the field to add to the knowledge to determine why there may be lower rates of autism.

CHAPTER 3: METHODOLOGY

The idea of and the word “research” often have negative connotations with Indigenous communities due to documented abuses of the communities by research (Kovach, 2011; Smith, 2013). The key parts to working with the community are: 1) Acknowledging the researcher’s positionality and bias; 2) Working with input from the community; 3) Use of Indigenous methodology; and 4) Protection of the participants. This chapter will describe how those key elements were met in this study.

Researcher Positionality

The researcher’s positionality plays an important role in the research. As a researcher, there is a certain amount of power that the researcher has over the participants and how their story is told (Ben-Ari & Enosh, 2013; Denzin, 2001; Goffman, 1959; Smith, 2013). Traditionally, academic research has been used to keep Indigenous communities colonized (Hart, 2010; Kovach, 2010; Smith, 2013). The research is steeped in Western science and power structures as well as an assumption that Indigenous people do not have the capacity to research their own communities (Smith, 2013). Although, I am Diné and using Indigenous Methodology to look at autism among Indigenous people, I want to acknowledge my positionality as a researcher and among the community.

Introducing Myself

As in Chapter 1, I will introduce myself in a traditional way. Yá’át’ééh shik’éí dóó shidine’é. Shí éí Christopher Cooper Trujillo y Sandoval y Quintana y de Herrera yinishyé. Ákót’éego diné nishłį̨. Ahéhee’. Hello my family, my people, and friends. My name is Christopher Cooper Trujillo y Sandoval y Quintana, y de Herrera. In that way I am a Diné man.

This introduction differs from a very traditional Diné introduction as it does not include my clans or what areas our family inhabits. I am of Diné descent. My grandmother was born in the early 1900’s in New Mexico in an all-white hospital. Her birth certificate and the certificates of all other Native children born in that hospital were lost in a fire, no birth certificates of white children were lost in the fire. This was a common event to keep future generations from being enrolled. My family does not know our clans. My paternal grandfather was an orphan and little is known of his family. So, this is how I was taught by elders to introduce myself, in a through my mother and father, my grandmother, great-grandmother, and great-great-grandmother.

My mother’s family has been in modern day New Mexico for over 500 years. The first Trujillo to come from Spain was a conquistador and married a woman in present day Mexico City. She did not have a name and the marriage is the first church record, meaning that she was an Indigenous woman. Besides Mexica, there were many other Tribes in the area. While the family moved to modern day New Mexico and throughout its time there, there were several marriages to women with no Christian names. My grandmother and great-grandmother were Diné. In my family, we know that we are Diné, Spanish, and mixed with several other Tribes in modern day Mexico and New Mexico throughout the centuries. Typically, the family would just say they are mestizo, meaning a mix of Spanish and Indigenous and that they are Mexican, as that area was originally a part of Mexico.

During the 1920’s, my grandparents eventually left New Mexico in search of work and to avoid the boarding schools. My grandparents lost their first three children at an early age, two to the Spanish flu, and another that was born with special needs. To protect the other children, my grandparents spoke Spanish and had Spanish surnames, so by cutting their sons’ hair, they could pass off as a more pure Spanish form of Mexican. Over the years, the family made their way to

Colorado and Wyoming, before eventually moving to the Yakama Reservation in Toppenish, Washington to transition from ranch hand to working for the railroad. During this time, my 3family began to identify as Mexican Indigenous. Finally, they settled outside of Richland, Washington, where my grandfather worked as a custodian at the Hanford Nuclear Reservation. The family would continue to Toppenish on the weekends, as many of my aunts and uncles had married into families there. However, my mom primarily identified as Mexican, and more specifically as Chicana as some family members were engaged in the Chicano political movement of the 1960's.

There are some events that changed my mom's self-identity from Mexican to Mexican and Native. As a young girl, she and her parents traveled to New Mexico to move her maternal grandmother in with them until she walked on a few years later. My great-grandmother did not speak English, but she spoke Spanish and Diné around my mother. She also insured that my mom attended Pow-Wows and other cultural events at Yakama, Nez Perce, and Confederated Tribe of the Umatilla Indian Reservation. My great-grandmother and grandfather walked on when my mother was a young teenager, the next summer, her and her mom spent the summer in New Mexico and Colorado visiting family and the various Tribe. My mom also recollects that the first weekend of every month, her and her mom would go to the Yakama Reservation to get commodities. Shortly, after getting married, my grandmother made my mom promise that if she had boys, what they did with their hair would always be their choice.

My brothers and I were raised more as Mexican and knowing that we were Native, but not that we were Diné until we were older. We learned Spanish. Even though we were raised as Mexican, we also went to the Yakama Reservation on most weekends. We went to community events at the cultural center and long house. We went to Pow-Wows there as well as

Confederated Tribe of Umatilla Indian Reservation, and Nez Perce. There were many Native families that relocated to our neighborhood for work, and my mom would tell us that we needed to learn from the stories and songs that they would teach us. What we knew was the culture of the local Tribe. And as we got older, just as my mom promised, whatever we did with our hair was our own choice.

Growing up, we knew we were Native, we just did not know the tribe. Although there were family members enrolled in local Tribe, and we learned much about culture, ceremony, and song, we knew it was not our own tribe. As we got near our teens, my mom told us that we were Diné, but I suspect only because we had older cousins trying to get enrolled with the tribe while at college. My mom also told us that we could not identify as Diné, because we were not enrolled, and the Diné people would not like us saying that we were Diné. I do remember being confused and upset by it, because I would not learn our own culture or songs or dance.

In my teen years, a movie came out, called *Stand and Deliver,* and a line from it inspired me. In the movie, the teacher tells the students, “Did you know that neither the Greeks nor the Romans were capable of using the concept of zero? It was your ancestors, the Mayans, who first contemplated the zero. The absence of value. True story. You *burros* have math in your blood” (Musca and Menendez, 1987). This made me realize that we had our own ways of knowing before colonization and made me search out books over the years on Pre-Columbian history. As I entered college and took research classes nearly 30 years ago, it made me think about why we never heard about our own ways of knowing in research methodologies or in science.

Over the years, I would only identify as having Indigenous roots, but never as Diné as my mom taught us. I would often use the word Chicano which is an Indigenous Spanish word meaning an Indigenous Mexican-American. To me, it also meant that my family was from the borderlands. My grandmother, mother, and aunts were a part of the Chicano movement of the 1960's. My grandmother and mom would spend their Saturdays outside Safeway urging people to boycott grapes as part of the Farmworker's movement. To my grandmother, the Farmworker's movement supported both Mexicans and the many Indigenous farmworkers. With this type of example, it was not unusual in our family to identify as Chicano, as it captured both sides of our identity.

Over the years, I would attend Pow-Wows, ceremonies, and sweats at college and the other areas that I would live. In my jobs, I would always do outreach of my programs to the Tribes and Latina/o community. In all my presentations, I did not identify as Diné when introducing myself. I would always say my ancestral homeland was the area of modern-day New Mexico, and people understood this to mean that I was Native. At the age of 43, I introduced myself as Diné at a conference in Los Angeles. I had done my normal introduction, but an elder challenged me, and said, my introduction was not good enough, and he wanted a specific tribe. My mom taught me to respect the elders and their wisdom, so I stated that I was Diné, and the reason why I did not introduce myself as Diné. He was a Diné elder, and instructed me that times have changed, and moving forward to always introduce myself as Diné. I have continued to do that.

Earlier, I wrote that my mom really did not raise us as Diné. As I have learned more about my own culture, I realize that although my mom did not teach us stories, language, songs, or dances, she did raise us in a Diné way. She allowed us to explore our environment and learn our limits (Connors & Donnellan, 1993). She taught us to respect elders at a very early age. We grew up along the Columbia and Snake Rivers and the elders taught us to be stewards of the river and the land at an early age. For my cousin, who was a special needs child, he was taken care of by the family, and fullfilled his own role and duties at family events (Conners, 1992; Kapp, 2011). We only visit the graves of our grandparents and great-grandmother after the grass has been mowed, so we do not leave footprints. Many Diné are Pentacostal (Conners, 1993; Lewton & Bydone, 2000), and we were raised as Pentecostal. Our family is very matriarchal (Bia, 2011; Kapp, 2011). My mom talks about how everything was done with her mother and grandmother's approval. They died before we were born, and my mom's two older sisters took on the family matriarchal role. Growing up and even afterwards, everything was done with my aunts' approval. In the end, we find ourselves in the same place as other Indigenous people that have relocated to urban areas have mentioned, with our own new cultures, a mix of our own culture and the Tribes around us (Blyly-Strauss, 2018; Ledesma, 1997), and the Indigenous people of another country due to a manmade political border.

I have talked primarily about my mom's side of the family. My father is of European descent. My grandfather was raised in an orphanage. His older sisters said the family was kicked out of Ireland in the 1800's. My grandmother and her family immigrated to the United States from Romania. That side of the family is small, and even though we spent time with the family, we were not raised in those ways. My mom is from a large family, and those were the ways that we were raised. For me, the biggest part is that I have an English last name and am one of the family members with a light complexion, so I am able to move between three worlds, Indigenous, Latina/o, and the predominant culture rather easily. I also realize that with an English name and light complexion, that I benefit from white privilege, in that I can chose to stop being in the other two worlds if I wanted to. It is a bias that I try to protect against in this research.

I am in the middle of decolonizing myself and learning of my own Tribal ways. In July, when I had to pivot with my research topic, I thought I could just write out Chapters One, Two, and Three in a few weeks. However, this process has forced me to look at my own identity in a deeper way. It has forced me to look at whether I am just being pan-Indian, or really, that is the culture that I was raised in. It has forced me recognize who I am and process my own trauma of not being raised in a traditional way as far as songs, dance, and ceremony, but also acknowledging that I was raised with traditional methods and ideas of Diné child development. Five years ago, I began to grow my hair out, somewhat for traditional reasons, but also to honor my grandmother. My mother always says how happy my grandmother would have been to see that one of her grandson's grew his hair out. Although I only wrote a few sentences on the Boarding School era, to read people's stories about their experiences in the boarding schools, put my grandmother being proud into a whole different context. My grandmother cut the hair and passed off being Mexican as a way not to lose her culture, but to protect her children. To read those stories, made me realize the sacrifice that she made. I had to actually stop writing for a couple days and process the immense sadness that I was having over that sacrifice. After some thought, I realized that for me to grow my hair, to begin learning to speak Diné, and participate in ceremony, was my reconnection of the next generation, is to show the survival and resiliency of coming out the other side of my grandmother's sacrifice. It was a way to understand the idea that not meeting a developmental timeline is not necessarily something to worry about, but to celebrate it when it happens. My first laugh ceremony happened when I was 43 a few months after the elder state that I always state that I am Diné. My mother might argue it was the first time that I not necessarily laughed, but that I did smile. For me it was a time to celebrate and acknowledge that it did happen (Bia, 2011; Connors & Donnellan, 1993; Kapp, 2011). It signified that I was finally able to separate myself from the spiritual world and survive in the physical world. To understand my grandmother's sacrifice, was to really show that I could survive on my own as a Diné male, it was really who I am.

Disclosure of Disabilities

Another part of my identity is that I have a speech difficulty. I was not diagnosed with a speech delay until entering kindergarten. At that time, my parents found out about early intervention. My younger brother at that time, received speech services before kindergarten, and does not have difficulties. I remained in speech group until ninth grade. My services did not end because my speech was better, but my family moved around the country often for my father's employment, so those services were lost in the shuffle of attending a new district in a different state every year or two. The speech difficulties continue presently.

Many special education professionals that I have worked with have questioned me about having Aspberger's Syndrome. Several of them believe that I am very high functioning Aspberger's. Aspbereger's Syndrome is within the autism spectrum. I have never been formally diagnosed, and I would never self-diagnose myself. However, I do admit to sharing some of the symptoms that are common in people that have Aspberger's. I also remember in junior high that they asked my mother about doing other tests on me besides speech. She declined, and she was not concerned, she just said that his brain works differently from everybody else. Most of my life and even today, my mom will tell me, "You just see things differently, you brain works differently from other people. That's a gift."

I do not believe that my speech issues or possible other developmental issues make me biased in this research. However, this fuels my desire to improve finding children eligible for early interventions and early childhood special education services.

Decolonizing the Imposter Syndrome

Kovach (2015) says that the researcher’s choice of using Indigenous methodologies creates an identity standpoint and the expectancy of doing future de-colonization work. The thought of this is where the imposter syndrome has impacted me the most. Although the imposter syndrome is typically said as a way that doctoral students do not internalize their academic success, it can be better described as a student not recognizing themselves as an expert on the subject matter (Clance & Imes, 1978). I cannot legally identify as American Indian because I do not have a Tribal enrollment card. Although growing up, we went to the Yakama Reservation on occasional weekends and ceremonies at the Longhouse, it was not my people or culture. I was not raised on my reservation. I was supposed to identify as Indigenous but deny that I was Diné. As stated at the beginning, we were raised more as Chicano/Mexicano. Throughout my doctoral program and this dissertation, the imposter syndrome has told me, who am I to use Indigenous methodologies, if I am not rooted in my own culture.

