Interactions in Healthcare: Social Perceptions and Experiences of Physical Disability Among Diné Individuals With Physical Disabilities, Family Members, and Diné/Non Indigenous Service Providers and Healthcare Workers

by

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ABSTRACT

In this dissertation, I examine how social perceptions of physical disability shape interactions in healthcare. Drawing upon the lived experience and insights of Diné (Navajo) individuals with physical disabilities, family members, and Diné/non-indigenous healthcare workers and service providers, I explore the interrelationship of social perceptions of physical disability with understandings of identity and performance of personhood. Embedded within discourses and critiques of ableism/disablism, narratives highlight the interconnection of constructs of personhood and productivity.

Findings show that social perceptions of physical disability are closely linked to broader cultural norms surrounding concepts of health/illness. I offer a critical analysis of contemporary impacts of colonization and historical trauma on the physical, emotional, sociocultural and economic wellbeing of Diné people and those who fill service provision roles for this diverse population. Situated within broader contexts of defining constructs of ‘Whiteness’ and ‘Indigeneity’, the role of culture and discourses regarding stereotypes are particularly prominent factors in shaping relationships.

This interdisciplinary ethnography brings together contributions from Anthropology, Disability Studies, and Indigenous paradigms. Placing a particular emphasis on the social dynamics in two urban centers in the state of Arizona, this ethnography centers on analyzing areas of medical practice that work well, as well as gaps in the provision of healthcare services, with a particular focus on systemic and infrastructural barriers. These concerns are shared not only by Diné individuals with physical disabilities and family members, but also by non-indigenous service providers and healthcare professionals.

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PREFACE

The issue of disability has long piqued my interest: as a part of the human condition it evokes powerful feelings, which have the potential to ignite fruitful conversations, make or break social relationships, and influence how people perceive their existence and participation in the social, political and material environment. Be it through conferences, workshops, support groups, health fairs, recreational and sports' events, conferences, workshops, support groups, health fairs, recreational and sports events disability is at the epicenter of public interest, receiving attention in the media, as well as in governmental and academic circles. In celebration of the triumphs of the disability movement, we have dedicated days in our calendars to various disabilities, while many cities in the United States hold disability pride parades. Academic circles have followed suit: scholars from various disciplines have grappled with the social, economic, and political implications of disability. Scholarly contributions have emphasized the role of medicine in shaping disability as an inherently biological/physiological problem and have drawn attention to disability as a social construct. As a response, in an effort to recognize the validity of the visceral aspects of disability and the emotions it produces, others discuss how the materiality of the body in addition to the social milieu shape narratives of disability.

This study contributes to indigenous perspectives of disability. Privileging the narratives not only of Diné (Navajo) individuals with physical disabilities, but also of those who provide everyday care and support to this important social group, the purpose is to highlight the lived experience of physical disability. The insights that participants have honored me with tell us as much about Diné and non-indigenous social understandings of physical disability and, by extension, cultural constructs of health, wellbeing, productivity and normativity, as they do about the positive aspects of, and tensions in, building and sustaining systemic collaborations, particularly in healthcare. In many, if not all, cases their examples are embedded within a broader social reality, which reflects how they understand being (or not being) indigenous in the United States today.

The dissertation is organized as follows: Chapter 1 introduces disability as a research problem to the reader. The overview that is presented is meant to provide the reader with an understanding of how disability affects the lives of (almost) all of us in some direct or indirect way, globally as well as in the United States. This introductory section suggests why an ethnography of physical disability makes contributions that are both academically relevant, and of broader social value. Chapter 2 outlines my theoretical approach to the subject matter. I highlight concerns surrounding ableism. I discuss personhood and identity in relation to productivity, while offering literary contributions on the connection between disability and bodily performance. The subsequent chapter (Chapter 3) discusses my methodological considerations. I engage in rethinking about the concepts of ‘the field’ and ‘fieldwork’, so paramount in the discipline of anthropology that we often do not think about the historical dynamics that have constructed them. Collaborations with gatekeepers, the process of recruitment, and ethnographic interviews are all entangled with one another, firmly situated within a context, which is informed by past and present relationships with Native American peoples. This chapter, therefore, would be incomplete without a detailed discussion of ethical concerns. In Chapter 4, I discuss my positionality in the field. Like all of us, I embody many identities: I self-identify as a young woman who was raised in a context very different to that of the United States, who engages in trying to understand others' perspectives of disability because of personal experience. The performativity of these identities (sometimes conscious and other times not) while doing fieldwork generated interesting and important insights as to how my participants and I view social categories that are tantamount in ethnographic analysis. Assumptions about shared understandings in relation to disability, at times, cemented relationships with participants, allowing me to literally and metaphorically 'move around' social spaces in ways that I could perhaps not have were I not perceived to be legitimately there.

Chapter 5 includes participants' discourses about cultural perceptions of physical disability. Their comments are imbued with their narratives about what it means to be productive in today's society, the social implications of being deemed '(un)able', and how assumptions around the social construct of 'normal' can serve as starting points for conversations about inclusion and diversity. The role of assistive devices proved to be an important parameter in discussing agency in relation to performance of physical disability. In chapter 6, I offer an analysis of the relationship between disability, colonization and historical trauma. A historical overview of what colonization has looked like is followed by participants' narratives of how their understandings of colonization and historical trauma contribute to shaping social attitudes toward individuals with physical disabilities. The men and women I interviewed emphasized that tensions are deeply rooted in the past and continue to this day; these tensions are an important factor contributing to the prevalence of disability among indigenous populations in the United States. In addition, many reminisce about life on the reservation and wonder how many social and cultural ties they have lost; others rejoice in being far away: no matter what the underlying narrative, individuals with a physical disability and those without have made life choices that are informed by social, cultural, and political constraints; colonization and historical trauma seem to be a contributing factor in shaping these realities. Chapter 7 is closely connected to Chapter 6 but hones in on the specifics of social relationships between healthcare workers/service providers and their clients. In this chapter, concerns about funding and inconsistencies in availability of supplies and staff shortages are intertwined with cultural perceptions and stereotypes of ‘Indigeneity’ and ‘Whiteness’.

The final chapter (Chapter 8) presents my concluding remarks. The interdisciplinary focus of my study sheds light on a topic that merits further attention, particularly when taking into account the population studied. Framed within a broader context of colonization and historical trauma this study offers insights into similar aspects and differences in relation to cultural constructs pertaining to physical disability. Focusing particularly on questions about personhood, identity and embodiment of disability it details understandings of health and illness. It emphasizes furthering knowledge on the dynamics of interactions in healthcare discusses areas of medical practice that work well, but also identifies infrastructural and systemic barriers in care provision.

CHAPTER 1: INTRODUCTION

I step into the parking lot of the meeting structure on an early morning of March 2018; nothing prepares me for the hustle and bustle that is going on inside the building. I see individuals of diverse ethnic, cultural backgrounds roaming around the main area, talking excitedly to one another, adjusting their mobility devices, getting things arranged for the big day. I remember thinking two things to myself: firstly, that I did not recall seeing so many individuals with a visible disability in one place at the same time. Secondly, that those loud clear voices and the ebb and flow of the conversation reminded me of a swarm of humming bees.

I wait in a corner trying to decide which direction to go in when I am met by two individuals who have honored me with their time, energy, and insights for this project. I greet them both, while one hurriedly leaves to put down assistive devices that will later be used in a workshop. As I comment on the number of people present, the remaining interlocutor shares their excitement about the community embracing the event and says something along the lines of: “Yeah, there’s a lot of us out there; you wouldn’t know it by walking around every day would you? But here we are”. We part our ways with promises to meet again at the end of the event.

A Global Perspective on Disability

The World Health Organization (WHO) approaches disability as the combination of multiple biological, psychological, social, environmental, and personal factors. It clarifies:

> [It is] an umbrella term for impairments, activity limitations, and participation restrictions. Disability refers to the negative aspects of the interaction between individuals with a health condition (such as cerebral palsy, Down syndrome, depression) and personal and environmental factors (such as negative attitudes, inaccessible transportation and public buildings, and limited social supports) (2011b, p.7).

Based on global population data of 2010, the World Report on Disability (WHO and the World Bank 2011b, p. 7) shows that approximately fifteen percent (15%) of the population worldwide is affected by some form of disability. Global reports that examine prevalence of disability across all ages indicate that conditions related to hearing are the most common disability worldwide, affecting more than fifty-four percent (54%) of individuals from zero (0) to fifty-nine (59) years of age in low and middle income countries, and almost nineteen percent (19%) of individuals over the age of sixty (60) in high income countries (WHO, 2008, p. 35). Depression is the most prevalent disability worldwide in ages zero (0) to fifty-nine (59) both in low income and in middle/high income countries at almost sixteen percent (16%) and seventy-eight percent (78%) respectively (WHO, 2008, p. 35). An estimate of one hundred and ten (110) to one hundred and ninety (190) million adults experience difficulty functioning due to a ‘severe’ disability, while ninety-three (93) million children (under the age of fifteen, 15,) experience moderate to severe disability (WHO, 2015a, p. 2). As the population continues to age and survival rates increase, leading to more and more chronic diseases, the rates of disability are also expected to increase (Murray et al., 1996). Changes in lifestyle (such as physical inactivity, tobacco and alcohol use) also contribute to this trend (WHO, 2005).

The WHO determines severity of disability based on seven (7) gradients, all with different weight. Certain mental health conditions (such as severe depression), and types of physical and sensory disability (for example, quadriplegia, or blindness) are included in the broad category of ‘severe’ disability (Class VII), as conceptualized by the WHO (2008, p. 31). Conditions like angina, alcohol abuse, and low vision are scaled as ‘less severe’ (Class VI) based on the WHO classificatory system (WHO, 2008, p. 31). Class I includes conditions that range from malnutrition to burns, while classes II and III encompass cases of asthma, incontinence, amputations, rheumatoid arthritis, or low alcohol abuse respectively. Heart failure, Parkinson’s and hearing difficulties fall under class IV. Class V is made up of conditions like cognitive and developmental disabilities or rectal/vaginal fistulas (WHO, 2008, p. 33)[1].

All individuals with disabilities have to navigate multiple barriers related to social attitudes that disempower individuals with disabilities, disabling infrastructure, policies

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[1] The examples provided are based on global weight, for both sexes and all ages (see WHO 2008, p.33).

that limit access to employment, healthcare and participation in social life (WHO, 2011a). Worldwide reports show that individuals with disabilities regardless of type of disability, sex or age, do not receive the same degree of care as individuals without disabilities (WHO, 2011a). Eighty percent (80%) of individuals with disabilities reside in low income countries[2]. Comparative data from the World Health Survey (cited in WHO, 2011a, p. 63-64) reveal that in low income countries the rate men with disabilities who could not afford a visit to a healthcare facility rose to almost fifty nine percent (59%), whereas among men without disabilities who faced the same difficulty the rate reached forty percent (40 %). In contrast, men with disabilities in high income countries who experienced difficulty visiting a provider due to financial duress amounted to thirty nine percent (39%) compared to twelve percent (12%) respectively.

Availability of equipment and provider skills are also examples of factors that impact individuals with disabilities to a greater extent than those without disabilities: across all participating countries, individuals with disabilities were faced with lack of equipment to accommodate their needs during medical visits at higher rates than those without disabilities. More specifically, inadequate equipment affected more than twenty-two percent (22%) of males with disabilities compared to less than eight percent (8%) of males without disabilities, whereas women with disabilities whose level of care was affected by infrastructure globally rose to approximately eighteen percent (18%), compared to ten percent (10%) for women without disabilities. An estimated sixteen percent (16%) of men and women with disabilities assessed that their provider did not

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[2] Based on data in reports by the UN (2013) as cited in WHO (2015a).

have the specialized skills to administer adequate care compared to approximately seven percent (7%) of both sexes without disabilities on a global scale (WHO, 2011a, p. 63-64).

However, not all individuals with a disability are exposed to the same degree of disablement (WHO, 2011a). Worldwide, vulnerable populations are disproportionately affected by disability (WHO, 2015a, p. 2). The elderly, children, displaced populations, indigenous peoples, and women are more likely to have a disability and experience its impacts, while those who have a disability and fall within the historically disadvantaged populations mentioned above, often experience discrimination to a greater extent, not only because of prejudice associated with disability, but also because of age, gender, and other misperceptions (WHO, 2015a).

In 2018, the number of children under five (5) years of age was lower than the number of seniors on a global scale. Globally, one (1) in eleven (11) people is over the age of sixty-five (65) in 2019, with seniors reaching one hundred and forty-three (143) million of the total population. By 2050, it is estimated that one (1) in six (6) individuals will be over the age of sixty-five (65), giving rise to the percentage of elders to a projected sixteen percent (16%) of the total population compared to nine percent (9%) that it is now, in 2019[3].

Seniors make significant social, financial, and cultural contributions. Elders sustain family by being the primary caregivers of young family members. Research

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[3] Based on data provided by the United Nations World Population Prospects: the 2019 Revision. Available at https://population.un.org/wpp/. Also see data provided by the United Nations on ageing at https://www.un.org/en/sections/issues-depth/ageing/

shows that elderly, particularly grandmothers, serve a central role in educating young mothers on reproductive health, feeding practices and child rearing in many societies across the world. Furthermore, elders are active participants in maintaining and enriching cultural practices (Aubel, 2012). Despite ageist misperceptions, those who are sixty-five (65) or older play an important role in sustaining the economy. They often support their family network by investing in younger members, and are avid consumers of services and commodities, even though their participation in maintaining cash flow has been overlooked (WHO 2015b; Lee & Mason, 2011). In the United States, based on 2012 estimates, seniors amount to forty-four percent (44%) of the total populations and to almost half of the Consumer Packages Goods (CPG) sales (Nielsen Company & BoomAgers LLC, 2012, p. 5).

Assessing prevalence and impact of disability among elderly populations is challenging, because of data scarcity. Many methodologies and datasets exclude individuals who reside in non-institutional settings, leading to questions regarding the validity of results, since a significant portion of the target population may be a priori living in facilities (WHO, 2011a). In addition, rates of disability among those who are sixty-five (65) years of age or older may be higher than presented due to reporting bias: elders may often view disabling conditions as an integral aspect of growing old, and may therefore not indicate that they have a disability when participating in research projects (WHO, 2011a). However, examples from across the world highlight that individuals who are sixty-five (65) years of age or older make up a high percentage of disability rates. For instance, in Australia, in 2015, approximately three and a half (3.5) million were senior, comprising approximately fifteen percent (15%) of the total population[4]. Almost fifty-one percent (51%) were living with some form of disability. Approximately ninety-seven percent (97%) of elderly living in professionally supervised housing had a severe disability[5]. The Federal Statistical Office of Germany (Destatis) determined that almost eight (8) million of the population had a severe disability in 2017[6]. Twenty five percent (25%) of this total estimation were aged sixty-five (65) or over[7].

Globally, individuals of both sexes over seventy (70) years of age, are most commonly affected by the following disabilities: dementia and other related issues, hearing loss, ischemic heart disease, and Chronic Obstructive Pulmonary Disease (COPD). Back and neck pain, as well as injuries due to road accidents, and falls ensue in rankings.[8] Prevalence of disability for individuals of sixty (60) years of age or older is higher in low income countries compared to high income settings (almost forty four percent, 44%, compared to approximately thirty percent, 30%, respectively) (WHO 2011a, p. 27). Multiple factors contribute to the prevalence of disability among elders:

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[4] According to releases of July 2015, the total population of Australia in 2015 was almost twenty-four (24) million, as of June 2015. This count includes the Jervis Bay Territory, Christmas Island and the Cocos (Keeling) Islands. See (Australian Bureau of Statistics, 2015). Demographic information is available at https://www.abs.gov.au/AUSSTATS/abs@.nsf/Previousproducts/3101.0Main%20Features1Jun%202015

[5] Based on data provided by the Australian Bureau of Statistics for 2015. Further details are available here: https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4430.0main+features302015

[6] The total population of Germany by the end of 2017 was eighty-three (83) million based on DESTATIS 2018 data. Source: https://www.destatis.de/EN/Themes/Society-Environment/Population/Current-Population/_node.html

[7] Based on DESTATIS 2018 data. An individual is classed as having a severe disability if a pension office has determined a degree of disability of fifty (50) or more and has provided some form of valid certification, i.e. in the form of a disability pass. Available at https://www.destatis.de/EN/Themes/Society-Environment/Health/Disabled-People/_node.html

[8] Based on information provided by the WHO (n.d) on disease burden and mortality rates. Further details are available at https://www.who.int/healthinfo/global_burden_disease/estimates/en/index1.html

lack of opportunities to engage in physical activity, barriers in securing adequate nutrition, problems with access to healthcare services, and stress related to providing care and/or financial support to family members (Teel & Press, 1999; WHO, 2015b; United Nations Department of Economic and Social Affairs, 2018). Data from across the world show that these issues are widespread among the elderly population and often reflect misconceptions about aging and disability. For example, WHO networks in Europe have identified a shortage of healthcare specialists who are trained to provide comprehensive information to elders on their overall health in a manner that includes clients' perspectives about the struggles they face (WHO, 2003). Seniors all over the world report that service providers prioritize treatment for young patients, consistently fail to transport elderly to hospitals during health emergencies, while providers' discriminatory behavior and stereotyping contributes to elders not having equal access to healthcare (HelpAge International, 2011).

In response to changing social, cultural, political and economic expectations, seniors may find themselves in circumstances that put them at risk for extenuating physical and mental health challenges. Shrinking family sizes, international mobilization, and relocation of the youth to urban areas have led to isolation of elders, and to shifts in the role of elders in family or community structures. Such changes have affected availability of support networks for the elderly, who are often left to take care of their own needs, while residing in remote, rural areas WHO (2015b). Gender norms, which tend to position women in care-giving roles, are also changing, creating interesting challenges in relation to the elderly. The introduction of women in the workforce has meant that more women have the financial security to enjoy life as they advance in age. However, at the same time, time constraints and the burden of work that women have to navigate, often means that support options become limited for those who are sixty-five (65) years of age or older (WHO, 2015b).

Evidence from thirty-two (32) countries, shows that elders face significant difficulties with meeting their everyday needs: securing food, water, electricity and housing is a challenge for seventy two percent (72%) of seniors worldwide, while this percentage rises to seventy six percent (76%) in rural areas. Compared to sixty-seven percent (67%) of elderly respondents who report not having the financial means to cover food expenses and basic services in urban areas, seventy six percent (76%) of those residing in rural areas report facing financial hardship to this dramatic degree (HelpAge International 2011, p. 3). A total of sixty-three percent (63%) meet barriers when trying to access healthcare services, while the issues are exacerbated among those who live in rural areas compared to those in urban areas, amounting to sixty five percent (65%) versus sixty percent (60%) respectively (HelpAge International, 2011, p. 3).

Ten percent (10%) of elders have experienced some form of abuse, while among seniors with dementia the rate of physical abuse rises to twenty-three percent (23%) (WHO 2015b, p. 133). Studies caution, however, that numbers may be higher as cases of abuse often go unreported (Lachs & Berman, 2011). Elderly women are more vulnerable than men to be victims of abuse (Lachs & Berman, 2011). For example, a study in New York showed that two-thirds (65.8%) to three-fourths (75.9%) of victims are women (Lachs & Berman, 2011, p. 132). Elders who depend upon others for their care due to physical and/or cognitive disability, seniors with low income and those who reside in institutionalized settings are particularly vulnerable to abuse (Johannesen & LoGuidice 2013).

Prevalence of disability, of any type, is higher among women compared to men at a global level. Based on data provided by fifty-nine (59) countries, the rate of women affected by moderate to severe disability globally was eleven percent (11%) higher than that of males (WHO, 2011a, p. 31,35). Alternative data show a sixty percent (60%) prevalence of disability among women compared to that of men, barely reaching fifty percent (WHO, 2011a, p. 35). This discrepancy is due to dearth of standardized methods of measuring disability and variations in data availability (WHO, 2011a). Across the globe, women navigate social contexts and infrastructural barriers, which put them at higher risk for disability. According to data from the World Bank:

> Every minute, more than 30 women are seriously injured or disabled during labor, thus rendering vast numbers of women in the developing world physically and socially disabled. For every woman who dies from complications of pregnancy, between 30 and 100 more live with painful and debilitating consequences[9].

Data from more than eighty (80) countries reveal that one (1) in three (3) women has experienced physical/sexual violence perpetrated by a partner or in a non-partnership relationship. Estimates of intimate partner violence range from twenty three percent

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[9] http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTHEALTHNUTRITIONANDPOPULATION/EXTPRH/0,,contentMDK%3A20286128~menuPK%3A632615~pagePK%3A148956~piPK%3A216618~theSitePK%3A376855,00.html

(23%) in high-income countries, twenty-five percent (25%) in the Western Pacific area, thirty-seven percent (37%) in the Eastern Mediterranean region, to almost forty percent (40%) in Southeast Asia[10]. Evidence shows that violence in intimate relationships generally affects women from a young age, as early as fifteen (15) years of age, and is most commonly found among women who are forty (40) to forty-four (44) years old (WHO 2013, p. 16). As a result of violence, women sustain physical injuries and experience mental health concerns. Population based data show that most injuries sustained during acts of violence against women affect areas of the head, neck and face, immediately followed by musculoskeletal impacts and injuries to the genital area (WHO, 2013).

Women who have experienced abuse are also impacted by mental health issues which can, in turn, produce physical disabilities and mental health challenges for their offspring. Data show a positive association between inter-partner violence, premature birth, and low birth rate[11]. Furthermore, women who have a history of abuse often engage in behaviors known to contribute to disability, such as alcohol abuse, drug use and smoking (Curry, 1998).

Women with disabilities experience limitations to fundamental human rights such as education, safety, and reproductive health and face inequity in opportunities. Data from all over the world show that they are three (3) times more likely to be illiterate and

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[10] https://www.who.int/news-room/fact-sheets/detail/violence-against-women

[11] Low birth weight was defined as less than 2500 g, preterm birth was defined as gestational age of less than 37 weeks, and growth restriction in utero and/or small for gestational age was defined as birth weight below the tenth percentile (WHO, 2013, p. 23).

two (2) times less likely to be employed, compared to men without disabilities (UNDESA, 2018, p. 7). In a national comparative study on the effect of physical disability on social relationships in the United States, Nosek et al. (2001, p. 8) found that women with physical disabilities and those with no physical disability experienced similar levels of physical, emotional or sexual abuse, at sixty two percent (62%). However, women with physical disabilities stayed in abusive relationships for longer periods of time and often also experienced abuse in terms of being denied assistance with personal hygiene, access to assistive, mobility devices, and/or transportation to medical appointments. Some data show that approximately thirty percent (30%) of expectant mothers with disabilities have access to skilled practitioners, and more than twenty percent (20%) of married women with disabilities face barriers in accessing family planning services (UNDESA, 2018, p. 5). Thirty one percent (31%) of women with physical disabilities in the United States report being refused services by a physician due to their disability, while forty one percent (41%) felt that the sexual and reproductive health needs of women with disabilities were not adequately discussed during medical visits (Nosek et al., 2001, p. 9). Stereotypical views regarding disability may contribute to these phenomena. Literature shows that individuals with disabilities are treated in ways that de-emphasize the fact that individuals with disabilities are sexual beings; this can be exacerbated by the fact that individuals with disabilities face difficulties engaging in intimate relationships due to practical constraints, low self-esteem and negative feelings about disability and sexuality (Taleporos & McCabe, 2001). In their work with women who have physical disabilities, Becker et al. (1997) highlight that the gaps that women with physical disabilities experience reflect the complex interconnections of self-perception and self-esteem, social attitudes, traumatic experiences (particularly in relation to healthcare providers), infrastructure and policy. Research shows that providers do not engage in direct communication with women with physical disabilities, disregard their insights about their health and reproduction and subject them to unnecessary pain and discomfort due to erroneous assumptions about their disability, sensitivity levels and relevant symptoms (Nosek et al., 1995). Furthermore, lack of awareness of how disability can impact fertility leads healthcare professionals to advise on contraceptive practices that are not only difficult on a practical level, but also contraindicated due to secondary conditions that go hand in hand with the experience of disability (Becker et al., 1997). In addition to lack of medical expertise, women often have to contend with providers' negative attitudes with regards to their reproductive rights and their parenting skills. Hurtful comments regarding participants' ability to bear children, misperceptions about their parenting skills and neglect, and/or insensitive practices toward new mothers with physical disabilities are common themes in relevant literature (see Becker et al 1997; Nosek et al.,1995, for further details).

For individuals with disabilities, interventions to normalize bodily performance often begin early in life. These interventions are carried out without a clear understanding of the objectives of procedures and without the direct engagement of individuals with disabilities in the decision-making process related to treatment. Exclusion from formative discourses surrounding their disability is coupled with pain, objectification of the individual, and medical practices that exercise power by transgressing personal boundaries (Nosek et al., 1995). As a consequence, women with disabilities have developed emotional responses toward medical providers (such as fear, a sense of powerlessness, or defiance), while the physical markers of medical interventions that often originate in childhood remain visible on their bodies throughout their lives (Nosek et al., 1995). Participants in the study referenced also mentioned being chaperoned to medical visits by their parents, which deterred them from actively seeking information about health matters and advocating for their personal needs. The need for a Personal Care Attendant (PCA) during doctors' visits may also be linked to infrastructural barriers. Women with physical disabilities have to contend with inaccessible medical settings that do not facilitate examinations. These include barriers accessing the clinic itself (e.g. inaccessible transportation) as well as having inequitable access to screenings and services during medical appointments (Nosek et al., 1995). Women with physical disabilities experience difficulties accessing information about their health due to shortage of materials and technologies that make communication with healthcare providers possible for all patients (see North Carolina Office for Disability and Health, 2007, for recommendations). Furthermore, healthcare professionals' awareness of accommodations that are needed during engagements with women with physical disabilities plays a role in women's levels of satisfaction with their providers' services. Women's narratives highlight that providers often seem inexperienced in regards to communicating with women with physical disabilities, while there is often lack of awareness in when and how to assist with preparation for tests and accommodating women's needs while performing tests on women with physical disabilities (Becker et al., 1997; Schopp et al., 2002). For some women, external stress often triggers an exacerbation of physical symptoms related to their disability, which can make the entire procedure even more challenging for all parties involved (Becker et al., 1997).

Disability Rates in the United States

Studies show that the percentage of individuals with disabilities in the US varies greatly based on the method of assessment, wording of questions, and inclusion/exclusion criteria (Andresen et al., 2000). According to statistics provided by the Centers for Disease Control and Prevention (CDC), twenty two percent (22%) of adults in the United States experience some form of disability today[12]. In 2016[13], one in four (1 in 4) reported having some form of disability, which amounts to approximately sixty (60) million adults in the United States (Okoro et al., 2018, p. 882). Almost fourteen percent (14%) of those who participated in the Behavioral Risk Factor Surveillance System (BRFSS)[14] telephone survey reported having a physical disability. Almost eleven percent (11%) reported

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[12] Based on current data of the U.S. Census Bureau, the total population of the United States at this time of 2019 is almost three-hundred and thirty (330) million. Source: https://www.census.gov/popclock/; For information on disability rates, see https://www.cdc.gov/ncbddd/disabilityandhealth/features/key-findings-community-prevalence.html

[13] The population of the United States at the end of 2016 was a little less than three hundred twenty-five (325) million. Source: https://www.census.gov/popclock/

[14] Data collected using this survey inform CDC statistics. Further details on the conceptualization, implementation, and limitations of this data collection method will be provided in the concluding section of this chapter.

having a disability that affects cognition, while approximately six percent (6%) mentioned that they experience a disability that affects their hearing, and a little more than four percent (4%) experience a disability that impact their vision (Okoro et al., 2018, p. 882). Disabilities of all types were prevalent among individuals who self-identified as American Indian/Alaska Native (AI/AN)[15] and those who self-identified as multiracial. More specifically almost four percent (4%) of AI/AN, ages eighteen (18) to forty-four (44), are affected by a disability related to hearing or vision compared to two percent (2%) for those who consider themselves White. Approximately nineteen percent (19%) were affected by disabilities related to cognition compared to almost eleven percent (11%) for those who self-identified as White; more than eight percent (8%) of AI/AN, compared to four and a half percent (4.5%) Whites experienced a mobility disability. Prevalence for disabilities affecting independent living and self-care was higher among AI/AN compared to Whites (Okoro et al., 2018, p. 883). For those who are sixty-five (65) years of age or older, rates of disability of any type among AI/AN surpass those of Whites at approximately fifty-five (55) versus forty percent (40%) respectively (Oroko et al., 2018, p. 884).

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[15] A number of terms have been used to denote Native Americans as a group. The most commonly used are American Indian and Native American, while Amerindian and Aboriginal Americans are less frequently used (Nagel, 1995). Literature points out that the term 'American Indian' alludes to the invasion of European colonizers on indigenous territory. The term serves a classificatory purpose: to assist colonizers to distinguish one population of the Indies from the other (Nagel, 1995). Hobson (1989), a Cherokee-Quapaw/Chickasaw, notes that the term 'Native American' is problematic as it draws upon blood quantum as a criterion as determining belonging. This is itself a practice of colonization as it superimposes determination processes that are foreign to indigenous worldviews. The most commonly used term used by my participants to characterize themselves was 'Native Americans' or 'Us Natives'. For this reason, I use this term when referring to my own research findings.

Southern States have higher rates of adults with disabilities compared to other States, perhaps due to the prevalence of chronic health conditions which may lead to disability[16]. Based on Census data for 2016, disabilities of all types amounted to almost forty-four percent (44 %) in the South compared to thirty-nine percent (39%) in the Northeastern regions. Mobility difficulties were the most commonly reported across all regions; Southern areas once again came first at almost twenty-nine percent (29%) as opposed to twenty-six percent (26%) in the Northeast (Oroko et al., 2018, p. 884).

In 2017, out of a total of approximately three hundred twenty-one (321) million non-institutionalized civilians, almost forty-one (41) million reported having a disability. There was a slight prevalence of disability among women compared to men. Disability of any type was prevalent among AI/AN populations at approximately seventeen percent (17%) compared to an estimate of thirteen percent (13%) among Whites. Those most affected were seventy-five (75) years of age or older at almost forty-nine percent (49%). Those between the ages of sixty-five (65) and seventy-four (74) ensued at twenty five percent (25%), while estimates show that disability is less frequent among children under the age of five (5)[17].

As occurs in other areas of the world, individuals with disabilities are less likely than those without disabilities to be employed in the United States. In 2017, seventy-six

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[16] https://www.cdc.gov/media/releases/2015/p0730-US-disability.html

[17] More details are available here: United States Census Bureau (2017a) *Disability 2017*. https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_17_1YR_S1810&prodType=table.

and a half percent (76.5%) of individuals without disabilities were employed versus thirty-five and a half percent (35.5%) who had disabilities, while the median earnings for those with a disability who worked full time, full year[18] almost reached forty-one thousand USD ($41,000) compared to an estimated forty-six thousand USD ($46,000) for those who did not have disabilities (Houtenville & Boege, 2019, p. 7). Data from the US Census Bureau for 2017 show that almost thirty-five percent (35%) of workers with disabilities, aged sixteen (16) and older, reported having a mobility disability, followed by workers with disabilities that impacted their hearing at a little over thirty-one percent (31%), cognitive disabilities at approximately twenty-nine percent (29%), and finally disabilities that affect independent living and self-care at an estimated seventeen percent (17%) and eight percent (8%) respectively[19].

Linked to the complex phenomena of historical trauma, colonization, and ongoing discrimination on multiple levels, which will inform chapters throughout this dissertation, unemployment rates adversely affect Native American individuals and communities; particularly those who have some form of disability. Data covering a two -year period (2009-2011) show that the employment rate of Whites, ages twenty-five (25) to fifty-four (54), was a little over seventy-eight percent (78%), while among Native Americans it reached a little over sixty-four percent (64%) (Ruggles et al., 2013, as cited in Austin,

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[18] More than thirty-five (35) hours/week; over fifty (50) weeks/year (Houtenville & Boege 2019, p. 7).

[19] United States Census Bureau. (2017b). American Community Survey: 1 Year Estimates (Available at www.census.gov/programs-surveys/acs/).

2013, p. 6) [20]. Fifty two percent (52%) indicated that they were single race (AI/AN), an estimate of eighty-four percent (84%) spoke only English at home, almost forty seven percent (47%) reported living on or near reservations. Over nineteen percent (19%) indicated that they had a disability compared to a little over nine percent (9%) of Whites (Austin, 2013, p. 12). Those who self-identify as AI/AN and have a disability are seventy-eight percent (78 %) less likely to secure employment compared to AI/AN without disabilities (Austin, 2013, p. 14) Based on data from 2011-2015, the American Community Survey (ACS) highlights that of a total estimated population of a little over one hundred forty seven (147, 748) employed AI/AN civilians aged sixteen (16) years of age and older, filled retail positions, followed by positions in the manufacturing industry[21]. In 2017, for ages eighteen (18) to sixty-four (64), those living below the poverty line who also had a disability amounted to almost twenty-five percent (25%), compared to those with no disability, estimated to be a little over ten percent (10 %)[22]. According to the Census Bureau, the poverty threshold for 2017 was $12,752 for one individual under the age of sixty-five (65) and $11, 756 for one (1) person aged sixty-five

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[20] Likelihood in the context of Austin (2013) is defined as the ratio of odds between AI/AN with a disability and without a disability.

[21] https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_15_AIA_DP03&prodType=table.

[22] There are two ways of measuring poverty: the first is the poverty thresholds. Used by the Census Bureau, it provides an annual, statistical overview of poverty rates with an emphasis on age. The second is the poverty guidelines, issued by the Department of Health and Human Services. This provides annual, state-by-state information, and is used to determine access to certain federal programs, which are relevant to this dissertation, such as certain aspects of Medicare and Medicaid. Age is not included as a variable. See https://aspe.hhs.gov/frequently-asked-questions-related-poverty-guidelines-and-poverty#programs and https://aspe.hhs.gov/frequently-asked-questions-related-poverty-guidelines-and-poverty#programs

(65) or older[23]. When using the poverty guidelines measurement, rather than the poverty threshold as a variable, the poverty line for one (1) individual is $12, 060 for the forty-eight (48) contiguous states and the District of Columbia. For Alaska and Hawaii, the amounts are $15,060 and $13,860 respectively[24]. Estimates of poverty among individuals with disabilities vary based on source. For example, for 2017, some mention that the poverty rate for individuals with disabilities, ages eighteen (18) to sixty-four (64), is a little over twenty-nine percent (29%), compared to a little over thirteen percent (13%) for individuals without disabilities (Houtenville & Boege 2019, p. 9); others state that the percentage of individuals with a disability, living below the poverty line, for the same age range as above, amounts to almost twenty five percent (25%), compared to a little over 10 percent (10 %) for those without a disability (U.S. Census Bureau, Current Population Survey, 2017 and 2018 Annual Social and Economic Supplements, cited in Fontenot et al., 2018, p. 18).

Poverty disproportionately strikes Native American families. In 2017, almost twenty-one percent (21%) of Native American families of all types were living in poverty compared to a little over nine percent (9%) of the remaining population[25]. According to Fuller-Thomson and Minkler (2005), there were two hundred thirty-nine thousand (239,000) Native Americans with a disability that affected their functionality in 2000, on

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[23] See https://www.census.gov/data/tables/time-series/demo/income-poverty/historical-poverty-thresholds.html

[24] See https://aspe.hhs.gov/2017-poverty-guidelines#threshholds

[25] Further data available here:
https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk

a national level, corresponding to almost twenty-eight percent (28 %) of all Native Americans aged forty-five (45) and older. Almost nineteen percent (19%) of these individuals were aged between forty-five (45) to forty-nine (49) years old, while an estimated sixty-seven percent (67%) were eighty-five (85) and older. Forty-four percent (44%) of those living under the poverty line had a disability, compared to twenty-five percent (25%) of those without a disability. Twelve percent (12%) of Native Americans with a disability relied on public assistance programs, while forty-one percent (41%) used food stamps (Fuller-Thomson & Minkler, 2005, p. 1945-1947).

The challenges individuals with disabilities face with regards to employment may be directly correlated to lack of equity in education opportunities. According to data published by the Institute on Disability/UCED, in 2017, more than eighteen percent (18%) of individuals with disabilities between the ages of twenty-five (25) to thirty-four (34) did not have a high school diploma, GED, or other relevant certificate (Houtenville & Boege, 2019, p. 11). In comparison, a little over eight percent (8%) of individuals without disabilities in the same age range do not have the equivalent educational certification. While college (Bachelor’s or higher) degree completion rates among people with disabilities from twenty-five (25) to thirty-four (34) years old reached a little over fourteen percent (14%), those without disabilities exceeded thirty-seven percent (37%). Data show correlations between disability status and other factors, such as race/ethnicity, age and other protected statuses. Based on data provided by the National Centers for Educational Statistics (NCES), Digest of Educational Statistics 2017, the rate of undergraduate students with a disability on a national level amounted to a little over nineteen percent (19 %), compared to more than eighty percent (80%) for undergraduates without disabilities for the academic year 2015-2016. Disability rates were higher among undergraduate students who self-identified as AI/AN, undergraduates who self-identified as having ties with two or more races, and Whites (almost twenty-eight percent, 28%, twenty-two percent, 22 %, and a little under twenty-one percent, 21%, respectively). The lowest rates were found among Asian undergraduates, barely over fifteen percent (15%). Prevalence of disability was higher among undergraduate students aged thirty (30) years or older, and those who reported veteran status: indicatively, disability rates amounted to twenty-three percent, 23%, among undergraduates who were thirty (30) years of age or older compared to almost eighteen percent, 18%, among those between the ages of fifteen (15) to twenty-three (23), while disability rates reached twenty-six percent, 26% for undergraduates who had veteran status, versus nineteen percent, 19%, for non-veterans[26]. Similar patterns can be identified when comparing disability rates for graduate students with/without disabilities: the rate of students with disabilities was almost twelve percent (12%)[27]. Data from the National Science Foundation (NSF), for 2014[28], show that approximately thirty-five thousand (35,000) graduate students received research related doctorates. The majority of recipients self-identified as White, at almost nineteen thousand (19,000), male (approximately twenty-one thousand, 21,000), and United States

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[26] Data cited herein as well as further details are available here: https://nces.ed.gov/programs/digest/d17/tables/dt17_311.10.asp?referrer=report

[27] Please see the reference note above.

[28] In 2014 the overall population of the United States almost reached three hundred twenty (320) million. According to Census data, a little over eighty-five (85) million people had some form of disability (Taylor, 2018).

citizens or permanent residents (almost twenty-two thousand, 22,000). Of the overall total stated above, less than seven percent (7%) reported having a disability, with the most common disability relating to vision (a little over three percent, 3%), and the least common to difficulties walking at a less than half percent (0.5%). Only sixty-one (61) individuals reported being AI/AN, six (6) of whom had a disability [29].

Legislative Contexts: Contributions and Challenges

Prior to the passage of the ADA in 1990, and before it went into effect in 1992, certain states had legal frameworks that set the scene for protecting the rights of individuals with disabilities in the form of 'judicial decisions' and 'statutory provisions' (Jolls, 2004, p. 4). States with legal provisions included Arizona, Colorado, Idaho, Iowa, Virginia, Washington, Wisconsin, among others. States with limited protection included Alaska, Florida, Georgia, and others. The only states with no protection were: Alabama, Arkansas, and Mississippi (Jolls, 2004, p. 11). These frameworks were relevant to employment. In states with full protection, guidelines determined that hiring and firing individuals on the basis of their disability was discrimination, while they outlined the definition of reasonable accommodations and dictated that employers provide those to their employees with disabilities. In states with less measures in place, employers were

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[29] Available at https://www.nsf.gov/statistics/2017/nsf17310/data.cfm

not mandated to provide accommodations, while states with no protection did not hire individuals with disabilities (Jolls & Prescott, 2004).

As the predecessor of the ADA, the Rehabilitation Act of 1973 recognized ongoing discrimination that individuals with disabilities faced on a daily basis and tried to address such phenomena by prohibiting discrimination on the basis of ‘handicap’ in the context of employment. The initial scope of this act was to provide the legal framework to eliminate discrimination against individuals with disabilities, however amendments passed in 1978, expanded the act to include affirmative action mandates (Henry, 1989). Congress legislation on discrimination prohibition on the basis of disability is primarily encapsulated in three sections: Section 501 (b) states that “each department, agency, and instrumentality of the executive branch is required to submit its own affirmative action plan for the hiring, placement, and advancement of individuals with handicaps” [30]. According to legislation by the United States Congress, Section 503:

> requires that federal contractors and their subcontractors "take affirmative action to employ and advance in employment qualified individuals with handicaps" in connection with the performance of any federal contract and subcontract "for the procurement of personal property and nonpersonal services (including construction)" in excess of $2,500 (USC § 793(a), as cited in Henry, 1989, p. 127).

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[30] 29 U.S.C. § 791(b) (1988), as cited in Henry (1989, p. 127).

The most widely known section of legislation is Section 504, according to which, "any state, any instrumentality of a state, any public or private agency, institution, or organization, or any other entity to which federal financial assistance is extended either directly or through another recipient" is subject to the act (Zimmer, 1981, p. 23). Section 504 of the Rehabilitation Act stated:

> No otherwise qualified handicapped individual in the United States, as defined in section 706(7) of this title, shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service (29 USC § 794 (1982), amended by 29 U.S.C. § 794(a) (1988), as cited in Henry, 1989, p. 128).

Certain parts of this section were amended in 1986 to reflect broader shifts in social attitudes toward disability. Disability advocates maintained that using the adjective rather than focusing on the person furthered existing stereotypes about individuals with disabilities. Following the testimonies of individuals with disabilities to Subcommittees of the Congress the term "handicapped individual" was replaced by "individual with handicaps" (29 USC § 794(a) (1988), as cited in Henry, 1989, p.128).

In the statutory sense, 'handicap' was determined if the following criteria were met:

> (i) a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) a record of such an impairment, or (iii) is regarded as having such an impairment. Second, there must be a determination that the individual is "otherwise qualified" for the job sought (29 USC § 706(8)(B) (1988); Supra note 14, at 640, as cited in Henry,1989, p.129).