I originally wrote this Chapter and excluded this section from my draft. In going back and reading Kovach (2015) stating that I am taking an identity standpoint, I realized that I needed to write about how I dealt with and decolonized the imposter syndrome in my identity of who I am. I do not need a card to tell me who I am, my mother’s and uncles’ stories over the years are enough to tell me who I am. I am connected not only to the land of Nch’i-Wàna (Sahaptin for Columbia River), Shawpatin (Snake River), and Pahto (Mt. Adams), but also to the lands of New Mexico. I have only been to New Mexico three times in my life, but it is a connection that I cannot describe in writing, other than to know it is where you are from, and to hear your ancestors speak to you. I also had to remember that Indigenous and Latino are the two most closely related cultural groups. My tia would always say, to be Latino is it be Indigenous, and to be Chicano is to recognize that Indigenous in you. I have also been encouraged to identify myself as Diné by a former supervisor and other Diné people. Also, at a Tribal public health conference, I ran into someone that I previously worked with in another state. During dinner at the conference, he told me that I was always welcome back home. When I said, I didn't want to move back home, he told me, "No, I mean, you are always welcome to move back home on the Rez." He was recognizing me as one of his own.

Kovach (2015) is correct in saying that using an Indigenous methodology makes you take a stand on identity and the expectation of engaging in decolonizing work. Throughout my doctoral program, I have promoted Indigenous Methodologies and Evaluation Frameworks. The first group project came along with the realization that all three of us in our group came from colonized groups and storytelling cultures. In that group, we combined decolonizing ideas and design thinking to create a mobile app for students and teens that were following thousands of years of natural migration paths. I worked with another student to look at both Indigenous qualitative and quantitative methods as frameworks for her work on Pacific Islander health disparities. In my own research and work, I want to be able to not only decolonize early childhood education but create culturally responsive child development screens. I want to delve more into Indigenous child development and public health, and how the two fields merge. It also means delving more into my own identity and culture. By focusing on all of these items, while writing this dissertation, I have been able to decolonize the imposter syndrome for myself and recognize myself as an expert.

Final Positionality

So how does one describe their positionality in all of this? Whenever, I have had to come to a major decision, my Creator has always placed a Diné elder in my path to join in the conversation about the situation and offer wisdom. In this research, it is no different. I originally started this program a year earlier, but had to withdraw the first semester, but I had a long time to think about dissertation ideas. Shortly before re-starting the program, I was at a health conference with people from Tribe across the U.S. I shared a row of airplane seats with two Diné elders on the flight to Phoenix, and we talked about me getting my doctorate. Their recommendation was to tell a story that was my story to tell. This was to safeguard from brining bad medicine into the community, even though I had the best intentions. There were several people that had ideas for my dissertation, but those ideas were not my story to tell. They were the tribe's story to tell.

Since a young age, I decided when I completed my doctorate, I wanted to use our own research methods to tell our story. I am Indigenous, and for me, that means Diné, Chicano, other Indigenous groups, and White. This means my viewpoint of the stories will be through multiple viewpoints. I have worked for twenty years in early childhood and with children with special needs and also done public health work. I have spoken about this topic of autism with elders, my advisory committee, and other community members. I may or may not be autistic myself. I feel that this dissertation topic is my story to tell.

Working With Input From the Community

There has been much abuse around research in Tribal communities (Kovach, 2010; Smith, 2013). Researchers come into a community with a topic that they have already decided to tell, and without consideration of the community (Smith, 2013; Wallerstein & Duran, 2006) The researcher has a position of power that can influence answers (Castleden, Garvin, & Huu-ay-aht First Nation, 2008; Wallerstein & Duran, 2006). This leads to further colonization of the people (Castleden et al., 2009; Smith 2013).

Community Based Participatory Research

One research practice to help address the issue of power and place in research is Community Based Participatory Research (CBPR) [Castleden et al., 2008; Kovach, 2010; Smith, 2013; Wallerstein & Duran, 2006]. CBPR is a Western research practice that is used to address power dynamics and ownership of research (Castleden et al., 2008, Smith, 2013; Wallerstein & Duran, 2006). It is derived from two concepts. The first concept is the Kurt Lewin's idea of social justice and confronting the objectivity of the researcher (Castleden et al., 2008; Lewin, 1946; Wallerstein & Duran, 2006). Paulo Freire further built on the idea by adding critical consciousness into the idea of research and education (Castleden et al., 2008; Freire, 1970; Wallerstein & Duran, 2003). This leads to the community identifying its problems and solutions to address inequity (Castleden et al., 2008; Fals-Borda, 2001; Tandon, 2002; Wallerstein & Duran, 2006).

Community Based Participatory Research is recommended for working in Indigenous communities (Kovach, 2010; Smith, 2013; Wallerstein & Duran, 2006). The key elements of CBPR are shared decision making between the researcher and participants, mutual ownership of the research process and product, and community consent (Viswanathan, Ammerman, Eng, Garlehner, Lohr, Griffith, Rhodes, Samuel-Hodge, Maty, Lux, Wedd, Sutton, Swinson, Jackman, & Whitener, 2004; Wallenstein & Duran, 2006). Shared decision-making means involving the community from the beginning on identifying issues and solution, and mutual ownership of the research and products is the community designing interventions and shared funding (Viswanathan et al., 2004; Wallerstein & Duran, 2006). In a meta-analysis, shared decision making in previous CBPR tended to be either manipulated, minimal, or sufficient (Viswanathan et al., 2004). Community input is often done through an advisory committee (Viswanathan et al., 2004). Community consent means getting approval for the research from the tribe through dialogue and partnership or through an approved Tribal Institutional Review Board [IRB] (Wallerstein & Duran, 2006).

For this dissertation, a community advisory board was formed. The advisory board started organically, as I talked about the original research topic with a Tribal elder who had a son that went through the special education system and often had difficulty getting him assessed and services. As we talked about development, the topic turned towards autism and the lack of data and difficulty getting services. We originally talked about doing this current research as a post-doctoral study. Through work, I have also known a Tribal member since her son was first involved in early intervention services. She often talked about the need for this type of research. When my research topic switched to the current topic, it was agreed by myself and dissertation committee that there needed to be a community advisory committee. There are some doubts about the surveillance and the number of AI/AN children with autism on the West Coast. Because of this, the research was exploratory and not focused on a tribe, but among the AI/AN living on the West Coast. The AI/AN population on the West Coast is diverse, not only with the 138 Federally Recognized Tribe in the states, but also due to several West Coast cities being a relocation site for AI/AN in the Plains and Southwest. For this reason, the advisory committee was comprised of AI/AN living in California, rather than being Tribal specific. The criteria for the advisory committee were to be AI/AN living on the West Coast and to have had experience working with the special education system birth through 21 with a child. The two people who were informally advising me became a part of the advisory committee. Recruitment for the rest of the committee was completed through posts on my Facebook account along with the criteria, and other people sharing the post. I received direct messages from fifteen people that are AI/AN. Although all respondents met the criteria of having experience with the special education system with their child, only three met the criteria of living on the West Coast. The advisory committee consists of 5 members, and four are women. Each committee member is an enrolled member of a tribe either from a West Coast tribe or elsewhere in the U.S.

In the initial start-up of this research, the advisory committee gave input in several areas. After developing a prototype of the initial Indigenous Child Development Model, committee members gave input to the model and recommend changes which I incorporated into the final model. Members reviewed the research design model. Although, I previously decided on a storytelling methodology, I sought approval of the methodology from the committee members. There was the potential, that I did not act as an equal on this part, and they may have felt compelled to agree with me on the methodology, rather than have me start over with a different methodology. I did not check on this. They gave input to the script for storytelling methodology. For the prompts, I asked them what they wish someone asked them about the assessment process for their child and how culture influenced how they approached the process and concerns. They also advised on the gift to be given to the participants. Within the Tribal community, a gift is traditionally given as a sign of appreciation and thanks. For the latter half of the research, the advisory committee reviewed the results and helped give recommendations for conclusions and research.

The participant also participated in the CBPR process. The participant reviewed the transcript and had opportunity to make changes by adding to or clarifying for cultural context. The participant reviewed the summary and initial analysis of the story and gave clarification or missing context. The participant also reviewed the overall results. The participant granted written permission to include her story as part of the dissertation.

This research had joint Institutional Review Board (IRB) approval. CRIHB, which is a consortium of over half the federally recognized Tribe in California gave Tribal IRB approval. The University of the Pacific agreed to the Tribal IRB approval and processes in their own approval.

Part of my job as a researcher was to identify my position of power and bias in the process. In truth, this was not a true CBPR project. Typically, a CBPR project takes one to three years (Viswanathan et al., 2004). The time constraints and expense of the dissertation process in the Western academia help prevent true CBPR work with Tribe. In the process, although I had talked about the potential research with an elder, I did not do it with the advisory committee, before making the pivot with the dissertation committee. For the approval to move forward with the change, I also specified an Indigenous Methodology to my Dissertation Chair and committee. In true CBPR, I would have made an advisory committee to talk about autism in the community and develop possible areas of research and methodologies prior to getting approval for the dissertation. However, moving forward, every effort was made to complete this research as CBPR.

Indigenous Methodology

When doing work with Indigenous communities, Indigenous methodology must be used (Hart, 2010; Kovach, 2010; Smith, 2013). Although AI/AN have Indigenous and Western viewpoints (Adams, 1995; Davis, 2001), they differ in realities and concepts (Battiste & Youngblood Henderson, 2000; Hart, 2010; LaFrance & Nichols, 2009; Simpson, 2000). A person experiences many truths based on their relationship with the spiritual, community, and self, and in research, it is imperative to understand where the participant is coming from with their answers (Battiste & Youngblood Henderson, 2000; Hart, 2010; LaFrance & Nichols, 2009; Simpson, 2000). Therefore, the research should be done in a framework that the participant understands (Kovach, 2010; Smith, 2013). This dissertation utilizes Indigenous storytelling methodology to answer the research questions of:

1. What developmental characteristics initially gave AI/AN parents' concerns about their autistic child's development.
2. Were the developmental concerns part of the recognized symptoms of autism as identified by the Mayo Clinic, or a different symptom?
3. How was the autism referral and assessment experience for parents?

The dissertation utilized Indigenous storytelling as its methodology. Conversational methods were considered a part of the storytelling.

Storytelling Methodology

Storytelling is an Indigenous methodology (Bird, Wiles, Okalik, Kilabuk, & Egeland, 2009; Kovach, 2015; Silko, 1998; Smith, 2013; Thomas, 2005). Traditional Indigenous knowledge was passed down orally (Corntassel, Chaw-win-is, & T'lakwadzi, 2009; Kovach, 2015; Thomas, 2005). This knowledge was core stories of the group's beliefs, traditions, and ideals (Caxaj, 2015; Corntassel et al., 2009; Kovach, 2015; Silko, 1998; Thomas, 2005). It was passed down orally versus in writing, as the meaning of the story could be lost when written down (Kovach, 2015, Thomas, 2005). Storytelling is also a way for the participants voice to be heard, as it is their own story. It also allows the participant to leave all of the context of culture, place, and interconnectedness in the story (Caxaj, 2015; Cruickshank, 1990; Thomas, 2005).

Three Types of Storytelling

In his book, *Research is Ceremony: Indigenous Research Methods*, Wilson (2008) gives three levels of stories as parts of traditional ways of knowing as explained by an elder of the Cree. "At a higher level are sacred stories in form, content, and structure. These stories themselves must be told at different levels according to the initiation level of the listener. Only those trained, tested and given permission to do so can tell these stories, which must never vary in how they are told. They are sacred and contain the history of our people. The second level stories are like the Indigenous legends that you may have heard or read in books. There are certain morals, lessons, or events that take place, but different storytellers, shape them according to their own experience and that of the listener. The intent or underlying message of these stories remains the same. The third style of story is relating personal experiences or the experiences of other people" (Wilson, 2008, p. 98). The participant in this research engaged om the third style of storytelling, relating her own experiences.

Differences Between Western Storytelling and Indigenous Storytelling

There is a difference between Western storytelling and Indigenous storytelling methodologies (Caxaj, 2015; Thomas, 2005) Western storytelling is based on narrative methods which is a telling of self (Caxaj, 2015; Zipes, 2013). People are taught to tell a story that includes the framework of a plot, structure, and a certain type of grammar (Cavarero, 2014; Caxaj, 2015; Labov & Waletzky, 1967; Lambert, 2013; Lipes, 2013). These aspects of storytelling show Western thought, and the product of the research may not be viewed as truth by an Indigenous person (Caxaj, 2015). Caxaj (2015) gives a great example of this through a story that creates a difference and conflict between the only man and nature. From an Indigenous standpoint, there is an interconnectedness between man, nature, and the spiritual, so there could not be separate conflict between the two. Indigenous storytelling is rooted in the storyteller's history, values, and ways of knowing that are unique to them and their people and may define the creation of knowledge (Caxaj, 2015; Corntassel et al., 2009). The story may have multiple truths and meanings (Bishop, 1999; Caxaj, 2015). People live and tell their stories not only in a way that gives meaning to self, but also gives meaning to the community (Clandinin, 2006). Stories may be political and teach resistance, defiance, that kept culture and tradition alive, or challenge the narrative about Indigenous people from the Western Perspective (Corntassel et al., 2009;

Thomas, 2005). Within the culture, Indigenous storytellers are honored and respected (Thomas, 2005). Analyses of Indigenous storytelling involves keeping the storyteller involved in the analyses of the data and reporting of the products (Thomas, 2005) as well as multiple types of analyses of the story (Bird et al., 2009).