Law-suits led to the expansion of protections for individuals with disabilities under the act and contributed to the clarification of the clause “otherwise qualified”. The School Board v. Arline case (480 U.S. 273, U.S. Supreme Court (1987) is such an example. For over a decade, Arline taught at an elementary school in Nassau County, Florida. Cultures taken in 1977 and 1978 revealed that she tested positive for tuberculosis after being in remission for twenty (20) years. Arline was dismissed at the conclusion of the 1978-1979 school year, after being on suspension with pay for a substantial amount of time during 1978. While the school had no complaints regarding her performance as an employee, she was terminated on the grounds of continuous occurrence of tuberculosis. Appeals reversed the District Courts’ ruling that Arline did not have a ‘handicap’, as contagious diseases were not included in the definition. The District Court concluded that even if the assumption that Arline was a person with a ‘handicap’ were to be accepted, she was not qualified to teach elementary school students. The Court of Appeals ruled that contagious diseases fall within the statutory purview of section 504 and remanded that reasonable accommodations be provided to allow Arline to fulfill her duties[31].

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[31] For further details see https://www.ravellaw.com/opinions/71e505b6c5b30fa78921bfd5ffb0ae5d

The above case led to the elucidation that is central in subsequent legal frameworks addressing discrimination against individuals with disabilities, namely the ADA (Henry, 1989). An employer can make the decision to hire or fire an individual protected under the Rehabilitation Act, and now the ADA, based solely on whether their qualifications meet the requirements for the stated position, without taking into consideration mental, developmental, and physical conditions protected under the act. Therefore, an employee can be terminated if they pose a direct, rather than perceived, risk for the health and safety in their work environment (Richards supra note, as cited in Henry, 1989, p.138). Furthermore, an employer is required to identify a specific risk to personnel and property and prove that no reasonable accommodation can alleviate that risk prior to termination of the employee protected by the ADA[32].

In addition to the Rehabilitation Act of 1973, several other acts in the 1970s and 1980s addressed disability-related discrimination pertaining to housing, voting, protecting individuals with developmental disabilities, and rights in education for individuals with disabilities (for more, see Burgdorf, 1991). These paved the way for the passage of the ADA in 1990. Heavily influenced by Section 504 of the Rehabilitation Act, the ADA approaches disability as “a physical or mental impairment that substantially limits one or more of the major life activities, with a record of such impairment, or being regarded as having such an impairment” (42 U.S.C.A. § 12102(2) (West Supp. 1990), as cited in Burgdorf, 1991, p. 445). The broad definition of disability ignited heated conversations

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[32] S. REP. No. 116, 101st Cong., 1st Sess. 27 (1989) referencing School Bd. v. Arline, 480 U.S. 273 (1987), as cited in Henry 1989, p. 131.

among Senators. Initially, several mental health conditions (such as schizophrenia, and manic depression) were not included in the Act, only to be rebutted by other Senators who highlighted that several prominent figures of the United States and global historical contexts lived with such mental health conditions. The ADA approached such mental health conditions as similar to kleptomania, pedophilia, voyeurism, alcoholism, gambling, homosexuality and transvestitism and were not viewed as a disability in the statutory sense, under Sections 508, 510 and 511 of the Act (for more see, Burgdorf , 1991). The ADA is comprised of five parts: Part I relates to employment; Part II to public services; Part III to public accommodations and services operated by private entities; Part IV telecommunications relay services, and Part V covers miscellaneous provisions (Burgdorf,1991, p. 434). Contrary to the Rehabilitation Act, to which only federal agencies and agencies that received federal funds were subjected, the ADA covers "all state, local, government facilities, services and communications" (42 U.S.C.A. § 12134(b) (West Supp. 1990), as cited in Burgdorf, 1991, p. 467). The aforementioned bodies have the obligation to make "reasonable modifications to rules, policies, or practices, to achieve the removal of architectural, communication, or transportation barriers, and to ensure the provision of auxiliary aids and services" (42 U.S.C.A. §§ 12131(2), 12132 (West Supp. 1990), as cited in Burgdorf 1991, p. 467). The obligation to make reasonable accommodation is waived if the employer can prove that such actions pose undue hardship on the employer (for further details on how undue hardship is legally determined, see Burgdorf, 1991). The Department of Justice (DOJ) and the Equal

Employment Opportunity Commission (EEOC) were appointed by Congress to oversee the implementation of ADA mandates (Feldblum et al., 2008).

The scope and terminology used in the ADA has been critiqued on the grounds that it assumes that determining a statutory definition of disability is a simple matter. While the basis of the ADA proposes to address discrimination, litigation success depends primarily upon providing substantial proof that the plaintiff meets the legal criteria to be considered to have a disability, rather than addressing the issue of significance which the ADA purportedly combats, discrimination (Bagenstos, 2003). Determining the effectiveness of legal frameworks largely depends upon expectations and the intent outlined (Tucker, 1989). While the DOJ interpreted Section 504 of the ADA as intended by Congress, the EEOC closely scrutinized the clause ‘substantially limited in a major life activity by impairment’ and narrowly interpreted both the threshold of ‘substantial limitation’ to include only those conditions that could not be addressed with medication, and limited the scope of ‘major life activity’ to working (Feldblum et al., 2008). Several disability related discrimination cases were ruled against people with disabilities due to the lack of clarity on how to delineate the existence of disability and how to interpret ‘major life activity’ and the effects of disability in that aspect of everyday life (Feldblum et al., 2008). Therefore, it soon became apparent to advocacy groups and their political allies in Congress and elsewhere that rather than protecting the rights of people with disabilities, the ADA unintentionally provided coverage only to those who met strict criteria regarding, primarily, the statutory definition of ‘disability’ (Feldblum et al., 2008). The hard work of activists, multiple reports and congressional hearings, as well as bipartisan support led to multiple amendments of the initial version of the ADA (for more see Feldblum et al., 2008).

Certain entities are exempt from being fully subject to ADA compliance requirements. United States' government owned corporations are not mandated by law to follow the ADA. Private membership clubs and places of worship are also exempt from following the title pertaining to public accommodations (Burgdorf ,1991, p. 492). Provisions protect small businesses from civil lawsuit, for a specific timeline: more specifically, no legal action can be taken against a business of twenty-five (25) or fewer employees with a gross income of one (1) million or less until July 26, 1992; and business of ten (10) or fewer employees with gross receipts of five hundred thousand (500,000) are not subject to ADA violation until January 26, 1993 (42 U.S.C.A. § 12181 note (West Supp. 1990), as cited in Burgdorf, 1991, p. 481).

Amid critiques regarding the effectiveness of the Americans with Disabilities Act (ADA) in protecting the rights of individuals with disabilities, particularly in terms of employment, literature shows that Section 504 of the Rehabilitation Act and the Individuals with Disabilities Education Act (IDEA), have promoted the educational needs of individuals with disabilities (Jolls, 2004; Aron & Loprest, 2012). Studies that focus on providing comparative conclusions on the effect of the ADA on education show that individuals with disabilities were more likely to report education qualifications as a factor in securing employment, and to participate in educational initiatives more after the ADA went into effect, particularly in states with no previous legal recourse for individual with physical disabilities (Jolls, 2004). More specifically, in States with no legal recourse against discrimination, individuals with disabilities reported not being employed due to participating in education at a 0.0098 probability during the pre-ADA timeframe, compared to 0.0158 probability after the ADA (Jolls, 2004, p. 12)[33]

The Elementary and Secondary Education Act of 1965 and the Education of the Handicapped Act of 1970 laid the foundation for the Individuals with Disabilities Education Act of 1990. The former was the first in the United States to provide funds for the education for students with disabilities at the elementary and secondary levels of education, while the latter expanded funding to higher education institutions. Amendments to this act in the mid-seventies enacted a principle that is central to education today: free, appropriate, public education for students with disabilities, also known by the acronym FAPE (Katsiyannis et al., 2001).

Four parts constitute the IDEA: Part A contains findings about the education status of children with disabilities covered by the Act and provides the rationale of the IDEA. Part B covers students with disabilities aged three (3) to twenty-one (21) and outlines the rights of students with disabilities to special education instruction, legal mandates for their protections and provisions to ensure that parents participate in the decision-making process with regards to provisions. This section also includes mechanisms to secure funding for educational institutions covered under this part of the Act. Part C covers infants and toddlers from birth to the age of two (2) and outlines legal frameworks for providing support to help this group with regards to mental, physical

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[33] This study used the Current Population Survey (CPS) question regarding the reason for unemployment being the pursuit of education. The timeframe 1987-1990 is defined as pre-ADA while 1991-1996 as post-ADA (Jolls, 2004, p.3,6)

challenges that may impact development. Any services provided at public expense to identify, prevent, or address existing developmental delays are subject to the guidelines specified in Part C of the IDEA (Kastiyannis et al., 2001). The final part, Part D, provides guidelines for miscellaneous services, such as initiatives to raise awareness about the rights of children, infants with disabilities, as well as training sessions and research relevant to disability aimed at this specific target population (Katsiyannis et al., 2001)

Prior to the passage of Section 504 of the ADA and the IDEA only one (1) in five (5) children with diagnosed disabilities attended public school. More than one (1) million were confined to institutions with no access to support that would allow them to pursue education, while some states had legal frameworks in place, which explicitly barred access of individuals with disabilities to educational settings. Individuals with certain disabilities, such as those that were labeled as 'mental retardation', or 'emotional disturbances' at the time, or with specific physical/sensory disabilities (e.g. vision or hearing difficulties) faced more stigmatization than individuals with other disabilities (Aron & Loprest, 2012, p.100). According to National Center for Education Statistics (NCES) data, estimates of participation of students with disabilities in elementary and secondary education show that in 1969-1970 less than six percent (6%) of students with disabilities were enrolled in public schools and received special education services, compared to more than ten percent (10%) in 1980-1981 (US Department of Education, Office of Special Education and Rehabilitative Services, cited in Lamar et al., 1993, p. 44).

The most recent Annual Report to Congress on the Implementation of the IDEA highlights that, in 2016, more than six (6) million students, aged six (6) to twenty-one (21) were provided with services under Part B of the IDEA, which accounted for nine percent (9%) of the total resident student population aged six (6) to twenty-one (21) (US Department of Education, Office of Special Education and Rehabilitative Services, 2018, p. xxiv)[34]. The most common disability pertained to specific learning disability[35] at approximately thirty nine percent (39%), followed by speech or language impairment at almost nineteen percent (19%). Intellectual disability and emotional disturbance were the two less common disabilities at approximately seven percent (7%) and a little over five percent (5%) respectively (US Department of Education, Office of Special Education and Rehabilitative Services, 2018, p. xxv). The overwhelming majority of students with specific learning disabilities were AI/AN, at almost forty-five percent (45%) (US Department of Education, Office of Special Education and Rehabilitative Services, 2018, p. xxvii).

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[34] The provided estimates are based on data from forty-nine (49) states, the District of Columbia, Bureau of Indian Education (BIE) schools, Puerto Rico, the four outlying areas, and the three freely associated states. For more details please see US Department of Education, Office of Special Education and Rehabilitative Services (2018). *40th Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act, 2018.* Department of Education.

[35] The IDEA of 2004 defines “specific learning disability" as a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which disorder may manifest itself in an imperfect ability to listen, think, speak, write, spell, or do mathematical calculations. Such term includes such conditions as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and develop mental aphasia. Such term does not include a learning problem that is primarily the result of visual, hearing, or motor disabilities, of mental retardation, of emotional disturbance, or of environmental, cultural, or economic disadvantage. (P.L. 108-466, Sec. 602[30]) (Kavale et al., 2009, p. 40).

Legislative Considerations for Native American Peoples

Per the United States Constitution, Native American nations have sovereign status. In relation to our objective in this section, the recognition of sovereignty is encapsulated in the Commerce Clause (Article 1, Section 8, Clause 3) of the United States Constitution (Akhtar, 2014, p. 259). Therein is stated the right of the United States Congress to "make treaties and regulate commerce with all foreign nations, including the Indian tribes" (Akhtar, 2014, p. 260). However, Congress also has plenary power over Native American nations, as federal law often conceptualizes them as 'dependent nations', as crystallized in early Supreme Court cases[36] (Akhtar, 2014). In terms of legislation, Congress has, at times, treated nations as States or municipalities, but determination of status is made clear in each case (see Bazan 1991, p. 2, 3).

Consensus as to whether all Titles of the ADA apply to, and should be implemented by, Native American groups has not been reached and is largely dependent upon court interpretation of the scope and language of the ADA. Title III seems to raise the most questions, as this title does not specifically discuss exemption of tribes and/or nations (for a more detailed overview of how arguments may be received in court, see Bazan, 1991). The United States Court of Appeals, 11th Circuit, was the first in American history to address allegations against a Native American group on violation of Title III of the ADA in 1999. The Florida Paraplegic Association Inc. and the Association for Disabled Americans, Inc. filed a lawsuit against the Miccosukee Tribe for alleged

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[36] For additional details, please see N.a, (1999). *Florida paraplegic association v. Micosukee tribe*. Retrieved September 25, 2019 from https://www.leagle.com/decision/19991292166f3d112611164

violations of Title III of the ADA (in areas of a parking lot, restroom and infrastructure of a restaurant owned and operated by the Miccosukee); the district court denied the Miccosukee's motion to dismiss. The Court of Appeals found that the Miccosukee were subject to the ADA as the case did not fall under 'self-governance' to justify an exemption to the applicability of the law. According to the Court, the fact that Native American groups are not specifically exempt from Title III of the ADA is indicative of its applicability to all entities except those specifically exempted. Furthermore, the Court stated that the establishment where the alleged violation of the ADA occurred was not privy exclusively to Native American members of the tribe, nor did it perform functions relevant to governance of the Miccosukee (Hasday, 2000, p. 1200). The Court, however, recognized that the Miccosukee were immune from "a private suit based on alleged violations of Title III" (Hasday, p. 2000, p. 1200). Essentially, this indicated that the Miccosukee were not required by law to "comply with ADA standards" (Hasday, 2000, p. 1200).

Native American individuals with disabilities find themselves at the epicenter of conflicting values. Acknowledging and legally upholding Nations' right to decide whether to adopt legislation that gives Native Americans with disabilities residing on Native American reservations recourse against discrimination respects sovereignty, a value that is hard fought by Native American activists and their allies on multiple issues. To superimpose legal frameworks that are not based on initiatives drafted, enacted and implemented by indigenous groups themselves is a practice that disempowers Native Americans, and furthers colonization (Bazan, 1991; Clift, 2002). Confusing rulings on the part of courts at various levels leave Nations unsure of what required provisions for members with disabilities residing on federally recognized reservations are, while introducing new questions and challenges for the scope and applicability of sovereignty (Bazan, 1991; National Council on Disability, 2003). Conversely, individuals with disabilities and Native Americans have historically shared parallels of prejudice, discrimination and policies that have promoted the extinction of individuals belonging to either of the two groups. As a product of multiple self-advocacy efforts, the ADA provides a common basis for addressing phenomena that have plagued both groups (Hasday, 2000).

On April 25 1979, the Navajo Nation Council approved the “Navajo Affirmative Action Plan” (formally known as the Navajo Tribal Council Resolution CMY 40-77 1979) to be implemented in schools, job sites and all agencies within the jurisdiction of the Navajo Nation. Also known as the Navajo Affirmative Action Plan for the Handicapped, the Task Force of the Office of the Chairman of the Navajo Nation Tribal Council was assigned to develop strategies to implement the Action Plan, in collaboration with the Navajo Nation Council on the Handicapped. In essence, the Act adopted Sections 501 to 504 of the Rehabilitation Act of 1973 and echoed its definitions of disability, accommodations, qualified individual, and overarching approach toward legislation on rights of Navajo individuals with disabilities on reservation land with regards to employment.

Equal Opportunity Offices were responsible for following due process. The Office of Navajo Labor Relations, the Navajo Housing Authority and other Committees related to housing, and the Navajo Maintenance Department and Design and Engineering were required under this Action Plan to collaborate with the rehabilitation specialists working in the Navajo Nation Vocational Rehabilitation Program to make changes to their policies, and infrastructure in order to maintain compliance with the Action Plan. In addition to architectural barriers, the plan emphasizes the detrimental effect of social barriers (such as prejudice against individuals with disabilities on the part of individuals without disabilities). Following the procurement of a position that falls under the category of 'employment' by an individual with a disability, the Vocational Rehabilitation Program collaborated with the individual with a disability and hiring agency to determine reasonable accommodations. For a period of thirty (30) days a rehabilitation specialist monitored compliance (Navajo Nation Council, 2018).

Amendments identified problems with the implementation and enforcement of the Act of 1979. Funding constraints and lack of clear directives are cited as the main reasons for not materializing the goals specified in the initial Act. In a much more specific framework, the Civil Rights of Individuals with Disabilities Act, passed on August 6, 2018, retains the definitions of disability, accommodations, and undue hardship of the previous act. The amended version emphasizes Diné[37] traditional perceptions of disability as a state of life that is sacred. In the context of cultural values of respect and reverence, the act states:

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[37] According to my participants Diné is the traditional term to refer to those who are also known as Navajo. This term is often translated as 'the Holy People'. Alternative translations include diyin dine'é or diyinii (Farella, 1984, p. 23). In their majority, participants noted that they preferred use of Diné in lieu of Navajo. I, therefore, use this in my own analysis unless discussing the insights of a participant who indicated their preference for the term Navajo.

> The Navajo Nation finds that discrimination against any individual with a disability is *naayéé*[38] and not only violates the fundamental individual rights of Navajos, but also disrupts efforts to maintain *hozhó*[39] across all Diné Bikéyah (Navajo Nation Council, 2018, p. 2).

In addition to all areas covered in the Act of 1979, this version includes requirements for free education in the least restrictive environment and provision of accommodations for students with disabilities residing on the Navajo Nation, in accordance with the Navajo Sovereignty in Education Act of 2005 (for more, see Navajo Nation Council, 2018). Prohibition of discrimination of incarcerated individuals with disabilities on the Navajo Nation on the basis of disability is also stated, as are mandates prohibiting discrimination on the basis of disability in relation to access to governmental services (Navajo Nation Council, 2018). The amended version substitutes the use of the term ‘handicap(ped)’ with ‘disability’ and announces the constitution of further committees to monitor compliance and provide services to individuals with disabilities residing on lands within the jurisdiction of the Navajo Nation. The Act of 2018 outlines criteria used to prove disability status when requesting coverage under this Act. As stated, the individual “seeking the protection of the civil rights (…) will have to demonstrate to a court, by a preponderance of evidence, that he/she has a disability” (Navajo Nation Council, 2018, p. 8). Determination of disability status relies heavily on

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[38] Also known as *nayéé*. Translated into English as ‘monster’, this term encompasses anything that disrupts harmony within an individual or group, including fear, anxiety, physical and/or mental health concerns (Farella 1984, p. 51).

[39] This term describes a state of goodness (Farella, 1984). Otherwise noted as harmony or beauty (Schwarz, 2001; Lewton & Bydone, 2000). Participants in my research referred to this concept in various ways including hope, beauty, harmony, or harmony through balance.

documentation provided by medical facilities and/or Diné specialists, such as medicine men (Navajo Nation Council, 2018, p. 8). The Act of the Navajo Nation follows ADA specifications of undue hardship in terms of determining eligibility for refusal of accommodations (Navajo Nation Council, 2018, p.7,8)

According to data provided by the Bureau of Indian Education (BIE) for 2016, there was a total of two hundred forty (240) AI/AN children, aged three (3) to five (5). The majority—two hundred twenty (220)— received services in Regular Early Childhood Programs for at least ten (10) hours. From a total of over six thousand (6,000) AI/AN students, aged six (6) to twenty-one (21), over four thousand (4,000) were in a regular class for eighty percent (80%) or more of the day[40]. Statistics from the BIE examine participation in education in a number of settings including correctional facilities, the home, hospitals, private and public schools. In addition, BIE data explore participation in programs, regular classes as well as separate settings, by type of disability. Disabilities that are included relate to hearing, and vision; others are: developmental, emotional, multiple disabilities, autism, specific learning disabilities, disabilities related to speech, traumatic brain injury, and others. However, a close review of available data shows that in many cases data in one or both age groups that are of interest here are missing, leading to questionable conclusions about the prevalence of disability in various educational settings available to AI/AN[41].

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[40] These data refer to the aggregate of disability. There are significant gaps in reporting by type of disability in one or both age groups of interest. Source: https://www2.ed.gov/programs/osepidea/618-data/stbate-level-data-files/index.html

[41] See: https://www2.ed.gov/programs/osepidea/618-data/state-level-data-files/index.html.

For the 2016-2017 School Year (SY), the total of teachers employed on a Full Time Equivalent (FTE) to provide support to children who received services under the IDEA, Part B, exceeded three hundred forty thousand (340,000) based on data reported by US States, Outlying Areas and Freely Associated States (US Department of Education 2018)[42]. A little over three hundred fourteen thousand (314,000) met or exceeded qualification standards and/ or certification requirements as outlined by State guidelines[43]. New York (NY), California (CA), and Pennsylvania (PA) were the three states that hired the most personnel at more than twenty-eight thousand (28,000), more

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[42] Additional data available at https://www2.ed.gov/programs/osepidea/618-data/static-tables/index.html#partb-pen. Data reported by the State of Texas has been excluded due to questionable data quality.

[43] The US Department of Education uses the term 'highly qualified' "based on the criteria identified in 20 United States Code (U.S.C.) section 1401(10). For highly qualified special education teachers, the term "highly qualified" has the same meaning given the term in section 9101 of the Elementary and Secondary Education Act of 1965, as amended (ESEA), except that such term also includes the requirements described in section 602(10)(B) of IDEA and the option for teachers to meet the requirements of section 9101 of ESEA, by meeting the requirements of section 602(10)(C) or (D) of IDEA [20 U.S.C. section 1401(10)]. In states where teachers who work with children ages 3 through 5 were not included in the state's definition of highly qualified, teachers were considered highly qualified if they were (1) personnel who held appropriate state certification or licensure for the position held or (2) personnel who held positions for which no state certification or licensure requirements existed" (US Department of Education. 2018, p. 35). based on the criteria identified in 20 United States Code (U.S.C.) section 1401(10). For highly qualified special education teachers, the term "highly qualified" has the same meaning given the term in section 9101 of the Elementary and Secondary Education Act of 1965, as amended (ESEA), except that such term also includes the requirements described in section 602(10)(B) of IDEA and the option for teachers to meet the requirements of section 9101 of ESEA, by meeting the requirements of section 602(10)(C) or (D) of IDEA [20 U.S.C. section 1401(10)]. In states where teachers who work with children ages 3 through 5 were not included in the state's definition of highly qualified, teachers were considered highly qualified if they were (1) personnel who held appropriate state certification or licensure for the position held or (2) personnel who held positions for which no state certification or licensure requirements existed. The Act was amended in December 2015 and is now known as Every Student Succeeds Act (ESSA), Public Law 114-95. The term highly qualified (as such term is defined in section 9101 of the Elementary and Secondary Education Act of 1965 (20 U.S.C. 7801)) was struck and the clause` `teachers who meet the applicable State certification and licensure requirements, including any requirements for certification obtained through alternative routes to certification, or, with regard to special education teachers, the qualifications described in section 612(a)(14)(C) of the Individuals with Disabilities Education Act (20 U.S.C. 1412(a)(14)(C)." was inserted. Based on author's interpretation of the PL 114-95 available at https://www.congress.gov/114/plaws/publ95/PLAW-114publ95.htm

than twenty-two thousand (22,000) and a little over twenty thousand (20,000) respectively[44]. Personnel hired to support children between three (3) to twenty-one (21) who received services under the IDEA, included (rehabilitation) counselors, medical/nursing staff, speech specialists, occupational and physical therapists, social workers, psychologists, mobility experts, interpreters and audiologists (US Department of Education, Office of Special Education and Rehabilitative Services, 2018). Over four hundred eighty-eight thousand special education paraprofessionals (488,000)[45] were hired, of whom approximately four hundred sixty thousand (460,000) special education were highly qualified, based on data published by the US department of Education in 2018[46]. The BIE hired almost four hundred eighty-eight thousand (488,000) teachers FTE to provide services to students aged six (6) to twenty-one (21), of whom two hundred thirteen thousand (213,000) were not highly qualified. Of the twenty-one (21) teachers employed to provide special education services to children, aged three (3) to five (5), covered by the IDEA, Part B, six (6) were not highly qualified[47].

The 1960s and 1970s brought with them a repositioning of individuals with disabilities in the social milieu. The drive to deinstitutionalize individuals with

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[44] Source: https://www2.ed.gov/programs/osepidea/618-data/state-level-data-files/index.html

[45] Special education paraprofessionals reported as qualified "(1) met the state standard for qualified based on the criteria identified in 20 United States Code (U.S.C.) section 1412(a)(14)(B) or (2) if paraprofessionals were not included in the state's definition of qualified, either held appropriate state certification or licensure for the position held or held positions for which no state certification or licensure requirements existed". (United States Department of Education (2018),p. 37).

[46] Please see https://www2.ed.gov/programs/osepidea/618-data/state-level-data-files/index.html for further details. No data is available for the State of Texas.

[47] More details are available at https://www2.ed.gov/programs/osepidea/618-data/static-tables/index.html#partb-pen.

disabilities was coupled with initiatives to provide education to students with disabilities in non-segregated settings (Walter & Petr, 2006). Responding to dramatic shortages of personnel to support individuals with disabilities, paraprofessionals were initially not trained to provide services, but were hired nevertheless as systemic inequities meant that professional help was limited to those who were wealthy (Kalafat & Boroto, 1977). The first movement of paraprofessionals, therefore, arose inspired by community-based models which prioritized hiring individuals from within the community, as they could act as ‘intermediaries’ between the individual concerned, their family, and the broader system (Kalafat & Boroto, 1977).

Legislative action related to the rights of students with disabilities in education, examples of which are contained in this chapter, prompted the establishment of guidelines not only in terms of principles providing education for students with disabilities covered under legislation in regular classroom, in the Least Restrictive Environment (LRE), but also enforced training standards for paraprofessionals (Griffin-Shirley & Matlock, 2004). The IDEA specifies varying degrees of training and accreditation based on the role that the paraprofessionals fill in the classroom (for further details, see Griffin-Shirley & Matlock 2004). The Every Student Succeeds Act of 2015 changed the requirements paraprofessionals must meet in order to be hired. Namely, a paraprofessional must have a high-school diploma, two (2) years of post-secondary study, a state selected assessment or a portfolio that meets the State’s hiring requirements (Bendada et al., 2018, p. 1).

Nowadays, a paraprofessional is defined as “a person who works in a school in an instructional capacity alongside school professionals and is supervised by the certificated or licensed professionals who hold ultimate responsibility for the student and programmatic outcomes” (French, 1999)[48]. When paraprofessional positions were first introduced in education in the early twentieth (20th) century their responsibility was mainly limited to clerical duties. However, today, in addition to instructional support, paraprofessionals may be involved in facilitating transportation for their students, contribute to building social skills and assist other professionals (such as therapists) as well as family members with pre-designated goals (Walter & Petr, 2006). While recognizing the important roles and responsibilities that paraprofessionals fill, literature also raises questions about the degree of involvement and proximity to students who need support (for example, see Giangreco & Broer, 2005). Paraprofessionals assume a growing number of roles in the classroom setting, making decisions that affect students’ attendance in regular classrooms, delivery of curriculum, and interactions with peers, while special educators spend less time with students who need specialized support (Giangreco & Broer, 2005; Tews & Lupart, 2008). In addition, studies have identified the need to increase communication between teachers and parents regarding the performance of paraprofessionals and its effect on student progress (Giangreco & Broer, 2005).

Students and paraprofessionals alike have expressed concerns about how the presence of paraprofessionals can shift relationships with peers. While paraprofessionals

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[48] Available at https://web-a-ebscohost-com.ezproxy1.lib.asu.edu/ehost/detail/detail?vid=0&sid=d14da5a5-415b-478b-b71d-093803b26eb8%40sdc-v-sessmgr01&bdata=JnNpdGU9ZWhvc3QtbGl2ZQ%3d%3d#AN=507648573&db=eft

express worry over whether their proximity helps the student develop skills to problem solve and resolve misunderstanding independently, students acknowledge the positive role that paraprofessionals play in improving academic performance, raising awareness about disability in the student community, and managing social relationships; however, feedback from students with disabilities also highlights that the presence of paraprofessionals can hinder interactions (particularly, with regards to romantic relationships); the success or failure of forming and maintaining interactions with peers highly depend upon the personality and skills of the paraprofessional (Giangreco & Broer,2005; Tews & Lupart, 2008; Giangreco et al., 2010).

Limitations: The Ethics and Implications of Measuring Disability

As part of the human experience, disability gives us the opportunity to engage in thought-provoking dialogue: it reveals what and how we think of ourselves, how we position others in relation to us and vice versa; a subject with profound social, economic, and political implications, disability highlights the relationship of the individual to the State and the ramifications of policies in relation to healthcare. Furthermore, several, interconnected questions arise, creating compelling challenges around the matter of introducing disability as a concept and operationalizing it in our academic discourses and research endeavors (Fujiura & Rutkowski-Kmitta, 2001). Any research is profoundly social: the results we generate tell us as much about the phenomena studied, as what we, as social beings operating within the trends and forces of our time, classify as noteworthy problems and valid practices for answering questions (Starbuck, 2006). An examination of these intricacies is important. As a social product, research contributes to definitions and metrics of disability. These research outcomes often form the basis for policies directly affecting individuals with disabilities, support networks, and the social milieu at large (Hahn, 1993).

Providing detailed information on disability rates is difficult for many reasons. Research design and implementation, stigma and self-reporting bias affect conclusions we reach about disability (Andresen et al., 2000; WHO, 2011a). Disability rates variation indicates the conglomeration of multiple factors including, but not limited to, differences in awareness and in attention to behaviors that are now socially recognized as a ‘disability’, due to legal frameworks and diagnostic practices (Aron & Loprest, 2012; Scull & Winkler, 2011).

A brief comparison of examples of widespread scales and internationally renowned classificatory systems highlights the complexity of this issue. They have served multiple purposes for disability related issues: firstly, they brought disability to the forefront: prior to these models, little interest was given to disability and how it shapes everyday life (Lollar, 2002). Primarily because of the inception and endorsement of these models by reputable national and international agencies, academics began focusing their attention on disability as a concern that pertains not only to the individual and social network directly affected, but as a possibility that could happen to anyone at any moment (Lollar, 2002). They have inspired intellectual contributions, treatment plans, and interventions in relation to disability. Debates surrounding classificatory models center on the possibilities for scientific advancement and the pitfalls of analyzing disability as a phenomenon that can be universally understood when applying a standardized framework (Bickenbach, 2012). Some recognize the value of having common language as a starting point for developing research projects that can promote mutual understanding across medicine and rehabilitation platforms, as well as bridging communication and knowledge gaps among clients, support networks and healthcare professionals (Stucki & Grimby, 2004). Others highlight the potential that these frameworks offer for comparisons within a singular population, and/or across countries (Kostanjsek, 2011). At the same time, the universalist principle upon which these models are based, has started conversations about ethical issues in relation to disability (see Fujiura & Rutkowski-Kmitta, 2001), and has promoted self-empowerment of individuals with disabilities (see Bickenbach et al., 1999). Ethical questions primarily arise with regards to the objectification of individuals with disabilities.

The Index of Independence in Activities of Daily Living (ADL) measures the degree of disability based on performance in key activities of everyday life. Following long-term supervision of patients with physical disabilities, Stephen Katz assessed patients’ performance in six domains: bathing, using the restroom, feeding, transferring, dressing and continence (Katz et al., 1963). The degree of severity of disability is determined based on the magnitude of support that an individual needs in order to accomplish these tasks: for example, one who accomplishes bathing with no assistance is ranked as having a less severe disability than a counterpart who needs assistance with bathing one part of their body. Respectively, one who cannot bathe without assistance is deemed to have a more severe disability than individuals who fall into the former categories. Furthermore, an individual who presents difficulties in one unit is ranked as having a less severe disability than a person who requires supervision and assistance in performing tasks in more than one of the six categories (Katz et al., 1963).

The ADL has been widely used in rehabilitation to determine the prevalence and impact of physical disability. Specialists from various fields have adapted the framework of this scale to meet the needs of their respective disciplines (see Law, 1993, for additional details). While recognizing that it has contributed to promoting attention to disability concerns, its rationale—namely to provide some form of standardization to assessing disability (Wade & Collin, 1988)— has been critiqued on the grounds that no single individual with the same disability has the exact same needs and can perform tasks in identical ways as to another (Law, 1993). Given the use of the ADL scale to determine whether or not individuals with disabilities can live in a community environment, rehabilitation services have adapted the original scale to assess clients' needs on a more individualized basis, which also accounts for the physical environment and the infrastructural barriers that the individual with a disability has to face on a daily basis (Law, 1993; Iwarsson et al., 1998).

The Behavioral Factor Surveillance System (BRFSS) takes a different approach to conceptualizing disability compared to the ADL. It follows the (CDC) definition of disability, which encompasses any limitations in terms of fulfilling a task be it related to cognition (learning, remembering, concentrating), physical activity, any use of any assistive device to fulfill tasks (use of cane, service animal, manual/motorized wheelchair or scooter) or general health issue requiring assistive technologies (such as ventilators, artificial limbs) (Andresen et al., 2000). It places particular emphasis on how disability affects productivity in the workforce (Andresen et al., 2000). The BRFSS was implemented by the CDC in 1981 to collect data on behaviors and practices related to health; trained personnel in participating State agencies engage in collecting data on self-reported behaviors among adults in the following areas: seat belt use, dietary practices, alcohol consumption, physical activity, etc. (Remington et al 1988, p. 370). Additional questions were added over a period of time (from 1986 to 1988), which covered preventative testing, reproductive health, work and childcare safety, among others (Remington et al., 1988). More recent versions (for example, that of 2011) examine marital status, education, and home ownership (Pierannunzi et al., 2013, p. 2). Responding to changes in communication practices, the BRFSS is now administered over cell-phones, in addition to landlines (Pierannunzi et al., 2013). Two questions are specifically designed to assess disability prevalence: namely, restrictions in regards to any activity due to health issues and use of assistive devices to perform activities. A positive response to either or both of these questions would indicate that the respondent has a disability (CDC, 2000). Studies have corroborated the robustness of the BFRSS, but have raised concerns about the social desirability effect with regards to responses to certain questions, pertaining to sensitive topics such as alcohol and sexuality (Stein et al 1996; Pierannunzi et al., 2013).

The BFRSS has been used in studies evaluating participation of individuals with disabilities in the workforce (Smith-Randolph & Andresen, 2004), making determinations about sufficient levels of physical activity for individuals with disabilities (Brown et al., 2005), and assessing obesity prevalence among individuals with physical and cognitive disabilities (Rimmer & Wang, 2005), to name a few examples.

The inception of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) serves as a poignant example of worldwide collaboration to raise awareness on disability. Following a resolution (WHA 29.35) of the twenty-ninth World Health Assembly, held in May 1976, the aim of the ICIDH is to bring to light the implications of disease, based on three taxonomies: impairment, disability and handicap. These concepts refer to functionality, identity, and social context of the individual respectively (Thuriax, 1995). With the active involvement of a number of countries (most notably the United Kingdom, Israel and France), in 1972, the World Health Organization (WHO) invited medical experts from a variety of platforms (e.g. hospitals, medical associations) to discuss concerns regarding the consequences of disease on physiological, mental and social aspects of everyday life. Experts proceeded to make classifications regarding the ‘burden’ of disease based on gradients of functional and social ‘limitations’ that were perceived to be a direct result of impairment (WHO, 1980). Subsequent critiques about the arbitrariness of these terms led to a terminological distinction between ‘impairment’ and ‘handicap’. Collaborations among the WHO, the International Continence Society, the International Council of Ophthalmology, the International and European Leagues Against Rheumatism, the International Society for Prosthetics and

Orthotics as well as Rehabilitation International, produced various memoranda on the implications of terminology and of classificatory categorizations (WHO, 1980). Further revisions were made after the International Conference for the Ninth Revision of the International Classification of Diseases in October 1975, where the category of ‘disability’ was added; therefore, the final version of the report of 1980 makes a three-fold, hierarchical distinction: the category of impairment (1009 items); of disability (338 items); and of handicap (72 items) (WHO, 1980; Thuriax, 1995, p.112). Below are the definitions as included in the WHO report (1980):

> Impairments: abnormalities of body structure and appearance and with organ or system function resulting from any cause; in principle, impairments represent disturbances at the organ level*;* Disabilities: reflecting the consequences of impairment in terms of functional performance and activity by the individual; disabilities thus represent disturbances at the level of the person*;* Handicaps*:* concerned with the disadvantages experienced by the individual as a result of impairments and disabilities; handicaps thus reflect interaction with and adaptation to the individual's surroundings (p. 14).

The report acknowledges its failure to address the complex interconnectedness of the personal aspect of disability and the environment in relation to the physical manifestations of disability. Variation in relation to context and individual response to the experience of disability is the main reason for this omission (WHO, 1980). ‘Mobility’, ‘physical independence’, and ‘capability’ to perceive stimuli from the external physical environment inform the process of determining gradation on the handicap classification.

Additional criteria include occupation, economic self-sufficiency and social integration. The report itself includes an analysis of why these markers are questionable; the difficulty—according to the WHO— lies in objectively assessing the circumstances that place individuals at a disadvantage. In fact, the report assesses the presence (or lack) of all three states in terms of an individuals' performance not falling within 'normal' range (WHO, 1980; 2001). Little, to no, emphasis is placed on the problematic conceptualization of these terms[49]. The report further clarifies: "In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (WHO, 1980, p. 28). In this framework, disability ensues from impairment and is followed by handicap, almost in a causal fashion. As a concept, it encompasses any difference in physical, physiological, emotional, psychological, and/or cognitive performance: any 'deviation' from normal expectations, and/or social 'transgression' would qualify the presence of disability (WHO, 1980, p. 28).

The ICIDH quickly gained popularity across various fields and disciplines. It has been translated into more than a dozen languages and has been one of the most cited materials in academic journals relevant to health issues (Thuriax, 1995). Hailed as the first to provide a systematic understanding of the impact of disease and a comprehensive basis for language to be used for assessment purposes, it explicitly aims to address the health needs and design interventions in order to improve the quality of life not only at

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[49] Subsequent chapters will discuss this topic in more detail

the individual, but also at the community level (Badley, 1987). Questions arise about the assumptions that have guided the conceptualization of this framework; most notably about the purportedly shared understandings of concepts that are integral to this framework and whether there is a general consensus about the goals of interventions for individuals with disabilities (Badley, 1987). While some analyses (see Badley, 1987) discuss the problems of approaching health, disease and disability primarily through a medicalized lens[50], the majority of critiques focus on conceptual inconsistencies (such as gaps in coding and in measurement scales), which affect the trustworthiness of the ICIDH to provide accurate data about disability, namely in terms of severity of the condition (Martini et al., 1995). Furthermore, the distinction made in the ICIDH between handicap and disability sparked controversy about definition of the terms, with some scholars choosing to use the two interchangeably, and others advocating for further clarity on definitions (Badley, 1987). Finally, a relevant literature review reveals concerns about the usefulness of the ICIDH as a tool to assess disabilities that are not chronic and do not present with the challenges included as indicators in this model (Martini et al., 1995).

As a subsequent version of the ICIDH, the International Classification of Functioning, Disability and Health (ICF) touts that it offers a new way to think about health and disease that can be applied universally to all people, regardless of whether or not an individual identifies as having a disability (WHO, 2001, p. 7). Adopted by the World Health Assembly in May 2001, this model proposes that health need not be conceived as the absence of disease, but rather as a state, which is comprised of

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[50] A more detailed analysis will be discussed in a subsequent chapter.

individual physiological characteristics, social responses, and external factors, which are not directly linked to individual performance (WHO, 2001, p. 3,4). The ICF centers on classifying health information measured by degrees, ability to perform tasks and participate in social activities; to evaluate individuals' health two main axes are used: firstly, functioning and disability, and, secondly, the social context and personal response of the individual (WHO, 2001, p. 7-8). The unit of functioning encompasses assessing physiological and anatomical aspects as well as activities and participation, which are assessed both in terms of capacity and actual performance (WHO, 2001, p. 8). The social context, which the ICF defines as "environmental factors", includes the physical space, social perceptions, and attitudes toward health and disease (WHO, 2001, p. 8,17). Formal support systems (such as services provided by private and State facilities) are included in this category. Like the version published in 1980, the ICF defines disability as the direct opposite of "functioning, participation and physiological integrity" [51] the lack of which can be mitigated by the enforcement of 'positive' attitude, and a facilitating environment (WHO, 2001). Little discussion revolves around personal agency, comprising of the "internal influences on functioning and disability", as well as the "impact of attributes of the person" (WHO, 2001, p. 11). Age, socioeconomic status, education and upbringing are some of the indicators that the WHO recognizes as part of the personal experience with disease; however, it deems these factors irrelevant in terms of consideration for measurement purposes (WHO, 2001)

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[51] These are terms used in the report and are not endorsed by the author.

There is undeniable value in having a national and, to the extent possible, a global understanding of prevalence of disability and its impact on everyday life (Fujiura et al., 2005). Population based statistics, such as those informing censuses, can give us valuable data that not only provide a generalizable view of important aspects of everyday life and their patterns of change within the boundaries of a nation, but can also assist us in determining comparability and in identifying important gaps (Howard & Hopkins, 2005; Fujiura et al., 2005). However, scholars and healthcare practitioners have questioned the ethics of using classificatory systems to measure the degree and impact of disability (Whalley-Hammell, 2004). Critiques I will elaborate on in this chapter focus on exploring the ethics of quantifying the experience of disability (Fujiura & Kmitta 2001). They revolve around examining issues of power in defining disability: more specifically, they ask us to consider the broader social and political implications of our definitions in terms of how they frame how individuals with disabilities are perceived in social contexts, who we include/exclude, and whether this practice of silencing the rich experience of disability is contingent to furthering disempowering policies that have detrimental effects for individuals with disabilities, particularly in settings with disproportionate access to opportunities (Fujiura et al., 2005). Interestingly, efforts to categorize disability and measure its impact were driven by a recognition of the need for fair allocation of services, which prompted major organizations around the world to support these models (Rock, 2000). An example of such an effort is the Disability Adjusted Life Years (DALYs). Defining disability as any condition that jeopardizes ‘complete’ health, the DALYs touts that it provides a common platform— for individuals on the ground and decision-makers alike— to reach ‘objective’ conclusions about disability and other, secondary conditions worldwide. Since the same methodology is used across contexts, it can be ranked creating hierarchical scales based on their impact on healthy life, which in turn assist individuals with the power to implement policies to have an awareness of the severity of issues and make informed decisions (for an overview of the DALYs, see Murray et al., 2012).

Classificatory models, such as these presented in this chapter, tell us how disability has been defined. More importantly, however, they highlight the assumptions inherent in such definitions and whose voices are privileged in these discourses. Disregarding disability activists who questioned these models on the basis of how they controlled the lives and narratives of individuals with disabilities and promoted constructs of ‘normativity’ and—by contrast— ‘deviance’ (Davis, 1995; Pfeiffer, 2000), the voices that counted most were those with ‘expert’ knowledge on how to spot and intervene to fix disability, while at the same time viewing disability as a plight that strikes some to a greater degree than others. Perceiving disability as an inherently bad or unfortunate state, it is therefore justifiable to rank these individuals on the basis of their disabilities to determine who is more likely to be fully rehabilitated in order to be more cost-effective for the good of overall society in the future (Rock, 2000).

Like any research tool, statistics are a result of morally laden conceptual choices that often reflect social attitudes and serve broader political interests (Fujiura & Kmitta, 2001). When systematic efforts to measure the needs of populations began in the mid eighteenth (18th) century, the goal of these initiatives was to shift the relationship of the State to those it recognized as its citizens. The push for reform was based on monitoring the needs of individuals constituting each nation-State and surveilling patterns of change in health, poverty and other social issues, in order to more systematically provide services (Fujiura & Kmitta, 2001). The United States government began collecting data on the prevalence of disability in the nineteenth (19th) century. Marshalls served the role of enumerators, while physicians also provided data on their patients. In addition to counting the numbers of individuals with physical disabilities, those with other disabilities were included toward the end of the nineteenth (19th) century. Labeled as ‘retarded’, ‘insane’, or ‘defective’, accounting for individuals with disabilities was part of the State’s initiative to determine cost effectiveness in terms of dealing with populations that were perceived as delinquent, promiscuous, and/or defective. The decision on how to classify individuals lay in the hands of marshals acting as the enumerator in each case, given that no State definitions were provided to differentiate by type of disability (Gorwitz, 1974). This example is far from unique: an examination of censuses reveals that pervasive patterns of prejudice are coupled with racism. For example, African Americans/Blacks, like individuals with disabilities, were classified as ‘insane’ in censuses of the nineteenth (19th) century (Gorwitz, 1974). Individuals who were poor, convicts, prostitutes and women working in saloons were also categorized based on evaluative statements regarding promiscuity and amorality (Gorwitz, 1974).

Following such findings, states established legal frameworks that promoted the decimation of individuals with disabilities either by introducing laws that regulated marriage, enforced sterilization of individuals with disabilities, and outlined institutionalization policies (Smith et al., 1914; Braddock & Parish, 2001). Laws differed by state. For example, Connecticut prohibited marriage if one or both was deemed "epileptic, imbecile or feebleminded" and if the woman was under forty-five (45) years of age (Smith et al., 1914, p. 5). Punishment for individuals breaking the law or aiding others in breaking the law was imprisonment for up to three (3) years and a fine (Smith et al., 1914, p. 5). Other States completely outlawed marriage to an individual with a disability (Smith et al., 1914).

United States' expansion into new geographical territories, colonial practices and State policies toward immigration are factors that have contributed to shifts in approaches toward race in censuses (Lopez, 2005). Indicatively, in the 1930s the United States shifted from welcoming Mexicans into its territory to increasingly xenophobic attitudes that were evident in policies to curtail migration to the United States. Soon after the enforcement of such approaches and within a general climate of distrust against Mexicans, the U.S. census bureau introduced racial categories to clearly mark the difference between the 'White race' and 'non-Whites'; such data were used to promote coerced removal of a large number of Mexican people lawfully residing in the United States to Mexico in 1931-1935 (Lopez, 2005, p. 44). Worldwide political changes, wars, and the need to restore severed ties to establish military fortitude led to reconsidering the positionality of Mexicans in the relation to the United States and censuses reverted to classifying them as 'White' (Lopez, 2005, p. 44).

As a result of sociopolitical shifts, census data show a marked increase in the rates of individuals who self-identified as American Indian in the 1960s to 1990s: within that timeframe the number of American Indians rose compared to previous years, from a little more than five hundred thousand (500,000) to more than one million (Nagel, 1995, p. 947). This increase highlights the intersection of United States federal practices surrounding defining race, and policies tied to the assimilation of Native American groups, as well as practices of resistance to colonizing practices on the part of Native American activists (Nagel, 1995). In the 1960s, the United States changed data collection methods with regards to censuses. Rather than having enumerators determine individuals' race(s), they encouraged self-reporting. This provides a possible explanation for the forty-six percent (46%) increase of Native Americans in a one (1) year period, from the 1950s to the 1960s (Nagel, 1995, p. 951).

An integral aspect of assimilation programs established by the United States was the relocation of Native Americans to urban areas. By the 1970s, nearly half of the Native American population[52] resided in urban areas (Nagel, 1995, p. 954). Language and cultural loss due to relocation efforts may have been mitigated by the birth of new partnerships that transcended tribal ties. Community centers and churches were central in developing networks that emphasized the commonalities in being American Indian, rather than inter-tribal differences (Weibel-Orlando, 1991). The recognition of colonizing practices against indigenous peoples and national/international initiatives to challenge them through activism, also contributed to promoting a sense of pride at self-identifying as American Indian (Nagel, 1995).

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[52] The total population of Native Americans in 1970 amounted to almost seven hundred sixty-four thousand (764,000). Source: https://www.census.gov/library/publications/1973/dec/pc-2-1f.html.

In 2016, the Special Rapporteur on the rights of people with disabilities and the Special Rapporteur on the rights of indigenous peoples for the United Nation invited indigenous individuals with disabilities and academics to a meeting to discuss the needs of indigenous individuals with disabilities. According to the United Nations' summary indigenous individuals with disabilities face "multiple layers of discrimination based on their disability, their ethnic origin and their gender"[53] . Our knowledge of prevalence of disability rates among indigenous peoples globally is compounded by social and political issues as well as infrastructural barriers: indigenous populations occupy vast and diverse geographical and social spaces (Kirkmayer & Brass, 2016). Many reside in rural areas with limited or no access to healthcare facilities; therefore, robust data on the health status of indigenous peoples, particularly in those areas are limited to periods when outbreaks occur and epidemiological teams are sent to monitor the situation and assist with crises (Stephens et al., 2006; Kirkmayer & Brass, 2016).

A contributing factor to the difficulty in assessing prevalence of disability among indigenous peoples relates to issues pertaining to screening services and practices. Use of such services is affected by systemic issues (such as access to services and insurance, social attitudes toward illness and medical practices, as well as perceptions of relationships with medical providers) (for a comprehensive overview, see Kolahdooz et al., 2014). As will be discussed below, the United States is not unique in overlooking utilization of screening services among indigenous peoples. This gap may very well

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[53] https://www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/IPDisabilities.aspx. The author reviewed this source across time in December 2018 and September 2019. There were no reports available on indigenous individuals with disabilities.

relate to the lack of equal distribution of services and technologies across healthcare facilities and/or funding constraints: much of what we know about the health status of Native Americans is a result of data collected and released by the Indian Health Service (I.H.S). Even though Native Americans, particularly those residing off reservations and in urban areas, utilize clinics other than the I.H.S., information on health issues is not comparable to I.H.S. as these facilities often do not have practices set in place to monitor, assess and release data on utilization and other health related patterns (Burhansstipanov & Dresser, 1994, p. 2-9; Risendal et al., 1999). Furthermore, some states began reporting on health-related issues among Native American people within their geographical boundaries later than others, affecting the validity of conclusions that are based on comparisons (Burhansstipanov & Dresser, 1994).

Contention regarding the definition of indigenous identity and lack of consensus on who should be included/excluded (Stephens et al., 2006; Kirmayer & Brass, 2016; Paradies, 2016) make it challenging to gain robust data on the health status of indigenous peoples on a global scale. For example, in Australia there are no national data on certain health conditions that affect indigenous peoples and their use of screening services because of misclassifications in registries and failure of the State to provide standardized methods for documenting use of healthcare related services on the part of indigenous peoples (Cunningham et al., 2008, p. 591). Lack of recognition of their status by federal governments positions indigenous peoples at a disadvantage in terms of advocating for— and securing basic human rights— such as equal access to healthcare, education, and employment (Kirmayer & Brass, 2016). Often data on the disparities that indigenous peoples face come from countries that have made a commitment to address these concerns (Valeggia & Snodgrass, 2015).

Inequities in access to employment, education, as well as land usurpation and ongoing trauma due to forced removal from indigenous homelands, war, and violence are experiences that all indigenous peoples share (United Nations' Inter-Agency Support Group on Indigenous Peoples' Issues, 2014). Not all indigenous peoples are subjected to the same degree of oppression. However, even in countries that have adopted policies to formally recognize the rights of indigenous peoples, they continue to have worse outcomes in relation to opportunities compared to their non-indigenous counterparts. For example, New Zealand has made important steps in acknowledging the rights of the Maori, and formally recognizes their language and culture as the second in New Zealand. Even so, the Maori have higher rates of unemployment and less opportunities for education compared to non-Maori (Mitrou et al., 2014). Indicatively, in 2006, the unemployment rate among Maori people ages twenty-five (25) to fifty-nine (59) was more than sixteen percent (16%) compared to a little over five percent (5%) among the non-Indigenous population in the same age range (Mitrou et al., 2014, p. 5).

Cultural perceptions of disability also shape the understanding of disability rates. Native Americans with disabilities are often not aware of their rights as individuals with disabilities, and/or the resources and services that are available to them (National Council on Disability, 2003). The experiences that are shared in reports like the one cited above provide voices of resistance to stigma and stereotypes surrounding disability. Drawing upon traditional teachings about disability from a variety of indigenous groups in North

America, the individuals with disabilities telling their stories in this report provide readers with knowledge on how to recognize disability related discrimination, information on services affiliated with indigenous nations, as well as avenues of recourse in instances of violations (National Council on Disability, 2003). In a nation-wide study, Fowler et al (2000) show that tribal leaders have limited knowledge of legal frameworks that protect the rights of individuals with disabilities (for example the ADA).Furthermore, most administrative buildings where central decisions are made regarding governance on reservations are inaccessible to individuals with disabilities (Fowler et al., 2000). The difficult circumstances present in most Native American reservations may mean that services are only available to those who have the financial means and transportation availability to travel vast distances to reach services (Fowler et al., 2000).

Conclusion

My aim with this chapter has been to highlight that a conversation about disability is important for a number of reasons. Disability (in whatever shape or form) affects a number of us: approximately fifteen percent (15%) of the world population is experiencing some type of disability (WHO, 2011b). An examination of disability as a phenomenon is telling of additional dynamics: broader issues that seemingly have little to do with disability itself all play a role in conceptualizing, measuring and discussing it.

There are epistemological concerns: our positionality as academics and researchers determines what we consider relevant to disability and how we assess its implications on everyday life. The development of classificatory models commonly used by renowned organizations, such as the World Health Organization (WHO) is an indicative example of this. In the 1980s a coalition of representatives the world over came together and developed the International Classification of Impairments, Disabilities, and Handicaps, better known by the acronym ICIDH. The purpose of the ICIDH was to provide an internationally agreed definition of disability in order to gauge prevalence of disability across contexts and contribute to the work of medical professionals in term of their aspirations to design and universal interventions. Despite enjoying international acclaim (Thuriax, 1995) critiques were quick to point out methodological issues relating to the reliability of the ICIDH coding system, as well as concerns relating to the implications of terminology, sparking controversy and debates in the academic community (see Badley, 1987).

Debates intensified as disability captivated the public eye. Its successes as a human rights issue placed it at center stage with in relation to legislation. Cases I highlighted in this chapter highlight that legal frameworks can have benefits, but also disadvantages for the individuals they are designed and implemented to protect. Studies, for instance, show that since the implementation of the Americans with Disabilities Act (hereafter A.D.A.) in the 1990s participation of individuals with disabilities in education has increased. More than six (6) million students receive disability support services compared to ten percent (10%) of students in the 1980s (US Department of Education, Office of Special Education and Rehabilitative Service, as cited in Lamar et al., 1993, p. 44). At the same time, questions on how to legally delineate the concept of disability contributed to unfavorable outcomes for individuals with disabilities (see Henry, 1989). The case of Native Americans is poignant as it highlights the complexity of the interrelationship between culture and politics. In their efforts to balance between tensions to maintain sovereign status and to honor traditional perspectives while meeting the needs of individuals with disabilities residing within their geographical boundaries, indigenous nations face challenges implementing and enforcing disability legislation. The latest amendment of disability legislation on the Navajo Nation, passed in August 2018, encapsulates these struggles. It discusses discrimination from the perspective of traditional teachings and identifies processes to increase accountability in terms of implementing legal frameworks (see Navajo Nation Council, 2018).

Finally, a critical analysis of the factors that shape the lived experience of disability reveals that economics and infrastructural barriers disproportionately affect those who are most vulnerable. As I have discussed in this chapter, individuals with disabilities are more likely to experience difficulties in healthcare contexts compared to those who do not have a disability. Data we have on indigenous people with disabilities not only in the United States, but also worldwide are unreliable. Inaccessible geography, dearth of healthcare facilities and gaps in screening and treatment are coupled with the seizing of land, and contentious relationships with governments (United Nations' Inter-Agency Support Group on Indigenous Peoples' Issues, 2014; Cunningham et al., 2008; Kirmayer & Brass, 2016). A long history of colonization, assimilationist practices and current human rights violations have contributed to the fact that indigenous individuals with disabilities experience unemployment, poverty, and fewer opportunities for equitable participation in education. For example, according to data provided by the National Science Foundation, more than thirty thousand (30,000) students received research doctorates in 2014; yet, only sixty-one (61) self-identified as AI/AN. Even more telling is the fact that only six (6) reported being AI/AN and having a disability[54]. The odds are not in favor of Native Americans with disabilities pursuing employment opportunities either, as they face an almost fourteen percent (14%) gaps in employment rates compared to Whites (Austin, 2013).

This dissertation brings together these issues. Throughout the chapters that follow the reader will be invited to explore how infrastructure, interpretations of history, and cultural perceptions pertaining to disability play out in conversations about interactions in healthcare.

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[54] https://www.nsf.gov/statistics/2017/nsf17310/data.cfm.

CHAPTER 2: THEORETICAL FRAMEWORK

Personhood

Theoretical engagements with the concept of personhood in the discipline of anthropology have focused on critically analyzing the following questions: who is considered a person? Is the concept of a person universal? What are the social practices that constitute a person? (Conklin & Morgan, 1996, p. 661). Early contributions examined cross-cultural interpretations of personhood incorporating questions of how persons are defined in contexts that were popular at the time. Personhood, therefore, first emerged in relation to works that focused on kinship, religion and ritual practices (Conklin & Morgan, 1996; Kaufman & Morgan, 2005). Contributions further discussed the role of symbols and objects in the processes of '(un)making' and 'removing' personhood (see, for example, Geertz, 1973). In his seminal work, *The Interpretation of Cultures*, Geertz (1973) invites us to consider that social contexts are occupied by persons who signify their belonging in this social category through their performance of informal and formal roles. According to Geertz (1973, p. 363), social roles become evident through symbols and interactions with others. Some of these symbols and interactions primarily refer to the individual: these ego-centric markers (such as name, title, age, occupation) allow the individual to position themselves in social interactions. Others situate the self within a specific time and historical moment. Examples include participation in, and engagements with, hierarchy systems (such as castes or bureaucracy). Drawing upon the example of patenting, Strathern (1999) examines how ideas of ownership and practices of labor can show us how we think of personhood. Much of the discussion, for Strathern (1999), therefore, relies on understanding the dynamics of ownership and power. Strathern (1999) thinks of ownership quite broadly and includes objects, titles, or information that can assist the individual in maintaining and advancing their social position. Think of this example: a scholar produces a new piece of knowledge. While circulating, knowledge almost becomes a 'person' in its own right, speaking about its creator, cementing and breaking relationships for the individual who gave it life. The social discourse of knowledge as an entity that was borne of an individual reflects how ideas of ownership are culturally translated into relationships. These processes reveal not only what constitutes personhood in various social contexts, but also gives us insight into the relationships that are most important and how power comes into play.

Anthropological contributions that explore cultural practices surrounding personhood are based on a conceptual juxtaposition between Western and non-Western societies. In his literature review on this issue, Spiro (1993) tells us that scholarship has constructed this distinction by emphasizing 'individualism' and 'independence' in Western societies, while portraying non-Western societies as 'relational' and 'interdependent'. Presenting us with case studies of non-Western societies wherein the role of the individual in determining their personhood is the norm, Melford Spiro (1993) concludes that an overemphasis of this supposed juxtaposition produces an unneeded conceptual divide. David-Bird (1999, p. S68) tells us that analytical approaches to personhood emphasize historically constructed distinctions between the physical and environmental spheres. Dualistic frames of thought have also superimposed the juxtaposition between the body and the spirit. For Conklin and Morgan (1996) this distinction also contributes to presenting cultural practices as shared with no questions asked, no negations performed, or resistance exercised. They emphasize that personhood is fluid: people choose to use their understandings of it to varying degrees and in different ways, depending upon their interpretations of themselves and the social context. While useful “for heuristic purposes”, such approaches run the risk of “overstating differences between societies while overemphasizing consensus within a society” (Conklin & Morgan, 1996, p.662).

In response to such critiques, more and more analyses have shifted their focus from cross-cultural comparisons to connections of personhood with phenomena within a specific social milieu (Conklin & Morgan, 1996). This shift coincided with social and political forces in the United States, which created fruitful ground for intellectual questioning on personhood. The impetus to intellectually examine the construct of ‘person’ is historically situated within a context of highly politicized, intellectually thought-provoking, and ethically/morally ‘jarring’ issues centered in debates over practices revolving around the beginning or ending of life (Conklin & Morgan, 1996). Abortion, assisted termination of life, euthanasia, genetic counseling, and technological interventions and monitoring of reproduction are only a few examples of themes that routinely invoke questions about the definition and nature of personhood (Kaufman & Morgan, 2005).

Feminist engagements with issues of personhood turned the emphasis toward exploring the dynamics of personhood to cultural constructs of birth (Kaufman & Morgan, 2005). For instance, in her ethnographic work on pregnancy, Gregg (1995) shows us how gender norms and social expectations revolving around this important part of life, as well as interactions with loved ones and healthcare providers shape women's choices during pregnancy. Further attention was later given to the implications of genetics and technology on social understandings of personhood. Depending upon their specific focus, these studies emphasize the interrelationship of technology toward 'disciplining' the body (see, for example, Martin, 1994) and examine how women's agency is compromised and/or regained when subjected to medical interventions (see, for instance, Rapp, 1999).

Tensions on how to define and discuss the category of personhood are exacerbated by the fact that doubts on who to define as a 'person' usually only arise when the social entities in question occupy a 'liminal space' (Turner, 1967): a 'grey zone' wherein social status, roles and expectations are culturally recognized as being in flux (Conklin & Morgan, 1996). In her work with individuals in a comatose state and their families in the contexts of a technologically advanced, and highly specialized medical facility, Kaufman (2000) shows us how definitions of health/illness vary from one individual to the next, as do understandings of personhood. Indicatively, when Mrs. Sato and her husband arrived at the facility, she had quadriplegia with secondary complications, but interacted with medical professionals, support staff who attended to her everyday needs, and her family. After suffering a series of seizures, medical professionals determined that her engagement with the external world had greatly diminished and encouraged her husband to think about removing support. When the continuity of her husband's care did not shift despite the professionals' counsel, Mr. Sato's actions were interpreted differently by those attending to the needs of his wife. Doctors seemed to think of his reaction as denial of the grimness of the situation, yet nurses saw his presence as an indicator that their patient was 'still a person' to him, and therefore interacted with her as they would with him, encouraging her to react to stimuli as people were waiting for her to open her eyes. Conversely, her husband saw his wife's seizures as a way of communication with him, as a performative act, alerting him not to abandon her. Personhood is "a social category that is inherently dynamic; people invoke certain ideas about how persons are constituted to legitimize their actions and position themselves in relation to others" (Conklin & Morgan, 1996, p. 658).

A growing interest in the interconnectedness of the culture of medicine and practices of personhood have led scholars to explore "hidden spaces" of social life (Kaufman 2003, p. 2250), and their relationship to personhood. Kaufman (2003) tells us that in American contexts, places where life and death decisions are made on a regular basis (e.g. medical facilities) can highlight practices that indicate being privy to the category of personhood. Highly advanced technological settings, such as medical facilities that care for patients that meet the 'vegetative state' by medical standards, are sites where questions surrounding 'what it means to be a person' brings ideologies about that very concept into sharp focus. In this contribution, Kaufman (2003) argues that the value of these "uncommon personhoods" is not that they help us define personhood itself as a concept, but rather invite us to consider how we think about persons. Much of our attention in determining whether an individual is a person relates to reacting to stimuli in ways that biomedicine acknowledges as ‘appropriate’, engaging in decision-making, and demonstrating the result of such processes to staff when the time is right, lest the product of this decision (a movement, behavior or emotion) be classified as ‘involuntary’. The situation is further complicated as in these cases, determination of the divide between ‘person’ and ‘non person’ status relies on others, who are in a position to paint a picture of how the individual was before the life-altering event (or a series of them) brought the individual and their loved ones to the locales so well concealed from routine social life (Kaufman, 2003). Family members and friends of the persons/non persons are called upon to describe how the individual was prior to entering this space of stark contestation of personhood. Based on the descriptions of others, expectations are crystallized and benchmarks are set for each of the patients, while those close to the patients either become advocates when medical specialists fail to see the potential to return to the ‘old self’ that they see, or fail to acknowledge that a flicker of movement, a sound, or cry represent milestones indicating that ‘their person’ is returning, as professionals assure them.

Across the world, individuals with disabilities occupy ‘hidden’ or ‘obscure’ spaces taken both in the literal and in the metaphorical sense. In their work on disability and personhood Agmon et al. (2016) show us how participants exercise their agency based on determining how to perform their disability, both in terms of physically occupying space, as well as making choices about social relationships they form while in the physical boundaries of a rehabilitation center in Israel. Mobilization in the space of the center is regulated by providers who, in their roles as caregivers, bar or allow their clients entrance to space. Administrators' definitions of health and illness shape social life in the rehab facility. Those who are not perceived as having a disability, but have health problems, are given minor responsibilities as support staff, in positions that clients with disabilities do not routinely occupy. Clients with disabilities vocalize their resistance to such distinctions by neither acknowledging these members as 'one of them', nor affording them the roles of caregivers.

Depending upon their status, the Songye (Africa) approach children with disabilities with deference, indifference, or fear. Those with physical disabilities are commonly known as "mwana wa kilema (a child with a fault)" and encompass children who experience the equivalent of polio, or spasticity resulting from problems at birth (Devlieger, 1995, p. 96). The quality of their social relationships as they grow into adults depends upon their ability to navigate the physical space and fulfill everyday activities that are gender specific. Those who must particularly fight the odds to have a prosperous life are 'faulty' girls: social participation largely depends upon their ability to perform manual labor, and give birth to healthy children. Those who cannot perform either of these tasks remain in their parents' company doing household chores while other family members take on their roles. Only once a woman with a physical disability gives birth to a healthy child does she gain the right to build her own house, while her child shoulders the manual labor that her physical disability does not allow her to perform (Devlieger, 1995).

Nicolaisen (1995) recounts how children with physical disabilities have to struggle to survive among the Punan Bah, Borneo. Their mobilization is confined to private areas (usually the house), with little contact with their parents and social interactions with their peers. For six (6) months after their birth, infants are not considered humans. Usually a product of ancestors’ decision to return to the human sphere, infants are celebrated in cultural practices that take place after that timeframe and are aimed at solidifying the infant’s position in relation to kinship ties. By participating in naming ceremonies, infants transition into the social category of ‘humans’. Once a child with a physical disability is born, questions arise about where they belong: are they part of this world, or have they come to humans as spirit beings? Concerns grow as physical evidence of a disability intensify. The root of the worry lies not in the presence of physical disability, but in the possibilities that the physical signs unearth. Rather than carrying their ancestors within them, those with bodily symptoms of a physical disability represent the failure to ward off spirit attacks. Overcome by evil entities the individual with a physical disability is not considered human. Equated to witches, individuals with physical disabilities are met with fear, in a social space where they are excluded from every day social obligations, while their perceived potential for wrath that can disrupt cosmic balance safeguards them from abuse and neglect, even though in the past children with physical disabilities were left to die. As Peter Singer (1991, p. 191) states “killing a disabled infant is not morally equivalent to killing a person. Very often it is not wrong at all″.

In their review of case studies in European contexts Whyte and Instag (1995) tell us that humanity and personhood are linked to one another. Based on this cultural premise, disability is met with apprehension and fear because its presence carries the threat of completely dehumanizing the individual with a disability. Individuals with a disability are denied their humanity, in essence because others see in them a digression of what is expected: a conversation about humanity, therefore, tells what the norms are regarding social relationships and practices (Garland- Thomson, 2005; Ralston & Ho, 2007). Depending upon the social context the humanity of individuals with disabilities is contested by comparing them to animals (see Singer, 1991), spirits (see Nicolaisen, 1995), or by objectifying them (see Speraw, 2009). For Stienstra and Ashcroft (2010, p. 196) humanity can be defined as "a state of mind, a force within, a passion or wonder for living as well as a need to feel connected with others (…) this understanding of spirit is an essential part of being human". The 'force' and 'vigor' that we find in bodily experiences (for example, eye contact, intimacy and closeness of bodies) constitute the crux of the concept of humanity; in our consciousness, disability is placed on the opposite of the pendulum (Stienstra & Ashcroft, 2010,p.196; Garland-Thomson, 2005). The experiences of individuals with multiple physical disabilities as analyzed by Speraw (2009) emphasize the power of aversion of the eye, silence during conversation, as well as physically leaving areas in order to not be exposed to disability in forming relationships with others. Much of the narrative offered in Speraw's work focused on the plea to recognize humanity, crystallized through moments of 'absence':

> Do you know that most nurses and doctors never notice my tracheotomy scar? You know why? They don't look at me. They don't really look at me (…) We went to this new doctor, and I was so tense. If we didn't find someone who could fix [the facial necrosis], then I was gonna die. It was really that bad. I had run out of chances to get this right. So we walked in, and [the doctor] said to me and my mom, "Why are you here? Can't nobody fix this. You're wasting my time." Then he turned and walked out. (…) I'm human. I have feelings. That hurts when people forget that I'm human. (Speraw, 2009, p. 739-740).

The social categories of humanity and personhood are imbued with norms and expectations, which are more clearly defined when we think of the rationale behind practices that are construed by individuals with physical disabilities as a negation of their humanity, such as those I outlined above. I would argue that the averted gaze speaks as loudly as staring. Even though the practices of staring and refusing to look differ as social acts, the target of either of these social acts has not changed: the body of those with disabilities inspires both wonderment and anxiety (Garland-Tomson, 2005). These reactions and the rationale that governs them are the products of social and historical processes. Historically, the richness and variability of experiences of individuals have been silenced, and the oppression to which individuals with disabilities have been subjected has been marginalized. (Silvers, 1998). For example, during the nineteenth century (19th), those with disabilities had prominent positions in 'freak shows', namely tours in various cities of the world where bodily difference was commercialized for those who paid to marvel at how different the bodies of those being exploited looked in comparison to those who were able-bodied (Garland-Thomson, 2005). Were we to engage in what Silvers (1998,p. 129) calls “historical counterfactualizing”, we would be able to recognize that practices of exploitation, silencing and oppression, have contributed to creating a ‘consciousness’ surrounding disability: seemingly ‘objective’ criteria that have taught us, as a collective, to think of able-bodiedness as a state of being that corresponds to the majority of the population. What would happen, asks Silvers (1998), were we presented with ‘counter-facts’ where disability was the norm? Her hypothesis is that diversity in interactions and bodily performance would be welcomed rather than stigmatized.

More recently the bodies of those with disabilities overwhelm the terrain of medicine, where interventions that strip the human body of differences that make it (and us) unique are sought after and welcomed in the name of ‘safety’ and ‘health’ (Garland Thomson, 2005). The introduction of technology in the field of medicine has contributed to redefining the way in which we see the body, particularly of those who do not meet normative social standards: from occupying the imaginary, exotic, remarkable, they now represent pathology. The ‘disease- stricken’ body hides within it, abject possibilities that cause fear and apprehension. Therefore, every possible action must be taken to rectify symptoms that mark illness. The body, then, becomes the locus of war: the medical professional equipped with specialized knowledge that only he is privy to, while technological advancement is the ‘weapon’ against the army of illness that has invaded and threatens to conquer the patient’s body (Martin, 1994; Garland-Thomson, 2005). Gaining more and more ground since the twentieth (20th) century, technological advancement ostensibly provides ‘reassurance’ against the possibility of future illness (Rapp, 1999; Lippman, 1991, p. 25). The proliferation of technology use in the medical field has promoted the necessity to control the experiences of illness. Ultrasounds, genetic testing, amniocentesis are examples of creating a culturally constructed, “particular yet limited kind”, as Lippman (1991, p. 25) asserts, need to monitor the body in order to control the course of what used to be ‘unknown’ and now reveals through the visibility that specialized knowledge offers (Rapp, 1999). The predictability that technology offers is precarious in the sense that not all disabilities can be detected by technological developments currently at our disposal (Lippman, 1991). In this context, knowledge carries power; the agency to construct, solidify, or sever social relationships. Women are called to interact with providers whose technological knowledge allows them to transgress bodily boundaries and gain intimate details regarding the fetus and the women’s bodies. In her analysis Rapp (1999) discusses how providers’ ability to decipher ‘illegible’ masses that constituted embryos led parents to renegotiate choices about knowing. One of the most powerful moments of pregnancy, determining the sex of the fetus, becomes the terrain through which women and couples in Rapp’s (1999) studies challenge doctors’ exclusivity of knowledge. Sharing knowledge of an intimate detail regarding the fetus (i.e. the sex) mitigates the power dynamic between the provider and patient as the provider was no longer the sole holder of private information.

Specialized knowledge frames women’s bodies in terms of producing ‘defective’ babies (Landsman, 1998). The transformation of the body of those who may be carrying the potential for disability and of those with a disability from something that caught the public’s interest because of its difference to a marker of pathology has created new expectations on how the unfamiliar body (now called a patient) should react (Garland-Thomson, 2005; Biehl, 2007b). The hegemony of biomedicine in engagements with the body have contributed to losing our “right to an unprojected future” (Biehl, 2007b, p.3). Discourses of risk create a narrative for making choices in the eventuality that a disability is ‘detected’ in the unborn fetus (Rapp, 1999). Visualization of processes that have gone ‘wrong’ produce a new cultural terrain, where the power to dictate the course of production, maintenance and ending of life produces new expectations. The women in Rapp’s work reveal the struggles that the “burden of choice” places upon them*: “*If something turns out to be wrong, maybe I'll be happy I've had it. But in some ways, I wish it wasn't available, I wish I didn't have to know (…)” (Rapp 1999, p. 117). The ‘knowingness’ that medicalization offers has entangled us in norms that place responsibility on those subjectivities who continue to have different bodily experiences and expressions than those that appear to be ‘in the norm’ (Garland-Thomson, 2005; Biehl, 2007b). Those who fail to comply with biomedical discourses risk losing valuable support networks that extend beyond those offered by medical providers. Biehl (2007b) emphasizes that medicalized interventions come with a set of ‘social values’, which are used to determine who is ‘worthy’ of receiving medical attention and supplies. Situated in the social context of a poor area in Brazil, the participants in Biehl’s work (2007b) realize that their survival and livelihood largely depend upon performance of socially approved patienthood: those who do not follow the regulations and social norms of the support network are quickly expelled, metaphorically and literally. Relationships with other patients are put to the test, as judgements regarding the commitment of those ‘deviating’ from medical regimes are made, and those who follow professionals’ directions are hailed as examples of “model citizens”: they secure prominent positions, remuneration for their services and are often at the epicenter of activist efforts to promote awareness of health inequalities. Biehl (2007b) asks what happens to those who escape this context of benign surveillance. The work of Gail Landsman (1998; 2009) begs similar questions: Mothers of children with disabilities often occupy a precarious position as they are both pitied for having a child with a disability and held accountable for the disability itself. Mothers’ discourses of disability are imbued with sentiments of guilt and the attribution of (self) blame, which involve attempts to pinpoint an action or behavior that could be attributed to the disability. Their narratives reveal definitions of ‘correct’ behaviors, assumptions of causal links between behavior and outcome, as well as social perceptions of those who ‘fail’ to adhere to doctors’ guidelines:

> I was meticulous as to what I ate and how often, and I gained eighteen pounds with him, just eighteen pounds. careful not to overeat and just eat the correct foods, vitamins, and I worked very hard in keeping him--knowing he would be healthy, which he wasn't. And there's hundreds that their parents eat junk food and smoke cigarettes and do drugs. These babies don't seem to be born with birth defects. The anger you feel when you work so hard, and you still end up with a baby that's got a problem (Landsman, 1998, p.81).

The emotions of sadness, frustration, and anger that mothers feel are not solely and directly related to the disability itself; rather, it is the expectation of stigma that informs women’s reactions to disability. Landsman (2009) shows us how mothers fear the emotional pain that their children will experience due to their disability. Stigma expands to those associated with the individual with a disability, not necessarily for the disability itself, but based on others’ expectations on how questions, as well as practices that reveal prejudice and social exclusion because of disability should be addressed. More specifically, the mothers in Green’s work (2003) discuss the emotional distress of continuously reflecting on the messages they are sending their children when responding to comments about their offspring’s disability. As a mother of a child with a disability shares: “I felt like I was constantly educating people but by being gentle but frank and saying just the right thing I broke down a lot of barriers ” (Green, 2001, p, 809). The pressure, according to these participants, is being aware that in a world where discrimination and injustice occur against their loved ones on a daily basis, as mothers they need to serve as examples to their children, having to internalize the turmoil they feel when receiving comments (Green, 2003).

Discourses that resist negative perceptions of disability, privilege rhetorics of disability as a gift. Disability is perceived as something difficult, a burden that only those few, possessing some form of inherent strength, openness to difference and patience, can shoulder (Landsman, 1999). Such narratives see disability as an opportunity to grow as a person; blame and hurt, therefore, transform themselves into specialized knowledge borne of the sacrifices that living with a disability entail. To paraphrase Layne (1999) the individual with a disability serves as embodying the essence of morality. It is a morality whose basis is love. It is a love imbued with important cultural metaphors: religious underpinnings of forgiveness and suffering are at the epicenter of this discourse. Individuals with disabilities serve as an example of how to navigate this world unscathed, forgiving prejudice and, discrimination with a smile, therefore, teaching others around them who are not privy to the experience of disability how to ‘love unconditionally’ (Landsman, 1999, p. 156-159).

The social constructs and connections between disability and personhood that I have outlined in the previous pages of this chapter are not universally shared. Research studies that have examined how Native American populations view disability suggest that the ability of the individual with a disability to perform social roles is privileged over the practical and behavioral adjustments that may be needed when coming into social contact with physical, intellectual or other forms of disability (Marshall & Largo, 1999). For example, defined as ‘physical or intellectual variation’, among the Lakota, a disability affords the individual and their social network the opportunity to critically think about the boundaries of these norms. Guided by the awareness that disability may lead to the need to address unforeseen social and structural circumstances, the Lakota recognize that it is necessary to be open to those who act and move differently (Pengra & Godfrey, 2001). Research collaborations with indigenous Nations in Manitoba reveal that discourses relevant to disability served as starting points to revitalize knowledge and reflect on traditional teachings. Those with disabilities are there to remind others of the importance of inclusion and equity. Individuals with disabilities often have key social responsibilities in the group. More specifically they serve in leadership positions, form mentorship relationships, and are instrumental in healing practices. As a living reminder of how to act with respect, kindness and strength, those with a disability are considered to be a 'gift from the Creator' (Shackel, 2008, p. 86). Lovern (2008) suggests that this approach to difference is based upon the social principles of personal agency and accountability. Fostering relationships with others is contingent upon the understanding that no one has the right to determine how others act. Exercising judgement upon the social performance of individuals with disabilities would violate a central concept in many indigenous worldviews: that each element has had life breathed into it and is serving its purpose. Within this context, the individual with a disability has the right to participate in the community without focus on their physical and intellectual characteristics (Lovern, 2008). The example from a Lakota individual clarifies: " Native people have respect and compassion for handicap people because we believe everything was created for a reason" (Pengra & Godfrey, 2001).

Notions of respecting difference are connected to the creation of the universe. In its current form, everything that makes up the human body can directly be traced back to the time that the universe was created. According to one version of Diné cosmology, the Holy People[55] decided that the first male would be white ear corn, while the first female would be yellow ear corn, which are also known as First Man *(Áłtsé Hastiin)* and First Woman *(Áłtsé Asdzą́ą́)*. Four (4) days their first coupling, First Woman gave birth to *nádleeh* (hermaphrodite) twins; subsequently, after the passage of another four (4) days, she gave birth to twins, one male and one female, who came together as husband and wife. First Woman bore twins four (4) more times and the offspring all formed husband

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[55] Participants referred to the Holy People as Diné. Alternative translations include diyin dine'é or diyinii (Farella, 1984, p. 23)

and wife unions (Zolbrod, 1984, p. 50-52). Alternative narratives tell us that First Man and First Woman thought the world as we know it into existence. Through prayer and songs, they created Sky and Mother Earth. Changing Woman emerged from the womb of Mother Earth. When Changing Woman was born, First Man turned her toward the sacred space that had nurtured her (a mountain) and together with First Woman played an integral role in raising her (Farella,1984, p. 56; Schwarz, 2008). The Holy People showed her parents where to find pollen from the clouds, sunray pollen, pollen from plants and flower dew to feed her, leading to rapid maturity (Schwarz, 1997, p. 23). The beginning of her menstruation on the twelfth (12th) day of her life is still celebrated today among the Diné, with a ceremony (Kinaaldá), which signifies the potential of every woman to bring forth life (Schwarz, 1997a). Taking parts from her body, corn, and materials from the four (4) directions that delineate the universe, Changing Woman created all Diné, who, therefore, are related to one another with strong family ties (*k'é*), and are connected to the sacred space where the creation of the universe took place (Schwarz, 1997a, p. 62; 2008, p.15). Natural elements such as air, heat, vibration and moisture, along with four (4) sacred minerals (white shell, turquoise, abalone shell, and black jet) are the components of the human body (Schwarz 1997a:62; Aronilth 1990, cited in Schwarz 1997a). In the wisdom of the universe, all bodies encompass the number four (4) within them: the digestive system, the nervous system, the skeletal system, and the respiratory system. Each of these brings life to the individual through the association with key figures in the Diné clan system, which defines the purpose of existence of all Diné individuals. The digestive system, which receives the sustenance a mother provides, is the person's mother; the skeletal system, represents the father’s ability to support his offspring and offer them the foundations to stand strong throughout life; the respiratory system encapsulates the parental grandfather’s teachings and the nervous system is the contribution of the maternal grandmother (Schwarz, 1997a, p.74).

Changes in the body (such as loss of bodily fluids or other body parts) are accepted among the Diné, as long as they occur as a result of a natural process. Certain losses (such as the first two (2) menstrual cycles, the falling off of the umbilical cord, or the expulsion of the placenta) are celebrated as they signify an important milestone in life. During Kinaaldá all relations pursue close interactions with the young girl who is at the epicenter of the ceremony as she has the power to cure illness and bring happiness to all those who come into contact with her (Schwarz, 1997a). Special care is taken when caring for the umbilical cord and the placenta as they have the potential to shape the personality and life trajectory of the child. Afterbirth is usually buried by parents or grandparents in a place that holds symbolic meaning to the family, deep within Mother Earth so that it remains intact and protected and pulls the child back home to their land and the Earth; while the umbilical cord is placed close to a space or object that the parents wish to strengthen in their baby’s life (Schwarz, 1997a). Responding to changes that affect Diné ways of life many individuals now choose to bury the umbilical cord in an object that has associations with education (such as a book) rather than close to spaces that would hone in skills with livestock (Schwarz, 1997a). Relocation from ancestral lands has always been rife with tensions. Fostering a connection with the location where the umbilical cord is buried through traditional knowledge is an important practice of empowering Diné people who have been forced to leave their homelands (Schwarz, 1997b).

Disability: Ableism/Disablism, the Body, and Productivity

The foundation of dealing with disability is based upon the premise that it is an individual problem. Prioritizing personal performance, this approach is premised upon the idea that disability is a consequence of a breach of moral standards, a result of some form of 'fault' within the Self (Oliver & Barnes, 2012). The conceptual equation of disability to personal tragedy contributes to the general social perception of those who experience disability as having fallen prey to difficult and painful lives brought on by fateful circumstances (Oliver & Barnes, 2012, p. 14). Unlike other social identities (for example race and gender) disability status is not shared by everyone: Disability represents "the natural that has gone wrong" (Michalko & Titchkosky, 2001, p. 208). This view has informed the positioning of subjectivities as dependent upon the intervention of others, particularly healthcare professionals (Goodley, 2017). Placing disability at the epicenter of medical efforts has resulted in mixed blessings: the intervention of medicine has positively shaped the lives of individuals with disability as it has increased survivability (Linton, 1998a). The focal role of medicine in treating disability has contributed to the medicalization of the experiences of individuals with disabilities (Goodley, 2017). Medical intervention has expanded its tentacles to areas of social life: through the prioritization of medical discourses in relation to disability, society has acquiesced to placing it in a seemingly ‘natural’ opposition to the ‘norm’, reinforcing the general consensus that disability is a health problem (Linton, 1998a). Because of the pervasiveness of medicalization in normalizing life experiences, disability is defined as a problem, rather than as a starting point for insightful conversations on social phenomena, or an opportunity to take a reflexive approach to how epistemologies have engaged with the process of constructing the concept of disability as it is today (Linton, 1998b). Placing the attention upon the individual experience of disability, rather than identifying that disability is a product of the constellation of personal experience, social attitudes and structural factors allows for existing systemic barriers to perpetuate the oppression of individuals with disabilities (Abberley, 1987).