Storytelling Research in Action

In preparing for the dissertation, I reviewed one other dissertations and a master's thesis that used Indigenous storytelling methodology. I wanted to see a more-in-depth look at the methodology in action versus what was written in a scholarly article.

Storytelling is iterative. Prior to writing her scholarly articles on Indigenous storytelling, Thomas (1993) used storytelling as the methodology for her Master's thesis looking at the experiences of First Nation's women that attended Kuper Island Residential School. In writing the stories, Thomas was cognizant of reflecting the storyteller's voice, and used various techniques to make sure it was the voice of the storyteller, versus her voice (Thomas, 1993). Storytelling is relational (Kovach, 2019; Wilson, 2001), and Thomas (1993) demonstrates the relational aspect by spending a year in building relationship with the storytellers over the period of the year in collecting the stories, analyses of the stories, and presentation of the stories. In reading, I found the storytelling process to be iterative. By iterative, I do not mean in the traditional sense of design thinking and prototype testing as learning in the program, but in the traditional sense of the story being multi-layered. Thomas (1993) would get the initial story, but because there was no relationship yet, there was no depth to the story. As she asked questions after processing the story, she would build relationship, and the story would get added depth (Thomas, 1993). This was in iterative process of telling the story, asking questions, telling more of the story, and asking more questions.

Storytelling creates space. Lipe (2013) used Indigenous Storytelling Methodology in his dissertation creating space for Indigenous Knowledge Systems in Scientific Viewpoints. Lipe's (2013) storytelling was also relational, but he had existing close relationships with his storytellers. As part of the relational aspect, Lipe (2013) would often tell his own story and his struggles to show empathy and understanding of the story that the elder told. This is considered normalizing the subject with an elder (Wilson, 2008). While Thomas (1993) analyzed her stories through the view of characters and the four traditional masks of the coastal Salish, Lipe (2013) analyzed through a relational reliability.

The Use of Conversation in Storytelling

Both Thomas (1993) and Lipe (2013) used conversation as part of their research. Storytelling is a relational methodology based on sharing and listening between the teller and listener (Kovach, 2019; Wilson, 2001). Traditionally, storytellers allowed questions during their storytelling for clarification or to learn another part of the story (Thomas, 2005). Conversation would happen within the storytelling (Thomas, 2005). Conversation may also happen after the story had been told to gain further understanding of the story, or add new layers to the story (Thomas, 1993).

Conversation can also be considered its own type of Indigenous methodology (Kovach, 2019; Thomas, 2005). Storytelling can take place within the conversation (Bishop, 1999; Kovach, 2019; Thomas, 2005). Among the Aboriginal of Australia, they refer to this as yarning, which is a relaxed conversation between the participant and researcher to explore an area of research (Bessarab & Ng'andu, 2010; Geia, Hayes, & Usher, 2013). For the purposes of this dissertation, I consider conversation as part of the storytelling.

The Telling of the Stories

Storytelling is the primary methodology for this research, and within the storytelling, conversation occurs (Bessarab & Ngandu, 2010; Kovach, 2019; Thomas, 2005; Wilson, 2001). This method is relational between the participant and researcher (Kovach, 2019, Thomas, 2005, Wilson, 2001). The relationship building occurs while the researcher is truly listening to the storyteller, and interacting with them (Thomas, 2005). As the researcher is listening, the researcher can ask for clarification, or ask other questions to explore that are pertinent to the story and the research (Thomas, 2005). The relationship does not end, when the story ends, but the relationship continues to grow, as the participant is involved in the analyses and reporting of the data (Thomas, 2005). Clarification may be asked throughout the process (Thomas, 2005).

Building relationship with the storyteller. The participant volunteered to tell her story. Storytelling is relational (Bishop, 1999; Lipe, 2013; Thomas, 1993; Thomas, 2015; Wilson, 2001; Wilson, 2008). Since I did not have an existing relationship with the participant, I started by telling my own story of my speech issue and getting services, as a way to build trust and normalize the process. I was raised to respect storytellers and to listen to the story versus doing other activities, so while the story was being told, I did not take notes or ask questions. I focused on listening to the story as a sign of respect to the storyteller. After the story was told, I typed my notes, thoughts, and questions into my computer. If I had questions or wanted clarification, I called the storyteller to ask the question and arrange time for the storyteller to tell more of their story. This was where the conversational part of the storytelling took place (Bishop, 1999; Kovach, 2019; Thomas, 1993; Thomas, 2005). Through this back and forth, we built relationship, and get more parts of the story. Asides from telling my own story at the beginning, if needed, I would talk about parts of it again, in order to show empathy and understanding, and my own struggles. I wanted to normalize the process as much as possible between me and the storyteller (Wilson, 2008).

Telling and listening to the story. The story told is a third level story of person sharing her experience with her child's autism (Wilson, 2008). Stories are a way for a person's voice to be heard (Thomas, 1993). The stories are oral, and so context will be lost, when the stories are put in written form (Kovach, 2015; Thomas, 2005). I wanted to be respectful of the story told, and when writing the story, to make sure that the story was in the storyteller's voice. To complete this, I transcribed the recorded stories and conversations myself, so I could concentrate on the voice and the story. I shared transcripts with the storyteller, so they could edit or add to the story. As I began to write the stories, I was mindful of keeping my own thoughts and ideas out of the story. My own thoughts and ideas are in the re-telling of the story through analysis in Chapter Four. The story was written in the first person. The story document was sent back and forth between me and the storyteller, so I assured it was being told in the storyteller's voice. Chapters Four is the story so that her story and voice can be shared. The names were changed, and their location removed to protect her confidentiality and her child's personal identifiable health information.

Data Analysis

Qualitative data can be difficult to analyze (Gibbs, 2018). How a person brings order to the data helps to manage and interpret the data (Gibbs, 2018; Renner & Taylor-Powell, 2003). The analysis must have a structure be remain flexible to look for new ideas that emerge from the data (Renner & Taylor-Powell, 2003). The use of computer software to analyze qualitative data is a choice (Gibbs, 2018). In doing this sort of traditional Western data analysis, all relationships in the data are removed, so that each piece can be looked at individually (Wilson, 2008).

Analysis Through an Indigenous Lens

Within Indigenous storytelling, there are many truths based on the person's own experiences and the interconnectedness of the spiritual, physical, culture, and environment (Bishop, 1999; Caxaj, 2015; Cruickshank, 1990; Thomas, 2005). Because storytelling is relational, the data cannot be separated out and removed (Wilson, 2008). Indigenous knowledge is about the relationship between everything (Wilson, 2001). As a researcher it is important to think about the relationship between ideas, beliefs, and with the world and community around us (Wilson, 2001). Since everything is related, Wilson (2001) argues that we are not concerned about reliability and validity in the research, but how we fulfill our relationship to the world and those around us. This is referred to as relational accountability (Wilson, 2001). In 2008, Wilson would go further and describe relational reliability, which means that a story has to be looked at as a whole, because the meanings and relationships in the story are connected. My analysis is not based on coding but based on looking at the relationships by using Member Check-In and Self-Reflection.

Creating Relational Accountability and Reliability

Indigenous research is ultimately defined by the relationship between the researcher, the participants, and community throughout the entire research meaning that there is input from the participants in the analysis (Smith, 2013). Thomas (2005) and Kovach (2019) recognize the need to include research participants as part of the analysis. Both Thomas (1993) and Lipe (2013) had participants help with the analysis of the data. Lipe (2013) chose to use Member Check-in as a way to keep the relationship going through the analysis of the data and to keep himself grounded in his culture.

Member check-in has traditionally been used to give trustworthiness or validation to qualitative studies (Birt, Scott, Cavers, Campbell & Walter, 2016; Carlson, 2010). It is a way to see if the researcher’s interpretation aligns with the participants experience (Carlson, 2010; Curtin & Fossey, 2007). Typically, participants would review transcripts for accuracy, edit, and provide context, and participants may also check for interpretation of themes (Carlson, 2010; Creswell, 2009). Member check-in may be done continuously or one time (Carlson, 2010; Doyle, 2007). Doyle (2007) refers to it as participative member checking, as participants are given some power by choosing how to engage in member check-in, and approvals of the research publication. Member check-in requires looking at the research through three lenses of the researcher, the participant, and those that will review the research (Carlson, 2010; Creswell & Miller, 2000). The three lenses and participatory nature show that the analysis is relational, which makes it ideal for reviewing stories and research that are relational. Lipe (2013) used it as part of his analysis. Member check-in provided a way for him to continue the relationship with participants throughout the research, and to enhance the relationship, by the participants building relationship with each other (Lipe, 2013). This enabled participants to review each other’ stories and how it compared with their own experiences (Lipe, 2013).

For Member check-in, I transcribed all recordings. Individual transcripts were shared in a word document with the participant via password protected electronic mail. I left track changes on, allowing both myself and the participant to make changes and edits, and give transparency as to who made the changes. After the participant’s story was written, it was shared with the participant to ensure that it was written in the participant’s voice. I conducted member check-in throughout the analysis of the stories and the concluding chapter of the dissertation to ensure that participant had a voice in the research and reporting of the results.

Self-Reflection. Storytelling is a way for people to talk about their experiences in their own voice. Stories may have multiple truths and meanings (Bishop, 1999; Caxaj, 2015). People live and tell their stories not only in a way that gives meaning to self, but also gives meaning to the community (Clandinin, 2006). There is also an interconnectedness of the story with the environment, culture, physical, and spiritual (Bishop, 1999; Caxaj, 2015; Cruickshank, 1990; Thomas, 2005). In my own self-reflection, I am considered a child development expert and have worked with autistic children throughout the years. I have a knowledge of autism symptoms. My knowledge is part of my interconnectedness to the story. In my initial analysis through self-reflection, I looked at the stories and how they fit into the Indigenous Child Development Model presented in Chapter 2 and also with the autism symptoms listed by Mayo Clinic. Table 1 shows the Social Communication and Interactions symptoms of autism and Table 2 shows the patterns of behavior associated with autism. Both tables are as defined by the Mayo Clinic.

Table 1
Social Communication and Interaction Autism Symptoms as Defined by Mayo Clinic (2020)

- Fails to respond to his or her name or appears not to hear you at times
- Resists cuddling and holding, and seems to prefer playing alone, retreating into his or her own world
- Has poor eye contact and lacks facial expression
- Doesn't speak or has delayed speech, or loses previous ability to say words or sentences
- Can't start a conversation or keep one going, or only starts one to make requests or label items
- Speaks with an abnormal tone or rhythm and may use a singsong voice or robot-like speech
- Repeats words or phrases verbatim, but doesn't understand how to use them
- Doesn't appear to understand simple questions or directions
- Doesn't express emotions or feelings and appears unaware of others' feelings
- Doesn't point at or bring objects to share interest
- Inappropriately approaches a social interaction by being passive, aggressive or disruptive
- Has difficulty recognizing nonverbal cues, such as interpreting other people's facial expressions, body postures or tone of voice

Table 2

Patterns of Behavior Associated With Autism as Defined by Mayo Clinic (2020)

- Has fixation with activities and inanimate objects with unusual focus or intensity
- Engages in repetitive moments such as spinning, hand flapping, or rocking
- Is not involved in make-believe or imitative play
- Engages in activities such as biting and head butting that could cause self-harm
- Established specific activities and routines and gets disturbed at any changes
- Sensory issues with light, sound, and touch. Indifference to temperature
- Problems with coordination, appears clumsy, and moves with exaggerated, stiff, or odd movements
- Defined food preferences such as resisting foods with certain textures or eating very little
- Doesn't understand overall function or purpose of an object but is fascinated by the details

After the initial analysis of fitting in the stories into my own truth and experiences, I presented my analysis to the participants to see how they felt their story fell into the symptoms, or if they felt my analysis was correct. I also reconciled the stories and transcripts with my notes and thoughts and sought clarification for better understanding.

Trustworthiness and Credibility

Qualitative studies must establish trustworthiness and credibility. It helps establish the credibility of the research. Due to the researcher's experience, establishing the trustworthiness and credibility also helps protect against bias by the researcher. With Indigenous research, there is also relational reliability to determine that researchers are accountable for fulfilling their relationship responsibilities in the research (Wilson, 2008). To establish trustworthiness and credibility, the following steps were taken. Criteria was established for participants.   I wrote the story in the voice of the participant and shared in this dissertation. I used member check-in with the participant to check for accuracy in transcripts and stories. I used track changes in shared documents between myself and the participant that provided transparency and accuracy. Analysis was conducted with participant.