An exploration of the politics of navigating the physical environment raises our awareness of the material and social divide between those who have a disability and those who do not (Michalko & Titchkosky, 2001). Perceived as part of life, structural barriers are a stark reminder of difference between those who can mobilize with ease and those who cannot. Depending upon which side of the spectrum one is on, barriers highlight the personal (in)capability to effectively resolve difficulties that are ‘to be expected’, while advocacy efforts to address barriers are met with surprising opposition, justified by concerns over disrupting access to space for others (those who are able-bodied) and financial constraints. Inaccessibility of the physical environment allows those who do not (currently) fall into the category of those who have a disability to assuage their fear; they have not crossed the divide, and they can forget about the possibility that they may claim membership in the group of those who have a disability in the near future (Michalko & Titchkosky, 2001).

The defining point of social attitudes is the association of disability to pain, loss, and ongoing suffering leading to reactions of pity, dread, curiosity, and relief all wrapped into one (Hughes, 2012; Goodley, 2014). Aversive responses to physical, intellectual, and developmental difference are spurred by the fact that individuals who do not experience disability masterfully avoid putting themselves in the position of the individual with a disability. According to Wendell (1989), if those who do not experience disability positioned themselves as potentially occupying a space in relation to disability, social attitudes would change. This tactic of ‘turning the blind eye’ to disability stems from a deep sense of insecurity that one may experience some form of disability at any point in the course of life (Hughes 2012). Signs of disability consolidate an ontological truth: all humans are finite, and what separates us from becoming a person with a disability is the blink of an eye (Murphy,1987; Hughes, 2012, p. 68-69). As Shakespeare (1994) states: “disabled people remind non-disabled people of their own vulnerability” (p. 297).

One could argue that it is because of these sentiments that two main responses to disability have gained such hold in public consciousness, namely disablism and ableism. As Campbell (2008a) states these two terms are often used interchangeably. And, yet, they each convey a very different approach to disability. According to Campbell (2008b, p. 154) disablism is defined as “a set of assumptions (conscious or unconscious) and practices that promote the differential or unequal treatment of people because of actual or presumed disabilities”. Goodley (2014) links disablism to the practices aimed at restricting the opportunities that individuals with disabilities have in equitable social participation, as well as responses that are based upon the assumption that disability is a phenomenon that is in its essence problematic. From the prism of disablism, he posits, disability occupies a “marked and stigmatized social position” (Goodley 2014, p. xi). At the heart of disablism lies the assumption that disability justifies treating individuals who live with it as inferior, primarily because of presumably reduced capability, presuppositions which have gained clout through the medicalization of disability and the inaccessible environments in which individuals with disabilities mobilize (Imrie & Wells, 1993). The structure of State mechanisms perpetuates disablism, as it positions individuals with disabilities in very particular ways in relation to others. Securing services and receiving benefits are processes that are primarily based upon medical interpretations of disability and privilege the (false) idea that individuals with disabilities cannot be productive (Imrie & Wells, 1993; Mays, 2016). Individuals with disabilities are, therefore, entangled in a complex dynamic of having to balance between discourses that promote incapability, while at the same time having to prove that assistance from the State is worth-while. The threshold for determining this depends upon the individual with a disability demonstrating an effort to change, to ‘ameliorate’ their life (Goodley, 2014). Zitzelsberger (2005) highlights how disablist discourses force the women with physical disabilities who participated in her study to conceal their disability by overcompensating with other identities (e.g. gender). The contribution of Loja et al (2013) points to the fact that individuals with disabilities face similar constraints in the workplace. Disablism is everywhere, Thomas (2006) tells us: in stereotypical narratives regarding the abilities, roles, performance and physical appearance of individuals with disabilities in the media and in interpersonal interactions, as well as engagements with professionals. The result, Thomas (2006, p. 182) concludes, is that the “psychological and emotional aspect” of disability, namely the erosion of defenses against these discriminatory attitudes, with repercussions on the physical, social and emotional well-being of individuals with disabilities, is often overlooked.

Campbell (2009) convincingly argues that ableism permeates every fiber of social life to such a degree that at the crux of disability lie not fear and anxiety, but more so a complete denial to even allow disability to enter into the thought process of those whose life experiences have not (yet) exposed them to disability. The robustness of the “network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human” – as Campbell elsewhere (2001, p. 44) defines ableism— depends upon the tenacity of ‘unthinking’ disability (Campbell 2009, p. 13-14).

For Wolbring (2008) the problem with ableism lies in the fact that it is the conceptual framework within which a number of judgements are made. He states: “Every -ism has two components. Something that we value and something we do not” (Wolbring 2008, p. 252). The bulk of Wolbring’s work (see overview in Wolbring, 2008) focuses on showing how ableism frames our understanding of ourselves and others in the environment. Ableism reveals a component of power in social structures. Wolbring (2008) asserts*:* “Ableism reflects the sentiment of certain social groups and social structures that value and promote certain abilities, for example, productivity and competitiveness, over others, such as empathy, compassion and kindness” (p. 253). Judgements based upon this sentiment contribute to attributing metaphors of ‘lack’ or ‘deviation’ from a norm that needs these boundaries in order to appear fixed, when in reality it is not (Wolbring, 2008; Campbell, 2008a; 2009). Idealizing (hyper) activity and (hyper) capability, ableism calls for individuals to almost transcend their humanity (Goodley, 2014; Hughes & Paterson, 1997). ‘Compliance’ with ableist standards requires never discussing the lived experience of disability, the difficulties involved in going about everyday tasks, seemingly at ease with bodies that feel no pain or tiredness; Admitting to feeling like this would negate efforts to erase disability all together; and yet, it is precisely because of the assumption that disability has negative implications on everyday life that participation in social life is hailed as an achievement in its own right (Shakespeare, 1992; Loja et al., 2013). Narratives from Loja et al. further explain the binaries that individuals with disabilities are called to bridge: “I am proud of the medals I won. It’s a medal. And then the ‘poor cripple’ is substituted by ‘There is a champion!’. But there are those people who say ‘Poor cripple, he can do so many things’ ”(2013, p. 194)

Overcoming[56] disability is the responsibility of the individual who is experiencing it. The choice of words is important here, as it suggests that disability is inherently a challenge; an obstacle that can be addressed. (Linton, 1998a). If only the individual with a disability were able to manifest enough willpower to overlook the physical, emotional, and social implications of living with a disability, then they could meet the ‘autonomy,

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[56] Emphasis added by the author

independence, and rationality' standards that form the crux of ableist discourses (Goodley, 2014, p. 36). To slightly paraphrase Campbell (2008b, p. 160), individuals with disabilities often engage in discursively and physically "embracing an identity that superimposes behaviors that are far from those of their own". This is not to suggest that identity is fixed, but to draw attention to the fact that ableism is propagated on two principles, both of which are closely connected to practices of silencing. The first is based on the assumption that ableism represents the gold standard that everyone wants—and should want—to meet: in every day conversations, most able-bodied individuals fail to recognize the impact that marginalization has had on the identity construction and (self) representation of individuals with disabilities. The second relies on the internalization of ableism by individuals with disabilities (Campbell, 2008b). As long as individuals with disabilities strive to perfect their performance in order to meet those normative social standards, rather than critique the rationale behind these discourses, problematic engagements with their own disability will continue (Linton 1998a; Campbell 2008b). The following excerpt from the work of Loja et al. illustrates how assumptions about disability can be appropriated by the individual themselves:

> In my first years after the accident, I didn't go out. I mean I didn't go out during the day. I only went out at night. During the daytime, people looked a lot at me; especially the elderly people and that bothered me a lot !.(2013, p. 196).

Scholars with disabilities, whose academic prowess depends on questioning 'taken for granted terms' (such as ableism), are very selective in disclosing how their disability shapes their performance in terms of 'labor production' (Murphy, 1987;

Wendell, 1989; Campbell, 2008a,b). Some choose very few trusted confidants whose contribution in addition to being partners in academic project also lies in assisting scholars with disabilities realize how deeply rooted ableism is within the psyche of the individual with a disability (Tregaskis & Goodley, 2005). Reasons for this reticence vary from one person to the other: the assumption that colleagues will not understand, fear of discrimination in the workplace and choices with regards to self-representation. What is common across the narratives of these authors is the realization that disability and productivity seem to be incompatible in ableist discourses. Goodley (2014) tells us that dominant discourses attribute the accomplishments of individuals with disabilities to serendipity and/or to emotive responses regarding the implications of disability (such as questioning the veracity and/or seriousness of diagnoses).

Privileging certain abilities over others, ableism contributes to constructing a certain kind of subjectivity in the workforce. Wolbring[57] indicates "competitiveness, consumerism, and cognition" as cornerstones of current expressions of ableism. In a world that emphasizes diversity, freedom of choice and personal advancement become the epicenter of our understanding of ourselves (Masschelein & Simmons, 2005). The premise of diversity, itself, is based on a contradiction, as our shared identity of diversity implies that difference has no implications in everyday life: "we are all different, therefore, we are all the same", as Davis (1995, p. 13) asserts. This generally accepted stance, Mc Ruer (1998) tells us, serves to blur the importance of critically thinking about power dynamics and systemic structures that perpetuate prejudice on the basis of race,

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[57] Source: https://ableism.wordpress.com/about-the-project, as cited in Goodley 2014, p. 22.

sexual identity, disability and many other identities. The work of Mc Ruer (1998) on the depiction of AIDS in children's books is a reminder that it is important to examine how the experience of illness differs from one individual to the next. Access to knowledge is the primary terrain through which differentiation is played out: while the emergence of AIDS as a social issue primarily owes itself to the activism efforts of individuals who self-identified as gay, representation of AIDS was appropriated by medical professionals leading to a deafening silence around gender inequities in the lived experience of AIDS (Mc Ruer, 1998). Participation in the processes of production becomes quintessential in the navigation of subjectivity in this correlation of diversity and sameness. Commodities and the possession and dissemination of knowledge produce a certain kind of subjectivity performance: one whose responsibility it is to value that we are all the same and yet find ways to individually progress through the use of marketable skills, that augment one's economic and social capital (Masschelein & Simmons, 2005; Goodley, 2014).

Corporeal engagements with the physical and social world have been at the epicenter of analyzing social dynamics of productivity. Practices of expressing our subjectivity depend on how we (and others around us) engage with our bodies (Loja, n.d). As Csordas points out: "The bodily experience is understood to be the existential ground of culture and the self" (1994, p. 269); a conglomeration of historical forces and current social norms (Scheper -Hughes & Lock 1987). The body itself is in a continuum, a process of becoming, embedded within the loci of internal and external processes (Ingold, 2013; Lock, 2015). The way(s) in which we perform our corporeal agency and the way(s) in which others position us because of understandings of our bodies can determine inclusion or exclusion from social relationships (MacLachlan et al., 2012).

Disability provokes us to think about the sociopolitical processes through which many constructs, such as ‘normalcy’, and ‘productivity’, are defined. Having acquired a disability later in life, Wendell, argues that she is one of many who perceived the category of ‘normal’ as having finite boundaries prior to her experience with a physical disability. This artifice serves a purpose she tells us, as most of us do not respond well to the notion that our identities are in flux (Wendell, 1996). The social ideas and ideals surrounding physical appearance and health become apparent only when we encounter their absence, a digression in what we want to make appear as the seamless narrative that is our identity (Wendell 1996, p. 89; Shakespeare, p.1996). For Wendell (1996) these ideals respond to a deep human need: that of having a (false) sense of control over our bodies. She acknowledges that the appropriation of norms, which portray the body as ‘infallible’ and ‘invincible’ gave her a goal to work toward, an aspiration during those difficult moments of having to navigate her disability, that her now ‘vulnerable’ body may return to its previous state of prowess. This desire confirms the argument posited by Mitchell and Snyder (1997): that the association of disability with inferiority and loss supersedes all others. The contribution by Davis (1997) details how, in the context of aspiring to embody ‘perfection’, the body becomes segmented: evaluative statements run rife, strengthened by associations with other social identities that we all embody. For example, while there are ageist discourses that promote the use of hearing aids as indicative of a state of being that is perceived by the majority of people as negative (old age), the use of glasses is not met with the same stereotypes. In addition, while questions arise about gender identity during bodily changes on the bodies of women (e.g. breast augmentation or reduction surgery) the same questions do not arise when men make changes to their bodies. Our bodies, therefore, carry the potential to insert or extrapolate us from a world that focuses on assessing the degree to which our performance can be turned into a commodity.

One could argue that the individual with a disability engages with their body while enmeshed in “cruel optimism” (Berlant, 2011, p. 24). She defines this term as: “a relation of attachment to compromised conditions of possibility whose realization is discovered either to be impossible, sheer fantasy, or too possible and toxic” (Berlant, 2011, p. 24). Optimism, she acknowledges, is a necessary part of life. It sustains us, guides us in our actions and allows us to interact with others. What is cruel, she clarifies, is that the object of our desire is often unattainable, placing us between a ‘rock and a hard place’: on the one hand, without the aspiration to reach our desired object our driving force would be diminished, or lost altogether. On the other hand, she maintains, that our failure to meet our desire can be as detrimental as the energy we put into denying the futility of this pursuit. The tenacity with which the body of an individual with a disability engages with technology is a testament to this pursuit.

Technology and Disability: Opportunities and Challenges

Rapid technological advancements have increased the visibility of technology in our everyday life. The internet, computers, communication devices, software programs, and others, have constituted technology as the primary agent of change in bodily performance. Ethnographic research that focuses on gaining a deeper understanding of the experiences of individuals with disabilities with technology shows that devices are perceived both positively and negatively. For MacLachlan (2004) there is a need to be vigilant as to whether technology empowers or disempowers those who use it. Technology and medicalization feed into one another, perpetuating the push for increased participation of medicine in regulating the body. The emphasis of biomedical discourses in obliterating embodied difference, he tells us, contributes to silencing the agency of individuals with disabilities. MacLachlan (2004) continues to emphasize that technological advancements are used both by those who self-identify as having a disability and those who do not, which can lead to interesting conclusions about empowerment. From reading MacLachlan (2004) one assumes that, since technology is used both by those with a disability and those who do not self-identify as such, it can be removed as a marker of difference when we think about empowerment. The work of Lupton and Seymor (2000) reminds us, however, that taking into account the cultural associations attached to assistive devices is important. The narratives of individuals with physical disabilities offered by Lupton and Seymor (2000) highlight that wheelchair users feel that their device is an impediment to forming relationships. Concerns over access to space, anxiety over injuring oneself or someone else, as well as the very physicality of the wheelchair are focal points in conversations. Similar insights are provided by other scholars. More specifically, Loja et al. (2013) and Goodley (2014) point out that the opportunities that individuals with disabilities have in social participation are curtailed by infrastructural concerns, as well as (perceived) reactions, such as curiosity, loss of patience, and irritation, that able-bodied individuals have toward individuals with disabilities. For the participants in Zitzelsberger's (2005) study these responses are linked to the fact that those who do not self-identify as having a disability fail to look beyond an assistive device. The 'fixation' of those who do not have a disability on assistive technology positions women in very particular ways, as they are called to redefine themselves in terms of their social (in)visibility. In other words, while their disability suddenly becomes the epicenter of attention, making them noticeable in relation to their disability, all other identities, aspirations and desires (for friendship, professional development, love, intimacy and motherhood) are cast aside. The women express their resistance to such positioning by emphasizing other characteristics that are shared with individuals who do not have disabilities (such as communicative practices and accentuation of their gender identities by adopting socially acceptable ways of attractiveness). On the other hand, assistive devices can contribute to empowerment of the individual, as they facilitate participation in areas (both physical and social) that were previously difficult to navigate (Zitzelsberger, 2005). Assistive devices are focal in claiming 'possessional territory' as Brooks Gardner and Gronfein (2006, p. 90), tell us. It is precisely the possibility of breaching social and physical space that assistive devices encompass that individuals with disabilities use to perform their agency. Assistive devices are therefore used to slip into the category of disability, with no questions asked about why one mobilizes in ‘unusual’ ways.

The proliferation of technology use in the workplace, according to Lupton and Seymor (2000), has contributed to the de-stigmatization of the use of certain devices by employees with disabilities. For example, users of communicative technologies share with these two researchers that their devices often help them emphasize their dexterity in navigating technology that is deemed as advanced by their colleagues. Owning a device and demonstrating their skill with it, serve as good conversation starters.

The workforce is the ideal social space for an examination of how Berlant’s (2007) concept of ‘cruel optimism’ relates to understandings of productivity among those who have disabilities. If we think back to how Berlant (2007) suggests we think of ‘cruel optimism’ as the relentless pursuit of a desire that cannot realistically be attained, the internalization of cruel optimism by individuals with disabilities sustains capitalist frameworks that are largely responsible for the increase of disability in the first place. Wendell (1996) reminds us of a time when social expectations around productivity allowed for individuals who wished, to modify their practices of participation in the workforce based on their needs. Goodley (2014) concurs and adds that cruel optimism creates a constructed divide between individuals with disabilities. Those who follow this frame of thinking prioritize ‘productivity’ in particular ways: Based on capitalist mandates that are centered upon swift decision making and mass production of goods, those who fail to meet those standards find themselves in a difficult situation, as their performance incites social judgement pertaining to their supposed lack of effort, agency and dependent position with the State. Not only are they deemed ‘unproductive’ individuals, but also lacking citizenship. These problematic connections are enforced even more strongly because of the juxtaposition to other individuals with disabilities who demonstrate their compliance to such ableist discourses (Goodley, 2014). In connecting ableism to State practices, Kolářová (2014, p. 264) shifts our focus a little bit by critically thinking of the “cruel velvet promises” upon which disability discourses are based in Czechoslovakia. Ideas of ‘individual progress’ and ‘personal betterment’ are advertised as guarantees for economic prosperity and, by association, happiness. In this context, individuals with disabilities play a focal role as the increased publicization of their experiences has reframed discussions of rights of citizens, which were cast aside by previous political leaders (Kolářová, 2014). Remešova (2009, cited in Kolárová 2014, p. 257) shares the example of Jan Potměšil, an activist, now living with a disability, who stated: “If I was to choose between the rule of communists and being able to walk again, I would take the chair”. Emblematic figures such as this one (who acquired their disability as a result of participation in organized efforts to overturn the previous political regime) are used by the State as symbols for the urgent need for political and social change, Kolářová (2014) asserts. The awareness of disability issues has marked a proliferation of rehabilitation efforts embraced by some individuals with disabilities themselves, as a hallmark of the new political scene: One that pushes for the return to ‘normalcy’ in order to ensure freedom of choice for all citizens. Similar to the insights provided by Phillips (2011) on performance of citizenship and disability in Ukraine, Kolářová (2014) tells us that individuals with disabilities find themselves in ambiguous positions. Their discourses reveal that they realize that they are forging new ground in claiming their rights as citizens, but some also adopt a stance of 'docility' in relation to their negotiations with the State. Their desire to make sure that they are not 'rocking the boat' too hard shows their struggles to determine how to pursue what they need. Within their quandaries lie ableist discourses of burdening the system that is already drained by broader political and economic shifts. This quote highlights their inner turmoil: "It is impossible to change everything by a blink of an eye and even we, the disabled, should be patient! (Juřenova 82, emphasis added). Do you not believe that this is not the most appropriate moment to […] burden the state budget further? ("Naš mikrorozhovor …" n.p., emphasis added*)* (Kolářová 2014, p. 266).

Phillips defines such performance as "mobile citizenship" (2011, p. 4). In performing their citizenship in such a way, the individuals with spinal cord injuries that Phillips (2011) worked with manage to practice their agency in a physical environment and system that is set up to limit their opportunities for equity in social participation. Unlike many of their fellow citizens with physical disabilities in Ukraine, Phillips' (2011) participants mobilized both literally and figuratively. In the physical and cultural spaces where Phillips (2011) did her work, a diagnosis of disability equals to confinement both physically and socially, as those with disabilities live in small spaces which they infrequently leave, a sense of confinement which is exacerbated by the use of no (or antiquated) assistive devices. The lack of physical presence is translated into social silence about disability issues. Advocacy efforts and disability rights campaigns (often inspired by similar movements outside Ukraine) require that individuals with disabilities transcend local discourses and occupy public spaces including the workforce. Phillips elegantly shows us the conundrums that individuals with physical disabilities face in Ukraine as those who fight to be included in social roles outside the household go back and forth between discourses that link disability to the private and personal, and between relationships with other activists whose presence is highly public and often non-Ukrainian. Ironically, the efforts to develop a personal and political voice to challenge these local discourses of confinement and make the issues that individuals with disabilities face known nationally throughout Ukraine, as well as internationally, are birthed in limiting, private spaces (such as individuals' homes and medical facilities). Their crowdedness facilitates the creation and sustenance of strong, close relationships where those participating in activism efforts can decide what to make public and what to keep private.

Conclusion

Corresponding to social and political shifts, anthropological examinations of personhood have broadened their focus. From concerns to 'how persons were made' in the realms of religious symbolism and family relationships (see Geertz, 1973; Conklin & Morgan, 1996; Kaufman & Morgan, 2005) the discipline now tries to understand how constructs of personhood intersect with gender identity, reproduction, and reproductive rights (see Landsman, 1998; Rapp, 1999).

The example of disability offers the opportunity to critically reflect on how social marginalization intersects with ideas surrounding personhood. Often overlooked, invisible in terms of participation in social life, yet incredibly visible under the inquisitive gaze, the individual with a disability is positioned in ‘in-betweens’ (Turner, 1967). The individual with a disability participates in processes of productivity that are birthed from disablist and ableist assumptions: within these discourses the individual with a disability is caught in a vicious cycle. Understandings of disability as a difficulty, that in the public consciousness seems insurmountable, position the individual with a disability at an inferior social position, that is inescapable (Linton, 1998a). ‘Validation’ for this position is strengthened by hegemonic discourses that define disability as an issue that is ‘of the individual’ (Linton, 1998a), disregarding the impact of disablism on the psyche of the individual with a disability and the effects of inaccessible physical environments (Michalko & Titchkosky, 2001; Thomas, 2006). In juxtaposition, there are those individuals with a disability whose performance places them on the other extreme. Individuals with disabilities who captivate the interest of others because of their ‘success’ (in the labor market, in achieving motherhood, and performing other roles that are culturally salient) have to face a quandary of a different sort: they are the heroes, caught in a dichotomous web of doing all that they can so that their efforts are not compromised, while having to be reticent about the difficulties that the experiences of disability can entail (see Goodley, 2014).

Indigenous literature tells us a different narrative. Contrary to the practices of exclusion that ableism/disablism promote, indigenous contributions also perpetuate a stereotype, albeit from a different angle, as they epitomize harmony, balance and a sense of community. These views are important and gain robustness due to the rich analyses of creation stories that offer insights into cultural values (see, for example, Schwarz 2001;2008). However, values of collaboration, respect and openness in terms of identity experience and bodily performance appear to almost be ubiquitous. And, yet, my work shows that this is not the case. Following a discussion of my data collection methods, I then turn to thinking about cultural perceptions of physical disability. I show that there is a variation of perspectives, regardless of participants' background.

CHAPTER 3: DATA COLLECTION METHODS, METHODOLOGICAL AND ETHICAL CONCERNS

Data Collection Methods

Much of the trajectory of this project reflects my relationships with important actors in two urban areas[58], where I did my fieldwork over an extended period of time (2016—2018) in disability related organizations, higher education institutions and, indirectly, healthcare facilities. The recommendations of these actors contributed to fostering either an indirect network in support of this project and/or provided opportunities for participant observation and recruitment of participants. My relationships with gatekeepers whose assistance has been invaluable to the fruition of this project, vary. In certain instances, connections were forged months or years prior to the beginning of this project and are due to my positionality as a young woman with a disability. My own identity as a young woman with a physical disability has contributed to my mobilizing in contexts that are relevant to disability issues. Individuals I had met prior to the research project and with whom I have maintained contact throughout the years, were eager to introduce gatekeepers in my fieldsites. In other cases, connections with appropriate gatekeepers within the aforementioned research areas were made through the recommendation of mentors and liaisons at my educational institution (Arizona State University). These opportunities led to additional contacts that I utilized in my fieldwork. Finally, potential collaborations were

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[58] All research activities took place off the Navajo Nation.

identified through personal research on organizations and facilities that met the research eligibility criteria.

A variety of recruitment practices were utilized. E-mail and phone communications invited gatekeepers and perspective research participants to consider the research project, flyers were posted in recruitment areas after introducing myself and the research project to appropriate gatekeepers, while announcements were also placed in social media. Personal meetings were also scheduled with gatekeepers to introduce the project, discuss my educational and cultural background, and provided fertile ground for gatekeepers to ask further questions[59]. I initiated most conversations with gatekeepers with an introductory email and allowed for a response time, before following up with another email, a phone call and attempts to schedule personal meetings. There was some variability to my approach depending upon the relationship I had with each gatekeeper, their preference, and time constraints.

Recognizing the importance of consistency, I approached gatekeepers a number of times, using one of the recruitment practices outlined above, in order determine whether or not they were interested in participating in the project[60]. As the research project evolved, personal engagements with participants, word of mouth and snowballing contributed to further interviews with research participants. Colleagues, family members, or friends who

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[59] For more details on the dynamics involved in the recruitment process, please see subsequent section.

[60] This was my standard practice, unless the organization/entity declined to participate.

experience a physical disability contacted me expressing their interest in participating after an individual they knew had taken part.

As I show in the section dedicated to methodological and ethical concerns that arose during my fieldwork, my efforts to develop rapport were met with varying degrees of success: Challenges impeded me from conducting research in healthcare facilities. In contrast, disability organizations and higher education institutions enthusiastically participated in the research project and supported me in my endeavors to engage in participant observation and conduct semi-structured interviews. I was invited to disability related events, support groups[61] for individuals with disabilities, and spent time at higher education institutions. In addition, I participated in activities that clients of disability related organizations were involved in and took part in celebrations commemorating important hallmarks in the course of disability history, holidays or achievements that marked shifts in the structure of the organization. Interviews also took place in participants' homes and public areas, based on participants' preference.

Interviews included the following general areas: Diné and non-indigenous social perceptions of physical disability; attitudes pertaining to physical disability; concepts relating to the maintenance of health and well-being, as well as medical practices that work well in healthcare contexts and areas that need improvement (see Appendix A for additional details). The duration of interviews ranged from one (1) to three (3) hours depending upon the circumstances. The average duration of interviews was one (1) hour and thirty (30) minutes and were conducted by myself in the English language. A total of

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[61] The dissertation does not contain any information discussed in support groups.

twenty-five (25) individuals took part in this research project. Seven (7) self-identified as Diné with a physical disability; twelve (12) fell into the category of Diné/non-indigenous service provider, two (2) self-identified as healthcare workers, and four (4) were family members (see Appendix B for additional details).

The Field and Fieldwork: Rethinking Epistemological Constructs and Understanding Messiness

Prior to beginning this research project, I felt—as I suspect many graduate students do—that fieldwork and the data collection process begins with removing myself from a familiar setting, traveling far away and reaching a ‘concrete’ fieldsite (Gupta & Ferguson, 1997). Throughout this research project circumstances have led me to reflect on the concept of the field and on the need to reconsider the complexities of fieldwork: though I self-identify as a young woman from Greece and this identity is signified as such to others by my linguistic, social, cultural, embodied and gendered performance, I had been in the United States as a student for three (3) years prior to beginning my fieldwork. I have asked questions that echo the aforementioned stereotypical portrayals of fieldwork, such as: is fieldwork that does not involve traveling to a faraway land and interacting with ‘exotic’ participants valid? What are the implications of my personal circumstances (i.e. the need to work while doing fieldwork) on participant observation during my fieldwork?

It is important to think of the various anthropological locations involved in research (Gupta & Ferguson, 1997), which include geography, as well as social and physical spaces. The constructed physical and social boundaries of the field go hand in hand with other epistemological conventions surrounding fieldwork, which include historically privileging White/male anthropological accounts and portraying the fieldworker as a solitary figure who, in the name of science, chooses to distance himself from everything that is familiar for the timeframe of fieldwork (Barley, 1983; Amit, 2000). These stereotypical views of the 'field' and fieldwork reflect social/historical constructs on what science looks like and how validity is perceived in dominant academic paradigms. In establishing itself as an academic discipline, anthropology has historically tried to enforce literal and metaphorical distance and detachment between the researcher and the 'subject matter' (Okely, 1992). Ugo Fabietti (2012) highlights that the practice of silencing how much of the success of our work depends on attempts to gracefully 'tiptoe' from one social context to the other, rather than on following standardized procedures, reveals the need of anthropologists to claim a place in a world of professionals who may not recognize our methods as 'valid', or 'scientific' enough.

Influenced by positivistic tenets, many academic disciplines privilege knowledge that verifies or refutes hypotheses in a measurable way (Adams et al., 2015). Under the guise of 'objectivity', the push for the production of such knowledge, permeates how we conceptualize the 'field', 'fieldwork' and relationships with our participants. Arguing for 'clear' boundaries reflects anthropology's effort to emulate the principles of hard sciences, such as the explanation of social life through observable truths (Adams et al., 2015). The distance between the researcher and the research participant has been hailed as a necessity in order to gain analytical clarity (Coffey, 1999). If we view ourselves (and are seen by peers, and superiors in academic circles) as insiders from the onset, then do we not miss out on insights gained while we are in the liminal (Turner, 1967) stages of fieldwork wherein we cannot make sense of the social reality of our fieldwork?

Traditionally, anthropology has tried to emphasize this distance between the researcher and the research participants in a number of ways: firstly, by normalizing fieldwork projects that put literal, physical distance between the researcher's familiar settings and their fieldsite(s) (Amit, 2000). Secondly, by promoting ideals about professional standards and performance in the field, which concentrate on the anthropologist's role as a constant documenter of knowledge, whose good name depends upon the ability to discard all other identities, and their social and emotional implications, while in the field (see Coffey, 1999, for more). As Coffey highlights: *"*the ethnographer-as-hero surrenders love, family, and familiarity in order to confront an unknown culture*"* (1999, p. 20).

Following Coffey (1999) and others (Bradley, 1997), I argue that such divisions between the researcher and the researched reflect our need as anthropologists to demonstrate to the academic community that we have gone through the trials and tribulations of gaining access and conducting research. In the case of anthropology, however, interactions and relationships with unique social actors whose agency lies at the core of success or failure of the fieldwork endeavor are the crux of the 'subject matter' (Okely, 1992). The viability of the research depends on the researcher's ability to develop rapport and gain participants' trust, which—in turn—rely on the researcher's skill to closely engage in private activities and conversations. At the same time, our discipline's paradigm has called for the production of analyses, which—in many cases—fail to draw adequate attention to how 'messy' fieldwork actually is (Amit, 2000).

Historically, the professionalization of anthropology has emerged through the distinction of anthropologists who have immersed themselves in theoretical engagements with their subject matters as opposed to those who emphasize practicing aspects of anthropology in their work. The bifurcation between 'theorists' and 'practitioners' comes with value laden assumptions about the academic prowess of one over the other: the commitment of those whose contributions fall under the umbrella term of 'applied anthropology' to anthropology as a wider discipline has been questioned more often than others (Greenwood, 2008). The reputation of academic departments in higher education institutions has been built and solidified by selectively validating faculty and students with specific interests that match the foci of their respective institutions (see, Greenwood, 2008, for an example involving an ivy league institution).

The ability to act as 'nomads', as Fabietti (2012, pp.15-17) calls the process of mobilizing in between cultural contexts, is the cornerstone of anthropological contribution, and yet the conundrums that we face as we make decisions are rarely discussed. This 'messiness' is brought into sharp focus as aspiring researchers are faced with contradicting messages about the process of fieldwork. On the one hand, universities in North America and Europe and funding agencies (some more so than others), demand a structured presentation of the research project, which includes specific questions, hypotheses, expected findings, and strict timelines for the completion of stages of fieldwork. While this step is necessary to ensure preparedness, it does also propagate the notion that fieldwork is a process whose mechanics can be predicted. On the other hand, graduate school classes and conversations with advisors highlight a very different picture, which emphasizes the importance of recognizing that fieldwork is not a linear process but rather an endeavor where the most useful data derive from unexpected events. It is those moments of confusion and frustration that are the most productive as they are telling of the social dynamics in the field.

My own experience attests to the complexities involved when trying to write about ‘the field’. Like Kurotani (2004), particularly at the beginning of my research project, I felt a certain amount of uncertainty as to whether the introduction of myself and my project to various gatekeepers ‘counted’ as fieldwork, since my field sites did not conform with portrayals of fieldwork that dominated most analyses I had read. Revisiting seminal works in my discipline that discussed these issues (see for example Wax, 1971, Clifford, 2007) provided some form of reassurance. In her seminal work on fieldwork, Wax (1971) cautions novices that— despite their expectations that they will enter the field and immediately begin collecting data—the process is much more complex and is dependent upon the specific circumstances in the field, therefore making it difficult to give standard guidelines to be followed. I admit, as does Kurotani (2004) in her analysis, that I was inadvertently delimiting ‘fieldwork’ as a “spatial practice of intensive dwelling” (Clifford, 1997, p.188). Contrary to the imagination of most graduate students, I did not work in an exotic space. For personal reasons that will become apparent in subsequent pages, my fieldwork required that I frequently mobilize from one large urban area to another.

While attention to processes of urbanization within anthropology have increased, this aspect of my fieldwork also felt ‘new’ to me as I was aware of the historically shaped distinctions between disciplines and the association of sociology to urban areas (Prato & Pardo, 2013). The expansion of the scope of anthropology to urban environments began in the 1960s and proliferated in the 1970s, as prominent figures within anthropology cautioned against such conceptual divides. The push to reconsider preconceptions was bolstered by the introduction of anthropologists who typically belonged to the populations studied into the professional realm of academia (Peirano, 1998).

After conversations with mentors (Drs. Jonathan Maupin and Monica Gaughan) I realized that fieldwork can encapsulate a multitude of dimensions: it refers to the geographical/physical space wherein the researcher interacts with research participants, the dynamics that the researcher has to navigate in order to conduct the research, and the modes of communication that the researcher must employ throughout their fieldwork. Geographically speaking, my research primarily takes place in two (2) locations. However, within those physical spaces, I have had to negotiate relationships with four (4) groups of research participants whose agency has shaped my fieldwork. Firstly, Navajo Nation gatekeepers and agencies/boards. Secondly, university IRBs and external research review committees. Thirdly, gatekeepers in organizations/healthcare facilities, and higher education academic settings. Additionally, I have had to navigate access to non-indigenous and Diné (Navajo) healthcare workers and service providers as well as Diné (Navajo) individuals with physical disabilities and their families.

As in Kurotani's (2004) case, timing seemed to delineate fieldwork: Especially at the onset of my project, my day seemed to be segmented into a frenzy of making phone calls, sending emails and making visits to gatekeepers in order to discuss my background and research during the day (usually from 9 am to 5 pm) and the lull that followed as I waited for something exciting to happen. During the initial phases of fieldwork, I became acutely aware of the need to balance these dynamics in the field with other professional commitments, including fulfilling my obligations to mentors and to a federal grant, which required reporting results at the end of the award cycle.

My sense of waiting (which at times seemed endless) was sharpened in my mind as I was aware that my engagements with individuals in the field were framed within a set of pre-existing stereotypes, based on a history of problematic relationships, which cause well-founded concern among the populations I collaborated with for the success of this project[62]. Conversations with mentors on the value of 'being there' while these processes unfolded (J. Maupin, personal communication, October 21, 2018) as well as analyses that focused on research collaborations with indigenous populations all over the world (see, for example, Hume & Mulcock, 2004), helped me realize that my interactions with gatekeepers were an invaluable reflection of the existing collaborations, tensions and opportunities in the field. Detailed insights can be gained about the dynamics in the field by engaging with research participants in activities that seemed irrelevant to the research project, or by

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[62] Further details will be provided in the following sections.

waiting quietly as conversations took place between gatekeepers (Hume & Mulcock, 2004) shares.

I now see that part of the internal struggle that I felt, especially in the first stages of fieldwork, speaks to the fact that I was not sure how to position myself in relation to my research. For reasons that will become apparent in Chapter 4, this project is very close to me personally and in some ways has helped me reflect on the impact of discrimination and prejudice and closely examine how I envision inclusion and diversity not only in academia, but also in wider society. I paraphrase Pigg (2013) whose analysis on 'sitting' and 'doing' resonates with my approach to my research study, particularly in the beginning phases. As many projects in my field, my research was founded on my eagerness to explore a social 'problem' that I had experienced, seen and heard about from friends, and read about in scholarly analyses: how people perceive physical disability matters because it shapes how we perceive ourselves, relate to one another, as well as how we interact with the State and the market as citizens and consumers with certain rights and obligations. Pigg (2013) is correct in contending that research studies can provide an arena to raise awareness, and in some cases suggest solutions.

The passion that not only myself, but also my mentors, had poured into designing the research did not correspond to 'sitting', when I wanted to be 'doing' something to contribute to equity for individuals who have disabilities and to provide a voice to those who work with them. 'Sitting' has also been an opportunity for me to increase my awareness of a concept that often appears to be fixed and stable, namely privilege (Bozalek, 2011), and how failing to engage in conversations about it perpetuates oppression triggered by ‘blindness’ (Ferber, 2012). While I share certain life circumstances with participants with physical disabilities, I navigate different environments, have access to opportunities to fulfill my education and career aspirations that my participants may not. Finally, I am not indigenous and, therefore, am not exposed to certain parameters that indigenous identity carries in social interactions.

Inspired by theoretical contributions relating to disability and indigenous concerns, I considered how well-meaning ideas of empowerment have very different interpretations for individuals directly living with the experience of physical disability and/or indigenous identity, and others, such as academics, funders, government bodies and other officials (Goodley, 2005; Tuhiwai-Smith, 2012). The answer (according to Tuhiwai-Smith, 2012) lies in academics having the commitment and patience that are necessary for indigenous peoples to decide how research projects are to be implemented, with the goal of serving the best interest of the group.

Contextualizing Recruitment: Stereotypes of Anthropology, Fieldwork, and Institutions.

Ample literature in anthropology and other relevant fields discusses the role of gatekeepers in research projects, as their actions can create, cement, or deny access opportunities (McAreavey & Das, 2013). As Feldman et al. (2003) point out, the metaphor of a door is often used to describe access. This metaphor invokes the mental image of a researcher persistently knocking a door down. Once that door is opened, the problems of access end (Feldman et al., 2003). While this may be true for some cases, my work is an example of how important it is to think of access to the field as a continuous process, which Feldman et al. define as ‘relational’(2003, p. x-xi). The focus of my work on a challenging subject, namely physical disability, and my collaboration with a population that has been subjected to historical trauma—and continues to be exposed to legal, social, embodied practices of colonization (see Yellowbird, 2004[63]; Walters et al., 2011[64]) means that I have had a number of opportunities to practice “the ability to be flexible, to be persistent without being annoying, and to recognize luck and accept opportunities” (Feldman et al., 2003,p. xi).

At the initial stages of my fieldwork, my days were filled with efforts to establish contact with important gatekeepers in the field (e.g. representatives who mobilized within my recruitment areas, members of external ethics’ committees and representatives within the appropriate office of the Navajo Nation), to whom I introduced myself and my research project. These individuals served the important role of facilitating access to the field by engaging in discussions with me regarding the permissions needed to begin my fieldwork and suggesting potential resources. The input of my advisors, networks I had developed and fostered throughout the years, and recommendations of friends with whom I share a commitment toward bringing forth further awareness of disability related issues were at the crux of expanding my network for this project, and identifying additional potential recruitment areas.

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[63] Michael Yellowbird self-identifies as Mandan, Hidatsa, and Arikara

[64] Karina Walters is a member of the Choctaw Nation

It is at this that I practiced what Feldman et al. call ‘developing a hook’ (2003, p. 25). This involves presenting the research project in a manner that not only appears relevant to the interests of the population the researcher wishes to study, but also demonstrates the extent of the researcher’s skill to perform reliability and trustworthiness in culturally appropriate ways. By this time, I had been a PhD student at my public research institution for three (3) years and had noticed several cultural differences between the general tenets that inform communication and interactions between individuals in the United States and my own country of origin (Greece). My observations led me to believe that cultural norms of accuracy and validity in the United States generally privilege written transmission of information when interacting with agencies and committees. In addition, I was well aware of the fact that politeness is a complex social act, which involves not only the language of message itself, but also how it is transmitted and performed, with the potential to facilitate or complicate my work, depending upon my communicative performance and how it was received (Sifianou, 1999).

I approached interactions with these gatekeepers as opportunities to reflect on Laura Nader’s (1969) contention that one cannot understand concerns of marginalization and oppression that most anthropologists (including myself) focus on throughout their careers without being aware of how power relations play out in settings where key decision making about the problems we study occurs. Echoing others (see, for example, Kezar, 2003), I felt that much of my training as a budding anthropologist has focused on being aware of the impact of the anthropologist’s presence in the field and issues of power that the anthropologist holds due to their positionality as a researcher in relation to other actors in the field. I had received much less formal training on what to expect when required to 'study up' first, in order to gain access to 'studying down', or on the contribution of critically thinking of how power relations permeate research projects (Nader, 2008, cited in Bowman, 2009).

Entering a research collaboration with individuals whose power in the field exceeds that of the anthropologist is uncomfortable in certain respects, yet productive, as it challenges assumptions of power that the researcher may not be aware of (Kezar, 2003; Bowman, 2009). In those early stages of fieldwork, I suffered from 'impostor syndrome' in my communications with gatekeepers who I perceived as elites[65] in my field, which was exacerbated by the spaces and dynamics in the field. In the context of my research, I follow the definition of elites as provided by Welch et al (2002) who think of elites as individuals who hold a senior or middle management position, enjoy high status and hold functional responsibilities in the field, and have a broad network of personal relationships (p. 613).

Similarly to Ross (2001), I wished to appear confident, but I wondered how my various identities as a young woman with a physical disability, who is also non-indigenous and a foreigner, would influence the questions that gatekeepers would ask. Communications with gatekeepers at this level focused on the topic of my study, my data collection methods, measures I had in place to address ethical issues and participant compensation, as well as the process of collaborating with indigenous governmental bodies relevant to the population I was interested in doing research with.

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[65] For an overview of definitions of the concept of elites, see Aguiar, 2012.

As I have indicated in a previous section of this chapter, my identity as an anthropologist undoubtedly played a role in the emphasis placed on these questions as, throughout history, interactions of anthropologists with Native American groups have been fraught with tension. This has been particularly the case with Arizona State University due to a history of significant violations in research protocols and Havasupai cultural norms. Notably, in the summer of 1989, Professor John Martin, assembled a research team to study diabetes among the Havasupai through the collection of blood samples from Havasupai participants. Under the direction of a team member, Dr. Markow, students on the research team also examined prevalence of schizophrenia with no documented prior approval from official university bodies in charge of monitoring research projects (namely the ASU Institutional Review Board) or officials from Havasupai governmental bodies. Furthermore, samples were shared with other institutions that utilized them for their own purposes. A number of dissertations and published materials were based on inappropriate dissemination of the samples that Havasupai members shared for the diabetes study. Further investigations highlighted omissions in the process of securing informed consent as well as failing to disclose changes of the topic of the study.

Following court battles with ASU, indigenous Nations across the country have condemned the way the research team and the institution handled the situation, while the Havasupai have now banned any ASU affiliate from stepping foot on their reservation (Bommersbach, 2008). In addition to concerns over research practices, this example provides insights as to why being culturally sensitive is imperative in research projects. Like many Native American groups, the Havasupai abide by cultural rules which frame navigating interactions with the physical body. Sharing bodily fluids is a practice done under certain circumstances and for specific purposes[66]. As an indication of trust, the Havasupai people decided that becoming more aware of the effects of diabetes would contribute to the well-being of the group and therefore cultural tenets could be renegotiated (Bommersbach, 2008).

The revelation of the Havasupai case brought forth difficult, yet necessary and productive conversations about ownership of knowledge. Academics argued that the project had advanced scientific knowledge, which minimized the damaging effects of research practices that the team engaged in. Yet others felt that the Havasupai were engaging in the perpetuating hurt inflicted upon them: a main concern among the Havasupai in reaching a decision on whether or not to share their blood had been that their knowledge of their identity is based on cultural traditions that discuss their ancestry and origins, rather than determined by blood. Barring access to practices that could advance knowledge that is central to understandings of origin among other peoples, strips other populations (who do not share the same cultural tenets as the Havasupai) of their right to understanding where they come from (for an overview of the conflict and array of views see Reardon & TallBear, 2012).

The critique of indigenous scholars on academic practices focuses on three main issues: firstly, the issue of representation of indigenous communities, which historically has led to the disempowerment of indigenous peoples; secondly, the issue of how knowledge is used, disseminated (or not) to the groups whose time, energy and kindness

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[66] Similar practices exist among the Diné. Please refer to Chapter 7 for more details.

we rely on to complete projects. Thirdly, and equally important, is the concern of accountability of academics to Native American groups (Tuhiwai-Smith, 2012).

Since its inception, anthropology has gone through various stages of developing professional practices to solidify the anthropologist as the ‘expert’ in the interaction between fieldworker and research participant(s) (for more see, Clifford, 2007). Sluka (2007) notes that systemic barriers (e.g. unequal participation in educational settings) have stripped research participants of the opportunity to voice their opinions about what anthropologists write about them. Determining the ‘expert’, of course, requires constructing the Other, whose disparities in privilege and access precludes them from participating in a dialogue about what is being produced by the ‘expert’ (Ranco, 2006)[67].

Cajete[68] (2012) sees current systemic issues as a product and continuation of colonization. The low representation of indigenous voices in relation to research, he says, is connected to the disjuncture between the values that current educational systems promote (such as excellence in personal performance, competitiveness) which contradict key values of indigenous ways of knowing and living, which emphasize the relationality between personal agency and communal strength as a way of empowerment for both the individual and the group.

Anthropology has played a significant part in challenging indigenous peoples’ humanity, by doubting their intelligence, strength, resilience both as individuals and as

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[67] Ranco is a member of the Penobscot Nation and self-identifies as a Native American anthropologist

[68] Cajete self-identifies as Tewa.

members of broader cultures, and ability to propose alternative models of producing knowledge (Sluka, 2007; Deloria, 1988). For many indigenous peoples, anthropological research ‘colonizes’ how indigenous people think about themselves, see the world, and respond to current challenges which affect indigenous groups (King, 2007)[69]. This form of colonization refers to the superimposition of foreign terms and categories to describe indigenous peoples and their experiences. King (2007) continues that some indigenous groups have been studied by anthropologists to such an extent that current generations have lost touch with traditional values leading to ‘self-colonization’. This form of colonization is closely linked to the physical outcomes of colonization (e.g. violation of human rights, land loss) that indigenous groups have been exposed to as it creates self-doubt about the value of indigenous identity and makes appropriation of knowledge and resources easier (Waziyatawin Angela Wilson, 2004)[70].

Throughout my interactions with administrators and gatekeepers at this level, I felt prepared to answer questions about the research topic, aims, data collection and analysis/dissemination: I had just been through the process of successfully presenting my research proposal to committee members and the public during my proposal defense, and I had submitted and been awarded a federal grant. I realize now that my initial conversations in the field were perhaps a little too focused on presenting the research without establishing a personal connection to the topic, partly because conversations with gatekeepers involved explaining bureaucratic processes and partly because I had (and to

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[69] Cecil King is an Odawa scholar.

[70] Waziyatawin is a Pezihutazizi Otunwe scholar

an extent still do) very rigid boundaries of what pertains to personal life; sharing what I consider/ed personal was irrelevant and uninteresting to gatekeepers in my mind.

What impressed me was that, even at this level of bureaucracy, gatekeepers (some more than others) seemed to be more interested in my background, why this project was important, and why I had chosen to work in locations that were not on the Navajo Nation premises. I realize now that throughout my numerous conversations with administrative gatekeepers I experienced what Wax calls “secondary socialization”, or “resocialization” (Wax, 1971, p. 14). Questions about my cultural background and identity revolve around the gatekeepers’ attempt to assess my commitment to and investment in the project.

During my research collaborations with healthcare facilities, organizations, support services for veteran populations, and higher education institutions, I had the chance to reflect on how the agency of gatekeepers affected the course of my research. The initial stages of my fieldwork focused on recruitment on healthcare facilities, but I realized that participant observation and direct recruitment would be challenging. Previous negative experiences with researchers, lack of protocols that provided guidelines on how to engage in research with scholars, and HIPAA concerns were cited as reasons for barring research directly with healthcare facilities.

Contrary to popular belief, legally, the Health Insurance Portability and Accountability Act (HIPAA), does not safeguard confidentiality of medical information; rather, it is concerned with providing mandates that dictate the disclosure of information (Sobel, 2002).This common misperception may be due to the fact that HIPAA is nascent of a legal context aimed at setting “a standard for privacy of individually identifiable health information" (Sobel, 2007, p. 40). According to Sobel (2007, p. 40) "the term HIPAA provides much less privacy than the term privacy rule suggests", even though patients and healthcare providers often think otherwise. First established in 1996, HIPAA responded to an increasing presence of technological advances in the relationship between client and healthcare provider (for an overview of legislation, see Ruebner & Reis, 2004; Sobel, 2007). Interestingly, certain state officials and entities relevant to promoting marketability of healthcare in the United State can access and utilize potentially sensitive information without the knowledge and consent of the individual directly concerned (Sobel, 2002).

Research reveals that privacy concerns affect the relationship between healthcare workers and their clients as well as the feasibility of research projects in healthcare contexts. A study done in 1999 by the California Healthcare Foundation shows that one (1) in five (5) adults in the United States believe that their medical information has been disclosed unnecessarily. Fifteen percent (15 %) indicate that they have modified their interaction with healthcare providers to protect medically related information. Examples include requesting that certain information is not recorded, taking on the financial burden of healthcare services to avoid disclosure to health insurance companies, not seeking medical care when needed for fear of disclosure to third parties and not visiting the same provider on a regular basis. Fifty-six percent (56%) of U.S. adults state that they are concerned about privacy during doctors' visits with a particular focus on unauthorized parties accessing sensitive information. Seven percent (7%) of all U.S adults indicate that they have been hurt or harmed because of inappropriate disclosure of their personal information, while this percentage rises to thirteen percent (13%) for individuals seeking care for mental health concerns[71].

A national survey of 1527 epidemiologists indicated that researchers with interests relating to health feel that HIPAA has negatively affected participation in research studies. A total of eight hundred seventy-five (875) respondents shared that HIPAA made research difficult, particularly in regards to timeline of completion and financial burden, while six hundred eighty-four (684) indicated that HIPAA affected their research protocols. Interpretations of the HIPAA among IRB officials resulted in lessening protections for research participants (Ness, 2007, p. 2164).

Anthropological scholarship has focused much of its attention on the process of gaining and maintaining access. In many cases, gaining access to the field and establishing trust mitigates the frustrations of securing collaboration (Hofman, 2008). Much more focus is needed on understanding and analyzing how gatekeepers express their agency throughout the process of fieldwork, by utilizing 'resistance tactics' (Wanat, 2008, p. 203). In my case, gatekeepers forgot to follow through with promises of assistance, defaulted to their superiors when refusing to participate, requested additional summaries of projects, further information on permissions and indicated the timely processes of reviewing research protocols with boards, additional committees and other gatekeepers.

I may have had better luck with healthcare facilities had I started from staff members rather than external gatekeepers. Wanat (2008) highlights how conflicting

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[71] Available at https://www.chcf.org/wp-content/uploads/2017/12/PDF-survey.pdf

interests and being connected to an external administrative gatekeeper (who may be perceived as superior to the gatekeepers of the facility from which I was requesting direct participation) complicate relationships.

Reflections on Conducting Ethnographic Interviews: Cultural and Ethical Considerations

Anthropological contributions have discussed the issues of power and agency in the relationship between the anthropologist and the research participant. Such analyses are particularly salient when examining experiences that touch upon difficult topics and/or involve populations that have been exposed to social marginalization and structural inequities.

In some cases, my fieldwork involved interacting with individuals whose direct or indirect experience with a physical disability intersected with their indigenous identity. In other cases, participants' departure from that indigenous identity marker shaped how they perceived themselves in their relationship with their indigenous clients and vice versa[72]. Either explicitly or tacitly, trust was a seminal question that I had to navigate throughout my fieldwork, albeit in different ways than I expected. I was fully prepared for the hesitation of Diné participants due to my Whiteness as well as my professional affiliation to a discipline that has a legacy of mistreating Native American peoples; concerns that I

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[72] Details of these insights are provided in subsequent chapters.

have discussed in previous sections of this chapter. I was surprised to find, however, how important other identities that I embody (namely, my personal experience with a physical disability and my status as a non-American) were.

As I devote an entire chapter to how my performativity of these identities shaped my relationships with participants in the following chapter, I will not delve into this here. However, a brief discussion highlights how my positionality affected the data collection process. Particularly Diné participants with physical disabilities and their families seemed to either assume that I understood their experiences, or perceive the assistive device that I use as a hallmark of the irreversibility of disability. Like Tregaskis (2004) whose initial trepidation of doing research on disability with individuals who are able-bodied was triggered by her own experience as a person with a disability, I wondered how I would respond if my participants expressed negative views on physical disability. In the instances where that did arise, I chose, as did Tregaskis (2004), to neither contradict nor validate this view. Depending upon the circumstances, I either simply acknowledged the response or asked the participant to clarify, as I would with any other question.

I realized after talking about these data with mentors that these uncomfortable moments were actually very telling of how pervasive stigma is. I was also concerned whether the social desirability effect would stop my Diné and non-indigenous participants who were not living with a physical disability from sharing their views (Tregaskis, 2004). Although this concern was never explicitly addressed in my research, I do not think it was a problem. I tried to address this through choosing how to perform my disability. In most cases, I chose to refrain from requesting assistance. In instances where participants offered to assist when we were navigating a context that to them appeared challenging, I accepted. There were certain moments when non-indigenous service providers intervened to advocate for me in cases of thoughtless comments/discriminatory behaviors made by strangers, and/or inaccessible environments.

Cultural considerations also impacted my data collection methods and practices of documenting information. This is a particularly sensitive aspect in interacting with Native American peoples, given cultural tenets that shape practices of sharing knowledge. Witherspoon (1977) explains that –for many Diné— words have agency, and therefore interlocutors must take particular care with regards to when, how and with whom words are uttered. According to certain interpretations of Diné traditions, the world as we know it has been created by Diyin Dine'é[73]. Often thought of as First Boy and First Girl, these beings entered a sweat lodge wherein they thought and talked the world into existence through the form of song (Witherspoon, 1977, p.17). As a male, First Boy represents thinking while as a female First Girl refers to speech. As we are all connected to First Boy and First Girl, we all have within us the capability for thought and speech, as we all embody two souls, each of which indicates these two attributes. Also known as *Są,'ah Naagháii,* thinking encompasses within it the continuous process of pursuing growth and maturity, while speech embodies beauty (also known as *Bik'éh Hozhó*) (Witherspoon, 1977, pp. 19,20, 23). Reichard (1950) interprets these two principles as reaching the culmination of perfection, walking in beauty toward the ideal state of life according to

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[73] There are various ways of writing and interpreting this term. Witherspoon (1977, p.15) spells it as I have here and translates the phrase as 'God' or 'supernaturals', cautioning against the translation as 'Holy People'. On the other hand, more recent contributions, spell this as Diyini and translate it as 'Holy People' (Farella, 1984, p. 23)

Diné, namely old age. Others (see Young, n.d, as cited in Witherspoon, 1977) relate these two concepts to perpetuation of the universe through the procreation of all living beings within it. Witherspoon (1977) tells us that the concept of hozhó cannot be understood without taking into consideration the physical, social, spiritual and cultural realms that make up the universe. The prefix *ho* indicates approaching a phenomenon in its totality, indicating that hozhó encompasses a beauty, harmony and balance that permeates the entire universe (Witherspoon, 1977, p. 24).

Thought, according to Diné traditional teachings, is located in the brain and becomes active in our mother's womb. Choices that we make about how to navigate physical space and interact with others are dictated by the process of thinking. Speech, is placed within us as we come into this world, in the form of our second soul, carried to us through the wind. Located in our digestive system, it is the successor of thought (Witherspoon, 1977). Intricate cultural classifications regarding inequalities in agency inform syntax and linguistic choices that Diné people make. Determination of how to utter words revolves around where the phenomena discussed are perceived to have similar, or more/less potent agency. Certain categories that in English would be considered inanimate objects, are approached as equally powerful, when they are both stationary. 'Inanimate objects', however, have some form of agency, which is indicated in their potential for movement. Because of this act, the universe is transformed. In such cases, the 'object' that initiated the process of movement acquires higher agency than its previously stationary counterpart. For example, a rock and a tree are both similar in their potential to transform the world. If, however, a rock makes the decision to move toward the tree, then the rock is thought to be more powerful as it has changed the tree (Witherspoon, 1977, p. 66). Given that humans are thought to possess superior capabilities of thought and intricate patterns of speech, [74]they are perceived as having control over a situation. Culturally appropriate phrasing would, therefore, be 'the man allowed the horse to kick him', rather than 'the horse kicked the man' (Witherspoon, 1977, p. 64). Cultural distinctions of personhood also come into play: for example, infants do not reach the state of being human until a certain period of time has passed and this milestone is celebrated with appropriate ceremonies[75]. In interactions with adults, it is culturally accurate to state that an adult allowed themselves to be afflicted by an infant, as the adult-either by choice or inadvertently- failed to foresee how possible actions would affect the context (Witherspoon, 1977, p. 79).

Language has the power to create circumstances and transform reality (Austin, 1962). In the context of addressing physical and mental health it can alleviate fear, as well as minimize the effect of afflictions and restore health/balance (Witherspoon 1977, p. 34). The themes of health and illness commonly emerged in my interactions with research participants. In many indigenous worldviews the topic of illness causation is deeply personal and risky as the individual asking such questions may be perceived as a

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[74] Others disagree with this assertion and highlight the importance of taking into account all aspects of the environment when discussing agency in relation to materiality. Scholars who work with indigenous peoples emphasize the importance of approaching all natural phenomena as dynamic, capable of shifting and regenerating the world (see Wildcat, 2009; Basso, 2000)

[75] A child reaches the potential for full personhood when it first laughs. The individual who causes the infant to do this is responsible for planning a ceremony, also known as First Laugh ceremony, to teach the child that he/she is part of a group (Schwarz, 2008. According to findings in Schwarz's (1997a, p. 113) work the Holy People instruct the child of ideal behavior from inside the womb. After a child is born, it is considered to be an integral part of harmony. This capacity is minimized at the age of eight (8).

‘witch’ (J. Riding In, personal communication, November 13, 2013). In probing participants to provide further insights on how these concepts related to perceptions of physical disability, I feared that research participants may feel that I was misusing words (Witherspoon, 1977) to create a challenging/unpleasant situation for them. When asking participants for further details on how cultural concepts of physical disability were broadly situated within social understandings of health and illness I rephrased to give a ‘positive orientation’ to the conversation and emphasized maintaining health, rather than falling ill, allowing the participant to choose if and how they want to respond. In addition, following Witherspoon (1977) who notes that the third person is often used to discuss experiences among the Diné, I tried to avoid using ‘you’ when discussing practices of maintaining health. More specifically, rather than saying ‘how do you maintain health?”, I asked “how can a person maintain health” in an effort to make sure that my participants did not feel that my question ‘targeted’ them.

I entered interview interactions with research participants indicating my knowledge of personal/cultural considerations that make recording challenging. Five (5) out of twenty-five (25) research participants declined to be recorded. Justifications for their choice were: they did not like it; recording contradicted with their internal values of humility; that their worldview is against being recorded; and, that they wanted to consult with elders in their family. In these cases, particular emphasis was placed on keeping as detailed notes as possible during and after the interview. As in all interviews, to ensure accuracy, I used various probing techniques, such as the echo probe and the tell me more probe (Bernard, 2011, p. 178) to encourage participants to provide clarification on relevant topics to the research scope. Aside from being an integral ethical question, thinking about recording data has implications on how anthropologists conceptualize power and agency in regards to participants' (self) representation (Bourgois, 2007).

Furthermore, many indigenous groups liken scientists and research practices to government officials, which may trigger traumatic responses due to the assimilation practices that government agencies have engaged in throughout their relationships with Native American populations, such as forced removal from homelands and attendance in boarding schools (Benedek, 1992). In cases where research participants indicated that they did not mind being recorded, I expressed my appreciation by validating how important the participant's knowledge is and how recording will assist me in not missing or misunderstanding anything (Bernard, 2011, p. 185). Following Bernard's (2011) recommendations, I engaged in chit-chat with the recorder on the table, but turned off, in order to give participants time to get comfortable with the process. In cases where the participant expressed an interest in technology or seemed nervous, I showed them how the recorder works and how they can stop it themselves at any time. (Kadushin personal communication, cited in Bernard, 2011).

In engaging with individuals with physical disabilities, their families, as well as service providers and healthcare workers my ethical quandaries revolved around my awareness that, as a subject matter, disability is sensitive and may bring up memories of stigma and discrimination, which may affect the feasibility of the study, but more importantly, may affect those who did choose to participate. In determining how to best address the question of sensitivity of my subject, prior to embarking upon fieldwork, I did extensive bibliographical research on the topic and became informed of local support networks that could provide services to research participants, if needed[76]. My desire to be prepared for moments where participants may share their emotions led me to think about my responses if such situations arose and develop a set of strategies to implement during interviews with participants.

There were times when my participants expressed emotion when describing social attitudes, most commonly frustration. Following Kavanaugh & Ayres (1998) I incorporated breaks during interviews, when the need arose and reminded participants of the voluntary nature of participation (including their right to decline responding to any question and to stop the interview). Reviewing Kavanaugh & Ayres (1998) during my fieldwork also reminded me that communicating emotions should not always be taken as a ‘bad’ sign by the researcher, as long as the researcher is engaged and aware of verbal and non-verbal cues.

Two participants explicitly shared that they appreciated talking about their experiences with regards to physical disability. Fiona[77], a Diné individual with a physical disability mentioned that she had not talked about things in many years, and “it is good [to talk]”. The other, a Diné family member who I will call Jane, directly connected sharing their experience to the fact that I was not from the United States: “It’s nice that you are from somewhere else” and continued that people have an attitude in the US, of

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[76] No occasions arose where this information was needed, but I still felt better having that knowledge during my fieldwork.

[77] All participant names are pseudonyms.

‘I’m through with you’ and show no interest in the person (paraphrased). Mark, a Diné individual with a physical disability, clarified that he did not want to be asked ‘how his disability happened’. I indicated that I understood his concerns and was interested in how people perceive physical disability, rather than in collecting information about the specifics of participants’ disability status. I reiterated that he could end the interview at any time, choose to not respond to any question and invited him to continue to let me know if any further unclear areas emerged.

Another strategy I used, I define as situational awareness[78]. In other words, I recognized that no one individual is the same as any other and adapted my response based on the environment, appropriate expectations based on my gender, age difference with the research participant, rapport I had with the individual and, in some cases, personal experiences related to my disability. My strategy was to remain silent, allow the individual to express their emotion, which helped me determine how to best respond to such situations with each individual. I have had the honor of mentoring alongside individuals whom I have observed in difficult situations and, in such cases, I tried to think how those individuals would respond.

Some participants welcomed sympathy, others did not seem to object to my sharing similar experiences as a way of validating their feelings, and others needed silence and a swift change of subject (see Kavanaugh & Ayres, 1998, for more details on how others transitioned to different subjects). In latter cases, I allowed the participant to

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[78] I have adapted the concept of embedded, localized ethics by Meskell and Pels, (2005). *Embedding ethics*. Berg

choose the direction of the conversation. Particularly with male participants, conversations shifted swiftly between perceptions and social attitudes toward disability and issues with healthcare or recommendations that that participant had about improving infrastructure. In other cases, Diné concepts of hozhò (harmony through balance) were often countered against experiences of stigma, discrimination and oppression in everyday life. Sharing such insights seemed to remind participants of traits they valued in themselves and allowed them to redefine their agency through providing narratives of resistance and resilience.

During my first interviews, I failed to recognize the use of humor, or –more succinctly— laughing at one's experiences as a potential way of discussing difficult aspects of physical disability. In her work with individuals with disabilities and their families, Rieger (2005) shows that the success or failure of turning the experience of disability into a moment of humor majorly depends on shared understandings of disability and a common sense of belonging to 'a' group, where jokes about one another would not be seen as offensive or hurtful. In her study, Rieger (2005) highlights that some parents felt that they could joke with their offspring about the latter's disability because their identity as a provider and their everyday engagement with the needs of the individual superseded the potential to offend. Others were more cautious and refrained from making jokes about their child's disability until their child indicated that they were open to it (Rieger, 2005).

It was only after initial review of my data that I realized the importance of this practice and the possible motives behind such actions. I myself was cautious about using humor, except if that practice was done by the participant first, and only if I knew them well, so as not to violate cultural norms of political correctness.

Talking about one’s experiences related to disability in a humorous way allows the individual to control how the narrative is framed. Individuals with disabilities themselves used laughter and their sense of humor to redefine their identity in relation to (perceived) social visibility of their disability (Rieger, 2005).

Rethinking the Value of Disability Research

Much of my first year in my graduate studies in the United States was consumed by my reflecting on concepts that were new to me, such as (self-)advocacy, (self)determination, and (self-) empowerment, which were prevalent in publications that I read about individuals with disabilities. These contributions emphasize the importance of including the voices of research participants in projects that concerned them. The work by Oliver (1992) produced some interesting, yet tough, questions for me, but helped me in reaching a decision about the value of pursuing a project on social perceptions of disability. His critiques lay not so much on the research foci in relation to disability, which, at the time, focused on examining policies for the integration of individuals with disabilities in the broader social milieu, but on the relationship between the researcher and their research participants: influenced by positivist underpinnings, researchers produced accounts of disability without acknowledging the agency of individuals with disabilities in the research process. The same, says Oliver (1992), occurs with interpretivist approaches which, while distancing themselves from the foci of other approaches, have yet to change the relationship between the researcher and the research participants.

A meaningful shift, according to Oliver (1992), requires the researcher being open about the motives of the endeavor, being aware of the power structures that shape the relationship between the researcher and the research participants, and changing how empowerment is defined, and most importantly by whom. Kitchin (2001) adds that an important part in this process of change in research on disability issues includes increasing participation of researchers with disabilities in disability related projects.

My internal deliberations on ethical engagements with historically disempowered groups intensified as I learned more about how a significant majority of indigenous scholars view(ed) anthropologists' interactions with Native American groups, to whom my interest in collaborating with for an ethnographic project on social perceptions of physical disabilities had narrowed down.

Influenced by Native American scholars (such as Metìs scholar, Adam Gaudry) who view research as colonizing endeavors because of their scope, methods and overall consequences on indigenous groups, I wondered if and how I could minimize "intellectual colonialism" (Gaudry, 2011, p. 114), i.e decontextualizing the knowledge that was shared with me and portraying the groups I worked with in a particular way, without thinking ahead of the consequences of what I write on the Diné. Certain instances were particularly challenging in this respect. During my fieldwork research, participants often discussed traditional knowledge as a key component of Diné perception of physical disability. Some explicitly shared their motives of doing so: Fiona shared that, while she was well aware of the concerns family members had about sharing knowledge about traditional practices, she wanted me to know as what I was writing would be read by others who could be helped in a similar way as she had been during very challenging times. Robert, a Diné service provider shared the following as I thanked him for participating in my project:

> it was actually therapeutic to like kind of, I don't normally talk about, um, my traditional side that I grew up with so(…)it was, like, um, cathartic to like be able to express it, cause you normally just refrain from talking about it.

A factor in the decision to share traditional views may have been how Robert felt about reactions that non-indigenous peoples have regarding indigenous knowledge:

> I guess in popular culture it's just kind of like an urban legend, like, Native American people have medicine men, and they have ceremonies, and they possess like a magic and they can do things, they curse people, and it's just like a really perverse, I really, take on the idea. And it's just always, I feel like the way things are now only, um, it could only really depend on, um, I hope that people will understand more.

Cases like this confused me because I did not know whose interests I should be safeguarding: It seemed that participants were sharing details about traditional practices that my engagement with indigenous literature cautioned me against publishing without carefully considering the outcome for indigenous peoples (Waziyatawin Angela Wilson, 2004). Part of the colonization process, I had learned, was failing to recognize that indigenous knowledge transmission practices differed from those of academics both in terms of transmission (oral vs. written) and in terms of why and how it was done. Fixico's work (2003)[79] on the social importance of stories and oral knowledge was prevalent in my mind, while the contribution of Tsosie (2002) had shown me alternative ways of approaching oral knowledge: as a valuable tool in the decolonization process, which should be treated with equal attention and care to concerns about land and human rights violations. Others [see Waziyatawin (2005)] contributed to my dilemma since they pointed out that certain knowledge (such as creation stories) have divine origins and should, therefore, not be shared with anyone.

At the same time, these participants wanted me to include these aspects of their perspectives, so if I chose to omit them, was I not stripping away their agency? Who was I to proclaim to know better how/when/and why stories should be shared, especially when participants explicitly encouraged me to incorporate these elements in my writing? Following the recommendations of Navajo Nation representatives, throughout this ethnography I discuss themes pertaining to traditional ceremonies in a general sense.

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[79] Fixico self identifies as Shawnee, Sac and Fox, Muscogee Creek and Seminole

Analysis of Findings

Thematic Analysis (hereafter TA) first emerged in the social sciences in the 1970s and has been widely used in qualitative research, and more recently in projects that focus on understanding health, in part because of its versatility and because of the opportunities it provides for researchers whose research projects yield rich descriptions to analyze a variety of phenomena. It became more standardized methodologically toward the end of the 1990s after Boyatzis' contribution published in 1998, which provided more standardized practices of making sense of data in the form of codes. Boyatzis (1998) tells us that the process of identifying a selection of codes that make up what is commonly known in qualitative research as a codebook, primarily depends on having the analytical skill to discern themes within data. According to Boyatzis (1998, p. vii) "a theme is a pattern found in the information that at the minimum describes and organizes observations or at the maximum interprets aspects of the phenomenon". Themes may emerge from the data themselves (inductive approach) or from theoretical contributions that a priori guide the researcher (deductive approach) (Boyatzis, 1998; Ryan & Bernard, 2003). In many cases, researchers use both the deductive and inductive approaches. According to Boyatzis (1998, p. 63) a code can be defined as "the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon".

In my work, examples of codes that were inspired by a deductive approach would include: ableism, productivity and/or personhood. Definitions of these codes were based upon literature I had reviewed prior to beginning my fieldwork; inclusion and exclusion criteria were determined based on theoretical contributions, while typical and atypical exemplars and, whenever applicable, ‘close but no’ criteria were established based upon findings during fieldwork. Phrases that I commonly heard in the field indicated what Ryan and Bernard (2003, p. 89) call indigenous typologies. Analytically, coding for these categories can help the researcher identify meanings that are not apparent (Boyatzis, 1998). An example of such a code would be the phrase commonly used among my Diné participants ‘disability can teach us things’. Usually, this phrase was used as a preamble to advance insights about other interconnected and culturally salient tenets, such as concepts of harmony and balance (hozhó), as well as constructs of respect and acceptance. While a theme can be a code (J.Maupin personal communication, October 23, 2018), codes may refer to concepts that are more specific than themes. As Dey (1993) stresses, the design of the research highlights the themes that the researcher is interested in examining, as do ethnographic interviews (Coffey & Atkinson, 1996), while Ryan and Bernard (2003) suggest that the transcription process is where the researcher throws him/herself into fully developing the analytical framework.

Concerns have been expressed about the reliability of Thematic Analysis (Braun & Clarke, 2014). Given that I performed all aspects of research (data collection, transcription, and analysis) I attempted to increase trustworthiness in a number of ways: my overall analysis was presented to the research team (committee chair and supervisory committee) and we engaged in conversations to determine applicability and validity of codes.

In determining themes and developing my code book (please see Appendix C for further details) I followed the six (6) steps identified in Braun and Clarke (2006). In what follows I outline the process: 1. Close engagement with my data: Initial codes were developed after extensive review of my data (transcripts, fieldnotes, memos). This process involved spending a period of time dedicated to finding patterns, meanings, and dissimilarities, which turned into themes and, in some cases, subthemes, which represents phase 2. The third step is the most exciting, time consuming and productive stage of analysis and revolves around refining my codes. This required me to define the themes, subthemes, and define my codes in order to move onto step 4, namely identification of the ‘bigger picture’ or the story that my data were telling me. Step 5 encompassed reviewing the entirety of my data a number of times. As I engaged in this process I identified themes whose importance I had failed to recognize while other data seemed less supported than I initially thought they would be, prior to completing the final step of the analysis, i.e. production of this written account.

As will have become clear to the reader, I have been working on a challenging topic with a population that is understandably hesitant to collaborate with anthropologists because of a difficult and painful past that has contributed to current contentious relationships. My awareness of this fact has shaped the content of this chapter. I now continue with a chapter that discusses a matter that is deeply personal to me, namely how my own identities contributed to the research process.

Conclusion

Responding to efforts to establish itself as a discipline, our field has established certain norms surrounding data collection practices. I suspect that most young anthropology students envision fieldwork as an endeavor that requires leaving all that is familiar in order to conduct research, as I did prior to embarking upon this research project. In this chapter I have offered a critical analysis of central concepts in our field: ‘fieldwork’ often does not meet constructed idea(l)s of travelling to a faraway place and studying a group of people who are seemingly distant from the anthropologist prior to his advent to the field. I collaborated with a group that considers the state that I call home (Arizona) their homeland. While I was raised in a country other than the United States and do not share any kinship ties with indigenous peoples, I have lived in the United States for a number of years now and, to an extent, share a similar social and political reality that my participants do. My work joins other contributions that have shed light on the disadvantages and value of doing anthropology in urban areas, and adds to analyses that focus on the dynamics of mobilizing in more than one fieldsites. Like Kurotani (2004), I felt that at times, my fieldwork was segmented into periods of intense activity and days where the pace of ‘doing research’ lulled and my efforts concentrated on identifying additional possibilities for recruitment. What I failed to realize from the onset of my endeavor was that data collection is not limited to conducting participant observation and interviews, but rather includes those moments that to me felt like an ‘intermission’ from doing ethnography (Wax, 1971; J. Maupin, personal communication, October 21,2018).

Much of my time when I was not conducting ethnographic interviews with Diné individuals with physical disabilities, families, and/or service providers and healthcare workers who self-identified as Diné/non-indigenous, was spent on efforts to establish trust: a difficult task when working on a subject that involves talking about personal experiences of physical disability, accentuated by the fact that I was collaborating with a population that has been studied extensively by anthropologists, but has often not enjoyed the respect they deserve. Indigenous scholars have described research practices have been described as colonizing (see Gaudry, 2011); others perceive interacting with anthropologists as a calamity (Deloria, 1988), as work contributes to the dehumanization of indigenous peoples and perpetuation of stereotypes (King, 2007).

Along similar lines, analyses reflect on how an increase in inclusion of research researchers with disabilities in academic endeavors can allow for a critical examination of power relationships in the field and yield important data, particularly in relation to the positionality of the researcher in terms of representing the experiences of individuals with disabilities (Oliver, 1992; Kitchin, 2001). My interest in disability was somewhat 'legitimized' in the eyes of gatekeepers and participants by my own personal experience with it. In the following chapter, I examine how assumptions about my identities (as a young woman with a physical disability whose background has differed from that of the United States) shaped my interactions with participants during fieldwork.

CHAPTER 4: WHY ARE YOU DOING THIS?: ON POSITIONALITY AND SHARING IN THE FIELD.

Introduction

The seed for this project was planted many years ago, during my first travels overseas. At the time, I had left Greece for brief study abroad opportunities in the United States and elsewhere. I observed great differences in infrastructure between the settings I had been exposed to in Greece and these new environments; however, I felt that the short stays in the United States (where I had always dreamed of pursuing studies in anthropology) did not give me enough information to evaluate whether the infrastructural provisions for people with disabilities went hand in hand with inclusive social attitudes.

I now recognize that my attention to cross-cultural observations, which have served as the starting point for my research trajectory, arose, in part, from the fact that I myself am a young woman with a physical disability, born and raised in a cultural setting that generally perceives disability as a personal matter and, therefore, conversations about the lived experience of disability and the joys, lessons, and challenges that come with it largely remain within the family of the individual with the disability, if that. In their ethnographic work on social perceptions of physical disability in two (2) Greek islands, Iosifides and Papageorgiou (2008) find that families discourage individuals with disabilities from leaving the house as they perceive that the stigma attached to disability reflects badly not only on the member with a disability, but also on the broader social network of the family. Negative social attitudes, coupled with infrastructural barriers affect social relationships, access to education, and employment: Twenty two percent (22%) of those participating (n=482) in their telephone survey declared that they would not form any social relationship with an individual with a disability, while thirty-one percent (31 %) note they would not form any professional relationship with an individual with a disability; seventeen percent (17%) mentioned that they had a close relationship/friendship with an individual with physical disabilities (Iosifides & Papageorgiou 2008, p. 21-22).

Most individuals with disabilities rely on associations targeted towards promoting inclusion for people with disabilities for gaining work experience and socializing, especially in tight knit, small communities as those described by these two (2) authors. Iosifides and Papageorgiou (2008) clarify that circumstances are better in large urban centers, however individuals with disabilities continue to experience discrimination and have to navigate substantial barriers to the physical environment. Comparing and assessing social inclusion of individuals with disabilities other than physical is difficult. As Dimitriadis et al. (2013) note there are no recent statistical data on how many individuals with developmental disabilities there are in Greece. Since the integration of Greece in the European Union in the 1980s the State has made considerable efforts to address gaps in education, healthcare, and integration of individuals with disabilities with the establishment of special education programs and care policies that are community oriented, rather than focused on institutionalization.

It is because of this silence that I was accustomed to and the differences I observed in the United States that I grappled with the feasibility of my study idea and the ethical implications of working with individuals with disabilities, let alone individuals with disabilities who also self-identified as Diné. I was interested in the social production of disability through attitudes, and in uncovering the correlation of attitudes with infrastructural barriers.

Representation of Disability in Academia

On an April morning in 2018, I find myself looking up at the sun, listening to the hustle and bustle of students and occasionally focusing on the sound that trees make in the wind. This is a brief break before I cruise through the campus areas looking at the signs of buildings and periodically checking whether or not the automatic mechanisms that enable individuals with disabilities access to spaces are working. When doors open, I am reminded of why myself and several of my friends call these ‘magic buttons’. I orientate myself and think of the meeting ahead, with one of the most influential gatekeepers for my work so far. The conversation begins with the usual questions about my research project (to which I gave my well-practiced answers); at some point in the conversation, the gatekeeper asked me why I am doing this project and why this is important.

It was perhaps the quiet of their office, their informal demeanor, and/or the fact that I had met them through a liaison with whom I was acquainted as a student at my institution (Arizona State University) that led to my decision to divulge further details about my personal experience with physical disability than I had with any gatekeeper at that point. I responded saying that it was of academic interest to me, of course, but that I also had a personal connection to the subject. While the gatekeeper patiently waited, I continued:

> I am not indigenous. I cannot fully understand what that is like (to be indigenous) today, but with regards as to why I am doing this, I come from a very small community in a country where people with disabilities are treated differently, so I have always been interested in how culture shapes how we think about things (paraphrased)

The gatekeeper proceeded to ask me what I meant by differently, to which I replied that there is limited support and accommodations for individuals with disabilities, legal frameworks for the protection of individuals with disabilities are rarely enforced, and there is very little infrastructure in place for people with physical disabilities in Greece and ended: ‘things are changing but we still have a lot of work to do”. The gatekeeper pondered on what I had shared and, after validating the importance of my story, continued to tell me something along the lines of:

> I appreciate your honesty. As you say, you are not indigenous, but you should share your story with the people that you are interviewing. That way they can relate to you. Family, human connection and sharing experiences like that are very important for us Native people.

Upon concluding the meeting, I reflected on what had led to my hesitation to share a social, legal, political, and infrastructural reality that I had experienced for many years until I left my country of origin. I would argue that history and (ongoing) social and political battles for recognition of our rights to accessibility, inclusion and full participation in social life have framed the way we—as academics with disabilities—talk about this aspect of our lives. In the United States, individuals with disabilities have been institutionalized, experienced segregation, and/or forcible sterilization, and have been stripped of their voices in crucial decisions made about their lives (Wehmeyer et al., 2000; Barnartt & Scotch, 2002). As Linton (1998a) notes, the deep rooted and long-standing social, political oppression and economical marginalization that individuals with disabilities have endured, and continue to experience, goes hand in hand with the availability (or lack thereof) of infrastructure and support networks. These social and infrastructural barriers have affected opportunities of access and retention in important areas of social life, such as education or the workforce (Linton, 1998a).

Despite an extensive overview of literature when I entered advanced higher education, I was able to find only a few analyses that focused on how the personal lived experience of disability shapes our research practices, which may relate to inequities in education that I have discussed in the introductory chapter of this ethnography. The dearth of academics with disabilities doing fieldwork may also very well be because of the nature of research itself. Fieldwork sometimes requires travel to distant locations away from home, in contexts where support systems cannot be a priori planned out (Bradley, 1997). Howell (1990) discusses the difficulties anthropologists across the world experience with regards to access to professional medical care during their fieldwork. It is, therefore, not surprising that researchers with chronic illnesses ponder over the feasibility of doing fieldwork (see, Bradley, 1997, for more). In my case, my physical disability played a role in my choice of fieldwork locations, as I was aware that the Navajo Nation does not have the extent of infrastructure needed to facilitate the research process, and that my own resources at this time could not secure the consistent support needed when navigating inaccessible spaces.

The silence surrounding the importance of disability in fieldwork, however, is an indicator of something as equally important as practical considerations that inform our research design: norms, cultural constructs, and perceptions in current academia that shape ideals about research practices (Bradley, 1997). In anthropological traditions, the body of the ethnographer is predominantly male, White, physically robust; this image is reinforced by the perceptions that most fieldwork novices have about the field itself: the fieldworker eagerly sets out to explore it and metaphorically conquer it through *his* perseverance (see Bradley, 1997). Similar stereotypes on the fieldworkers' performances pervade other relevant disciplines (see Hall et al., 2002, for more).

As anthropologists, we have failed to take into serious account the ableist underpinnings that inform the experience of fieldwork, which has led to, and continues to perpetuate, the marginalization of voices of fieldworkers with disabilities. Academics with disabilities have contributed toward this exclusion of our own voices, as it has taken us some time to challenge epistemological conventions surrounding research practices. This may be because sociopolitical, historical and personal circumstances have undermined the value of analyzing our own personal role in our research (Tregaskis & Goodley, 2005). As Kasnitz notes, she was cautioned against doing fieldwork on disability: “because studying a group to which you belong may not provide you with the appropriate culture shock” (Kasnitz & Shuttleworth, 1999, p. 15); or, “you can’t study yourself, at least not for your first project” (Kasnitz & Shuttleworth, 1999, p. 3).

As scholars with disabilities, we have engaged in silence regarding the role of our very own experience with a disability in conceptualizing, carrying out research projects, and analyzing data (Tregaskis & Goodley, 2005). This could be for many reasons, including the fact that research opportunities do not allow us to critically analyze our identity performance and be challenged to realize why we do things a certain way by others who have a different experience (Tregaskis & Goodley, 2005). Tregaskis and Goodley (2005) highlight how conversations about their identities as a researcher with a disability and an able-bodied researcher respectively led to many fruitful conversations about how their identities shaped their perspectives and knowledge production practices throughout their research collaboration. Part of their academic partnership, they say, included pushing the researcher with a disability (Tregaskis) to recognize that her disability served as an opportunity to relate to research participants and the data in different ways than her able-bodied, male collaborator (Goodley). Her journey involved realizing that her silence on the subject of her identity was part of engaging in defense mechanisms: namely, overcompensation and (or as a means of) avoiding conversations about the implications of her disability openly “because of fear of seeming vulnerable, or due to her concerns of self-disclosure” (Tregaskis & Goodley 2005, p. 366). These normative, ableist discourses frame the social/academic milieu within which the ethnographer is called to operate, as an individual, pedagogue, researcher and writer. In an insightful reflexive analysis, Bradley (1997) discusses the difficulties she faced while conducting ethnographic interviews in western Kenya. Part of her challenge, she says, was: “I did not want to accept the limitations diabetes and insulin placed on me (and) partly because I was afraid I wouldn’t meet the standards of fieldwork ethic I had internalized” (Bradley, 1997, p. 7). Bradley continues: “Like other features of the capitalist society (…) fieldwork is guided by a work ethic. The fact that the day is exhausting is no secret (…) there is rarely the suggestion that it should be done any other way” (1997, p. 4-5).