Participants and Participant Protection

Parents are recognized as the best experts on their child's development, so parents are the best participants for this research. Storytelling participants were parents that self-identify as AI/AN and live in California, Oregon, or Washington. The participant had to have a child that received an autism diagnosis within the last 10 years. Due to poor surveillance information about the number of AI/AN children in California, Oregon, and Washington, I tried not to set the parameters for participants as too restrictive. By choosing people that self-identified as AI/AN, it allowed for participants that were either from federally recognized or non-federally recognized Tribe, people that are not enrolled, but of lineal descent, and people that have been disenrolled from their tribe due to political reasons. It also protected Tribe from being identified in any of the data. Participants were recruited through invitations to Tribal Health Clinics, Urban Indian Health Clinics, Tribal Head Starts, and Regional Developmental Centers in California, Oregon, and Washington. Participants were also recruited from social media postings on my Facebook and LinkedIn profiles, and the sharing of those posts by others. The snowball method was also used were participants were asked to refer other potential participants. Through all of this effort, one participant was found that fit the criteria and wanted to tell her story.

Issues Impacting Recruitment of Participants

I knew that recruiting participants would be difficult. Although autism in not a culturally taboo subject, the stigma of the diagnosis is taboo to many people. There were six other people that wanted to participate, but their children received a diagnosis over ten years ago, and the age of their children were over twenty. These parents wanted to tell their story just now at this point in life. I asked if they had anyone, they could recommend anyone for the research. Each of these parents responded no, because this was not something that is talked about in the community. They also warned me that it would be difficult to find participants.

A couple of weeks after recruitment of participants started, Corona Virus Disease 2019 (COVID-19) shut down California, Washington, and Oregon. This changed how staff were working at the places that I attempted to recruit participants. As COVID-19 highly impacted Tribal communities, it also changed priorities from helping recruit participants to focusing on COVID-19.

Because of the dynamics of a subject that people didn't want to talk about, and COVID-19 happening, recruitment was kept open through late May in attempt to find a second participant. After consultation with my dissertation chair, it was decided move forward with just the one participant's story. The justification was that this dissertation is exploratory in nature and no previous parent stories existed in the research community. One story now existed which was more than existed before.

Honoring the Storyteller

Storytellers are respected and honored (Thomas, 2005). It is also customary to give a gift to a person to help you. I was also raised with this tradition. At the recommendation of the community advisory team, participants were gifted with an abalone shell along with a bundle of sage and a braid of sweetgrass. These are considered traditional for ceremony and medicine. It would be culturally inappropriate to set a value on traditional items and medicine. However, for the purposes of the research and IRB, the items were under $30 for each person. Participants were not made aware that they would receive a gift for their participation, and each participant was awarded the gift after the completion of this research.

I gave the participant the opportunity to tell her story via Skype and similar technology. Skype is an online communication application. The participant signed consent forms prior to the start of the interview. Autism is primarily thought of as an educational diagnosis. The CRIHB Tribal IRB also pointed out that autism is a health diagnosis and is protected health information

(PHI). The parent also signed a Health Insurance Portability and Accountability Act (HIPAA) authorization form to be able to share their minor child's autism diagnosis. At the start of the story, the participant also gave verbal permission.

Transcripts are kept on a password protected computer. After 5 years, transcripts will be deleted and scrubbed from the computer. Audio files and printed copies of the transcript are locked in a file cabinet. After five years, they will be shredded with a confidential shredding company. Members of the dissertation committee have full access to the data minus personal identifiable information. The participant access to her own story. The participant's name and her children's name were changed in writing the stories for the dissertation to protect their identity.

Protection of Participants

There have been many abuses of research with Indigenous communities (Kovach, 2010; Smith, 2013). The protection of the participants is considered paramount to ethical research with Indigenous people. This chapter has noted many protections of the participant and her community. Tribe are not recorded in this research to protect Tribe. The research utilizes CBPR by using a community advisory board to give guidance and cultural context to the research. The participant was recruited and volunteered to participate in the research. Recruitment occurred form a large geographical area to keep PHI confidential. The participant gave consent to participate in the research. Analyses of the data was completed with the participant's review and input throughout the analyses. Results were reviewed and approved by the participant and the community advisory team. Tribal IRB review and approval was given as the primary IRB. I invited the participant to the dissertation defense to hear my storytelling of the research. Table 3 shows the primary protections given.

Table 3

Protection of Indigenous Participants

Protection
1. Utilized an Indigenous community advisory board.
2. Research reviewed and approved by Tribal IRB
3. AI/AN Ph.D. on dissertation committee to provide guidance.
4. Voluntary participation.
5. Participants included throughout the data analyses
6. Results of research reviewed and approved by participants and community advisory board before reporting

As a part of other protections and ethical considerations of the research, the participant parent was viewed as the expert on her child. The participant identified as AI/AN. The participant's identification and Tribal identification were confidential. Because the participated throughout the research, I utilized Indigenous methodology and an Indigenous Community Advisory Team. I completed the primary IRB review and approval through the CRIHB Tribal IRB. Both IRB's considered the research as minimal risk.

The researcher and all members of the dissertation committee maintained current CITI certification for working with human subject during the research process.

Role of the Researcher

The researcher has worked in early childhood education for over 20 years. He has a Bachelor of Science in Psychology and a Master's in Education in Early Childhood Education with an emphasis in Special Education. His Master's was obtained at a university located on the Yakama Reservation that works closely with the tribe but is not a Tribal College. He has worked with screening and assessing children for over 20 years. The researcher has worked with the ASQ, DIAL, CDI, and Batelle Developmental Inventory. His master's thesis looked at the inter-reliability and validity of the Spanish versions of the Ages and Stages Questionnaire: Social Emotional and Devereaux Early Childhood Assessment. The researcher has performed screenings, assessments, and Child Find Activities for several years, as well as working with medical clinics to improve screening techniques. The researcher has worked with several young children on the ASD spectrum over the years. The researcher used Member check-in and included participants throughout the research to guard against bias.

Dissemination of Data

Indigenous communities are one of the most over researched communities, and after research is complete, the researchers are never heard from again (Smith, 2013). Much of the research has been unethical, with dissemination of the data harmful to Tribe (Smith, 2013). A copy of the dissertation was provided to the storyteller and to CRIHB's Institutional Review Board. As part of the participative checking in, the participating storyteller approved including her written story as a chapter in the dissertation. She also approved publication of the dissertation as an open dissertation in ProQuest. Any resulting article from this dissertation will be completed in conjunction with CRIHB IRB approval of the written article. Another part of the dissemination is through presentations. The results will be presented to Tribal Head Starts so programs can better work with parents in identifying autism concerns and working with parents through the assessment process. Presentations may also be done at Tribal Health and Early Childhood Conferences.

Summary

This is exploratory qualitative research utilizing Indigenous methodologies to look at autism among AI/AN in California, Oregon, and Washington. There have been many abuses by researchers in Indigenous communities (Kovach, 2010, Smith, 2013). As a part of talking about the methods of this dissertation, the chapter addresses the researcher's positionality, community input into the research, Indigenous methodology, and the participants and their protection.

The researcher is a Diné male. Although being raised among other Tribe and without his own culture, he is in the process of learning his own culture. Although he was not raised with his language, culture, or songs, he was raised in other traditional Diné ways. In looking at various dissertation topics, he looked for a story that was his to tell. This research is an area that he can tell the story.

Research in Indigenous communities requires CBPR. Since this research is not specific to any one tribe, a community advisory board was formed consisting of AI/AN parents in California with experience with their child in the special education system. Although the committee was not formally involved with the beginning of the research, every effort is being made to have the committee advise the research.

Research with Indigenous people requires the use of Indigenous methodologies. These methodologies provide the correct framework and context to the research. This dissertation utilizes storytelling with conversational methods intertwined into the storytelling. This type of methodology is relational, and keeps the participant involved throughout the remainder of the research process.

The participant is a parent that self-identifies as AI/AN and live on the West Coast. The participant had a child diagnosed with autism in the last ten years. To protect the participant, data analyses was completed with their input and review. Tribal IRB was the primary IRB review and approval.

Chapter 3 focuses on the methodology. Chapter 4 presents the storyteller’s story. Chapter 5 presents analysis of the story while Chapter 6 presents conclusions and recommendations for future research.

CHAPTER 4: TIFFANY”S STORY

Introduction

Typically, a story is told orally, but the dissertation process requires it in writing. To protect the storyteller’s confidentiality, her name and the children’s names have been changed. Her and her husband’s Tribal membership is withheld to protect the confidentiality of their Tribe. Other than, that, the story is in her own words and reflects her voice. According to Wilson (2008) this is a third level story, as the teller is telling about her own experience.

Tiffany’s Story

I am a citizen of my Tribal nation. My husband is a citizen of his Tribal nation. Um, we have our oldest son. His name is Timmy. He’s nine, um, he will be 10 next month, and then Thomas, our youngest is 3. So, when we had Timmy, there was nothing, no type of complications during pregnancy or anything like that. Everything was really normal.

Um, I don’t really know when we noticed that anything was amiss. Mostly because one of the main signs of like autism is eye contact, and I just didn’t notice that. I mean he seemed to make eye contact, and maybe it wasn’t as much as they’re supposed to make. But, we just didn’t see anything. It didn’t seem like that was an issue. I do remember him um being younger, like 2 and 3, and line up all his cars in a row. Like there would be 50 cars or trains, and all lined up. I didn’t know that was a sign. You know, there are so many things they don’t tell you. You know like general awareness is always about eye contact, and I didn’t even see that.

Anyway, I noticed he had a really hard time with transitions. But as first-time parents, I mean I don’t know what’s the difference between someone who is a bratty toddler, or that there is something else going on. We just didn’t know.

Um, we did notice, he wasn't talking very much, so we started, we got um like a lot of hearing tests done and did that part. We started speech therapy at the Scottish Rite Center. They have speech therapy, so we started going there. And you know, there was one day he was going to speech therapy appointment and she (speech therapist) was running late. She didn't walk right in, and he had a meltdown. Um, and then during some of the activities, they were changing things, and like he was super rigid. It was actually the speech therapist there, who said, you know, I think there might be something else going on. Um, and so she was really delicate about it, and I'm like just spit it out, you know. And she was like, I think you know, he might be on the spectrum. But I can't diagnose that, but I think maybe its something to look at. she was like yeah, you know, you need to see if there is something else going on. She was actually like the first person to even think that way, to have him checked out. She was also the first person to tell us about the regional center.

He was probably about 3 or so at that time, and it was like ok, you know, not a problem, because like I said, it did seem like some things were off. I have a nephew who is 8 months older than my son, so they just weren't at the same level, but also kids change so much, that even 8 months difference to like a toddler is a difference, so it just wasn't super clear.

So we go to try and get a diagnosis. I didn't know that you could get services from the school district at age 3. So, it was just like I was turning to our insurance and trying to call the regional center, and then do all of those things. When you call the regional center, they are kind of like, they say that they are like the last resort if you can't get it somewhere else. And then I was calling our insurance and trying to figure out through them.

Who could do the test? I didn't really know what test to ask for. Which, you would think that they would know. Ok, well, totally getting the run around. You need to call these people first, you need to call these people first, you need to go do this, have you tried this. Um yes, this person can see you, but it is a 6 month wait list. And it was really frustrating because all you hear about is early intervention, but you're now telling me that, I have to wait 6 months to even get any of these things started. So we ended up (pause) seeing, he was like a neurological person, who doesn't actually diagnose autism or not. So, I-I-I don't remember exactly what their job was, all I know is it was a waste of time. We went and saw them it didn't help. Then he saw, eh a pediatric neurologist, and they said that there was a language delay, impaired social interaction, and obsessive behavior. Then, it must have been, I think we went outside of network, and then I can't remember who we saw that gave us the diagnosis. It, because then it was like later after he turned 4, that we went back to our doctor, and it was officially um, you know the autism spectrum disorder. We get the diagnosis, we go to the regional center, and they re-diagnosed, and I was like why couldn't we just come here in the first place?

It was March 2013 when we first told our, um well like primary care that we thought something was going on, or that we thought the speech thing was going on. It was a full year before we got an autism diagnosis. So, from 3 to 4, it was just back and forth with different doctors. I just remember being super frustrated, that it felt like, you guys say we need to get these interventions, but its literally taken me a year to have someone help us. I felt like we really got the run around.

And so then, we got that diagnosis, and then we were able to start services. So, once we had a diagnosis, everything, it, really everything did change for us. We were able to go to the school district and get him enrolled in preschool. Um, because he wasn't in preschool because preschool's not free. So, he was like at daycare, um, sooo, we enrolled him in preschool. And then we got ABA therapy. Because now he was older, he was able to get his speech therapy and occupational therapy through the school. Because we had done the occupational therapy through our insurance, while we were waiting for him to start school. Yeah, he was able to, yeah, once we got that diagnosis, it was like ahhhh, you know?

You are getting all those services. People you know, our friends and family, they were like, oh how you feel? And I was like, I'm just glad to know what was going on. That was the thing, when I don't know as a parent, is this normal, is this not normal? What, like what's it gonna take. And even if there were things that were wrong, and he didn't have a diagnosis, he wouldn't have been able to get help anyway.

So, the diagnosis part was great, because at least we now know what we need to do to have all these services available. I would say though, that the family or families did not handle it well. But I think in a lot of families, it's like there is nothing wrong, they're fine, they're just gonna talk in their own time. They are just gonna do this in their own time. And it was a lot of training in our family of, of like, you know, there is something, not something like wrong, but like, he does have this condition. So, don't just grab him like that, or don't, don't just think that he is being defiant. And I think that's a big issue, that people look at it like, he is being defiant. And it's like, no, that's not the case. Um, I even had a cousin, who I asked Timmy a question, and Timmy was like, "NO!" I asked him a yes or no question, and my cousin was like, no, you don't say no to your mom, like that's not how you talk to your mom. And I'm like the fact that he understood my question, and was able to respond appropriately, whether I like that response or not, like that's a good thing. Don't tell him, he can't tell me no, when I asked a question. Like that's great. And, um, we are still dealing with that. Because in our family when someone calls your name, you say yes, you don't say what. So that's kind of a hard concept for someone to understand, because you learn like, who, what, where, when, why, but then when someone calls your name you can't say what, because that's rude. So, we are still dealing with all those things like family wise.

There were symptoms that showed that I didn't know. I knew about eye contact. I didn't think he wasn't making it. Eye contact is normal, I think more so in my culture. So, I come from a mixed family. Um, so I think for us, it more normal. And then in my husband's family, they're more traditional. There's not much eye contact and there's not much in general. So, I don't think it was a big thing that he would have noticed. And for me too, I think that things are different, you know your child acts differently around you than they do others. It felt like, he was not making eye contact with me. And now, I see it more. Like when I'm scolding him or disciplining him since he's older. I 'm like you need to look at me. And he will look real quick and look away. And now I can see like, ok, that's what this looks like. But you know, I think when you think about eye contact in this instance and you don't have any kids or anything to compare it to, you think of it as like won't even look at you at all. Not that it's just not sustained. I think we just didn't you know.

Also, I think that you know, him lining up his cars. Not playing with toys the way they were traditionally meant to be played with. That was something, that we just didn't even think anything about. The way he lined up the toys, being very like rigid. And some of his like scheduling and stuff were if he had expectations, like when we went to speech therapy and he like flipped out when she was late. Then also I remember, we went to go get photos taken when he was three with like my nephew. There was just something, I don't know if it was just like the noise or lights or something, but he was like not having it. He had like a total meltdown, like really like frightened and afraid. Like maybe he was overstimulated. We're not professionals, we just didn't know.

I think for me, the biggest like cultural piece to me was like there’s nothing wrong, they will be fine. It’s just that’s the way they are. They will get caught up. And you know, people don’t want like a label, in like that aspect of it. And also, I think just also how complicated the system is, that you don’t even know what you are asking for, what you need, and it’s not easy to figure out.

And then with our three-year-old, obviously, we knew what more to look for. He just had a speech delay as well. Um, so we a got the hearing test and got speech therapy started. And I demanded an autism a test. I didn’t think that he was on the spectrum, but I’m not gonna sit here and wait, Until I do, and take a year, so I just demanded that they give us the test. And they said that he does, there’s no signs of autism. But I just felt better knowing one way or another. Yeah, and that’s kind of the story that we’ve had.

CHAPTER 5: RESULTS

Making Sense of It All

This dissertation focused on exploratory research in an area where there was barely research, or the research was non-existent. I sat and pondered; how would I make sense of this all? Was one story enough? How did I ask a person to tell a very personal story, a story that is rarely told, and then analyze it? To say I used Indigenous Methodology through storytelling was the easy part, but to use it in the analysis was the hard part. The Imposter Syndrome crept back in with thinking if I was Indigenous enough to properly make sense of it? Was I the right person, to present this story, which was the first research into this area in the community? Traditionally, stories were meant to share wisdom, and the story should stand by itself. However, in my position of power as the researcher, I wrote on the wisdom and knowledge that is gained from this story. Would my analysis and what I wrote be good medicine?

Seeking the Advice of an Elder

To better prepare, I first spoke with my mom. I explained my issues to her, and difficulty with starting this chapter and assessment. It is traditional to ask, because she has been the only matriarch of our extended family since 2009. First, she expressed regret for not raising my brothers and I in our culture, and only concentrating on the Chicana/o culture, because it would have been helpful. She then mentioned that it is hard for me, because it is the first time that I have been challenged by anything in school. The third thing was to remind me that as a child, a medicine man told her that her first child would be a curandero. Traditionally, a curandero was a person who was a healer that used traditional remedies to bring healing for physical, spiritual, emotional, and mental illnesses. As mom said, curandero was a Spanish word for medicine man. But it was important to my mom to remind me that although I was not a medical doctor, this research was the research of a curandero, meaning I was using traditional ways to try and bring healing to the assessment process.

Finally, my mom told me to go home to the reservation and participate in a peyote ceremony, and I would see clearly, with the answers coming to me. I am quite familiar with peyote ceremony as it is considered a sacred medicine among Tribe in Northern and Central Mexico which many of the Southwest Tribe were originally a part of Mexico. Peyote was used in a healing ceremony and prayers and introspection were done during the ceremony. I did not take part in a peyote ceremony. This chapter was being written during the COVID-19 pandemic, and Diné Nation was highly impacted as a hot spot. This prevented me from going home to participate in any type of ceremony, and I am uncomfortable in participating in a peyote ceremony. However, I understood what my mom was saying. There was a spiritual component to the analysis, and I need to prepare my mind spiritually. So, I burned sage to purify myself, offered tobacco in my prayers, and meditated for introspection.

Introspection

The introspection caused me to re-read my first three chapters, the stories, *Indigenous Methodologies: Characteristics, Conversations, and Contexts* (Kovach, 2009), *Research is Ceremony: Indigenous Research Methods* (Wilson, 2008), and *Decolonizing Methodologies: Research and Indigenous Peoples* (Smith, 2012). Two sections stuck out to me that frame the analysis of the story. Kovach (2009) wrote:

> "I offered her the best guidance I could should she choose Indigenous Methodologies‒start where you are, it will take you where you need to go… Since this time, I have heard variations of this narrative, not all but many from young Indigenous people who share a story that holds an undertone of a deep desire to come back to one's own culture. Many non-Indigenous young people are attracted to Indigenous approaches as well because, I believe, it has to do with a generation seeking ways to understand this world without harming it" (pp. 10-11).

Wilson (2009) encouraged me in writing:

> "So analysis from a western perspective breaks everything down to look at it. So you are breaking it down into its smallest pieces and then looking at those small pieces. And if we are saying that an Indigenous methodology includes all of these relationships, if you are breaking things down into their smallest pieces, you are destroying all the relationships around it. So an Indigenous style of analysis has to look at all those relations as a whole instead of breaking it down, it just won't work. So it has to use more of an intuitive logic, rather than a linear logic, because you can't just break everything down into small parts and use linear logic to bring them back together to a whole. You have to use intuitive logic, where you are looking at the whole thing at once and coming up with your analysis that way. So it's mostly innate within us. So there are different ways of doing that" (p. 119).

The words of these authors reminded me that this was the appropriate methodology that would take me where I needed to go, and to look at everything as a whole. I prided myself on the ability to see systems and how the different parts of the system worked with each other. Systems required relationships between the parts and the system in order to work. This idea made sense to me and allowed me to begin to see how to make sense (analyze) of the story.

Analysis Method

The analysis became a story, but a different type of story. The participant's story and my self-reflection were known as the third style of story in Indigenous Methodology. The third style or level of story told of personal experiences (Wilson, 2009), and those stories told those experiences. The analysis chapter was a second level story. According to Wilson (2009), a second level story taught lessons but the storyteller, used their own experience to tell the story, however the story remained the same. In the analysis, I was the storyteller of the second level story. In creating this story, I used the prior research in Chapters One, Two, and Three, the Participant's story in Chapter Four, my self-reflection in Chapter Five, and my own professional and Diné knowledge. I also used my Indigenous Child Development model from Chapter 2, to look at the relations of the intersections of ASD, Indigenous Knowledge, and Western Knowledge. This analysis answered the following questions:

1. What developmental characteristics initially gave AI/AN parents' concerns about their autistic child's development?

2. Were the developmental concerns part of the recognized symptoms of autism as identified by the Mayo Clinic, or a different symptom.

3. How was the autism referral and assessment experience for parents.

Moving forward, there are two things to keep in mind. It is typical to honor a storyteller and to say who the story came from. With that in mind, in retelling the story, I will move forward into referring to the storyteller as Tiffany. Tiffany is the name that was chosen to use to maintain confidentiality. Also, graphics are done in turquoise. Turquoise is important in Diné culture. Besides the idea that it protects us from evil, there are stories of it forming from tears and being a home of turquoise on the Western horizon. Turquoise connects the water, the land, the sky, and the heavens, it symbolizes the interconnection between all. The choice of using turquoise was a way to keep me connected to my land and environment as I did my analysis.

Initial Analysis

Initial analysis of the story began as part of the storytelling methodology and member check-in. As the stories were told, I actively listened and did not take notes. After the storyteller finished, I asked questions to clarify or get new information. At the end of the first story, I asked if anyone referred the family to the school district for the assessment, because I had only heard parts of the story dealing with the medical diagnosis. Figure 3 shows gave a visual of this research methodology as analysis.

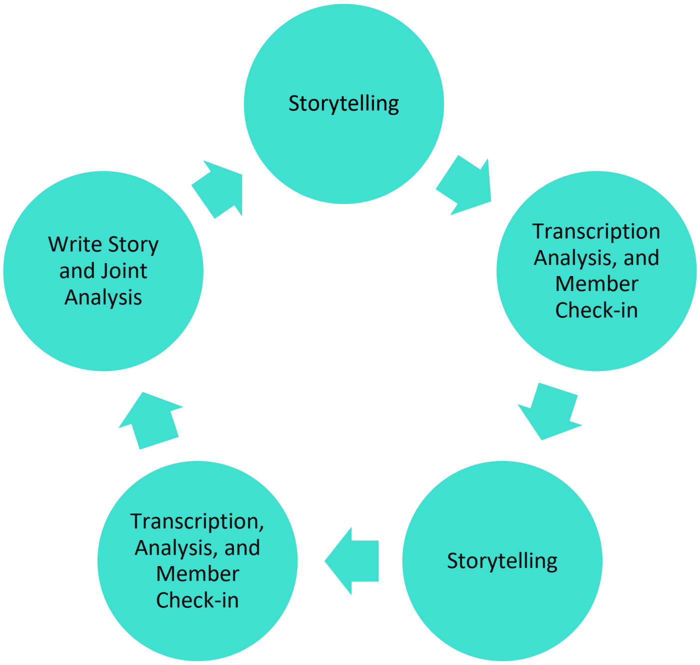

Figure 2. Storytelling methodology and analysis.

I transcribed the story myself, to allow myself to fully concentrate on re-hearing the story. It allowed me to hear the tone of voice, the pauses, frustration, and hesitation that may be missed with just a written story. With member check-in, the participant received the transcripts to review and add to the story, delete from the story, or clarify. The participant returned the transcripts with no changes.

By transcribing and listening to the story, I developed more questions. Another time was scheduled with the storyteller to tell more of her story by asking the questions I developed. Her story had layers that needed to be peeled by asking questions. My questions focused on if the speech therapist referred her or told her where to go for testing. Why the parent chose to get a medical diagnosis versus an educational diagnosis? How long it took between the two diagnoses? Were there other symptoms of autism that she noticed that she didn't know were symptoms? In the first story, there was a frustration in her voice while talking about the assessment process, I wanted her to give words to that frustration.

Writing the Story

Once again, I transcribed the story, and focused in on listening. I began to see the whole picture of her story. The participant returned the transcripts with no changes. So, I began writing her story. The goal of the story is to write it in the storyteller's voice, based off the information that they have given you. Traditionally, stories were always oral and not written, because things were lost in writing the story (Kovach, 2015; Thomas, 2005). I found it difficult to write, as I lost the pauses and deep thinking that was done in telling the story. I lost the frustration in the voice and the nervous laughter that would happen. In the end, I realized that the best thing to do was take the story directly from the words that the storyteller had said in the two sessions. I wrote the story in her words, cutting and pasting various parts of the transcripts to compose her story. As Wilson (2009) mentioned, this is where I began changing it to a second level story, by retelling the story with my own twist. I sent the finished story to the storyteller and removed one line that she thought was redundant. The storyteller told the line both times, that she told parts of her story, so I wove it into the story twice for added emphasis. But in reading her story, she thought once was sufficient.

Joint Analysis of Themes

After completing and agreeing on the story that was written, the storyteller and myself engaged in e-mail discussions on what themes we saw in the story. The first theme was a lack of knowledge about symptoms. The second theme was hurdles to diagnosis. The third theme was frustration. Culture was not viewed as a theme, because the study was designed specifically to look at autism through the experience of one culture. Traditional Western research would try to break all of these into small pieces and bring them back into a linear model, but in Indigenous

Methodology, would look for the relationship of each of these with each other. I believed the theme was a relationship of the three themes together. If a parent lacked possession of knowledge of the symptoms or systems, they encountered hurdles, which caused frustration. Each of these themes worked together like gears in a machine to create a total experience. Their relationship will be laid out through the answering of the questions in this chapter.