In her work with educators of various rankings in universities of the United States and Canada, Brandão Dolan (2018) highlights how internalized ableism is intertwined with current expectations of productivity among academic circles. Faculty are expected to obtain prestigious grants, do research, mentor and teach while institutions are struck by financial pressures that have lessened the number of faculty serving a growing population of students. Amid this climate of general pressure, faculty members with disabilities go to lengths to conceal their disability from their peers and those higher in academic hierarchy. A senior faculty member shares:

> People don’t know how to act around disability. It’s sometimes easier not to talk to my peers just because it’s so hard to make them understand. I don’t want people to feel sorry for me or that I can’t do some aspect of my job. I’m trying to be promoted. I really want people to think I’m doing a good job. I am doing a

> good job, but I don’t want them to know that sometimes it’s a struggle more than others (Brandão Dolan, 2018, p. 87).

Research on the effects of concealability on overall health show that the effort to keep conditions hidden has negative effects on physical and emotional health, contributing to illness and mental health issues (Santuzzi et al., 2014). And yet, those with invisible disabilities have to carefully consider whether the benefit of social support, particularly in professional environments, outweighs the risk of experiencing prejudice and discrimination when making decisions about disclosure (Chaudoir & Quinn, 2010; Acemoglu & Angrist, 2001). This aspiring tenure track professor shares:

> I had fantasies of getting tenure or getting a real job. I mean, I used to be much more nervous about revealing [my disability, so I] worked harder and I covered it up. I was on a tenure track and once let it slip to a member of my hiring committee that I was struggling with [the side effects of my disability]. Because the school was located in a remote area, they had trouble to find decent hires. Her comment in response to my revelation was, “Oh, you know, we always get the damaged goods. (Brandão Dolan 2018, p. 111).

Titchkosky (2003) reveals that following the revelation of her disability, fellow academics doubted her decision-making capacity and professionalism. In his narrative, Murphy (1987) discusses how disability, for him, carried the risk of being excluded from a realm that was central to his social performance—academia—and of returning to a socioeconomic status that he had worked so hard to dispel. Furthermore, it signaled the loss of many identities upon which he based how he perceived himself and his social roles. In his moving and poignant analysis of his experience with a physical disability acquired later in life, Murphy (1987) demonstrates how the visibility of his disability caused for renegotiation of his role(s) and relationships in academia. He was met with fear, hesitation, praise, as well as surprise that he could fulfill his academic duties. Like all individuals with disabilities, the scholar who self-identifies as a member of that community has to navigate disabling infrastructural barriers, the relentless drive to meet socially constructed epistemological standards, as well as broader social perceptions about people with disabilities.

As I have shown in previous chapters (Chapter 2), dominant definitions of meritocracy in the United States place personal responsibility on the successful fulfillment of social roles that promote advancement, which in these discourses is equated with maximizing productivity (Goodley, 2014). Academia is hailed as a space of entrepreneurship, advancement of knowledge, and promotion of diversity. Yet, research shows that women and people of color have to navigate the additional stress of systemic inequities in addition to their responsibilities as faculty members (Hendel & Horn, 2008). Particularly those whose minority status intersects with other minority identities, spend more hours working toward fulfilling their professional obligations because of overburdening (Muzzin et al., 2008).

The bureaucratic processes and monetary concerns of addressing accommodation needs for employees in academia coupled with policies that present elusive concepts (for example diversity) as well-defined contribute to less opportunities to critically think about how disability can be actively addressed as a diversity concern (Brandão Dolan, 2018). The social values of diversity and inclusion that are so crucial in formulating social discourses in our era portray variability of the human experience in a certain way, which fails to acknowledge the wide range of disability experience(s) (Davis, 2013). Certain conditions are too much for the public eye, evoking social acknowledgement once the sufferer has ‘overcome’ the disease, and is hailed as a hero ready to move on with life. I would also add that seeing the bodies (scars and all) may remind us of the limitations of our medicalized responses and interventions (Davis, 2013; Goodley, 2014). Access to medical care, technological progress and the overall pharmaceuticalization of disability, open up new conversations about the social definition of ‘(ab)normal’ and shape social performance expectations (Biehl, 2007a; Goodley, 2014).

Interactions With Research Participants

This paper is a product of many conversations with mentors and friends who took it upon themselves to show me the value of self-reflexive contributions. These conversations also led me to consider an important ethical concern for me both in my role during interviews and other engagements with my research participants, as well as in my role as a writer: as I became more and more immersed in the field, I asked myself what right I had to not disclose details about how my culture informs my experience as a woman with a disability. If I was asking research participants to share their reflections, which sometimes involved conversations about pride, developing new skills and knowledge, anger, sadness, and vulnerability, how could I not return the trust that they have shown me?

The foundation for reflexivity as a concept and methodology in the social sciences was established in the 1960s when various contingencies that reshaped anthropology occurred: firstly, anthropologists began realizing that fieldwork cannot be likened to methodologies that other disciplines use. In the United States reflexivity proliferated in the 1980s as access to the contributions of French poststructuralists increased (Marcus, 1994). Scholars began to rethink the value of standardization in ethnographic methods. In addition, anthropology began to acknowledge that its history is deeply entrenched in colonization. Finally, seminal writings (see for example contributions by Clifford & Marcus, 1986; Clifford, 1988) which critiqued anthropological practices began to include critiques about the process of writing in anthropology. This push signaled the shift of anthropology from a discipline that documented ‘culture and history’ to a field that critiqued these concepts (Marcus, 1994).

As a young scholar with a physical disability, I have grappled with a conundrum similar to that in Tregaskis & Goodley (2005) about the value of acknowledging the specifics of my own positionality in regards to the research and writing processes. Haraway (1988) encourages us to critically think about the interrelationship between identity and sociopolitical circumstances that shape how we think about knowledge.

Feminism has been an integral part of highlighting reflexivity both on the level of theory and on the level of data collection methods. The focus of feminist contributions toward identifying power structures have intellectually pushed anthropology to examine how power affects the relationships that we build with research participants (Wolf, 1996), as well as how positionality shapes the process of analysis of our research findings (Devine & Heath, 1999). More recently, feminist approaches have critiqued contributions that have focused on thinking about gender for overlooking power struggles that women of color and indigenous women face. Black feminists argue that much of the focus of White feminists has been to identify sexism without acknowledging how racism intersects with gender inequalities. The issue is not only that Black feminists have not been included in feminist studies to equal extents as their White colleague. It is also a matter of countering analytical categories that are central to feminist theory (such as patriarchy) and yet do not do justice to the complexity of the experiences of women who come from diverse backgrounds (Carby, 2007). Babb (1984) tells us that indigenous feminists in India ask whether feminism can ever be dis-engaged from knowledge frameworks that are Western in scope. Native American feminists critique feminist approaches in North America for failing to acknowledge the impact of colonization on theoretical frameworks. Smith (2017) tells us that polarization within feminist scholarship on issues of race from Black feminists as well as on sovereignty from indigenous feminists maintains rather than challenges the power issues that both groups are so diligently working toward identifying and minimizing. Similar concerns have been shared by feminists with disabilities. Feminist contributions on reproduction and sexuality, for example, have failed to look at the particularities that women with disabilities have to navigate in order to perform their sexual identities and secure equity in reproductive rights (see Chapter 1 for further details on these issues). Feminist frameworks position women with disabilities ‘between a rock and a hard place’, as they are called to balance between conflicting identities. To discuss gender would silence disability and to critically examine disability minimizes the complexities of gender performance that some women have to navigate (Lloyd, 2001).

Reflexivity has been critiqued as being ‘mere navel gazing’ (Okely, 1992, p. 2), while engaging with our role in the production of knowledge through our interactions with our research participants in our scholarly work somehow seems to be transgressing the boundaries between divulging information that is personal, and (therefore, to who oppose it, irrelevant) to the research process and doing scientific research (Okely, 1992). Drawing upon Robertson’s (2002) critique of positionality as ‘self-stereotyping’ (p. 789), I wondered: when I identify as a young woman, international scholar, and individual with a physical disability in my research, publications and pedagogy, am I opening up a dialogue about what these identities mean, or am I pigeonholing myself and allowing others to engage in stereotyping my experience and the experience of others based on my use of these terms? Robertson’s (2002) examples and argument also highlight that the identities that make us unique may not have the same meaning for the writer as they do for the audience(s) (p. 788-789).

After much deliberation, I would state that, for me, writing about my experience as a young woman with a physical disability, of Greek origin, in the field can serve toward expanding knowledge of issues that need to receive further attention in the field of anthropology, such as those I elaborated upon in the previous section. While I consider(ed) the danger of stereotyping, I feel the conversation needs to begin somewhere, even if presented in a way that is read and taken in a different way than that intended.

The fact that English is not my native language and that I inserted that I am from Greece in my communications with a number of gatekeepers and research participants signified to them (and sometimes myself) that I am foreign to the settings that I am navigating. More often than not, my difference and distance from them has served as a starting point for interesting conversations about a variety of themes that are relevant to my research, including interactions with doctors, systemic challenges they face in relation to healthcare settings, and the effect of policies on the provision of services to individuals with physical disabilities. I realize the privilege that these identities bring with them: they allow me to have discussions about another sensitive issue that informs indigenous reality today; namely, the history and ongoing practices of colonization in a way that garners insights about how my indigenous participants define ‘whiteness’, problematic stereotypes about indigenous peoples, politics etc. I am not so naïve as to say that my identities as an anthropologist and a Caucasian are forgotten in my interactions with research participants, but I would argue that my performance as a person who could not be identified as an American, led to assumptions about my lack of knowledge of what colonization is—and looks like in everyday life— which, in certain instances, yielded detailed accounts of how colonizing practices pervade the provision of services.

Throughout my fieldwork, my disability has been at the epicenter of interactions with research participants (prevalent in some cases, less obvious in others). The mobility device(s) I use, my body, and my behavior in relation to my disability have become starting points of interesting conversations. One of my first interviews involved interacting with a young Diné individual with a physical disability, who I will name Mark. I paraphrased his insights. When I asked him how one can keep healthy, he replied: “slow down, eat healthy, exercise”. Pointing to my assistive device, he continued: *“*I did everything I could, eat healthy, exercise, so I don’t end up like you”. Sharing his experiences with a physical disability, he recalls how he was: “pissed off at himself with the pain” and “could not sit in the hospital*”*. While this is probably the most direct comment I have heard in relation to my being in a chair, sentiments of fear about being, or ending up, in a wheelchair are quite common.

It seems that the use of a mobility device, for some of my participants, highlights the finality/irreversibility of their disability. Charmaz and Rosenfeld (2006) discuss the impact of technology on performance of disability identity and (self) representation: The visibility of assistive devices means that the user has to renegotiate mobilization, agency and (self) disclosure in relation to disability. Acknowledging the need for an assistive device means reconciling with making your disability public (Charmaz & Rosenfeld, 2006). After sharing how people with disabilities have been the focus of annihilation efforts throughout history, John, a non-indigenous healthcare worker, asks me if I have had a disability since birth. I provide an excerpt from our interview together: “nothing personal but like were you, since your birth were you in a…(pointing at my assistive device)?*”*. When I respond, he continues:

> So, for you it would be much more difficult to hide those disabilities, I think from perception is if you look normal people don't assume you have a disability. I

> don't(…)that's never come across my mind. I'm, like, you don't have a disability but it's because I'm looking for something physical but then I hear people talk about anxiety, or that they're depressed in that, you know ,is equivalent to having a type of you a mental disability, so yeah I do have that perception, is, that when people walk in and they are perfectly normal, I'm like what are you doing here?.

For James, a Diné participant with a physical disability, one of the hardest parts of coming to terms with his condition is change, or as he clarifies, change that does not match aspirations. Comparing disability to a journey and the hunt for resources to being on an island, James states:

> you're gonna realize that the journey may be difficult to get to the next island but you're searching for what you need ,cuz this place does not have what you need to survive and there's a lot of fear involved in that ,you know, people, people are, it's not so much that they're afraid of change as I think it's more that they're afraid that it's not gonna be the change that they want .

He laughs and continues:"it's not what they're expecting or were hoping it would be so you have to accept certain things the way they are and certain things you have to change", and concludes: "Well I know you understand, better than I do".

In April 2017, I arrive early at the designated meeting area, and am thankful that I had the foresight to provide a description of myself to the young Diné individual with a physical disability who I will call Bret. I reflect that it has become customary for me to include 'I use a red mobility device so I am hard to miss' when finalizing plans to meet with participants; my device becomes an identity marker that I would refrain from inserting in the beginning of my fieldwork, but as time passed, I realized that some participants associated my ‘legitimacy’ to ask questions about disability to the fact that I have one myself. In some cases, my mobility device served to strengthen relationships with participants through a shared experience of being exposed to infrastructural difficulties, as I would discover upon the arrival of Bret to our meeting area. As we navigated toward the room where the interview would be held, we discovered that the pathway was too narrow for me to enter the room without scraping the wall. Those who know me well will be able to guess what happened next: I apologized and joked that I would leave my mark in this world one way or the other. Bret laughed, and said something along the lines of: “you know, I wish all of them could be in our shoes, they really don’t realize that they don’t make it easy”, after which I proceeded to share stories about my driving skills (or lack thereof).

The use of the Us/Them dichotomy in this instance is a practice of resistance, a call for disability to become visible, a social concern in the public sphere (see Oliver & Barnes, 2012; Patterson & Hughes, 1999, for more). Medicalization of health and illness have contributed to viewing disability as a merely personal issue, a health concern that the individual needs to address (Oliver & Barnes, 2012). Furthermore, focusing on external barriers that the individual needs to navigate removes the possibility of examining disability as an *experience*, which encompasses choices on how to respond to oppression, the emotional and physical toll of discrimination, as well as recognizing disability as a source of pride (Patterson & Hughes, 1999); an identity that involves resistance: when individuals with a chronic illness/disability exercise their agency to define themselves without the interventions that are there to decrease or eliminate the marker of difference (i.e. disability), responsibility, blame and questions arise as to their resistance to comply with normative performance standards (Biehl, 2007b; Goodley, 2014). Rather than thinking of disability as a personal tragedy (Oliver & Barnes, 2012), this narrative situates disability as a product of shared responsibility that individuals other than the person with a disability have in creating social contexts and physical environments, which reinforce exclusion.

At the same time, Bret’s narrative highlights a desire to express solidarity. Choices that people make with regards to highlighting their similarity or difference in relation to the (perceived) Other reveal determining the benefits and risks involved in aligning or distancing oneself from the dominant group (Wendell, 1996, p. 118). As an act with political and social implications, solidarity challenges power structures that individuals with disabilities have to contend with: emphasizing shared understandings and experiences indicates, not only to those with a disability but also to those who do not have a disability that concerns that are overlooked in everyday interactions are important and that the voices of individuals with disabilities have the power to bring forth change (Wendell, 1996). I find Bret’s last statement particularly poignant, since it encompasses strong emotions: on the one hand, frustration due to exclusion from social spaces and physical (and emotional) strain from having to overcome barriers, and on the other a sense of wanting others to share the experience to see not only the difficulties, but also the fact that disability just *is:* neither positively, nor negatively charged; but a human condition whose social and political implications depend on what we and others around us make of it.

Conclusion

My personal experience with a disability and upbringing in a context other than that of the United States have been central in determining my choice of research topic and the approach I have taken. From a very young age I reflected on why there is a lack of conversation surrounding disability in Greece. The silence surrounding the variation of experiences and needs that individuals with disabilities have in Greece is deafening (Dimitriadis et al., 2011). My interest in asking questions about how definitions may vary within and across cultural contexts stems from the realization that social attitudes are intertwined with systemic structure, as well as the physical, economic, and political environment. As in other parts of the world, individuals with disabilities in Greece have to navigate exclusionary practices spurred by inaccessible infrastructure and intense stigmatization. Studies that I have examined in this chapter highlight that a large percentage of Greeks see little value in forming close relationships with individuals who have disabilities, while employment opportunities are limited, a situation that is exacerbated due to employers' misperceptions about disability (Iosifides & Papageorgiou, 2008). The home is the primary area of mobilization for the individual with a disability in order to avoid negative associations with the broader family due to disability status (Iosifides & Papageorgiou, 2008).

Practical considerations as well as social norms have barred equal representation of researchers with disabilities in academic circles. Data demonstrate that very few individuals with disabilities remain in doctorate granting institutions. Indicatively, according to data by the National Science Foundation only seven percent (7%) of a total of over thirty thousand (30,000) PhD recipients reported having some form of disability[80]. Epistemological expectations (particularly in disciplines like anthropology), as well as infrastructural barriers can create challenges for those aspiring to meet academic milestones. Often, projects of interest to those pursuing education in fields related to the humanities and social sciences require fieldwork in locations that are inaccessible, and lack appropriate support services to accommodate researchers with disabilities (Bradley, 1997). Researchers with disabilities have highlighted that hegemonic discourses in the academic environment complicate the matter further: social expectations of hyper-productivity (Bradley, 1997) fear of the implications of disclosure in processes of hiring and maintaining an academic position (Brandão Dolan, 2018), as well as internalization of ableist/disablist attitudes (Tregaskis & Goodley, 2005) contribute to silencing scholars with disabilities.

Conversations with trusted mentors, engagements with gatekeepers and questions, insights from participants convinced me of the merit of examining how my positionality, primarily in terms of my physical disability, could provide fruitful opportunities to critically think about interactions in academia, as well as with research participants. Assumptions and reactions to my disability revealed how participants perceived risk and

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[80] https://www.nsf.gov/statistics/2017/nsf17310/data.cfm

how they determined whether or not to disclose disability status, served as a moment of distancing, as well as an occasion of solidarity. My physical disability is readily visible to others, for some made more apparent by the use of an assistive device. In such instances, I seemed to represent a ‘dangerous’ state: the visibility of my physical body, accentuated by the presence of an assistive device, signified irreversibility of disability. Drawing upon their perceptions of my disability, participants disclosed the practices they followed to avoid ‘walking in my shoes’ at all costs. For others, my personal experience with disability was recognized as an effective way to develop rapport with a population with which I had no ties prior to the beginning of my research. Realizing that I am privileged in comparison to others (regardless of disability status), I carefully selected how, when and to what end to express that I shared an understanding of the reality that those participating on a daily basis. There were times, however, when my disability serves as a starting point of solidarity. Particularly, Diné individuals with disabilities and family members shared that they were certain I understood their difficulties, and proceeded to clarify why research projects (particularly when led by researchers with disabilities) are so important in promoting empowerment and (self) advocacy.

CHAPTER 5: CROSS CULTURAL PERCEPTIONS OF PHYSICAL DISABILITY

Introduction

Disability 'talks': I am using this phrase to highlight an interconnected duality. On the one hand, the phrase refers to conversations I have had throughout this fieldwork research about the constraints and potential of living with a physical disability. These conversations reveal that thoughts on what it means to be 'able', and 'normal' were focal to understanding one's personal positionality in the social milieu and contextualized perceptions of, and engagements with, others. Cultural norms and teachings (as Diné participants refer to social regulations guiding our behavior) of individual and collective responsibility and in(ter)dependence were critical in bilateral understandings of Diné and non-indigenous identity. A closer look, however, tells us that—as a social phenomenon— disability seems to have agency in itself. Participants' narratives show us that, as a term, disability (and others that have accompanied individuals with disabilities throughout the emergence of disability as an issue of public concern) have connotations, both positive and negative, that share a common characteristic, as identified by a number of scholars (Longmore, 1985; Zitzelsberger, 2005): once an individual is identified as having a disability, this term begins 'talking' to others about the person who embodies it, despite efforts that individuals make to 'take the focus off' of the physical and social implications of disability on their everyday life. I, therefore, begin this chapter by highlighting some reflections on terminology, which offer insights as to the strategies that participants use to 'talk back' at assumptions about the experience of disability. Situated within a broader framework of stigma, and moments of social inclusion/exclusion, the connection disability to empowerment, disability also ‘talks back’ at social marginalization that individuals with physical disabilities have faced, at social and infrastructural barriers, which exacerbate challenges for equity in participation in social and cultural life.

Notes on Terminology: Disability ‘Talks’: Reflections on the Interconnectedness of Words and Social Attitudes

Labels

Early on in my fieldwork I realized that discourses around labeling disability would be an important aspect of my analysis. Reflections about terminology encompassed a variety of responses. Other than participants who felt that the choice of terms did not matter in the context of discussing social perceptions of physical disability, some participants (across all sample categories) expressed that attention to language indicated a commitment to inclusion. Others commented that these terms made them feel frustration, and/or anger. Yet others, prioritized actions over an emphasis on the implications of language for individuals with disabilities. No matter what the reaction, all responses were embedded within rich descriptions of social engagements with others.

For some, the pursuit of appropriate terminology is futile, a sentiment that springs out of the realization that it would be difficult to reach a consensus, rather than from the belief that the quest for an appropriate term is unimportant. Kudlick (2003) associates this lack of consensus to the fact that as a social category 'disability' describes a variety of experiences that are all the result of social and historical processes. Frameworks that help define disability (such as legislation) are purposefully broad, perpetuating the allusiveness of the concept and preventing from constituting terminology that is shared within a specific social context. Zola (1993), however, cautions us that the reasons for confusion are due to complex social and political dynamics that relate to the emergence of disability as an issue of public concern. For him, the experience of disability is shared by individuals across ages, gender performance, class, cultures, and socioeconomic strata preventing the establishment of a shared understanding about the implications of the identity of disability. Unlike other social identities, he adds, individuals with disabilities may spend a significant amount of their time throughout their lives trying to actively conceal the effects that disability has on their everyday life and social relationships.

The People First Approach and the Identity First Approach to Disability

The birth of the People First approach is attributed to a group of individuals with disabilities in Salem, Oregon, who began publicizing disability issues using the phrase 'we are people first' in the early 1970s. In 1974, it was renamed to People First and advocated for the deinstitutionalization of people with disabilities and greater equity in social life (Edwards, 1982; Perske, 1996; Lehr &Taylor, 1986). Imbued with connotations of (self) empowerment for individuals with disabilities, this perspective gained ground after the intellectual contributions of theoretical approaches that emphasize the social construction of disability and focus on understanding the role of social and infrastructural barriers in defining ‘disability as a problem’. The principle of people first language has been hailed as empowering individuals with disabilities (Snow, 2005). Gernsbacher (2017) defines the people-first approach as

> the structural form in which a noun referring to a person or persons (e.g. person, people, individual, adults, or children) precedes a phrase referring to a disability (e.g. person with a disability, people with blindness, individual with intellectual disabilities, adults with dyslexia, and children with autism). (p. 859).

As Joan Blaska notes (1993):

> the philosophy of using people first language demonstrates respect for people with disabilities by referring to them first as individuals and then referring to their disability when it is needed. This philosophy demonstrates respect by emphasizing what people can do by focusing on their ability rather than their disability and by distinguishing the person from the disability (p. 27).

This term raises awareness of a long-forgotten fact: namely that individuals with disabilities share the same humanness as everyone else (Mackelprang, 2010) Snow (2005) draws our attention to the fact that adjectives that have commonly been used, such as ‘handicapped’ or ‘disabled’ are used to describe spaces or objects that are not performing according to their specifications, rather than humans. The people first approach has been adopted both in formal structures (such as legislation) and in informal parlance.

For example, the United Nations uses the person-first approach in their UN Convention for the Rights of People with Disabilities and organizations in the US whose work focuses on educating the public about disability issues promote the use of this approach (Schur et al, 2013, p. 6). Medical schools and other professions that fall within the US healthcare system provide guidelines on how to interact with clients who have disabilities, which also include trainings on terminology implications. Suggestions include replacing ‘confined to a chair’, ‘lame’, ‘disabled’, with ‘person who uses wheelchair/crutches’, ‘person with a disability’, or ‘person with limited mobility’. For individuals who are blind, materials propose using ‘person who is blind’, ‘person with low vision’, ‘person who is visually impaired’ in lieu of ‘the blind’, ‘afflicted’ (Limpscomb, 2009, p. 22). Language referring to individuals with hearing difficulties denotes the importance of gradients: those who have no hearing are referred to as ‘person who is deaf’, individuals with some hearing are referred to as ‘person who is hearing impaired’, while those with acquired difficulties are referred to as ‘post-lingually’ deaf (Limpscomb, 2009)

Reflections regarding terminology pervaded the narratives of participants regardless of sample category. Janis, a non-indigenous service provider, tells us:

> it's interesting that you mention that, cuz we've been, professionally we're having lots of conversations within the disability community about terminology and whether that term is, is needed or is there something better and so I always say, you know, I think there's something better we are just trying to find that you know? (…) so people- first language is what I've been trained to use because that's been the most commonly used you know kind of training or guideline within the disability community so when I started working with people with disabilities that's what I was trained to use, you know, and so I'm, at that time, you know fourteen, fifteen years ago that was my first time of of hearing language that had specifically been I've been strategic have been thoughtful about getting rid of old words getting rid of language and you know hearing words like cripple or gimp or you know those are very painful (…) so when I came to and learned about people first language it was the first time I had really heard people say, those words are horrible, those are negative those are not true, they're stereotypes let's get rid of them, and so I really felt so happy and glad that there was you know a tool for people to use to say no longer do we need words like that we don't need the word handicap, we don't need mentally retarded we don't use cripple or gimp and it's so for me it was like wonderful you know.

A number of healthcare workers and service providers connected their concerns over using appropriate terminology to their training, personal ventures into literature and (self) advocacy efforts. Training sessions, I was told, emphasize the development of a 'positive' self- image toward disability. This approach pervades many of the spaces of disability related organizations I collaborated with: upon entering these social spaces one is struck with a wealth of information meant to foster a sense of community among individuals with disabilities: Pamphlets regarding voting rights and education, training sessions on how to secure employment as well as support groups for individuals with disabilities and workshops on how to ‘manage’ disability related symptoms. My research shows that this narrative begins with being mindful of not using words that have negative connotations attached to them. The people first approach was an important part of this conversation. Elena, a non-indigenous service provider, states:

> I would try to say person with a disability cuz um I think it’s more respectful yeah (…) differently abled, yeah I just heard that pretty recently and I thought it (…) you know, the person who was talking about it is um (…), they just said you know I like it better because it doesn’t have a negative connotation(…), um where dis usually is something like not or can’t or whatever, not working you know so disabled in like if you didn’t use it for a person I mean a machine does it work? So, um, yeah, the more positive terms for, um, anything is good for me.

Elena continues: some of my friends use terms and I am like ‘you can’t say that’, and they look at me like I’m crazy you know or whatever, but I just try to s, like when I first tried to, you know, started maybe going to some advocacy and self-advocacy meetings I was very in the person’s face if they used the word retarded you know not calling somebody else retarded, but being like ‘I was so retarded’ and I would be like ‘what? No!!’and yell at them and they’d get all like she’s crazy. Now I just try to say ‘can you use a different term?’ you know ‘I know you’re not trying to be derogatory towards anybody but that has been a term that has been used (…) as a really mean label for somebody with a disability um (…) and so I feel like if you can try to remember.

As individuals with disabilities share their experiences and voice their concerns, discussions on connotations of terminology have proliferated: Jenny Morris (2001) a disabled[81] feminist argues that the ‘people first’ approach serves to set individuals with disabilities apart from the experience of their disability and from other minorities. For example, she urges us to think that we do not refer to sexual orientation, race or any other identity using the term ‘with’. For both Morris (2001) and Mackelprang (2010) the addition of the term ‘disability’ onto one’s identity brings back memories of looking at disability as a static label through the lens of medical discourses. Sinclair (2013), who self-identifies as autistic, maintains that the ‘people first approach’ perceives disability as an appendage which the person could do without. Morris (2001) cautions us that the phrase ‘person with a disability’ is imbued with power of those who do not have a disability over those who do. She sees this power in the fact that this term has been adopted by research agendas, policies, and everyday discourses that do not place disabled people at the epicenter of such conversations. The first step toward changing this power dynamic according to Morris (2001) is to embrace disability identity. Professional associations in the US have adopted this approach. For instance, the US National Federation For the Blind rejects people first language on the premise that it conveys ‘defensiveness’ and ‘shame’ toward disability.[82].Sinclair (2013) takes it one step further

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[81] I use this term to refer to this author as she has indicated such preference.

[82] See nfb.org/images/nfb/publications/bm/bm09/bm0903/bm090308.htm, in Schur et al (2016*). People with disabilities: Sidelined or mainstreamed*. Cambridge University Press, p. 7.

and tells us that the fact that there highly politicized discussions about terminology reveals a shared social misperception that disability is a phenomenon that is ‘out of the norm’. It is so imbued with bad connotations, he tells us, that we do not know where to place it or how to talk about it. Janis tells us that this space of confusion can generate productive conversations:

> As identity has come about the last couple years, you know, people have started having that conversation. I thought that it was a good conversation to have and I understood why groups like individuals with kind of learning disability started people first language, cuz they said I don't want to be called those horrible words. I also understood why autistics would come forward with identity first language and say ‘listen this is okay to be me it's okay for me to claim it and identify as it, there's no shame, there's no, I’m autistic and that's okay’ because that community has is a, is a good example of the community and that has been told you are wrong we need to fix you you are you are a mystery and so for them to take ownership of that word and say I’m autistic and this is who I’m meant to be, very much like the Deaf Community has done and saying I am a person who is deaf capital D and that's part of my culture that's part of my identity that's who I am that's who I meant to be I felt a lot of pride that those communities were taking ownership of those words and telling people how they felt about the language they wanted to be used the way they felt about their identity their culture and so you know I feel a lot of pride and understanding about why identity first language is, is, is coming forth.

More and more questions are arising regarding appropriate terminology. After mentioning that she has heard various terms being used, including ‘person with a disability’, ‘disabled’ and ‘differently abled’, Violet, a non-indigenous service provider, notes: “I feel like (all these terms) they’re all pretty similar (…), adding, “it’s often how it is with terminology I feel like there’s never a consensus”. Elena also shares with me that she does know what terminology would be best: “you know I don’t you know um there’s so many different terms I don’t it’s yeah I can see that can be a negative and I’m reading a lot of things”.

Reactions to Labels: Connecting Terminology to Social Attitudes

Findings in my research reveal interconnections between the process of using terminology and social attitudes toward disability. Carol Thomas (2006) whose argument I have detailed in a previous chapter (see Chapter 2), draws our attention to the fact that assumptions about disability often spill over to characterizations of the person. Individuals with disabilities are, therefore, called to balance social attitudes that challenge their self-esteem and social value.

Labels have the capacity to stigmatize (Longmore, 1985). During our meeting, John reveals that he has a physical disability, but is also a healthcare worker. He shares that labels are dangerous as they lead to assumptions, in this case that physical disability always comes with cognitive disability:

> I think that's the biggest one mental retardation; I think most of it comes down to me as a person is when people assume that I have some type of mental disability, I kind of jump on that and tell them no I'm not retarded (…) I have to explain that to people, but that's whether they may feel whether or not they may feel something else I don't ever let it get to that point cuz I'm very quick to just kind of jump on that and say no. I guess I can say I feel angry, but as far as what else I feel yeah that's pretty much it mental retardation is what people assume in that (term), you know I get angry all the sudden.

The structures of health and education are excellent examples of structural, systemic Othering, according to Abigail, a non-indigenous healthcare worker. New labels that emerged in the 1960s to diagnose disability, such as Learning Disability (LD) and Emotional Disturbance (ED), quickly proliferated in education (Gartner &Kerzner-Lipsky, 1987). White, middle class children flocked to special classrooms in order to ensure access to academic support services. While the rhetoric in these environments is to facilitate meeting goals, research shows that students receive differential treatment based on their race. White students receive support in the form of accommodations during tests with an emphasis on participation in general education classrooms. Students who are not White, however, have less access to general education settings and experience poorer transition outcomes (Coutinho et al., 2002; Artiles et al., 2002). Abigail elaborates:

> I would say um from a very early age, it's a very rough situation. There's a lot of segregation. Most people with disabilities are placed in a separate classroom, there's not a lot of social integration, um I mean there's a lot of types of

> disabilities and not others because people don’t wanna talk about it, but they don’t wanna deal with it or whatever, um, so I see a lot of that. So, um I would say that perception(…) I feel like a lot of disabled people are just like lumped together.

After emphasizing that categorization is a central trait of American culture, she continues:

> (We are) very into labels as a society. You’re taught from an early age that you are to want to become a specific thing you know? Um, career guidance and school and things like that, where it can be helpful but it also puts people in a box, you know? (…) I would say that our very language and the way that we speak, it carries over. In a lot of different ways. We’re just very into labeling and um I dunnno if that makes sense, but it’s very, yeah, someone is how they are perceived (…) and they are labeled in that way.

Firmly situated within disablist and/or ableist discourses, indiscriminatory use of terminology promotes structural violence (Farmer, 2004), creating and perpetuating systemic inequalities that disproportionately affect individuals with disabilities and their families. The non-indigenous service provider whose insights I have just provided above, tells us that terminology is closely connected to systemic frameworks. Making a distinction between ‘disability’ and ‘disabled’, the participant clarifies that the former refers to a condition, while the latter is an all-encompassing term: “there are differences in that I feel like disability is specific to a thing with someone (…) Like blindness is their disability. Um and then to just call someone disabled is like a blanket term that covers everything”. This argument resonates with Longmore’s observation on the effect of labels. More specifically, Longmore (1985, p. 419) asserts: “They obscure all other social characteristics behind that one and swallow up the social identity of the individual within that restrictive category”.

For some of the participants, particularly those who engage with disability on a professional level, terminology choices are part of promoting awareness. I first meet Rose, a non-indigenous service provider during an introductory meeting regarding the possibility of my research collaboration with the disability related organization she is part of. Shortly after our meeting she tells me that the organization she works for is part of a larger national network of support services for individuals with disabilities. A casual look at the space around us affirms what Rose tells me. The space we are in is cozy and welcoming, with information reminding those who are there of events, fun activities for individuals with disabilities and their loved ones, conferences that focus on disability issues, as well as credentials that highlight the organization’s achievements and its ties to other national networks. The hustle and bustle of the staff quieten when Rose leads me to a quiet area of the organization and our conversation turns specifically to the focus of my research. During our interview, Rose comments that the terminology she chooses to use depends upon the circumstances. More specifically she stresses:

> Like when I write the word I’ll do Dis in lower letters and then I'll write ability all in capital letters because we have abilities, we just have to do things a little bit differently. It emphasizes that I have more abilities than disabilities (…) I can still be a mom, I can still be a grandmother, I can still work, I can still go shopping I'm able to do things (…) I'm still the same person (…) maybe a little more

> cantankerous and you know feisty (…) so yeah, that’s (…) I make (…), you have different abilities. Don't, what’s the term people use? Don't dis my ability you know don't make fun of it, don't think, I can't do things.

Throughout our conversation, Rose emphasizes how language can turn the power relationship that she feels exists between those who have a disability and those who do not. Along similar lines, Janis says:

> I think there's, there's a lot of good to come out of people within the disability community having conversations like these. I think if anything it's, it's overdue and (…) the fact that we can have conversations about what do I prefer we see that other communities have done this as well, you know, people taking back words that maybe were negative and taking those back and claiming them, I think it's, it's only natural and, and, and as long as people with disabilities stay open to the conversation and, and respectful of you know the fact that each person is going to view it a little bit differently I think those are healthy for our community to, to have those kind of conversations and, and I think it's going to evolve and it's going to change and I think we should have better words than disability. You know, we should evolve, we shouldn’t get stuck, you know, we should have better words, better terminology.

When probed for recommendations on alternatives, Janis provides further details:

> You know, I do, I always come back to thinking about ability so when I'm talking with somebody (…)the disability conversation that actual medical diagnosis

> conversation is a really short conversation you know I'm as I work with them it's you know this is what's happened, this is the diagnosis, this is the you know the challenges or or these are our, this is what life is like for me, the rest of the time it's talking about what do you care about what do you dream for yourself what do you bring to the table what goals do you want to work on and that's all about ability that's not about disability so I think ability is a big word as we .

Ableism: Reflections on Normative Constructs and Social Relationships

In the quiet, the sound of ice hitting the walls of the mug fills the room. Fiona, a Diné individual with a physical disability, apologizes for not thinking of the effects on the recording. To me, the sound provides a tempo to our conversation, signifying when a pause is needed, as this individual describes the trials, tribulations and lessons of love and strength that their experience with a physical disability, has had to offer. Similar conversations took place on numerous occasions during my fieldwork research. Enmeshed in these contradicting conversations are stereotypes that are centered upon conflicting understandings of what it means to be ‘able’ and ‘normal’, as well as interpretations of connections between social value of the person and physical disability.

Literature on Native Americans often presents romanticized accounts of health and wellbeing through oversimplifications of harmonious relationships with nature, when, in fact, the engagements that Native American individuals have with nature vary from one individual/culture to the other (Pierotti &Wildcat, 2000). Ubiquitous understandings of harmony and wellbeing reflect broader dynamics centered upon stereotypes of Native Americans as noble savages whose responsibility it is to safeguard the environment Krech (1999). Highly profitable ventures to commercialize health have based their discourses on the interconnectedness of physical and emotional health to 'sacred' knowledge that some populations are privy to and others must work toward attaining. New Age movements are examples of such romanticization (Sebald, 1984). Some Native Americans still practice their interpretations of 'harmony' in their every day lives. Others feel that utilizing the land to promote personal advancement and wealth does not go against the concept of harmony; yet others, are aware of it as a concept in many traditional stories, but find that it is not applicable to life today (Krech, 1999).

My research highlights that there are diverse perspectives with regards to the relationship of disability to 'harmony'. For some, the concept of 'hozhó' is an important value that they use to make sense of their identity as individuals with physical disabilities, explain practices of inclusion, and counter experiences of discrimination. In other narratives, 'harmony' and 'balance' are concepts that emerge in nostalgic reflections as they describe difficulties in relation to physical disability. A careful examination of discourses highlighted in my research shows that participants interpret cultural practices as mechanisms to exercise pressure, as responsibility is placed upon individuals with disabilities and their families for violating cultural norms that they are not aware of.

Davis (1995) emphasizes that engaging with disability is shaped by ideas of functionality, the epicenter of which lies in evaluating the potential of the body to fulfill social roles. Judgements are made based on questioning whether (or not) individuals with disabilities can engage with the world: hearing, seeing, and walking become signifiers of (un)successful performance of social norms (Davis, 1995). Martha, a Diné service provider, associates disability to lack of ability. She shares: “For me not being able to do things for yourself, I think that’s just mostly it.”. Violet comments:

> Yeah, I think, like, people are like surprised of how, like, talented a lot of people I work with are, because like maybe if you are working with someone with a disability like people aren’t thinking of all the ways that they are able, you know? I don’t know if that makes sense(…)I don’t have the right words to say it um like, yeah, the abilities that they do have (…) I still feel like people have ideas of what people with physical disabilities are like and what they’re able to do. Like, in that way, I feel, like, it’s still, there’s room for improvement (…) people’s ideas of people with physical disabilities like not being as capable, that kind of stuff.

As I have shown in previous chapters (see Chapter 2) disability exists in tandem with concepts of ability. The complexity of the interrelation between the two constructs is centered upon the fact that while we tend to think of them as oppositional, they are actually in a mutually reinforcing binary: one cannot exist without the other (Goodley, 2014; Goodley & Runswick-Cole, 2016). Our sense of self, Goodley and Runswick-Cole (2016) tell us, relies on the categorizations that binaries allow us to produce. Based on work by Goodley (2014), they add that our desire for control of our socially constructed reality urges us to fashion ideas around normative ways of thinking, capability, and being in the world. Interactions with individuals with physical disabilities led service providers to critically think about pre-existing biases. Violet tells me: “Like I wasn’t aware of how much clients could do on their own, so I kinda assumed I would have to help more, so that kind of stuff. So…yeah”.

Research findings concur with literature contributions I have examined (see for example Davis, 1995; Goodley, 2014; Goodley and Runswick-Cole, 2016) who draw connections between concepts of ‘being normal’ and ‘being capable’, that are strongly influenced by the manifestation of symptoms which are defined as a disability (Davis, 1995). John highlights that: “I believe disability means someone who doesn't have the normal capabilities of somebody who was born without whatever specific disability they may have”. A Diné participant with a physical disability, who I have named Henry, concurs: “people are not as normal…normal as they should be”. James, another Diné individual with a physical disability, indicates that life creates the illusion that ‘being normal’ is fixed, clearly defined and finite: a state from which the individual with a physical disability can lapse, and has to fight to get back to: “everybody who has any type of physical challenge or disability is always hopeful you know or should be hopeful or try to be hopeful you know to get some aspect of their normal ”. He clarifies:

> this could happen to anyone at anytime at any moment but it’s having everybody understand, you know, we need to help these people return get back to whatever aspect of normalcy because not everyone is going to get back to a normal life

. He approaches the social category of normalcy as fluid, dependent upon circumstances and the person’s frame of thought: “ I hate to call it normals because everybody’s normalcy is different (…) just like everybody's challenges are different it's whatever that makes you happy in your life for that time being".

Janis connects social perceptions of normality, specifically in non-indigenous cultural settings, to processes of promoting Otherness. Similar to theoretical contributions I examined in Chapter 2 (see, for example, Linton, 1998a; Oliver & Barnes, 2012), Janis highlights the dangers that she sees in this association:

> we still tend to default to, I think it's getting better, the inclusion piece of it, I think we're coming towards that in some in some ways but I still think we default to thinking (…) not that disability or health conditions are normal part of living but we still default to thinking of that is other or abnormal (…) and when I get frustrated is, you know, when you actually are working with families and talking to people every family is touched by cancer, by diabetes, by heart disease, by disability and yet we don't ever acknowledge that this is a normal part of the human experience. We still we have families come to us all the time that, you know, (tell us) I felt so alone 'I felt so isolated I thought this was just happening to us (…)' that's because that's what they were told, you know, those subliminal messages about 'oh you've had a stroke you know, oh this is just you know, this is a family problem', you know this is happening to families every day, all across (…) everywhere and we teach people isolation vs. teaching people inclusion you know? that this is a normal part of living that your family will be touched by this and there are resources there that connection is good that you should seek out pure support you should seek out counseling you should be on the medical model you

> should seek out resources because everyone is going to need this instead of normalizing that, we, we teach isolation.