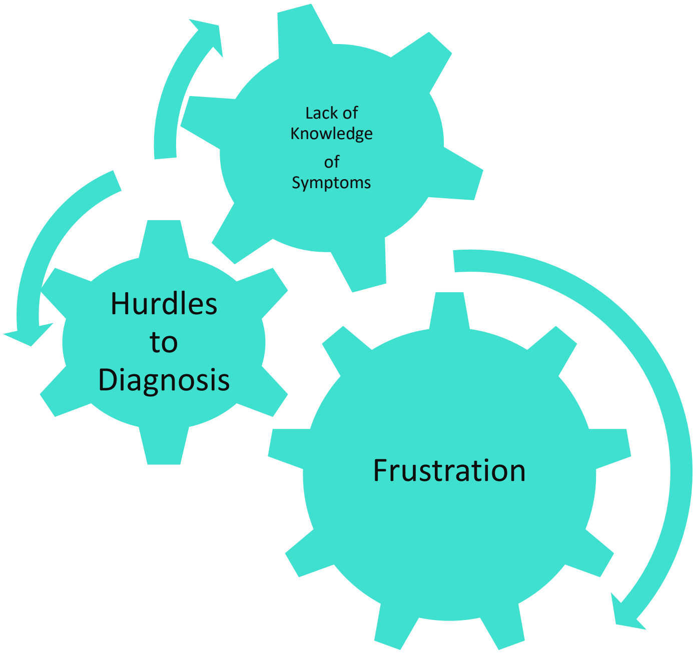

Figure 3. Themes of the research.

Developmental Characteristics That Initially Gave Parent Concerns

Parents were considered the most knowledgeable about their child's development (Beckman, 1984; Bricker et al., 1988; Lichtenstein 1984, Lichtenstein et al., 1984). Even first-time parents were considered experts, because they compared their child with other children of a similar age (Glascoe & MacLean, 1990). Timmy was Tiffany's first child. In this case, Tiffany did not see anything wrong with Timmy. She compared Timmy with an older cousin but realized that with the cousin being eight months older, there would be a difference in development. As Tiffany mentioned, she was not sure what constituted abnormal behavior or bratty behavior.

Tiffany mentioned that she had a normal pregnancy. There were no complications. This showed that she was aware that her child was at less risk of developmental issues.

Speech

The DSM-5 has autism as a disorder that impacts communication and social interactions (APA, 2013). The only concern identified by Tiffany is that she had concerns about Timmy's speech, he did not speak much. She had him tested for speech which included hearing tests. This was consistent with research that showed that 78% of parents reported a speech concern before their child was diagnosed with ASD (Richards et al., 2016). During this initial assessment, no one identified a concern for autism. It was solely for speech. Speech was the most common concern first identified by parents of ASD and non-ASD diagnosed children (Richards et al., 2016).

There are three speech issues that although not specific to autism, were typically thought as symptoms of autism: echolalia, pronoun reversal, and production-comprehension lag (Gernsbacher, Morson, and Grace, 2016). None of these speech issues were mentioned by Tiffany.

Eye Contact as a Concern

Outreach materials emphasized a lack of eye contact as a part of autism symptoms. Specifically, the Question 10 of the M-CHAT said, “Does your child look you in the eye for more than a second or two?” Tiffany voiced her awareness of lack of eye contact as a concern to observe. She stated, “You know like general awareness is always about eye contact, and I didn't even see that.” Tiffany thought that Timmy was making eye contact with her. Her idea of lack of eye contact meant that there was not eye contact. Timmy looked at her but turned away very quickly. It would be a few years after Timmy's diagnosis that Tiffany realized that it meant that the child did not make sustained eye contact.

The role of culture on lack of eye contact as a concern. As previously mentioned, outreach efforts about autism awareness focused on the lack of eye contact. The M-CHAT needed to be adapted in other countries due to its focus on lack of eye contact as a primary symptom of autism as eye contact is considered disrespectful among many Indigenous groups and other countries. As Tiffany mentioned that was aware of eye contact from all the outreach, but thought her child had eye contact. This was an area that I asked for clarification not only on her part, but also if her husband would have had a concern.

Tiffany quickly pointed out that she was mixed. She did not say if this meant mixed race or a mix living on the reservation and an urban area, so one cannot fully hypothesize, what was meant by the word "mixed'. Because she was mixed, eye contact was normal. Tiffany's husband on the other hand was raised more traditional, and eye contact was not normal. Tiffany does not believe her husband would have noticed if there was eye contact or not based on his culture.

Other Atypical Behaviors Not Seen as Concerns

There were other behaviors that Tiffany saw, but as Tiffany mentioned, she was not sure what was typical development for a child and what was "bratty". To paraphrase, bratty behavior was the "terrible twos" stage of development, where children may have tantrums and defiant behavior, which is a natural part of development. The behaviors described were atypical development. Timmy would have meltdowns when his routine was changed at all. Timmy had a meltdown when overstimulated by lights during a photo session. He lined up all his toys cars meticulously. Timmy did not use toys the way they were meant to be used. This is consistent with Richards et al. (2017) that parents of children with ASD did not recognize multiple signs of autism but had at least one concern.

Which Developmental Concerns Were Part of the Recognized Symptoms of Autism as Identified by the Mayo Clinic, or a Different Symptom

Tiffany only identified one concern that she had with Timmy. It was a speech concern; he did not talk very much. The Mayo Clinic (2020) has two specific speech symptoms. Tiffany's concern fitted under the symptom of delayed or no speech, or speech regressing. Another symptom is speaking in abnormal voices or tones and may sometimes use a robotic or sing-song voice. This was not mentioned by Tiffany.

Eye Contact

Tiffany felt that Timmy made eye contact at the time, so lack of eye contact was not a concern. It would be years, before she figured out what was meant by eye contact. She was quite aware of eye contact as a symptom, even mentioning it is all that is talked about. Although eye contact was not mentioned as a concern at the time, it is listed as a symptom by the Mayo Clinic (2020). Mayo Clinic (2020) lists the symptom as having poor eye contact and lack of facial expression. This is different from the M-CHAT which says 1-2 seconds of eye contact and does not mention lack of facial expression with the symptom.

Other Symptoms

Tiffany did mentions other symptoms that were behaviors that she noticed, but not a concern. Timmy had difficulty with changes to routines. He got overstimulated. He engaged in repetitive behaviors such as lining up all his cars and did not play with toys in a normal way. As a professional that had worked with children for over 20 years, I know these to be possible symptoms of autism, and would recommend an assessment to a family.

Table 4 lists the behaviors noted by Tiffany and Mayo Clinic. It includes observations that Tiffany had but were not concerns. This table leaves out lack of eye contact, because during the time, Tiffany believed that her child was making eye contact.

Table 4

Autism Symptoms Identified by Parent and Mayo Clinic

Speech concern- delayed, no speech, or speech regressing
Difficulty with changes to routine
Not playing with toys in a normal way
Repetitive Behaviors
Sensory overstimulation

Parent's Experience With Autism Referral and Assessment Process

This is the area of re-telling Tiffany's story that gave me pause and reflection. I am truly re-telling the most important part of Tiffany's story. In re-telling and looking at how to analyze this part of the story, especially in referring to cultural pieces, the Imposter Syndrome sneaks in. It is a different type of the syndrome though because it causes anxiety. It is a feeling that moving forward with this story, I am introducing bad medicine. Bad medicine can be described as even though you have good intentions, you are bringing something into the community that causes harm. The idea that there are only three papers on autism in AI/AN communities and the difficulty in getting storytellers increases that anxiety.

To avoid this anxiety, I reminded myself that there were people interested in telling their story, but their children were diagnosed almost twenty years ago. They were just now ready to tell their story, and encouraged the research, because it was a story that needed to be told. I also created safeguards to help safeguard against bad medicine by reviewing the results with my Community Advisory Board and having this chapter reviewed by Tribal IRB. With these thoughts, I moved forward in telling Tiffany's experience.

There Might Be a Problem

Tiffany did not know that her child, Timmy, might be autistic. She had concerns about his speech, which 75% of parents had the same concern about their child before an autism diagnosis (Richards et al., 2017). Timmy started receiving speech therapy services through the Scottish Rite. The Scottish Rite is a part of the Free Masons, and speech services are part of the free services that they provide to children in addition to the Shriner's Hospital.

During speech therapy, Timmy exhibited two behaviors in front of the therapist during meetings. The speech therapist was late which changed the routine of the speech meeting, and Timmy had a meltdown over the change to the routine (Autism Speaks, 2020; Mayo Clinic 2020). He was also rigid while receiving services (Autism Speaks, 2020, Mayo Clinic, 2020). For people working with young children, it is important to be aware of the signs of autism, so you can talk with the parents about it, when seeing the symptoms (Nuner & Stevens Griffith, 2011). These signs gave concern to the speech therapist, and she told mom. Tiffany felt the speech therapist was kind of beating around the bush, but the therapist was being fairly consistent with recommendations in talking with parents about referring their child for assessment (Nuner & Stevens Griffith, 2011). Finally, the speech therapist just said, I think Timmy is on the spectrum.

Making the Referral

When listening to Tiffany tell her story, she spoke of the therapist with a good voice with a happy tone. It sounded like a relief to say that Timmy should be checked out. I cannot assume, but they had been noticing more behaviors, and she had mentioned not being sure if her child was just being bratty or if there was something going on. This would give the sign there was something impacting her son versus being bratty. However, she still had to go through the assessment process, starting with the referral.

The speech therapist referred Tiffany to her state's regional developmental center. After contacting the regional developmental center, Tiffany learned that the center only does assessment as the payer of last resort. This meant that Tiffany had to find a way for the assessment on her own. Although Timmy was now 3 and eligible for Early Childhood Special Education Services, no one referred Tiffany to the LEA for an assessment.

In this area, the speech therapist and regional center failed. As someone that works with young children, it was viewed as her responsibility of how to refer families and be aware of the places to refer a family (Nuner & Stevens Griffith, 2011). Although there is no specific research on referrals from regional developmental centers, in studies of general practitioners, only a third of them referred children to the LEA for services even after an autism diagnosis (Rhoades, Scarpa, & Salley, 2007). They may not have been fully knowledgeable on where to refer a family to get a diagnosis, and this left Tiffany on her own to work on getting a diagnosis.

Working Towards a Medical Diagnosis

Tiffany was left without a guide for getting an autism diagnosis for Timmy. While describing this time, her voice became frustrated. There were several pauses. This part was lost in writing Tiffany's story, but it plays heavy into the analysis.

Tiffany encountered many hurdles in attempting to get a diagnosis. She did not know the language to ask for a diagnosis. This is an extension of the research of Rhoades et al. (2007), who found that parents didn't share original concerns, because the parent did know the language, it now extends also in asking for an autism assessment, once a concern has been raised.

Since Tiffany did not know the language to ask for an assessment, she began trying to get an assessment through her health insurance. The family was already using it for speech and occupational therapy. Besides not knowing the language to ask for a test, she felt like she was getting the run around from the insurance company. They did not help her in telling what to ask for as far as testing or refer to the appropriate. It was a 6 month wait to see a specialist, and the specialist could not diagnose autism. Tiffany had to get two diagnoses before receiving services, and the final diagnosis was from the regional developmental center that could not do an assessment at the beginning of the process. From the time a concern was raised by the speech therapist until there was a diagnosis that helped get services, Tiffany said it was twelve to eighteen months.

No one ever told her that she could get an assessment through the school district, and she would not learn that until Timmy had the second diagnosis and started receiving services with the school district. It was the school district that mentioned that she could have gone there at the beginning.

Tiffany's frustration can be summed up with her comment, "And it was really frustrating because all you hear about is early intervention, but you're now telling me that, I have to wait 6 months to even get any of these things started." Although, she was not sure about the signs of autism, now that she had an idea, she was fully aware that early intervention would help her child, and it was taking so long to get an assessment. She was going through the process without a guide and did not know the language. The professionals did not give her enough information. There were multiple hurdles. All of this led to great frustration.

Once Tiffany mentioned the second diagnosis, her voice changed. It was a voice that reflected relief, and she began to smile. The nervousness in telling her story disappeared. With that second diagnosis, the services opened up to Timmy. He was enrolled in an Early Childhood Special Education preschool. He received Applied Behavior Analysis therapy. Timmy got occupational therapy. A whole new world opened up to Tiffany and her son.

Assessment for the Second Child

Tiffany had speech concerns for her younger son, Thomas. She was now aware of autism symptoms and behaviors and did not have the same concerns for Thomas. However, she wanted him tested to make sure, and she knew the language of what to ask for. Consistent with the research of Ryan and Salisbury (2012), the assessment happened quickly for the second child when there is already a child with an autism diagnosis. Tiffany was also ready in case there was a long wait time for the assessment. Thomas was just a few months shy of his third birthday, if the waiting time was too long, she would wait until his third birthday and call the school district for an assessment.

The Role of Culture in the Process

Culture has been involved in various parts of the process. The idea of lack of eye contact was viewed differently by mother and father based on how traditional they were with their culture. Culture also played a role in the view of the diagnosis. Tiffany did not mention if any of the professionals that were used were AI/AN or not. The diagnosis and services will be looked through the Indigenous Child Development Model (Figure 2) shown in Chapter 2.

The Child

Timmy was four years of age when he was diagnosed with autism. In early childhood, children are often considered sacred (Bia, 2011; EagleWoman & Rice; 2016, Light & Martin, 1985; Sarche et al., 2016). He was at an age, where he was still considered sacred. Issues of specific roles for Timmy or language and cultural teaching were not told in Tiffany's story.

The Parents

Tiffany and her husband both wanted services for their child. Tiffany continued to fight to get Timmy assessed. She got Timmy enrolled in services and continues to get services for him. She learned more about autism to understand her child and explain his behavior to others as well as to get her other son assessed. Tiffany educates others within the circle of child development such as elders and extended family on how to understand and work with Timmy’s behaviors. Tiffany and her husband are from different Tribe, and she mentioned that her husband’s family was more traditional. Tiffany did not mention which Tribal beliefs Timmy was being raised with or how traditionally he was being raised.

Elders and Extended Family

The elders of the family and extended family felt that Timmy would outgrow the speech issue and autism. This is a good example of a traditional Indigenous viewpoint about disabilities. Developmental milestones are different, and a child will meet them in their own time (Bia, 2011; Kapp, 2011; Wendt, 2010). Within the family, it is expected that a person responds when their name is called. Timmy rarely responds which is a sign of autism (Mayo Clinic, 2020). If Timmy does respond, he may say words such as “no” or act in another way that the elders and extended family consider inappropriate. They may want to correct Timmy, whereas Tiffany understands that it is a part of his autism. She is just happy that Timmy even responded. Tiffany is continually educating the elders of the family and extended family about how autism looks, and how they should work with Timmy.

The Community

Typically, the community would mean the Tribal community. In this case, the community has been extended by Tiffany to include the school district, teachers, speech and occupational therapists, and others that provide services to Timmy. I did not discuss this with Tiffany. Since I was not raised traditionally, to extend this meaning of community to include the service providers as part of the results may show acculturation on my part.

Summary

This is exploratory research that looked at the experience of one AI/AN parent's experience in getting an autism diagnosis for their child. There was very limited research looking at parent's experience pre-diagnosis, so some of the results in this analysis are new, and do not have previous research to tie to the results.

Tiffany's original developmental concern for her child was not speaking much, which is a symptom of autism as noted by the Mayo Clinic. Tiffany felt that her child made eye contact with her and it was not a concern to her. It would be years later before she fully understood the symptom of lack of eye contact and realized that her child did not make full eye contact. Because of her husband's upbringing, he would not have considered lack of eye contact to be a concern. There were other behaviors that were not considered a concern, because the parents did not know what normal development was and what was not normal. These behaviors included ritualistic and repetitive behaviors.

The assessment process was very frustrating for Tiffany. She encountered several hurdles, did not know the correct language to use to ask for an assessment, and had no one to walk her the process. Neither the speech therapist, regional developmental center, or health insurance referred her to the LEA for an assessment. The parent had to get a diagnosis for her child twice before services started, and it took between a year and a year and a half to get an assessment from when the concern was identified. The parent was aware the early intervention services would help her child, and that helped lead to the frustration over taking so long to get the diagnosis. Once there was a proper diagnosis, services started right away.

Finally, in comparing the story with an Indigenous Child Development Model, the two areas impacted by the referral and diagnosis are extended family and the community. Tiffany has to educate the family about the signs of autism and her son's behavior, because the extended family believes he will outgrow it and he will start talking a lot. They do not understand the disorder or that certain behaviors expected within the family, will not happen with Timmy. The definition of community has been extended beyond the Tribal community to include the service providers for the child, who have become a part of the family’s community.

CHAPTER 6: DISCUSSION

Reviewing the Story to Create New Stories

This is the final chapter of the dissertation. This chapter will review the problem, the methodology, the questions answered by the original story, and finally discussion and recommendations to help create new stories. I will maintain the idea of stories throughout the chapter.

Why a Story Was Needed

This dissertation started as the thought of creating a culturally appropriate child development screening app. In presenting prototypes of an app, people who had children diagnosed with ASD at a late age, kept asking if there could be a built-in autism screen into the app, as it would have really helped them. Preschool age children are diagnosed with autism at a lower prevalence race than all other races. Outreach efforts have focused on lack of eye focus as a symptom. With my committee, it was determined to focus on cultural issues around autism symptoms. After proposing the dissertation, it was decided to do a meta-analysis, however, there was not enough literature, even after expanding the parameters of the research. Based on the lack of research around culture and autism, it was decided to look at what AI/AN parents viewed as initial developmental concerns.

This was exploratory research to answer three questions: 1) What developmental characteristics initially gave AI/AN parents' concerns about their autistics child's development; 2) Were the developmental concerns part of the recognized symptoms of autism as identified by the Mayo Clinic, or a different symptom; and, 3) How was the autism referral and assessment experience for parents? Research in AI/AN communities often happened with good intentions but no understanding of the community when creating interventions (Echohawk, 2017). To do the research, the researcher needs to understand the community and their stories (Echohawk, 2017).

Telling the Story

This research used Indigenous Methodologies. Permission for the research was given by a Tribal IRB as well as University of the Pacific's IRB. It utilized Community Based Participatory Research by having an advisory committee to advise the researcher, models, and results. The participant storyteller engaged in Indigenous Storytelling methodology. In two different settings, the storyteller orally told the story of concerns about his/her child and the autism diagnosis process. The storyteller was involved in reviewing transcripts and making changes as needed. The written story was passed back and forth between the storyteller and researcher to make sure it was still the storyteller's story when it was changed from an oral form to a written form. The storyteller helped with the initial analysis of the story.

There were others that wanted to tell their story but did not meet the participant criteria as far as child's diagnosis of ASD within the last 10 years. Their children's diagnoses were fifteen to twenty years ago, and the parents were just now ready to tell their stories. When asking if they knew of another person that they could refer, the answer was always no, and good luck finding participants. It is a subject that is really not talked about in the community.

COVID-19 Pandemic

Recruiting storytellers was impacted by the COVID-19 Pandemic. As the researcher, I had outreached to Tribe and Tribal health clinics in late-February to help with recruitment shortly after receiving IRB approval in Mid-February. They were going to refer patients that had children with autism and place on social media. However, by the middle of March, the West Coast of the United States had been shut down due to the virus. COVID-19 highly impacted Tribe and clinics, and their focus rightfully changed. I began calling AI/AN friends and family to see if they had a friend or family member that would want to participate. This is what lead to meeting people just now ready to tell their stories after fifteen to twenty years. To expand the inclusion criteria would have involved needing to also go through Tribal IRB, and the agency was closed at that time due to COVID-19. Storytellers continued to be recruited until the first part of May. The West Coast was still closed up at this time. With every effort having been made, it was decided to move forward with just one storyteller.

Analysis of the Story

When analyzing a story, the researcher is creating a second level story (Wilson, 2009). The storyteller has told a third level story, and the researcher is re-telling the story with some twists, in this case the twists were where the story aligned with existing research or created new knowledge. Before re-telling the story, the storyteller and myself looked at themes throughout the story. The themes were: lack of knowledge with the symptoms, hurdles to a diagnosis, and frustration. These themes were seen throughout answering the three research questions: 1) What developmental characteristics initially gave AI/AN parents' concerns about their autistics child's development?; 2) Were the developmental concerns part of the recognized symptoms of autism as identified by the Mayo Clinic, or a different symptom?; and, 3) How was the autism referral and assessment experience for parents?

Developmental Characteristics That Gave Initial Concerns to Parent

The original concern that the mother had was a speech concern. Her child spoke very little. Speech issues are the most common pre-ASD diagnosis concern that parents have (Richards et al., 2016).

Mom was aware of eye contact being a symptom of autism. Mom thought her child was making eye contact. It was not until years later that Mom realized what was meant by lack of eye contact. Mom was raised “mixed” and so lack of eye contact would have been a concern to her, Dad was more traditional, and lack of eye contact would not have been a concern.

There were other behaviors that mom did not realize were signs of autism. She thought her child was throwing tantrums and not engaging in other behaviors. Other behaviors included: meltdowns when overstimulated; meltdowns when the routine changed; not playing with toys as intended, and lining cars up in a certain order each time. These are ritualistic type behaviors.

Mom did compare her son with an older cousin, but also knew that children developed at different rates, and the cousin was 8 months older. Mom also mentioned that there were no complications during the pregnancy and that the pregnancy was full-term.

Symptoms That Align With Mayo Clinic’s Listed Symptoms of Autism

The developmental concerns fell within Mayo Clinic’s list of autism symptoms. The original concern that Mom had was a lack of speech. This is listed as a symptom of autism on Mayo Clinic’s webpage. At the time, mom felt her child had eye contact. The Mayo Clinic says poor eye contact and a lack of facial expression is a symptom of autism. Other behaviors that the child had, mom thought the child was being “bratty” but are listed as symptoms of autism by Mayo Clinic.

The Assessment Experience

Mom had an assessment experience that was frustrating to her. The child’s speech therapist mentioned that she thought the child was on the autism spectrum. The speech therapist referred mom to a regional developmental center for assessment, but the regional center was the payer of last resort for assessment. Even though the child was three years old and qualified for early childhood special education under IDEA, she was not referred at any point to the LEA. She did not know what to ask the insurance company for in how to get an assessment. There was a long waiting list to get an assessment, and the first assessment did not work. It took between a year and a year and a half to get a diagnosis. This caused frustration because mom knew that early intervention was important for autistic children. At the end, mom got a second diagnosis from the developmental regional center that qualified her son for services. He began receiving services from the school district.

Assessment for younger child. Mom had another child. Although the child did have a speech issue, she did not think this child had autism, because she was now aware of the symptoms. This child was assessed quickly because mom knew what to ask for. This is consistent with research that the second child is assessed quicker (Ryan & Salisbury, 2012). This child was not autistic.

Looking at the Story Through an Indigenous Child Development Model

The child was at an age where he was still considered sacred. Mom began trying to get him help and a diagnosis during this time. The parents have worked hard to educate their extended family and family elders about autism and understand the child. The family feels that the child will outgrow it, which is consistent with many traditional beliefs about disabilities (Bia, 2011; Kapp, 2011; Wendt, 2010). The community was extended to include the school district and other autism service providers.

Creating Conversations and New Stories

This chapter transitions to creating conversations and recommending the creation of new stories. Research on parent’s experience of the assessment process exists scarcely. The first conversation examines how the story supports existing research. The second conversation looks at the overall system of autism concerns and assessment through the idea of being uninformed. The final section makes recommendations for creating new stories.

Finding Commonalties With the Existing Research

There has been little research of parent's experience during the pre-autism diagnosis period, as most research on autism in the pre-diagnosis stage has focused on identifying symptoms. The scarcity of the research and different types of studies led to limitations in the studies and the ability to compare with other research. However, in this study, some commonalities appear.

Speech

The child's lack of speech was a concern to mom. Her concern started as a speech concern. Seventy-five percent of parents originally had a concern about their child's speech before diagnosis (Richards et al., 2017). Speech is a very common initial concern.

Local Education Agencies

When referring the child for assessment, mom was never referred to the LEA for an assessment. Although research has not focused directly on the research of where children are sent for a referral outside of the medical system, research shows that after receiving a diagnosis, less than a third of doctor's referred the child to the LEA for services. It appears that the services of the LEA are not known as well in both the assessment process and services offered. However, this is not definitive, and this is an area of possible future research.

The Assessment Process

Mom was highly frustrated during the assessment process for her child. She reported not knowing the language to use to get an assessment. Parents routinely felt uninformed, dissatisfaction, and unadvised during the assessment process (Braiden et al., 2010; Selimoglu et al., 2013; Wong et al., 2017). The state regional developmental center and insurance company bounced mom around in trying to get a diagnosis. Mom shares this commonality with other parents (Midence & O'Neill, 1999). Mom knew the importance of early intervention with autism yet noted that it took between a year and a year and a half to get a diagnosis. Previously parents said that assessment did not happen in a timely manner (Keenan et al., 2010; Wong et al., 2017). Mom's story confirms other people's experiences with the assessment process. The regional developmental center, insurance, and speech therapist failed in being able to guide mom through the assessment process, and it is important for people to be knowledgeable about the process and be able to guide them through it (Nuner & Stevens Griffith, 2011).

Autism and Culture

In this research, I withheld the parents' Tribal affiliations as a way to protect the identify of the parents and also to protect their respective Tribe. However, I examined the research for similarities with published research of autism in Diné communities and other research. The family thought that the child would grow out of the symptoms. This reflects not being as focused on developmental milestones as Western Culture (Bia, 2011; Conners, 1992; Kapp, 2011; Wendt, 2010), so the child develops when he or she is ready (Bia, 2011; Kapp, 2011; Wendt, 2010). The father would not have noticed a lack of eye contact, as not looking into the eye is typical in his tribe. The story did not note anything about pointing with a finger. In many AI/AN cultures, eye contact and pointing are culturally inappropriate (Albores-Gallo et al., 2012, Morris, 1994; Zhang et al., 2006).