Davis (1995, p. 24) tells us, the idea of the norm as “not deviating”, regular”, and “conforming to” first appeared in the English language in the 1840s and is closely tied to the notion of the ‘ideal’. The norm, Davis (1995) continues, feeds off of our senses: we engage with disability through visualization. Meanings result from the assumptions we make about what we are seeing. Our urge to prioritize vision over the other senses goes way back, according to Goffman (1963). We learn to prioritize vision over the other senses, Goffman (1963, p. 1) states, from the Greeks who would mark the bodies of those who occupied lower social positions (such as criminals and slaves). These bodies would always carry stigmata (which birthed the term stigma) to denote their inferior, morally objectionable status. Goffman (1963) tells us that the process of stigmatization begins when we are called to interact with someone or something that does not neatly fit within the boundaries that we have in place to make sense of our reality.

The works of Zitzelsberger (2005) and Thomas (2006) show that the appearance of physical disability redefines gender performance because of ableist/disablist judgements on attractiveness and sexual performance. Lupton and Seymor (2000) shows that the visibility of physical disability leads to exclusion and stigmatization based on associations between markers of physical disability to lack of intelligence. Her participants share: “ That is, as soon as you pull out a long white cane, then people start making assumptions, sometimes right, sometimes wrong, about your level of vision, about your level of intelligence ” (Lupton & Seymor, 2000, p. 1859).

Findings in my research highlight that social perceptions and assumptions about physical disability shape social relationships. Abigail connects disablist attitudes regarding the capabilities of individuals with physical disabilities to social exclusion. She clarifies:

> I think that again the term disabled is so generalized and it's such a wide spectrum that, that people are contained in that box. I dunno, yeah. I mean there's just this assumption going in to things, that someone can't do something (…) It's an assumption and it's not, it's not ok you can do it this way, let's find a way to do it, it's just oh they can't do that so don't invite them to that or they don't need to take that class because it's never gonna be applicable to them. That person never needs outdoor education, because they're in a wheelchair, they're not gonna be outdoors, which is horseshit

Similar to theoretical contributions I have outlined in Chapter 2 (see for example Loja et al., 2013 and Thomas, 2006) individuals with physical disabilities in my project reported that expectations of others' reactions informed participation in social life. I paraphrase Bret's insights who shared that he feels apprehension about how he is received. He contextualizes his fear of being received negatively with his understanding of Diné and Anglo culture. In both cultural contexts, the urge is to push people with physical disabilities, in fact all disabilities, away. The negative views reflect the complex relationship between broader cultural practices and infrastructural barriers. In American culture, the participant points out, family bonds have become less strong and a strong sense of personal space contributes to distancing among individuals: “people are like I need my space” (paraphrased).

The issue of social support is central in the narrative of Jack, a Diné service provider. Those with physical disabilities report not receiving enough support. He elaborates: “for certain people it's going to be kind of hard, cuz they don’t have, the people there don't have their support, so”. When I ask why, he clarifies:

> Because a lot of people don't understand what disability means, a lot of people have… Some open mind to what disability is, a lot of people don't want to be around people with disabilities. They consider them as outsiders.

Making comparisons between social perceptions among Diné individuals and non-indigenous cultural frameworks this participant offers:

> From what I've seen it's still the same as how Navajos or Diné look at people with disabilities. They look at them like they're weird, outsiders, or they're not fully there. Some, a lot of Anglos don't know what the person is going through. So yeah it's the same way for the Navajo. A lot of people don't know what disability is. They don't know what they have. It would be better if people knew what disability was.

Elaborating on the concept of ‘being an outsider’ the participant discusses exclusion from everyday life: “Social life, anything that normal people, let's say normal people do. They don't want them joining them there”. Identifying common traits between non-indigenous and Diné cultural perceptions of physical disability, Robert, a Diné service provider, shares: “ an objective problem, being like this weird allusive problem that they can see, someone that doesn’t have a full intelligent potential, but there’s no way to try to make that person normal I guess” .

Like Hughes (2012), Loja et al. (2013), and Goodley (2014) whose contributions I analyzed in a previous section, my findings show that individuals with disabilities become objectified: they occupy a precarious place in the social milieu, as attitudes are driven by conflicting emotions around disability. Bret shares that people feel fear around individuals with physical disabilities. When asked to provide further details as to the rationale behind this response, he says he feels that differences in personality shape how people react to physical disability. Reactions center around practices of seeing and being in space: “People don’t see us, they don’t ask us (…) while others are always there”. A number of participants align with the argument of Garland-Thomson (2006) on the dynamic and complex shifts in practices of looking, or averting the gaze. Michelle tells me that she is aware of the interrogatory gaze or lack of consideration that people with physical disabilities face, as she has seen it when providing support to her clients in social environments: “some people have attitude of rude or look at them”. She continues that sometimes people get angry, other times they point, while others are fascinated about the experience of physical disability and their questioning can challenge personal boundaries and personal space. Narrating a personal experience, Fiona, a Diné participant with a physical disability, shares:

> this lady will sit next to me and she's staring at me and I can feel her eyes but she just scoots further closer and then she's, like, ‘I'm sorry to bother you and I, you

> don't have to say anything if you don't want to, but I just wondering what happened ?' .

Centered upon stigma, Fiona's narrative highlights the complexity of reflecting upon the correlation of social attitudes and physical disability. A defining characteristic is location:

> on the rez when you see someone using an assistive device[83] they stare (…) they stare and they try to figure it out but they don't know that they're so they can be seen as staring they don't know that there's you know they're viewed as staring at you (…) they stare and it makes you feel uncomfortable but here[84] it's normal people see it all the time there's rules about it like (…) and so everyone knows rules and everyone abides by them and the common courtesy. On the rez you don't have much of that (…) so I think like the rez is a little bit different. They'll stare there's a little bit more judgement, there is a little bit more like how do you do things? There's a lot more questions and there's less support I would think on the reservation than in the city, like Anglo society.

For Fiona the presence of family mitigates the difficulties of navigating infrastructural and attitudinal barriers. She tells us

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[83] Paraphrased to protect the participant's privacy

[84] This research took place off the Navajo Nation reservation. The participant is referring to one of the off-the-reservation field sites.

> on the rez you have your family that protects you, you have people that don't say anything, you know (…) so, definitely, the stigma here is a lot different for being disabled than it would be on the rez (…) On the rez it’s a little more community.

Beth, who cares for individuals with physical disabilities both at home and professionally tells me something along the lines of “Diné people care more”. The insights of the following participant clarify how ‘caring’ is culturally defined and performed. Referring to contexts that are not Diné, Sarah, who has a family member with a physical disability, comments: *“*just from personal experiences, I don’t know, I see people just divert away from people with physical disability (…) I think they would try to avoid a situation that would spend more than, I guess, a couple of minutes you know?”

In response to my probing to expand on her insights, she shares that Diné social norms engage with individuals who have a physical disability differently: “when you walk into a room you say hey, ya’ateh, you know just regular stuff (…) I don’t know, I see that approach differently. I don’t think necessarily more time, but like the attitude is different, you know, the tone”.

Based on their interpretation of findings by Marshall and Largo (1999), Pengra and Godfrey (2001) point out that Native American worldviews generally do not exclude individuals with disabilities. However, my research aligns with Lovern’s (2008) cautionary note on the need to be aware of the variability of perceptions among and between indigenous peoples. Carol Locust (1985) notes that this approach to individuals with disabilities may be due to general cultural norms among indigenous peoples, which tend to privilege the individuals’ ability to fulfill their social obligations driven by the principle to be part of the group rather than perform roles with the aim of showcasing individual strengths. Similar insights were provided to me during my fieldwork. Lisa, a non-indigenous service provider, highlights that culture plays a major role in determining interactions with people with physical disabilities. She elaborates:

> well in the, in the Anglo culture people I think they fear differences (…) and so therefore those people that are, fear differences tend to hate people with a disability, is, because they don't understand it and they're afraid of it. I mean maybe some of them are so stupid they think it's contagious, but people that don't, that's… still think that there is some kind of aura of badness in a person with a disability, they're not perfect, they're not right there not you know? (…) In the Navajo population I think there are more accepting of people with disabilities than the Anglo culture is for whatever reason.

After some thought this participant adds:

> not standing out and that's something I learned, that's one of the things that they definitely point out is that Americans want to excel and stand out where as it's much more important to Navajos to be part of the group and not stand out you know?(…) I think, I think Americans are so worried about, what do I want to say?, keeping up with the Joneses, (being) as good or better, whereas Navajos are much more interested in being a part of the group and blending in, and the important thing to them is helping their family; that is the huge thing in Navajo culture so helping their family is certainly helping with the kid with the in a wheelchair or you know babysitting for child that cannot be left alone or working

> to learn sign language for a kid that is deaf. Families will work on that really hard because that is probably the, I would say the number one value in Navajo culture is helping their family.

Pengra and Godfrey (2001) emphasize that the concept of ‘assistance’ is also culturally constructed. Defined as part of personal responsibility among the Lakota, acts of assistance are done regularly to express active interest in playing one’s own part in ensuring that family matters run smoothly. Assistance provided to individuals with disabilities are seen as an integral part of this commitment to community cohesion, rather than guided by assumptions about disability, and individual incapability (Pengra & Godfrey, 2001).

Allison, who is involved in providing care for a family member, shares that the emphasis indigenous worldviews place on family involvement can have its difficulties. More specifically, she discusses how cultural expectation can create certain challenges:

> The cultural way of doing it, is the family comes together pulls its resources and takes care of the disabled person. I'm not saying there's anything wrong with that, that is the traditional way to do it (…) Many families feel forced to take on that person's care. And sometimes that they may not be the best people to take care of that person. And really that goes back to culture, like the culture expects you to embrace our problems and take them in. And, and, and take care of them. And like I said there's nothing wrong with that. The problem is that belief is thrust upon people that may not be ready for it. Those people have their own problems and then you're asking them to make life changing decisions and changes in their

> own family, so that they care for that person and they may not be in the best position to do that. And, unfortunately the person who pays the price when a situation, situations like that happen is the disabled person. And that, that breaks my heart.

Cautioning against generalizations with regards to the universality of Native American responses, Elena shares that because of the stigma that exists around disability some families distance themselves from the individual with a disability:

> so we see because of the field we’re in we see a lot of families that don’t care sometimes (…) there can be judgements based on that just because a lot of our clients are Native American, but I don’t think that has anything to do with, it’s just based on the family either not being able to deal with it .

Narratives of assumed/real difficulty in conjunction with disability offer a deeper understanding of the dynamics of balancing practices that promote and/or challenge (in)dependence and assistance. Michelle, a non-indigenous service provider states: “ I can say limit too (…) some part must be difficult or maybe some people feel difficulty a lot, yeah” . When I encourage her to discuss the aspect of difficulty further, she states that difficulties encompass all spheres of life including the physical experience, mentally as well as emotionally. The major difficulty, according to this participant, lies in accepting a life that emphasizes differences.

Acknowledging that each individual is different, the participant continues:

> Because you have to deal with, cannot change, have to have that way in life and everyday living (…) have to face your limit or feeling less at some point, so, so that point I say mentally, yeah how to cope, how to get over it that must be very difficult.

The concept which remains unnamed in this participant’s comment (to have that way), namely disability, and its association to feeling less, and the participant’s wonderment around coping, frames disability as a static category, that is inherently challenging, an experience that is to be addressed and left behind depending upon the skill of the individual with a disability to work toward that goal; but, at the same time, it cannot, since its marks are ever-present (Oliver & Barnes, 2012; Linton, 1998a). This response is an attempt to preserve the constructed, which most consider stable and fixed, concept of the norm.

For Papadimitriou (2001) our failure to approach disability as a fluid circumstance, a moment in life that anyone could enter or exit at any time portrays disability as one part of a binary: either one has a disability or they do not. Once (re)defined as falling into the social category of those who have a disability, the person enters a delicate dance, which is primarily orchestrated through efforts to help. The construct of assistance is based upon three main ableist presuppositions: first, that the individual with a disability lives a passive life, stripped of any sense of personal fulfillment. Second, that the individual with a disability, because of that identity, requires assistance not only in matters directly pertaining to their disability, but in all aspects of life. And finally, that the individual with a disability is only on the receiving end of assistance (Hughes, 2012).

The process of ‘Othering’ disability is further strengthened by the power relationships that shape every day interactions between individuals with disabilities and those who are able-bodied. Able-bodiedness builds upon the assumption that robust physical health and financial wellbeing sustains those at the other spectrum of the ‘binary’, namely those who are at a social disadvantage because of their (assumed) need to rely on others (Hughes, 2012). To validate these dominant identity constructions, individuals with disabilities become “objects of benefactions” as Loja et al. (2013, p. 193) show in the following excerpt:

> I was shopping and a lady approached me and gave me a coin and said ‘Take it. It’s the only money I have’ (…). It was humiliation. It was like diminishing me to the bottom (…). It’s not because I am in a wheelchair that I am begging. I was really shocked with that situation .

Along the same lines, Violet adds:

> I don’t know, I think there’s people, kind of, well I think sometimes people wanna be extra accommodating to people with disabilities so like they are, I don’t know how to say it, like, maybe over enthusiastic to help but it’s kinda coming from like you’re just assuming about a person that they can’t do something, which is, like, yeah, I think, like, a lot of times it’s coming from like a thoughtful,like, place, but then I think then like maybe because, I don’t know, because maybe

> there’s less like, I don’t know there’s like a lot of it being that public space is not accessible, so like if it’s not accessible for a person then they are not there to like, show what they can do?.

Elena highlights the dangers of stereotyping as it impacts participation in social life and aspect of self-determination:

> (People with disabilities) um, always haven’t been treated in a kind way or might have grown up in a way that somebody didn’t really think they could do anything (…) so they did everything for them and then you’re an adult and then you’re expected to work and you’ve never really had the chance to do things on your own, and then you learn that don’t do it somebody’s gonna do it for you so it’s hard to change that mentality and you’ve grown up with it and now you’re in your thirties or forties and somebody expects you to work and maybe in the past with a family member when you’re growing up if (clears throat) if there was like some kind of negative reaction that you’ve had that works to not do whatever you didn’t wanna do.

Pity, Hughes (2012) asserts, stems from the position of no expectation. In this scenario, individuals with disabilities are deprived of the epicenter of every social relationship: reciprocity. Perceived as inferior to the able-bodied person who has the capital to save them, as the receiver of this act, the individual with a disability serves to validate the superiority of the other end of the binary. Like Papadimitriou (2001), participants across sample categories felt that providing, denying, requesting, or refusing offers of assistance was central to the agency of individuals with disabilities. For many of my participants, centering interactions on decision-making circumvents problematic assumptions of normality and ability.

More indicatively, Abigail states:

> Um, I had to learn not to do that. Because it was important for that person to be able to do things for themselves. Um, and that was hard to not do it for them, having that background of I'm supposed to, ‘let me to take this from you’ um, and I had a client who didn't want my help, they wanted to do it themselves and I had to step back and be like wow I’m an asshole, like you have every right to make your own sandwich or whatever the case may be, like that's a part of your human experience and there's this perception that I didn't even think about of let me do this for you it's important that you are able to make your own way and just even everyday common stuff. I think that’s taken away a lot. Decision making is huge like, it’s so frustrating cuz there's a lot of non-nonverbal people and so people make decisions for them, because they cannot audibly make those decisions themselves. However, they are making those decisions (…) They’re just trying to find a way to communicate them to you and it's your job to bridge that gap.

For this participant, providing assistance without asking the individual with a disability if they wish to receive it demonstrates disablism, which is also practiced in initial hesitation to allow individuals with physical disabilities to clearly state their needs: “I think it’s like we talked about earlier it’s often looked at as you can’t, instead of how do we make this work? And so, decisions are made for people, based on what their physical limitations are perceived to be”.

For John, the choice of whether or not to offer assistance speaks to issues of social equality:

> I mean if, they may have a physical disability, before you open a door for them or you do something that's not what you would do for the average normal person ask them, ‘hey, would you like me to help you?’ only because I feel like sometimes people with disabilities get treated because they have a physical ailment that they, they have to be dependent on others and people don't like that.

Fiona shares how difficult it is for individuals with physical disabilities to have a voice in everyday interactions. Her comment highlights the internal struggle over how to contain frustration borne out of the realization that certain activities are physically taxing:

> The dis and the ability I think is really telling someone you can't do it, and that's not the case; you can do it, but you can do it in your own way. And you have to figure out what works for you.

She continued to share how receiving unwanted assistance causes frustration and anger, because the desire to help originates from the assumption that disability equals suffering. Describing her daily life with a physical disability she tells me she yelled, got angry, and/or give instructions to those involved in her care as a way of reacting to their efforts to intervene.

My data highlight that cultural definitions of productivity are central to the performance of disability. Concurring with attitudes noted in literature I elaborated on in a previous chapter (see Goodley, 2014, who notes the toll of ableist stereotypes on the work performance of individuals with disabilities), Bret shares that disability, "is a funny thing that is in an individual. Because of it, people with disabilities have to deal with a lot of negative attitudes, like they are seen as not a person*"*. He elaborates that "a misconception is that people with disabilities do not want to work*"* (paraphrased). The insights offered by Janis draw our attention to the impact of medicalization on assumptions surrounding the potential of individuals with disabilities to participate in the workforce. She shares:

> I think there's lots of stereotypes about, people can't live well that's been, that having a disability means that you can't live well, or that you're not happy or that you're not productive, that you're not apparent, you're not contributing in any way that and that that's a stereotype right? That, that we need care that um, that we wouldn't actually be the ones providing care, right?.

Janis adds that productivity is a value laden concept. Current frameworks emphasize the number of hours, rather than focusing on what is socially valuable, such as actions that help others. To resist this push, the participant shares, individuals with disabilities have to remind themselves what they have to offer.

Keltner et al (2005) share that indigenous cultures determine the degree of wellbeing based on the ability of the individual to participate in social life, rather than on the increase/decrease of symptomatology. In compliance with this observation, among the Diné, what seems to matter is participation of all family members in sustaining this important nucleus of social life and –by extension the wider community— to the extent possible, rather than how tasks are performed. Joe (1997, p.254) suggests that the degree of severity of disability is culturally assessed based on individuals' performance of important tasks that demonstrate personal autonomy (such as eating, walking) as well as dedication to promoting community well-being (for example, completing chores around the house). Performing everyday tasks with minimal or no assistance is perceived as contributing to family well-being, as the individual signifies their consideration for the time and energy of others, regardless of the success or failure of mastering the activity itself (Connors & Donnellan, 1993). Pointing at me, Beth, who is involved in providing care for a family member, shares: "Look at you, you are going to school, working hard, you are funny, I don't care you don't walk". She concludes our conversation making an important distinction: "Disability means hard to get around (…)" Pursing her lips toward me, she reiterates: "You work, you can do things. Disabled means when you have to feed them, wash them. Disabled is a health problem" (paraphrased).

Abigail discusses the correlation between productivity, disability, and representation:

> You're not seen as an individual, it's not thought of as such a wide human experience, it's very um contained and generalized and it's treated that way in how you are supported as well in society (…) there is this idea that you have to be useful in a very commodity style. Any human being. You are expected to produce (…) whether that's children, money, um some sort of product, that's something that is very, very saturated, especially in a capitalist society (…) and I feel like often times people who are in any way a minority group it's more impressed on them to be able to be thought of as useful, to give them worth, versus a different

> way of producing self- worth. It’s like, I often saw it as ‘ok, you’re never gonna be like them’, so you need to be something so you can survive (…) but you have to survive in this idea that you have to be useful and, and useful specifically in the terminology of like able to contribute to society (…) a lot of people who do not live with or experience disabilities first hand have a privilege that they don’t understand (…) there’s this idea um specifically in media, which media controls our framework for how we view as society and authority and things like that I think, so it's, it's relevant of someone being too disabled (…) I mean that, they're never going to put someone who has cerebral palsy and a cognitive disability on Big Brother (…).This person’s human experience is not easily digestible, it's, it's pushed away, it's not marketable and because it's not marketable, it's not useful by, by those um defined lines.

Mirroring Landsman’s work (2009), Abigail pinpoints the problem to the fact that certain disabilities birth emotional responses to a greater degree than others. Landsman (2009, p. 64) tells us that the mothers with infants with disabilities whose insights she has documented, often chose to speak about their newborns conditions in very specific terminology, rather than broad terms: for example, cerebral palsy and/or developmental delay were avoided in everyday discourses because of fear of the associations that American cultural contexts may have constructed, because of the wide spectrum that general labels cover. Women, therefore, preferred sharing specialized medical characterizations as the likelihood of others’ not knowing the meaning of specific labels is higher.

Assistive Devices

As I have highlighted in Chapter 2, scholars have noted that an examination of the role that assistive devices play in interactions highlight varying interpretations of disability based on cultural meanings attached to assistive devices. In her work with individuals with spinal cord injuries Papadimitriou (2008) highlights that assistive technologies (in this case the wheelchair) are perceived as a quintessential marker of transformation. Rehabilitation staff present the wheelchair as the hallmark of transition from being ‘immobile’, ‘confined’ to participating, living in action, albeit in new ways, a view that is recognized as partially valid by individuals who are wheelchair users. For the participants in Papadimitriou’s (2008) work, redefining the body requires getting to the point of feeling like this assistive device is a part of the self; this sentiment is sanctioned by healthcare providers working with individuals who have spinal cord injuries, who are responsible for ensuring that the person is ‘reborn’ with a consciousness that incorporates the wheelchair. Individuals who have been injured are only allowed to exit the phase of rehabilitation and enter into the ‘real’ world after they succeed in medically determined tests that are accepted as ‘benchmarks’ of excellence in wheelchair use. Once re-introduced as embodying disability, individuals have to navigate unwanted attention drawn by the wheelchair. Assumptions of invisibility and incapability that I discussed in Chapter 2 (see Zitzelsberger, 2005) are countered by (hyper-)activity and through emphasizing other aspects of identity. For example, Papadimitriou (2008, p. 699-700) tells us that participants engage in sports, driven by their desire to prove to themselves and to others that they can do things; others, emphasize their masculinity through engaging in culturally defined masculine practices (e.g. fighting) to counter assumptions of loss.

Rose notes that assistive devices can cement relationships with individuals with disabilities who share similar experiences. Gesticulating toward me, she shares that she is certain that if bystanders saw us together people would think ‘you were just sitting in a chair. The moment you were asked to move then it would become very clear that you use an assistive device’. Rose continues:

> some people act like we have leprosy like they're going to catch what we have. Now, you can't catch our disability, you can't catch our abilities, our handicap or whatever you want to term you want to use today we're still people (…) They don’t wanna touch us or have anything to do with us. It’s like, ‘come on we’re people’. Once they see the assistive device (...)[85] it's like ‘oh my God am I going to catch what they had if I touch it’. Or it could be on the opposite end, they think ‘okay that's an extension of you I don't want to touch it because what if I damage it (…)’ So they, could be that they're afraid of it (…) so it's the whole combination of everything [86].

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[85] Paraphrased to protect the participant’s anonymity

[86] Certain details have been omitted and/or slightly paraphrased in order to protect the anonymity of the participant.

Like Hughes (2012) and Papadimitriou (2001), Fiona feels that— in addition to assumptions of incapability because of a physical disability— acts of assistance can be driven by the need to feel good about oneself by doing a ‘good deed’ for individuals who are deemed helpless. The following excerpt shows how resisting such narratives is embedded within broader concepts of embodiment of disability, which are centered on the role of assistive devices in shaping ideas of the self and the body: Referring to her assistive device, Fiona tells me:

> This is part of me. Don’t just grab (…), grab it, dig around, yeah (…), they adjust, and pull and yeah (…) Yeah, (we need) a stay 5 feet away from a disabled person bumper sticker, that’s what we need (…) DO NOT touch MY things” [87](…) People do that all the time (…) they’re like ‘ok I’ll help you up’. Like ‘leave me alone, back up, fool, give me my stuff back’, but they don't get it, it’s just like ‘oh they're not able to do it so I need to be a good person’. And I mean they probably mean it in the best way possible but it really makes me angry. I’m just like ‘get away from me you are messing me up’ .

During my fieldwork research I observed and participated in a number of interactions revolving around assistive devices. Conversations about the potential of devices to facilitate participation in social life, as well as to provoke frustration served as moments of cementing relationships with individuals with disabilities who share experiences of assistive devices, but also highlighted providers’ insights. Elena shares: “ I

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[87] Author’s emphasis

don’t know if people take into account the caregiver, um, how on you’re like the way some wheelchairs are the back and stuff um, um trying to get people um up off a curb ”.

Constructing Personhood: Social Relationships and Understandings of Health and Illness Through Narratives Surrounding Physical Disabilities

Literature that explores perceptions of disability in Native American/indigenous contexts paints a picture that is radically different from contributions that contain findings from other cultural settings. Some scholars tell us that Native American worldviews do not stigmatize disability (see Lovern, 2008). Others suggest that perceptions of disability have changed over time: the defining turning point, according to these contributions, can be attributed to the detrimental effects of colonization and historical trauma, which have redefined every level of life (culturally, politically, socially, spiritually and economically) (Connors & Donnellan, 1998; Weaver, 2015). Yet others, tell us that not only are individuals with disabilities accepted, they are revered, as they epitomize traditional concepts of harmony and respect (Shackel, 2008; Kapp, 2011).

I found a variety of perspectives. As I have suggested in the chapter outlining methodological and ethical considerations (Chapter 3) these disjointed ‘realities’, constructs rather than objective truths, that resist neat categorization, show us the complexity of analyzing social phenomena. In the context of my research, conversations surrounding physical disability are inextricably linked with the social dynamics of making persons, which occur in broader context discourses around health and illness.

A number of scholars who have collaborated with indigenous peoples on projects related to disability note that many indigenous worldviews contain no specific terminology to refer to disability, since disability is not a signifier of difference but rather a mere characteristic that the person embodies along with others (Connors & Donnellan, 1993). Carol Locust (1985) emphasizes that the interest of indigenous worldviews in promoting inclusion of all members may reflect this omission of a word to refer to disability. Joe (1997) concurs; she shares that among the Diné there are no negative associations made with disability. For example, among the Diné, the term ‘mental retardation’ is not used; rather, one may use descriptive ways to discuss an individual’s performance, such as ‘this person lags or falls behind (others*)*’ (Joe, 1997, p. 254). Connors and Donnellan (1993) attribute this phenomenon to cultural definitions of personhood. They note that disability is seen as an integral aspect of the individual’s performance. For example, seizures, tears and differences in verbal practices are seen as traits that may influence the individuals’ mannerisms and engagement with the world and others, but are approached as unique characteristics that make them who they are.

My research findings highlight that the situation is a little more complex. Embedded within insights about social expectations and support networks, some narratives highlight analyses I have just presented, while others present a completely different perspective. In many cases, participants offer rich, contradicting information. In no case but one (1), which I outline below, did Diné participants offer a singular word that would translate to disability. Robert clarifies: "How can I say, um, there's no set word for a disabled person (…). They would just be called person that can't walk, person that has blank thoughts or something ". Adding that social engagement with individuals who have physical disabilities depends upon the area and the family, the participant comments that, generally, individuals with disabilities are included in community affairs. This openness toward people with disabilities can be attributed to familiarity:

> Everyone is familiar with everyone else. They, if you don't know that person, you know that person's family so someone that has a disability, they already know where his family is from, or they know his story already and just word travels fast (…). So, in tight knit communities like that they are well perceived, he's just different .

> Comparing this view to non-indigenous cultural perspectives, Robert states: disabled people are kind of seen as, trying to think of what the word is, um, like an annoyance. Something that you can walk around (…) it's usually until people get to the city then they're cast in a different light. Then they are vagrants, criminals, treated like vermin [88].

Taylor, a Diné service provider, shares: "I have never seen that[89]; we know that if they want help, they will ask (…) my community comes together". She offers: "My culture sees disability differently". Comparing Diné to non-indigenous approaches,

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[88] The narrative of the participant reveals that they feel that many vulnerable populations are treated in a similar fashion, due to lack of time to meaningfully connect with others and lack of trust.

[89] Referring to stigmatization and/or social exclusion of individuals with disabilities.

Taylor continues: “they show no respect (…) they have ideas about what normal is and they shun everyone else. Diné people we will ask: ‘are you ok?’ (…) We look at helping the individual (…) disability can be a learning moment”.

When asked to elaborate, Taylor highlights: “We can learn how to behave (with kindness and respect), now there is much more information from the White man” (paraphrased).

Similar perspectives were shared by Diné participants from all sample categories. I paraphrase the perspective of Jane who points out that Diné individuals would probably refer to ‘disability’ as “having a hard time” (*bich’I’nawina*)[90]. Adding that the community are aware that individuals with disabilities are members of the group, she clarifies: “I have never heard anything negative (…) we don’t see them in any way” (paraphrased).

Making comparisons between Diné and non-indigenous frameworks of personhood and disability performance, Lisa shares that in the event of a disability many parents (particularly in non-indigenous contexts) go through a period of grief and mourning:

> one of the things that happens when a mother is born be, while she's pregnant, this is Anglo, she is picturing this perfect child, everybody in the family is picturing this perfect child you know that looks like Grandpa John and has mom's eyes and you know when a mother has a child that isn't perfect in some way whether it's physical whether it's mental whatever then that whole family goes through a

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[90] I refer to this term in a subsequent chapter (Chapter 7).

> grieving process, like a death, because they have lost the perfect child. Now some people and families get over right away, say ‘okay, well hey I'm fine with this difference and we are going to, you know, it doesn't make any difference if my child doesn't exactly look like that perfect child I was thinking about because I love this one so we're going to go with it you know?’ and, and some people never get over grieving from that lost child it breaks up marriages, I mean some parents could never like a child with a disability, some parents are anxious to give them up if it's a severe disability, you know all of that kind of thing.

Landsman (2009) relates this perception to cultural constructs of personhood: in American contexts, she suggests, disability threatens the full personhood not only of the individual with a disability but also of the mother, some more so than others. Situated within broader frameworks of commodification, women are expected to want and produce perfect babies. Any divergence from this cultural ideal calls for efforts to compensate, or ‘fill gaps’ in narratives that challenge the full personhood, as indicated in the examples provided above.

In the following narrative, Sam, a Diné individual with a physical disability, reveals how they envision themselves in terms of personhood. Contextualizing their insights within the framework of “gradation of personhood” (Landsman 2009, p. 61), they comment: “in my dreams I see myself, I am a complete person, one head, two hands”[91].

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[91] This quote has been paraphrased to protect the anonymity of the research participant.

Perspectives on stigma and practices of resistance to negative stereotypes reveal the relationality of disability and personhood. Elena shares:

> I don’t know if it’s fear, I think people don’t know what to do (…) Um, or not sure how they should… a… communicate with the person (…) I don’t know if it’s the lack of awa… maybe like just because they didn’t go to school with somebody like that so they didn’t have that kind of experience that makes them um oh don’t don’t stare you know those typa things you know I don’t see that as much with somebody with a physical disability as with um a developmental disability or some kind of um speech (…) because of developmental delays or things like that people don’t, think that they don’t know what they really want (…) I think everybody knows what they really want. I mean we all want to have, be happy, be loved um make a difference whatever way, whatever way that works.

Robert tells us that one of the most important determinants in personhood performance depends upon following norms of self-representation. In a society that privileges commercial value disability can raise questions about credibility as a person (Loja et al., 2013). After clarifying that the emphasis on this criterion is present in both cultures, but more prevalent in Anglo frameworks, Robert elaborates:

> unless you can add to the workforce I guess, you don’t, you don't have any value unless you're making money. So, unfortunately, that is one thing that you always kind of live with any modern culture like this could like consumer culture change from being successful you are kind of measured by the amount of material items that you have. I mean you could be lazy and irresponsible but if you have a nice

> car you have value in society (…) I mean people just judge, it’s kind of been built into Western society, you know the clothes make the man, um, if you look like you take care of yourself then, you know, you’re a trustworthy person, a stand up person. It's just like, you look good, people will um have a better opinion of you.

The participant reflects on similarities and differences with Diné cultural frameworks:

> there was, like, a cultural shift, like, in the early, when a lot of the areas right outside the Navajo reservation, before those are being developed before they were cities, yeah, I think people were valued on their character (…) but now the ideals have changed, things have just been so convoluted and you know, it's not so much like that anymore and it's just something that people reminisce about.

Robert explains the rationale behind shifts:

> being good to your family, being responsible with your responsibilities at home, being a hard worker. Cuz I think back then things of that kind of merit were measured in homestead (…) So, you have a house, and you know it’s well taken care of and you have livestock and they're all healthy, that is just a visual sign that you take care of your surroundings, but yeah things have just kind of, as things have changed, people have lost touch; and then TV is widely available they only care about the super visual images right now (…) Because we are so preoccupied with wanting to fit in with the idea of society cuz it is all white and I notice when I watch TV

> I don't keep into account that everyone on the other side of that TV screen is white. (…) we are receiving this idea that this is how you supposed to be and I forget that I'm brown, I forget that I have an entire culture.

The insights of this participant echo the perspective of Michael YellowBird (2004), whose work I have examined in previous chapters of this manuscript. According to YellowBird (2004) the commercialization of indigenous worldviews contributes to the perpetuation of stereotypes, making it difficult to resist to colonial narratives. According to Weaver (2015) the imposition of oppressive frameworks, which distance indigenous peoples with disabilities from their cultural practices, constitutes an act of colonization. In the context of disabilities, colonization is at play when individuals with disabilities feel forced to perform their identities drawing upon normative ideas of productivity and individualism, which overgeneralize and misrepresent indigenous paradigms.

Robert contextualizes how the social push of determining value largely depends upon visibility of disability:

> if someone is well spoken and intelligent but there's a few things still off about 'em, and they can work and keep a job down and pay attention to responsibilities, yeah, he's gonna get better treatment, much better than someone that probably has trouble walking, or bursts of anger, things like that. That's seen as just a violent person that could be avoided (…) I think for disabled individuals it is the same way and they don't have um you know the foresight to see like, the perception of what people would think and power do I use perception that people have them to their own advantage so, if I'm well dressed and clean cut I could get a job,

> whereas a disabled individual does not have the self-awareness to have, to have good hygiene or you know an abstract idea of fashion, they're not gonna be visually acceptable.

An excerpt of my interview with Fiona highlights the complexity of discussing these issues:

> that was a challenge for me, was to identify myself as disabled and I felt at that moment that disability had a negative term on it (…) really puts a weight on how you are valued in society. If you can't do things for yourself and you need assistance, then you're probably going to drag other people down and you're probably going to be a burden and so (…). Yeah, so I think that (there) should be a different word for it.

D: What would you recommend?

F: Umm, I would recommend, um, I want able to be a part of it. It probably won't be one word, it probably be like a group of words but able will definitely, you're, that you have ability to do things you just do it in your own way.

D: Ok.

F: So I would just say like unique ability or I think the other ones like timely, it will take you time to do something?

D: Ok.

F: You’re able to do it, it’s not timely, but it’s um, it's not unique, yeah I would think it would be like considerate

Fiona links interpretations of social perceptions surrounding physical disability to cultural definitions of productivity:

I think they[92] see strength and I think they see, I would definitely say that they see um you can offer something, everyone can offer something, everyone has something to offer in the community, everyone can provide something, whether it's you know buying KFC and then bringing it to the community or you know community potluck and be like well I can't cook, but I can buy food and give it, and so everyone has something even like the kids (…) disability doesn't stop people from being who they are and doesn't stop them from offering thing .

Contextualizing Personhood: Disability as a Teaching Moment and the Relationality of Kinship.

The concept of offering is centered on social skills in appropriate performance of kinship roles, knowledge and demonstration of a desire to follow norms of reciprocity while little emphasis is given on whether the act of reciprocity is done with or without assistance in performing tasks. Taking care of sheep and childcare are some of the tasks

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[92] Referring to Diné cultural perceptions

that individuals with disabilities are trusted with among the Diné, while high unemployment rates place individuals with disabilities who receive benefits in an esteemed social position due to their contribution to the financial well-being of the family (Connors & Donnellan, 1993). Cultural perceptions of autonomy and self-determination have also contributed to the perception of individuals with disabilities as equal, even valued, members of society. (Connors &, Donnellan, 1998). From a very early age, children learn accepted social behavior and obligations through active participation in family responsibilities (such as taking care of younger siblings). Parental focus among the Diné tends to encourage growth through encouraging questioning, exploration of the physical and social environment, and praise for social participation, rather than admonishment to regulate social behavior (Connors & Donnellan, 1993, 1998; Frankland et al., 2004). Child rearing practices emphasize individual freedom to behave as one would wish, since each individual has been brought to this world to fulfill a particular role, which may also explain why individuals with disabilities are generally not stigmatized (Connors & Donnellan, 1998).

Ruth, who has a family member with a physical disability, juxtaposes limitations that physical disability poses to ‘positive’ developments in terms of personality: “Well, growing up like for the traditional ways we are always reminded, like, we have two hands and legs you can use it to help yourself (…) like, just take care of yourself and provide for yourself”. When asked how this notion relates to physical disability, she expands:

> I think it just makes you stronger (…) because you have to double for it I guess (…) . Like, compensate. Like, you’re facing like a bigger challenge than most

> people facing so makes you stronger get through it, like in any way like mentally, physically, emotionally. Maybe, like, also in a spiritual way too. yeah, yeah I think the strength would be mostly maybe spiritual (…) let me see how I can say this. Like, you're, you're made differently, like, specially so, like, have a deeper connection with spirituality in our tradition (…) they have to learn how to do, like, things that a person would normally know how to do in different ways.

In fact, like other studies (see Shackel, 2008), throughout my fieldwork research, Diné participants shared that interacting with individuals who have a disability can contribute to personal and communal growth. Jane says that “handling challenges” on a daily basis gives individuals with disabilities internal strength, as well as intelligence, which can teach others in the social milieu acceptance. She further highlights: “People with disabilities think a lot more (…) we can learn ‘don’t make fun’ and accept people” (paraphrased).

Contextualizing what acceptance looks like, she emphasizes the issue of respect, at the epicenter of which lie concepts of humility and trust in others. In engagements with individuals with physical disabilities respect is shown in ensuring social participation. According to Jane: “Respect can mean saying hi, making room for a person” (paraphrased). She sees similarities between Diné perspectives and non-indigenous understandings of disability in terms of providing assistance for individuals with disabilities and encouraging them to fulfill their goals, but differ in perceiving differences. I paraphrase her clarification: “Diné people, we treat everyone the same, no class difference”. She adds: “For Anglo people, it depends how they were raised” (paraphrased).

Narratives that discuss the potential for individuals with disabilities to fill mentorship roles encompass cultural understandings of social values. Cultural constructs of respect and the pursuit of happiness are focal for those who view disability as a ‘teaching moment’. Beth shares that disability can “make you happy”; she adds that people with disabilities “smile more and think straight”. When asked to elaborate they share: “People with disabilities get a chance to clear your mind, think through agony, life, work it out*”* (paraphrased).

The concept of thinking clearly (*nitsa’hakés*) is a central Diné construct that frames Diné perception of interconnectedness of the embodied self to the physical environment. After the creation of First Man and First Woman, First Man threw rocks at the East, West, North, South, and created four mountains, which delineate the homeland of the Diné (Zolbrod, 1984). Gorman-Keith (2004, p. 30-31) adds that these four mountains are the guiding principles for healthy living: to the east one finds hayoolkaal (the dawn of the new day), which corresponds to the season of spring and represents nitsa’hakees (thinking, knowledge and values). From the south, where Mt. Taylor lies, Diné individuals draw the strength to engage in Nahat’a, in other words, skills to plan for the thinking to materialize, or plan on how to act toward social wellbeing. San Francisco Peaks represent Lina (living, and social wellbeing), and correspond to the fall season. To the north, there is darkness encompassed in Dibe Nitsaa. Representing the winter season, this mountain urges all Diné to safeguard the future and protect the next generation.

Farella (1984) adds that all natural phenomena (such as the sun, rain, thunder) are, in fact, sacred beings—known as *diyinii*—who helped construct the universe and natural world as we know it. Given that the Diné also view human kind as being born from the interaction of the *diyinii* with the First Man and Woman, everyday human practices, e.g. breathing, reproducing, should be perceived as sacred acts that are an integral part of hozhó (harmony through balance).

Linking the formation of clans to natural phenomena or animals (e.g. the bear or water) the principle of *k'é* is intended to provide individuals with a sense of belonging, both in spatial and in social terms. While particular importance is given to connection with the mother and her clan, each and every Diné individual embodies four clans; namely the mother's, father's, maternal grandfather's and paternal grandfather's. Each of these encompasses the four cardinal directions (East, South, West, and North respectively), thus positioning the individual within the Diné homeland (Farella, 1984).

The relationality of Diné to the physical environment and to the social milieu through the performance of kinship relationships is an important concept in understanding well-being and illness. According to Lewton and Bydone (2000) balance within the individual and the universe depends upon being aware of the dynamics of space, individual actions, as well as maintaining group prosperity and living life in a way that ensures the existence of respect in all of these three principle areas of social life. Lewton and Bydone (2000, p. 249) add that reverence, kindness and cooperation ensure "receiving that which is good in life-it is the very basis of healing and well-being". Bret confirms:

> in Diné culture, we see people as a whole, not disabled. Everyone has a disability. A disability is not acknowledging the uniqueness of the person (…) Wellbeing means equilibrium you have to eat the right food, be emotionally healthy, equilibrium can be spiritual too: looking up to a higher power. How you see yourself also matters. Keeping equilibrium and walking in beauty help maintain health (paraphrased).

He elaborates upon the principle of walking in beauty: “That means keeping focus on your thoughts, thanking Mother Earth for her abundance and for taking care of us” (paraphrased).