Issues of Knowledge in the Assessment System

Originally, I named the section "*Uninformed*". It became too difficult to write. I wrote ideas and notes and would just sit at the computer for hours trying to write, only writing a sentence and erasing it. This is the section of the dissertation where the research and writing truly becomes my voice. Traditionally, this new knowledge would be shared orally, but the process demands that I put it in writing. I could orally say what I wanted in my own voice, but to put it in writing became a huge task in re-finding and not losing my voice in the writing. I re-named this as issues around issues of knowledge, because in my own voice, I see things as bigger picture and systemic. This section shows the systematic issues around knowledge in the parental concern and assessment process.

What Is Meant by Issues of Knowledge

The assessment system for autism is complex. It requires a parent being knowledgeable about the symptoms and developmental concerns. There are several resources for identifying symptoms that are not clear on symptoms. People must know the system to be able to ask for help, and people have to be familiar with the system to be able to guide parents through it. In the early analysis of the themes of mom's story, the gears of lack of knowledge of symptoms, hurdles to diagnosis, and frustration that worked together to create mom's assessment experience. However, each of those issues was caused by issues of knowledge around not only the symptoms but also by professionals that created the hurdles and frustration. They are all very interconnected.

Tiffany's Knowledge

There are aspects about autism that Tiffany was very knowledgeable about. Tiffany mentioned that her pregnancy was normal, there were no problems, and she carried Timmy full-term. This shows that she was knowledgeable that greater risk existed for developmental issues if there were complications with her pregnancy, or if Tommy had been pre-mature. Even though Tiffany was a first-time parent, like many parents she knew to compare his development with other children (Glascoe & MacLean, 1990). She also knew that children developed rapidly at this age and comparing Timmy with a nephew that was eight months older did not truly show any developmental issues due to the age difference and rapid development. Tiffany knew that early intervention was important for children with autism. She shows a general awareness about most of the messaging out there on child development.

The Issue of Eye Contact

Tiffany knew that lack of eye contact was a symptom of autism. It was highly repeated knowledge that she shared. She said she just did not see it, as Timmy looked at her. It was only a couple years ago that she found out what was meant by eye contact. Issues of knowledge raises its head in this area. Autism Speaks which is the largest Autism support organization in the U.S. and research supporter feels the symptom that the child sometimes may inappropriately or misunderstand use of eye contact (Autism Speaks, 2020c). CDC adds another requisite with eye contact by saying the child will avoid eye contact and want to be alone (CDC, 2020). The Mayo Clinic also adds another requisite. Child has "poor eye contact and lacks facial expression" (CDC, 2019). The M-CHAT-R/F which is the autism screen asks "Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her" (Robins, Fein, & Barton, 2009). These are four resources with differing ideas about eye contact, so it would take be easy to believe your child does not have eye contact when, the child look into your eye briefly before pursuing another activity. These are confusing items of knowledge that lack agreement. Agencies need to gather and come up with common examples of eye contact that they share as a group, so there is no confusion when parents have a concern.

Knowledge of the Language of Autism

Knowing and understanding the language of autism is an integral part of the autism assessment. When parents don't know what to say, delays in assessment exist (Martinez et al., 2018; Ryan and Salisbury, 2012; Woolfenden et al., 2015; Zuckerman et al. 2014; Zuckerman et al., 2015). Tiffany faced delays because she did not know the language of what to ask for. She already knew her child needed assessed, but the insurance company sent her to a doctor that could not diagnose, but only refer the child. In my own professional experience, I have witnessed this. A parent goes in for an autism assessment, but then is only diagnosed with speech, because they did not use the right terminology in expressing the other concerns. I interject with the behaviors through autism terminology, and then people doing the assessment, will say, oh, that changes things, we need to re-assess for autism. I should not have to interject like this. The onus should not be on a person to know the professional language to get an autism assessment for their child. That not knowing the language of autism creates delays in assessment is well documented (Martinez et al., 2018; Ryan and Salisbury, 2012; Woolfenden et al., 2015; Zuckerman et al. 2014, Zuckerman et al., 2015) and improvement in this area is something that continues to need to be addressed by the professional community.

Lack of Knowledge About the Assessment Process

Nuner and Griffiths (2011) talked the need for early childhood professionals to know the autism assessment process well, so they can help parents through the process. This includes the need to know where to refer people, how the process works, and being familiar with Child Find processes (Nuner & Griffiths, 2011). A key part is knowing who can actually do an autism diagnosis (Nuner & Griffiths, 2011). In Tiffany's case, no one was completely familiar with the process. The speech therapist knew enough to refer Tiffany to a regional development center but did not show awareness of Child Find or other resources. The regional development center only said they were payee of last resort and did not refer her anywhere. The insurance company referred her to the wrong type of doctor, who could not do a diagnosis, but only a referral. Even though the child was three years old and qualified for services under IDEA, not a single person referred her to the LEA. It cannot be said that they did not know that the LEA could do an assessment, as that was not researched. However, it gives the appearance that no one knew about referring to the LEA. Tiffany did not know the process, and no one really helped her through the process. It seems to be a lack of knowledge about the resources. It is important not only that doctors and therapists be fully aware of the autism diagnosis process to be able to provide the right information to parents, but also for school districts to partner with medical clinics to create a referral process for diagnosis when children are screened for autism at the clinic.

Improving Autism Awareness Outreach to AI/AN Communities

The research on autism awareness outreach to AI/AN communities is non-existent. Recommendations on other outreach has focused on educating people about eye contact as a symptom in the communities. This recommendation is culturally insensitive as lack of eye contact is normal for many communities. It is demonstrated in this research where even though Tiffany was aware of eye contact, her husband was from a different tribe would have never noticed as lack of eye contact was normal within his tribe.

Although this research is cannot be generalized to the population, it offers symptoms to examine as potential areas of outreach for awareness. Those symptoms include difficulties with developing specific routines and upset if changed, overstimulation from lights, and not using toys in a way they are meant to be used.

Creating New Stories

This research was exploratory in nature. It is only one person’s story and is not generalizable to the AI/AN community at large. Even if more participants existed, it would not be generalizable as each tribe has its own traditions and culture.

This research hinted at some acculturation issues around viewpoints of autism and symptoms. Tiffany mentioned that she was mixed, she did not say if this meant racially or by locations and she viewed eye contact differently from her husband who was from a different tribe and raised traditionally. Differences exist between those raised away from tribal homelands and those raised in a more tribal traditional manner (Blyly-Strauss, 2018; Ledesma, 1997).

There have only been two papers and one dissertation completely focused on autism within the AI/AN community. Two papers were very Tribally specific. In the process, I feel that I learned why only a couple papers exist since 1992. Often in trying to recruit families, people kept informing me that it is not a topic that is discussed in the community. The reason for not discussing is not because of something taboo, but just something that is not discussed. More than one person told me to pick another subject, because it would be difficult to find someone to tell their story. Perhaps the stigma attached to the label of autism kept people from telling their story. Among some people, autism exists as something normal and not a disability (Conners, 1992; Kapp, 2011). The children of people interested in telling their story were in their twenties, between fifteen to twenty years passed since the child's diagnosis. People needed that long to feel comfortable about telling their story now. This is an area that needs further exploration. Why does it take so long to want to tell their story? Do commonalities occur in the parents' experience of the assessment process from twenty years ago and from currently? There is a need for more research on the subject.

As previously mentioned, these results are not generalizable. Each tribe has their own culture. Future research should be completed at the Tribal level with the permission of the tribe. The results should be housed with the tribe, so the tribe possesses data to utilize to inform special education, their health clinics, Indian Education funding, and develop culturally appropriate interventions. The data research needs to be completed in analyzed in that specific tribe's culture and knowledge.

Implications for Indigenization of the University

University of the Pacific agreed to this research and the use of Indigenous Methodology. The research tried to utilize CBPR, but true CBPR did not happen. The dissertation timeline and pivots prevented true CBPR. At the researcher, I defined the research and methodology before ever creating an advisory group for CBPR. I used a position of power and the need to get done with my dissertation to dictate the terms of the research. In making the pivot, I did not first create an advisory board first and discuss the issue before making a pivot.

The methodology was difficult to use at the time, and the chair learned the methodology as I went through the dissertation process, wrote, and our bi-weekly check-ins. There was a faculty member that had engaged in research in Tribal communities and a familiarity with Indigenous Methodology. However the lack of crossover between staff between the Benerd School of Education at the two-campuses and the lack of a published curriculum vitae for each faculty member containing published research and research interests on the website prevented me from knowing that such a person existed. I discovered that such a faculty member existed a year into my dissertation process and only when submitting my IRB application for the faculty review process before formally submitting to the IRBs.

I would advise the University that if they are going to allow students to use Indigenous Methodology, that they need to have students start with an advisory group at the beginning so the group can give proper guidance to the student's ideas and areas of interest. Also, CBPR should be taught in the methodology courses. Finally, all students should be aware of which professors have engaged in appropriate research with Tribal communities so they can pick appropriate committee members and chairs. I encourage the school to continue the indigenization process for research.

Final Self-Reflection

This research was not only an exercise to learn more about autism in AI/AN communities, but also an exercise in better developing my research positionality and viewpoints. I am by nature, a quantitative person, and love quantitative research. I thrive with statistical analysis. Quantitative research is the methodology of any previous research I worked on.

However, I also do want to know the stories behind the research, and so I chose not only to do something qualitative but trying to add to the restoration of Indigenous knowledge and ontology.

In Chapter 3, I laid out my positionality and my lived experiences as Diné. I was raised differently. I am a mixture of those cultures that I am a part of and where I was raised. I am attached to a different land and often reflect that in my thinking. I know a criticism is that this was not true Indigenous Methodology, but a hybridization of western storytelling methodology. However, like Kovach (2009) writes, start with where you are at, and the methodology will lead you where you need to go. I started with where I am at currently in relation to my culture. I continue to learn my culture and tradition, and at times, it will be mixed with other methodologies, because that is who I am. It is composed of all the relations in me. As I learn more of my Diné traditions and songs, I know my ideas and views will be shaped more by that side of me. I know that it is important that as I do further research, to stay grounded in my culture and with elders to help me grow in my wisdom and knowledge and worldviews. I am committed to that, as I want to know and learn. At the end, this is where the methodology led me: self-growth with the need and desire to learn more.

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APPENDIX A: HIPAA AUTHORIZATION FORM

Authorization to Use, Disclose or Release Health Information that Identifies You for a Research Study

If you sign this document, you give permission to Christopher Cooper at the University of the Pacific to use, disclose or release your health information that identifies you for the research study described here:

Exploring the Identification of American Indian Children with Autism Spectrum Disorder Through the Stories of Their Parents. This research is to learn more about what concerns parents had about their autistic child before the child's diagnosis and how the assessment process was for the family,

The health information that we may use, disclose or release for this research includes:

The health information being asked for is developmental concerns about the child and the child's Autism diagnosis. This information will be gathered from your story about your child and the assessment process. This information is being given by the parent about their minor child.

The health information listed above may be used by, disclosed or released to:

The researcher's dissertation committee: Dr. Fred Estes, Dr. Rod Githens, Dr. Linda Webster, Dr. Anna Epperson.

The "covered components" of University of the Pacific are required by law to protect your health information. By signing this document, you authorize the covered components of the University of the Pacific to use, disclose or release your health information for this research. Those persons who receive your health information may not be required by Federal privacy laws to protect it and may share your information with others without your permission, if permitted by laws governing them.

Please note that:

Your decision to not sign this Authorization will not affect any other treatment, health care, enrollment in health plans or eligibility for benefits from the covered components of the University of the Pacific.

Please also note that:

You may change your mind and revoke (take back) this Authorization at any time. Even if you revoke this Authorization, Christopher Cooper and his dissertation committee may still use, disclose or release health information they already have obtained about you as necessary to maintain the integrity or reliability of the current research. To revoke this Authorization, you must write to: University of the Pacific,

Christopher Cooper/Dr. Fred Estes

3200 5th Ave

Sacramento, CA 95817

This Authorization does have an expiration date. The expiration date is the end of this research study.

- Your health information will be used or disclosed when required by law.
- Your health information may be shared with a public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability, and conducting public health surveillance, investigations or interventions.
- No publication or public presentation about the research described above will reveal your identity without another authorization from you.
- If all information that does or can identify you is removed from your health information, the remaining information will no longer be subject to this authorization and may be used or disclosed for other purposes.
- If you revoke this Authorization, you may no longer be allowed to participate in the research described in this Authorization.

I have read this HIPAA Authorization form describing how my health information will be used. I have had a chance to ask questions about the use of my health information and I have received answers to my questions. My signature below indicates that I agree to allow the use, disclosure, and release of my health information for the research purposes as described above.

Signature of Participant or Participant's Personal Representative		Date:	
Printed Name of Participant:			
Printed Name of Participant's Personal Representative:		Representative's Authority:	

You will receive a copy of this signed form. Please keep it with your personal records.