Discourses of thankfulness and respect reveal cultural interpretations surrounding disability. Sharing that individuals with physical disabilities have to be mobile physically to maintain health, Jane clarifies: “Everything is up here. Be thankful. You may not have your eyes, but you have your mind” (paraphrased). Emphasizing the importance of a healthy mind, Mary, a Diné healthcare worker, clarifies that the concept of walking in beauty refers to ensuring that the mind is not distracted by negative thinking:

> it doesn't mean you walk in, like, all beautiful or gracefully, it means in whatever, whatever the world opens up to you, think of it as a learning process and try to use that, use it as a learning tool and not against others, but use it to a build yourself ,and make yourself grow with it ,so that you can actually put back into, um, life, you know? You know as a whole you have to remember that's why life is here, so that's walking in beauty being able to walk through something bad and being able

> to bounce back, back and forth and that's sustaining life. Yeah. So, finding the beauty in life again, that’s walk in beauty

Along the same lines, Martha shares that it is important for an individual with a physical disability to believe in themselves and follow cultural practices to remain healthy. She adds: “ (They can) like eat right, I mean eat healthy, stay fit, exercise (…) yeah, whatever you can do I guess to pump up your your your energy or, clear your mind, stuff like that”. Prayers, ceremonies and doing blessings were also mentioned by Diné participants across sample categories. Fiona shares why these practices are so important: “having that belief and having that respect in that morals where you come from (…) that's the creation stories” .

A number of narratives among Diné participants situated maintenance of health for individuals with disabilities within a framework of promoting awareness of disability related concerns. Reflecting on how to improve oneself, focusing on actions that promote wellbeing for others and the environment, as well as discussing important issues of social justice were cited when discussing harmony through balance in relation to physical disability. This concurs with what other scholars (for example, see Lovern, 2008; Weaver, 2015) highlight. They have found that following social norms that promote key principles of kindness and respect is more important than experiencing a disability. Drawing upon the fact that I have a physical disability myself, Taylor clarifies:

> balance, walking in beauty, hozhó, you see all these when you show respect, think clearly, not focus on what people look like. Gesticulating in the direction where I

> was sitting, she elaborates: I see an example (of hozhó) right here (…) what you are doing here, you are doing something important. You have a disability but you are doing something to raise awareness. We need to talk about it (paraphrased).

As a Diné individual with a physical disability, Henry takes pride in being an advocate for his needs and for the needs of others. Participating in efforts to promote inclusion and making sure that individuals with physical disabilities and their parents understand that they have nothing to blame themselves for is imperative: "I…personally think that it's not, it's not their fault (…). That's what I was told. That person, that person should've been…, should've been, should've been corrected before mistakes happened (…) But that person is not gonna know what mistake is happening".

As Connors and Donnellan (1998) suggest Diné healing practices focus on identifying how an illness occurred. Taylor highlights: "disability is something that is in you, not medical, but supernatural, something the creator put in your path. It is not something that can be fixed, you can give purity back (…) Diné people think about how it happened, you may be off balance" (paraphrased). Breaches of cultural norms particularly during liminal phases in a person's life (e.g. pregnancy), interactions with animals and other natural phenomena, and exposure to traumatic events were cited as 'causes' of physical disability (Milne & Howard, 2000) [93]. A prevalent theme revolved around actions of parents and relatives. Ruth shares: "Maybe like your relatives did something". Others pointed out that mothers carried a special responsibility in ensuring

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[93] The author is unable to disclose further details on this culturally sensitive knowledge following the advisement of Navajo Nation representatives.

harmony through balance. Acknowledging that some Diné recognized biomedical explanations for disability (such as genetics), Lisa emphasizes: “a mother did something wrong, and that it was being visited upon the child, so there were Navajos that had that kind of perspective”. In their work on developmental and cognitive disabilities Connors and Donnellan (1998) discuss how parents of children with such disabilities looked for culturally relevant explanations for their offspring’s disability. Some, they tell us, attributed their child’s disability to contact with animals, witchcraft, and use of alcohol or drugs. John tells us that explanations centered upon substance (ab)use promote stereotypical views of Native American peoples. More specifically they state: “some people might assume that it has to do with alcohol and the parents (…) or drug addiction”[94].

While Diné participants mentioned that following a healthy lifestyle was part of performing hozhó, making healthy choices was also emphasized among non-indigenous service providers and healthcare workers. In general, they acknowledged the importance of staying active, having a balanced diet, and being mindful of medications and their side-effects. Similar to Biehl (2007b), Janis states:

> other stereotypes I think are around(…) health and wellness, you know, I hear a lot of people that don't take responsibility about eating right, exercising taking their medications the right way because they've been told or they believe that it doesn't matter, that they don't think that that you can be healthy you know?.

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[94] This has been paraphrased to respect privacy.

> They've, they've, they've equated that with it doesn't matter what I eat, when I take my medicine it doesn't matter that I that I exercise and that couldn't be further from the truth you know?.

Conclusion

Balancing conflicting social perceptions, the men and women whose narratives I have incorporated in this chapter expressed their struggle in determining their positionality in relation to disability. Often the two main views presented in this chapter were both internalized in participants. Privileging harmony, balance and beauty, indigenous frameworks suggest that no matter the degree of difference, all individuals are equals. Rather than leading to exclusion, individuals with disabilities are positioned in privileged position in relation to those who do not have a disability. Because of their life experiences, individuals with disabilities lead the path for others: demonstrating resiliency, a deep understanding of Diné cultural teachings, they show others an alternative to stresses of life.

The counterpart view has its foundation in disablist/ableist underpinnings: in this frame of thought normative representation of oneself as well as participation in the market play a focal role in discussing constructs of personhood and social belonging. Hegemonic understandings of ‘ability’ and ‘normalcy’ position individuals with disabilities in a context where opportunities for social inclusion depend heavily upon learning to respond to others in ways that emphasize self-empowerment. In this context, assistive devices play a dual role: on the one hand they are clear markers of difference, which opens up the possibility of stigma. However, assistive devices indicate choice, as they are often used by participants to delineate boundaries and offer strategies to resist offers of assistance from others, when unwanted.

Internalization of disablism/ableism, by indigenous and non-indigenous participants alike contributed to the association of disability to a state that departed from normalcy. Social expectations surrounding social performance, assumptions about capability in assuming responsibilities and performing tasks were important discourses when reflecting about the meaning of the term disability and its impact on everyday life.

CHAPTER 6: COLONIZATION AND DISABILITY

Colonization takes many forms. Around the world, colonizers have mistreated indigenous peoples, with policies and practices aimed at physically exterminating indigenous populations. The goal of colonization is also to erode cultural norms to impose new frameworks, which shape perceptions and responses to phenomena, including disability (J. Maupin, personal communication, October 2, 2019). The colonized have worked as slaves in the colonizers' plantations, as servants in their homes, and in the reservations and boarding schools wherein they were forced to reside due to assimilation policies established by colonizers' governments (Grech, 2015; Denetdale, 2008). Death and disease followed in the wake of colonizers' invasion. Colonizers brought with them measles and smallpox: research shows that among Native Americans the prevalence of measles, mumps, chicken pox and small pox was two (2) to three (3) times higher than the national rates (DeJong, 2007, p.58). The usurpation of lands and natural resources led to poverty and hunger, while deplorable living and working conditions contributed to physical disability (Grech, 2015). In the name of expansion, economic development, and assimilation, the bodies of indigenous peoples were transformed to expendable commodities: those colonized were forced to work for the benefit of the colonizer, while torture was inflicted upon those deemed 'resistant' or 'unproductive'; the visceral results of cruel corporeal punishment were then flaunted to others in order to ensure compliance (Rao &Pierce, 2006).

Children were forced to abandon their homelands and attend boarding schools. By 1890s (a few years before the first boarding school opened its doors in Carlisle, Pennsylvania) the total population of Native Americans had been decimated: only five hundred thousand (500,000) remained in the United States, while more than one hundred thousand (100,000) children were forcibly removed from their homes to attend boarding schools (Grinde, 2004, p. 25; Smith, 2004, p. 89). In order to ensure financial viability of boarding schools, ‘students’ spent more time performing manual labor than focusing on their actual education. Autobiographies from youngsters attending boarding schools highlight that children as young as twelve years old worked six (6) days a week, in an array of manual jobs, including rebuilding boarding school facilities, preparing food, and doing gender-specific maintenance jobs (Smith, 2004; DeJong, 2007). Male ‘students’ worked as carpenters, and built and repaired facilities in the boarding school, while female ‘students’ were trained in chores that emphasized domesticity, such as laundry and kitchen duties (Cooper,1999; Lomawaima, 1993)[95]. Based primarily on bread, tea, and potatoes diet was inadequate and of bad quality. The lack of food incited tensions between attendees. Snatching girls’ portions, boys would often get more to eat, while matrons took away the food that girls would hide in their uniforms, as boarding school officials felt that spending the extra time to eat would interfere with their work schedules (Brown, 1952; Cooper, 1999; DeJong, 2007). ‘Students’ lived in overcrowded rooms and shared facilities. Data show that enrollment in boarding schools exceeded their maximum

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[95] Lomawaima is a member of the Mvskoke / Creek Nation

capacity: some hosted more than sixty (60) students beyond their maximum capacity leaving little light and fresh air to 'students' (Gessner, 1931, p. 165).

'Student' enrolment in the Phoenix Indian School burgeoned from the time of its establishment in 1891 to its closure in 1935. Indicatively, "for the fiscal year 1921-1922 average attendance reached 789, even though funds were provided for 750" (Trennert, 1982, p. 169). For fear that government officials would take their children farther away from their homelands, Native American populations, primarily Diné, Hopi and Papago, relinquished their children to this school. By 1928, Phoenix Indian School had close to one thousand (1,000) attendees in facilities made to host close to seven hundred (700) (Trennert, 1982, p.176). Evidence shows that two (2) or (3) children slept in one (1) bed and shared bedding, often intermingling healthy and sick children. The ventilation issue was further exacerbated, as windows were nailed shut to make sure that no child was able to leave the facility (Gessner, 1931; DeJong, 2007). Children in the Phoenix Indian School were also exposed to other bad living conditions. Restrooms were in desperate need of repair and there was no heating due to lack of funds to repair furnaces, while students had to use porches as their changing areas, because of extreme space shortage (Trennert, 1982). Reports (as cited in DeJong, 2007, p. 258) highlight that, in 1915, the rates of tuberculosis in boarding schools were four (4) times higher than that among non-indigenous populations in the United States, while one (1) in three (3) children in boarding schools were infected with trachoma. More than three hundred twenty (320) children at the Phoenix Indian School contracted measles in 1989, while sixty suffered pneumonia, which took the lives of nine (9) children in the duration of ten (10) days. In

1912, seventeen percent (17%) of Diné children attending the Phoenix Indian School returned to the reservation with tuberculosis (Gessner, 1931, p. 221). In the late 1950s, fifty percent (50%) to ninety percent (90%) of children of school age suffered from trachoma, while Diné children attending boarding schools and day schools had the highest rates among those documented at more than twenty three percent (23%) per approximately one thousand (1,000) (Cobb & Dawson, 1961, p. 151). Children returned to their homes very sick or blind after their residence at boarding schools. The eyesight of thousands of children was affected, not only directly due to trachoma itself, but also because of the carelessness of doctors. Parents were told that tarsectomy would prevent recurrence of trachoma. Procedures were performed by inept doctors whose lack of skill led to blindness (Gessner, p. 1931).

In addition to physical ramifications, attendance in boarding schools also had implications on the mental health of students (DeJong, 2007). Determining the prevalence and severity of mental health issues and the effect of boarding schools is challenging due to various factors such as small sample size and difficulties in conceptualizing a research design that accurately measures mental health (Kleinfeld & Bloom, 1977). Estimates of prevalence of mental health issues among students in boarding schools vary, ranging from forty nine percent (49%) to seventy-five percent (75%) (Kleinfeld & Bloom, 1977, p. 411; McShane, 1988, p. 97). Surveying four (4) boarding schools in the Alaska region, Kleinfeld & Bloom (1977) measured the prevalence and severity of mental health issues using participation in drinking, criminal activity and sexual violence as indicators. They found that out of a total of one hundred thirty-two (132) students in boarding schools, forty nine percent (49%) of freshmen had emotional issues that affected their school performance, an issue which became more prevalent with the passage of time, affecting fifty-nine percent (59%) of sophomores. While only a small percentage of students (eight percent, 8%) engaged in drinking during their first year of attendance, this phenomenon intensified in subsequent years reaching forty percent (40%) among second year students. In schools with extremely strict policies against drinking, fifty five percent (55%) of freshmen suffered from mental health issues, such as depression (Kleinfeld &Bloom, 1977, p. 414-416).

An important aspect of colonization involves the silencing of indigenous voices (Abbott Mihesuah & Cavender-Wilson, 2004)[96]. When efforts to 'educate' Native Americans began in the early seventeenth (17th) century, initiatives lay in the hands of missionaries, whose primary mission was to eradicate the spiritual beliefs of Native Americans and indoctrinate them to Christianity. Establishments built by Jesuit priests served as the first schools for Native Americans; throughout the 1869 and 1870, more schools were built on reservations, while Congress set aside funding to establish boarding schools on reservations (Smith, 2004). US congress members were torn: some felt that expansion and land ownership efforts were being slowed by the presence of Native American populations and were in favor of continuing acts of violence and war to physically annihilate the population, while others supported enforcing policies aimed toward eradicating the cultural practices, religious beliefs, and languages of Native American peoples, with the aim of "Killing the Indian and Saving the Man" (Adams,

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[96] Abbott Mihesuah is a member of the Chocktaw nation.

1995; Smith, 2004, p. 89). The first boarding school, in Carlisle, Pennsylvania, opened its doors in 1891 and served as a ‘model’ for all subsequent boarding schools. Previously sheltering soldiers, the grounds of the boarding school were in derelict condition when the first students arrived. Carlisle was spread out over twenty-three (23) acres and included a bakery, a hospital, a dining hall and a guardhouse (Cooper, 1999). The first days of the boys’ sojourn in the boarding school involved transforming the bodies of these young boys. Their names were changed, their hair was cut and their clothes and personal belongings were taken away from them (Adams, 1995). Staff were burdened with monitoring the actions and behaviors of students and reported back to the appropriate authorities in order to understand how to ‘best’ intervene and resolve what they perceived to be a threat to White domination (Lomawaima, 1993). Pratt’s ideology was riddled with ‘cultural racism’ (Grinde, 2004, p. 28-29)[97]. The politics of stripping all signifiers of Native American identity were driven by acknowledging the humanity of Native Americans, and their potential for change that was—in the eyes of the colonizers— better than the social structure of Native Americans. Failing to recognize the value of indigenous worldviews, instruction methods, governance and complexity of social norms and roles, the colonizers insisted that boarding schools offered Native Americans the opportunity to become ‘civilized’. The aim of such tactics was to subvert any expression of individualism and any performance of indigenous identity (Lomawaima, 1993). To intensify the eradication of indigenous identity, curricula focused on teaching students the English language as well as basic math. Regulations in

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[97] Donald Grinde has Yamasee ties

boarding schools dictated that all students not speak their indigenous language, emphasizing the superiority of English, and a means of connection to Whites (Adams, 1995; Grinde, 2004). If students were caught resisting these ‘civilizing’ practices they were beaten, often by older students who were charged by boarding school administration with ensuring that younger boarding school residents upheld the rules (Hirshberg, 2008).

According to some participants in my work (both Diné and non-indigenous) the experience of boarding schools frames current engagement with disability. Lisa’s narrative highlights how stereotypes permeating boarding school discourses inform attitudes on disability today: “when White people, biligána, like us interacted with the Native American populations, not just Navajos, they went through that whole period of taking the children”. Lisa shares that the fear of officials would lead parents to urge their children to hide in safe places to minimize the likelihood of being taken away: “they brainwashed them, they cut their hair, they didn’t let them use Navajo or whatever their Native language was. It became a stigma to speak Navajo, call yourself, you know what I mean?” As we continue our conversation on social attitudes regarding physical disability, Lisa stresses that some White people enter into the life of a Native American person with a disability with disrespect: “Some people, White people, just come in and dismiss the child’s culture”. For this participant, the root of this kind of disrespect goes back to religious and other forms of practicing power and domination over Native Americans:

> most Christian religions believe that if you don't believe in their framework then you are doomed to hell and are some kind of a less than pagan, savage, I mean you name the word that people want to use and most of the people that originally interacted with

> Native American populations were trying to save them from being savage. Okay? so therefore the, the Native Americans that didn't crumple and go oh yeah okay I'm going to quit being an Indian and believe in your white man's religion, those people were looked down upon because they were still considered savages, unsaved the great unwashed you know?

Lisa notes that such colonizing practices continue to occur today, albeit in more indirect, subtle ways. The danger lies in not exercising critical thinking in everyday life, particularly when one has the authority to determine how they will shape the lives of Native Americans with disabilities, and whether they will be an empowering presence or not. Prejudice is the driving force behind assimilation practices. Lisa elaborates:

> I think it is really important to counter the effects of people (…) with Save The Savage attitudes (…) as far as I'm concerned because somebody that comes in like that is still trying to do the whole assimilation thing and they're out there strong still.

In a poignant vignette, Lajimodiere[98](2012) highlights how her father, who had been in a boarding school, realized the politics of assimilation, only when she showed him a documentary she had discovered. She discusses how conversations about the experience of colonization through the arena of boarding schools can have a healing effect; yet, the journey is difficult since Native Americans have lived the reality of colonization over

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[98] Denise Lajimodiere is an enrolled citizen of the Turtle Mountain Band of Chippewa, Belcourt, North Dakota

such an extended period of time that they cannot identify the problem and name the implications.

Colonization, Historical Trauma and Disability

Sources relate trauma to an event, or a multitude of occurrences, that constitute an assault to the physical or emotional boundaries of an individual. Any kind of shock that challenges the physical and emotional sense of well-being could fall under the purview of trauma. Therefore, the concept could include direct or indirect exposure to war, assault, environmental hazards and natural disasters, as well as serious accidents, and/or loss[99]. Trauma is defined not as much from the stimulus or event itself but rather by the consequences that events have on the individual and their participation in social life[100]. (Waldram, 2004; Denham, 2008). Initial interventions examined trauma among Indigenous peoples drawing upon popular interpretive models like PTSD. The framework of PTSD examines reactions to trauma within a span of a life time and recognizes the avoidance of social situations, detachment, estrangement from family members, feelings of sadness, anger, fear, as well as disturbing memories as examples that signify exposure to a traumatic event [101] (Evans-Campbell, 2008). PTSD interventions focus on the

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[99] See American Psychiatric Association https://www.psychiatry.org/patients-families/ptsd/what-is-ptsd

[100] https://www.psychiatry.org/patients-families/ptsd/what-is-ptsd

[101] https://www.psychiatry.org/patients-families/ptsd/what-is-ptsd

individual and overlook the role of social support (or lack thereof) in trauma response; Secondly, they fail to recognize the importance of previous generations, and the traumas they have suffered, in shaping the experience of trauma for current Native American populations; thirdly, they pay little attention to how history has shaped contemporary social structures, and by extension, social relationships within and between social groups. Finally, they overlook the agency of the group that has experienced/is experiencing trauma in addressing the issues itself, if given a platform (Evans-Campbell, 2008).

Historical trauma emerged in the field of mental health in the 1990. Initially focusing on the psychosomatic and psychosocial effects of experiences like the Holocaust, Historical Trauma Theory is based on four main premises: firstly, that individual and collective trauma results from the deliberate domination of a target population. Secondly, that this trauma does not trace back to a singular event, but rather encompasses multiple areas of physical existence and social life over a prolonged period of time. Thirdly, that this trauma affects a population, rather than an individual and, finally, that trauma impacts the physical, emotional, social and spiritual wellbeing of the target population (Sotero, 2006; Gone, 2013a, b). It was first associated with indigenous peoples by Lakota social worker and health specialist Maria Yellow Horse Braveheart[102] and colleagues (Yellow Horse Brave Heart & DeBruyn, 1998; Gone, 2013). Yellow Horse Brave Heart (2000, p. 246) defines historical trauma as “cumulative wounding across generations”, a result of physical, emotional and psychological violence against a group (because of shared identity and culture) that occurs throughout a life span and

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[102] Yellow Horse Braveheart is Hunkpapa/Oglala Lakota

within specific historical contexts (Yellow Horse Brave Heart, 1998; Yellow Horse Brave Heart et al., 2011).

Hailed as emancipatory, Historical Trauma theory provides a framework for Native Americans and specialists—particularly those working in mental health— to interpret health disparities that affect indigenous groups in a way that acknowledges the particular historical context and ongoing oppression under which many indigenous populations operate. Therefore, the contribution of Historical Trauma has been to point out the need to critically think about the implications of solely holding the individual, their ‘faulty’ genetics, ‘dysfunctional’ behavior, ‘disordered’ psyche, responsible for not being able to ‘cope’ and ‘overcome’ traumatic events (Gone, 2013a). Historical Trauma recognizes that the process is more complicated, and identifies a link between psychosocial response and historical context. Individuals who are part of a group subjected to military invasions, relocation, physical decimation, as well as cultural oppression may experience cumulative trauma on multiple levels (Gone, 2013a, p. 687-688). More recent experiences and practices targeted against Native Americans, such as forced attendance in boarding schools, negation of the veracity and validity of ongoing oppression many of the Native American people have to navigate in their everyday life, appropriation of important symbols and cultural references and as well as having to succumb to circumstances which dictate unwanted relocation to urban areas due to disparities in equal opportunities further exacerbate existing historical trauma (Prussing, 2014). What distinguishes Historical Trauma from other approaches is the fact that it examines the connections between reactions to current traumatic events and trauma that has occurred in previous generations. This tenet proposes that the exposure of previous generations to physical and/or emotional violence increases the preponderance of future generations to mental health concerns in response to stressors (Gone, 2013a, p. 687-688). The initial inception of Historical Trauma theory in conjunction with the Holocaust, and its subsequent association with the experience of indigenous peoples have contributed to a legitimization of the ongoing oppression that indigenous peoples have been subjected to, leading to an increase of scholarly attention to issues of empowerment among Indigenous groups (Kirmayer, et al., 2014)[103]. Furthermore, signifying a digression from biological explanation of the health disparities, Historical Trauma has led to the awareness of the importance of promoting empowerment of indigenous peoples by recognizing their role in addressing trauma through Indigenous knowledge and practices (Gone, 2013b).

Given the fact that Historical Trauma is fairly new as an approach, scholarship is exploring its intellectual contribution and debating about gaps in this theoretical framework. Conceptual premises upon which this approach is based make reaching measurable conclusions difficult. Research on trauma is challenging because of the sensitive nature of this topic. For example, Goodkind et al. (2012) point out that studies that explicitly look at historical trauma among the Diné are limited. Diné traditional practitioners caution against direct questioning about trauma as discussing trauma may cause the individuals to relive the experience described. At the same time, elders point out that recognizing and learning more about the impact of trauma is an important aspect

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[103] This source offers a summary of critiques.

of healing. An additional concern lies in the fact that manifestation of trauma and physical/emotional response to traumatic events is highly varied from one individual or group to another. The expectation of mass trauma after a devastating effect is also an assumption. Future generations often actively use past traumatic experiences that family members have gone through as a means of revitalizing culture, honoring traditions and empowering themselves and their offspring (Denham, 2008; Walters et al., 2011). Critiques mainly point out the need for further examination of whether psychological responses and health disparities are indeed compounded by past traumatic experiences, even if the individuals exhibiting trauma symptoms have not been exposed to traumatic events themselves. In addition, more research is needed to determine causal links between previous trauma and current mental health concerns, as well as developing measurement tools to assess the prevalence of historical trauma (Denham, 2008; Palacios-Portillo, 2009; Whitbeck et al., 2004).

The work of Whitbeck et al., (2004) with elders on two (2) reservations revealed that language loss, distance from family and community ties, denial and violation of treaties, as well as alcohol and drug use were prevalent themes that participants related to trauma. Results showed that forty four percent (44%) of participants reported that they sometimes felt sad when thinking about loss; more than thirty percent (30%) mentioned feeling angry. Almost forty nine percent (49%) reported recalling events related to loss when they did not wish to, while more than thirty two percent (32%) said that they felt that policies that contributed to loss were happening again. Finally, more than thirty percent (30%) mentioned that they avoided places or people who reminded them of loss.

To determine the veracity of the claim on intergenerational nature of historical trauma research has focused on documenting the relationships between older and younger generations (see, for example, Cross, 2010; Goodkind et al., 2012)[104].

Much of the disintegration of communication is due to the internalization of negative discourses surrounding Native American identity throughout the boarding school era. Centered in promoting racial and cultural inferiority of Native Americans, messaging emphasized that indigenous peoples lacked the skills to raise their children, legitimizing removal from their familial environments (Yellow Horse Brave Heart & DeBruyn, 1998). Research shows that the experience of boarding schools has instilled a fear in Native American people of forceful deprivation of their offspring, which influences parenting style by sharpening hesitation to ask for welfare and other support by the State when needed (Cross, 2010).Those who attended boarding schools mention that, as a result of boarding school life, they experience difficulty maintaining their native language and having a positive sense of themselves. More specifically, participants in Hirshberg's (2008) work share that they feel ashamed of their culture and traditions, doubt their intelligence, are critical of their physical appearance. Goodkind et al., (2012) observed a generation divide among the Diné who participated in their research project. Elders felt that not sharing traumatic events that had happened to them and/or their ancestors protected their offspring. On the other hand, younger parents felt that the silence around the issues of loss made communication with their parents difficult. Young

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[104] Goodkind is a member of the Navajo Nation.

parents emphasized the need to talk about history in order to remind future generations of the strength, resilience and resistance of their ancestors.

When I began my fieldwork, I was aware of the devastating impacts of colonization on Native American groups. I realized that colonization was a major culprit of the health disparities that Indigenous groups across the world are experiencing [105]. However, I failed to fully grasp the extent to which colonization pervades participants' narratives in relation to the lived experience of physical disability. This oversight was a product of my ignorance, in part resulting from my own inexperience and in part due to the theoretical engagement of the disciplines I move in with the term 'colonization' itself. Anthropology, disability studies and other disciplines have been using the term 'colonization' rather freely, almost as a metaphor to describe various discourses and practices of oppression of people of minority status (including those with disabilities). In this sense, colonization is equated to disempowerment, domination and subjugation, detached from the systematic, pervasive and violent practices within our past, often also overlooking the current and ongoing infringements against indigenous peoples that have redefined geography, changed the relationship of indigenous populations to natural resources, and limited the rights of indigenous peoples to equal participation in political, social and religious life (Grech, 2015; Grech & Soldatic, 2015).

Those who are engaging with disability as scholars operate within pre-existing constraints, in the sense that available terminology fails to accurately describe indigenous concepts regarding disability, or –worse yet—redefines the experience of 'disability' as

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[105] For more details please refer to the Introductory section

dis-ability (with all the connotations that this term carries within it) in Indigenous communities (Lovern, 2008; Meekosha, 2011). Narratives that research participants offered contextualize this terminology concern within a critical analysis of the historical context that has shaped current understandings of cultural norms. Jack tells us: “Yeah so I don't know if there's anything, I don't know if we had disabilities back before everything happened, back in the old days”. When I asked for further clarification Jack connected the emergence of disability to biomedical interventions and colonial presence. He shares: “Adopting the white way medicine or what not so (…) I don't know if there was any disabilities back before the treaty-signing and everything*”*.

Elders who collaborated with Connors and Donnellan (1998) highlighted that prior to the advent of colonizers, Diné cultural frameworks did not define most conditions that are defined as disabilities today as such. Prior to colonization Diné individuals lived in a greater state of peace, since their worldviews did not differentiate between those with and without disabilities, as most conditions that are defined as disabilities today were not seen as problematic.[106] Other scholars have reached similar conclusions. The following excerpt from the work of King et al. (2014) highlights the complexities in defining disability across cultural contexts:

> I guess, as we started travelling to remote and isolated Indigenous communities, we would make a telephone call and they would say, ‘Oh look, we don’t have anyone here with a disability.’ We would travel to that community anyway, Mornington Island was a good example, and … over the course of a couple of days, from a

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[106] For more details, please refer to Chapter 5

> community that said it had no people with disabilities, we saw about nine to ten people with various forms of disability in their homes (p. 744-745).

The systemic efforts to eradicate indigenous traditions, worldviews, and religious beliefs, as well as the systematic imposition of cultural, social, political norms, have contributed to the loss of indigenous knowledge of terminology and shifts in interpretative frameworks in relation to social phenomena (Fixico, 2003; Cavender-Wilson, 2004). Concerns over not recalling traditions and teachings were a common theme that Diné participants brought to my attention during my fieldwork. Diné individuals with physical disabilities, service providers and family members alike attributed lack of familiarity with important cultural concepts to the effects of trauma. More specifically, silence around traumatic experiences is exacerbated by the fact that elders do not wish to share what they know because of internalizing dominant discourses that put indigenous knowledge in a negative light. For example, in response to my question about social perceptions of physical disability among the Diné, Allison, responds: “You know, I can’t tell you”. Thinking that I may have touched on a sensitive issue, I tried to quickly change the subject, when she continued to share that a family member had gone to a school where they were taught that traditional views were wrong. Thereafter, family members refused to speak Navajo[107], and teach their children. Allison further explains that she was raised in an environment where “beliefs, things like that, are not something to be proud of, why things are the way they are (…). In terms of disability, no one ever sat us down and said this is what the traditional ways are”.

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[107] I am using Navajo as this is the term this participant used throughout the interview.

Research on historical trauma by indigenous scholars shows that generations following those that have been directly subjected to ongoing trauma experience a multitude of emotions that can be associated to trauma itself and to perceptions of themselves in relation to the individual who was directly subjected to traumatic events. For instance, a 1992 study on the effectiveness of Lakota cultural tenets in discussing and resolving emotions examined the correlation of traumatic events (such as land loss and boarding school) to incidences of primary and secondary trauma. Findings highlighted that almost seventy percent (70%) of the participants in the study felt anger when recalling traumatic events that they or their family members had been exposed to and expressed concerns over the possibility of presenting aggressive behavior; sixty seven percent (67%) of those participating indicated that they felt sadness; almost sixty-one percent also reported feeling guilt for not having been exposed to that kind of trauma themselves and for not being able to understand and relate to others, a sentiment which was compensated by suicide and rescue ideation (Yellow Horse Brave Heart, 2000, p. 249, 253). Mechanisms to address the memory of trauma included focusing on traditional cultural tenets and using their experiences with trauma to help others and/or safeguard the physical and emotional wellbeing of future generations (Yellow Horse Brave Heart, 2000).

I noted similar patterns in my fieldwork. In certain cases, the physical hardships and emotional duress that Diné have suffered at boarding schools have become a reminder on how to ensure that the past is never repeated. Hope, a Diné service provider shares:

I think a lot of them found a lot of unfairness and I think they found their own way to kinda go around that or to think of can I go around that or to think of issues that way they could have come out either bitter or understanding about it. I have family members who went through the same thing and they came out maybe slightly prejudiced because of that. Um, because what they had to go through during that time you know they had to be removed from their families and go to boarding school and we were taught to like they can't speak their language so my grandparents went through that and I think they came out the other end of like you know we don't repeat the cycle rather than ya be angry about it. So they told me they saw that unfairness and that, you know, the disadvantages of everything we went through so they kinda brought that upon my family and I kind of grew up as, I always thought that was normal and it wasn't until my, like, that, like, doing my life I found out that there was people who thought otherwise and I thought it was.. a.. I thought it was kind of taught to everybody just it was as it was taught to me, but I found out otherwise again. I was growing older, so I kinda keep that concept though because I feel like they role model me from, you know, going through hardship and teaching me that so I think by honoring that I should teach that too, to keep it going so that's why I always see, like because they went to, unfortunately I think for the color of their skin or their ethnicity of, we went through the hardship, unfairness so you know I shouldn't be that way towards anybody for the color or you know a physical disability or appearance wise either so that's why I kind of proceeded that way growing up.

Divided from other areas by a plastic partition that lulls voices on either side, but allows for individuals to freely come and go from one area to the other, the room where I am waiting for the participant, is comfortingly dark and quiet; a welcome moment of respite from the busy environment with lights, computers and noise that I am exposed to in everyday life. The sound of music, chatter and the scent of food give me a sense of returning to a familiar place. I have been fighting a cold for a while, and am feeling physically drained, but when the opportunity to conduct more interviews arises, I grab it. In the quiet, I hear a voice asking if the professor from the university has arrived. I ponder on how many times participants have prepared for my visits, excitedly sharing their efforts and progress on bringing about awareness of disability issues. I then think of how I could better clarify my role to participants. Those who have known me realize that I am a student, doing a research project on physical disability. Others, continue to think I have other roles, despite my assertions to the contrary.

My croaky voice produces quite the reaction from Henry, who has met me before and knows me well from previous visits to the organization. The ice is broken as we discuss how strange I sound, much to the merriment of the participant. Henry asks how voices sound on the recorder and advises that I erase any coughing bouts from the recording. The smile quickly transforms into seriousness when I ask if he can tell me about how Diné culture views physical disability. In what ensues Henry shares that self-blame and placing responsibility of disability on the parents has detrimental effects on the well-being of the individuals with a disability and their social support networks[108]. High sugar

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[108] See Chapter 5 for more information.

intake and alcohol use, as the main culprits for physical disability, are embedded within a broader context of change. From his perspective, occupation of the reservation by other peoples has led the Diné to stray from their spiritual path, to lose the close connections with ancestors and spiritual beings who provided Diné people with the principles to live balanced, happy and healthy lives. The participant reflects: “I think I see it, like, you know, part of something that [happened] a long time ago, something was involved with the Navajo long time ago”. Henry concludes by telling me that many Navajo people now are afraid to speak their truth, accept themselves for who they are, forgive each other for the mistakes that have brought about difficulties that people experience today. Meaningful change for the person can come about by us “returning to the light”, which encompasses understanding the value of difference in people and realizing the bigger picture, rather than judging the person:

> We just have to bring up the truth. There’s already a lot of barriers that we can’t, that we can’t um uncover (…) You see people in wheelchairs and that um brings up the truth of how it happened. That, that that could be people with um birth defects, but how, how, how did that begin, see?.

Like many other Diné and non-indigenous participants, Henry emphasizes that disability can serve as a starting point for important conversations. Their hope is that individuals with disabilities will find the courage to speak their truth, share their story with others, and follow Diné principles in order to promote understanding rather than divisiveness.

Severing and Cementing Relationships: Opportunities and Losses

Discourses about locale were central throughout my fieldwork. Narratives were imbued with nostalgia about life on the reservation, with comments regarding opportunities and tensions in physical spaces off the reservation, as well observations about the interrelation of place and social attitudes. An analysis of participants' perspectives on the potential and limitations of off the reservation locations highlights connections with the social importance of belonging, social attitudes towards disability, and understandings of illness and health.

The desire to pursue education and achieve career advancement, infrastructural considerations, socialization constraints and opportunities, as well as concerns regarding availability of and access to healthcare facilities and resources were common themes that emerged in my interviews and interactions with (primarily) Diné participants. Among Diné participants with disabilities being off the reservation often signified greater freedom in terms of mobility and socialization because of better quality of infrastructure. As Sam, a Diné, participant with a physical disability shares living in an urban area means that people with a physical disability can do more things. He mentions that Navajo stories about the reservation tell us that "people no going anywhere, no land, no food, nothing (…) sleeping outside, on the ground, on the floor ". He continues that in the city things are different: "it's different cuz, um, going out to places, movies, restaurants". Diné individuals noted that residing in urban centers provided them with the opportunity to broaden their horizons and widen their circle of acquaintances, particularly when concerns about meeting peers. According to some participants, mobilizing in off- the-reservation locations also facilitated the formation of romantic and intimate relationships, as the number of eligible partners was greater than on the reservations, and the population was more diverse.

Allison connected urban centers to more accepting attitudes toward individuals with disabilities. According to her, inclusion and positive social attitudes toward disability are due to the fact that individuals in off-reservation locations have been exposed to diverse experiences and are, therefore, aware of the needs of individuals with disabilities and their families. She reflects:

> I have to help [with everyday activities] (…) when they see us moving around, someone is always grabbing a door. Someone takes the time to say hello and if they see us doing something, ask how they can help (…) Those are just little examples. If I go back on the reservation, people won't hold open the doors, won't take the time to be generous um there is a lot of staring (…). I'm not saying everyone's like that on the reservation but it happens enough.

The opportunity to access healthcare services more readily off the reservation was also mentioned as a benefit of residing in off reservation locations. Allison explains:

> I grew up with IHS healthcare(…) there are some really bad experiences that I had through them (…) the only reason those experiences were bad was because it was the doctors and nurses that were implementing the care and how they did it in that, in that health care. That was such a big problem for me. Today I will do everything I possibly can to be able to afford insurance so that I don't have to take

> me or my kids back to Indian Health Services (…)This is going to sound awful, but I'm always grateful that we don't live on the reservation because so many things are so much harder, like life. Life is so much harder. In a lot of ways and it's dangerous up there and I think we live where we live now because everything is readily available, we have different resources to use down here. I don't rely on my tribe to provide any, any kind of care or help.

Sentiments about mobilizing off the reservation were not always as straightforward. Diné participants disclosed having experienced negative encounters relating to disability, which they connected to lack of support in urban centers and defensive reactions toward disability. Diné individuals with physical disabilities, family members, as well as Diné and non-indigenous service providers pointed out feeling frustration, sadness, and anger when confronting physically inaccessible environments. The issue, for many of my participants, is not that inaccessible environments exist. That is recognized as an unfortunate reality. What has been equally difficult to reconcile is that inaccessible structures often lead to assumptions about disability that extend to everyday interactions with individuals who live with a physical disability. The narrative of Fiona is centered on the provision of social support on the reservation:

> it's definitely different here. Here they, they already put that stigma out there here cuz there's more people around there's more social here but on the rez you have your family that protects you, you have people that don't say anything (…) it's the family really strengthens you and they understand and they watch after you.(…)

> Here in the city it's not so much, you’re like, you have to figure out how to do it on your own, everyone's has their 8 to 5 job Monday through Friday.

Sam shares that the government is providing help for people with disabilities, but needs to increase their efforts even more, and promote an environment where individuals can approach disability and those who experience it in everyday life with understanding and compassion: “(they need to) make more places, ramps, let’s see(…) homes” They conclude their narrative with the acknowledgement that people are angry, but “they need to calm down a bit” . Rose shares:

> they say oh they never come here, well because people park in our spot, we have something up on the second floor with no elevator, you have steps going up into your place. Sure you're not going to see anybody with a disability because I can't get into any building. I can't get… just parking is a big huge thing and the buildings to be able to get into ‘em”. She continues*: “*sometimes that’s only how you can get things across to people is to cuss and swear. It’s like why should we have to get so angry you know? To do what we want? Why does there always have to be anger involved?.

Participants across all categories recognized that unwillingness to make changes to inaccessible spaces was due to lack of funds, but also due to power relations between individuals with disabilities and those making important decisions that could affect the degree of equity in participation in social life for individuals with disabilities and those assisting them in their everyday life. Violet reflects:

> Obviously, like, architecturally speaking, like being more considerate of how like buildings aren't accessible so things like that (…) Yeah, and like I view like buildings not being accessible as like a form of like you know ableism has come into everything. Like architecture, cuz it's like people who are in positions to design cities and stuff like that they maybe are just I dunno, they're just like not thinking about people who are not them. And yeah, cities are like structured like in a way like I dunno just like an interesting way that like everything in society is like organized.

Diné participants with physical disabilities, family members , as well as Diné and non-indigenous providers offered a variety of solutions to addressing exclusion of individuals with physical disabilities from the social milieu. These included encouraging individuals with physical disabilities to share their story so as to promote understanding, recognizing the value of peer mentoring in the lives of individuals with disabilities, promoting awareness of the rights of people with disabilities to equal participation in social life with accommodations in areas of life, such as the workplace and housing. Including more individuals with disabilities in decision-making positions, as well as increasing exposure to reservation life were also mentioned as important ways to increase awareness of disability issues. Beth grows concerned about my being in a big city, away from home, and too focused on work and concludes that things like that can make you sick. Being in a big city is dangerous because it places you at risk and compromises your physical, social, spiritual and emotional wellbeing. I paraphrase what she shared: "There is too much going on in the city, things you don’t know; it is important for the person with a disability to be close to their family and greet their clan”.

Keith Basso (1996) tells us that places carry with them memories. Reminiscing about place then marks our identity, gives us a sense of belonging. Furthermore, Basso notes that places are an integral part of constructing history and changing our social reality. When thinking about place, one does not consider geography alone, but also situations and actors within them. For indigenous populations, place is intextricably linked to making sense of the world and the Self within it. Glaskin (2012) who works with indigenous peoples in Australia, highlights that personhood cannot be imagined outside the relatedness of the person to a place, ancestors, and all natural phenomena, which exist alongside us as equal partners in defining the world. Many indigenous knowledge systems are based upon the premise that the natural world exists in tandem with human, and that human negligence and unwillingness to acknowledge and accept the premise of collaboration has led to natural disasters and social ills (Wildcat, 2009)

In addition to concerns directly connected to disability, narratives juxtaposed life on the reservation to experiences of living in an urban area. While residing in urban centers, Diné participants mentioned that they have to contend with a higher likelihood of exposing themselves to more illnesses, because of interactions with more people. In addition, individuals have to think about the risks involved in having to adapt to new diets, environmental factors (such as pollution and climate change), as well as the effects of the invasion of technology in our everyday life. Mary highlights:

> You're like darn!! You could never be too careful. You could never determine who's right and who's wrong within the culture (…) yeah, overpopulation and then the behavior of the people, of the person if you choose to live with a lot of media that exposes you to a lot of, or travel, you know, that risky behavior you open to traveling a lot, then you expose yourself to a lot more things, you know, always being on the road or um but who knows? Then there's food, foodborne yeah, you think you're eating healthy next thing you know you ooh the lettuce was affected.

Mary acknowledges that in the city she is more likely to get into an accident compared to the reservation, because of the mere fact that there are more vehicles and there is so much more confusion and commotion. In addition, Diné individuals with physical disabilities, family members who provided care, as well as Diné service providers, emphasized that distance from the environment of the reservation can affect how individuals think about themselves and others, since difficulties arise in performing an important Diné value: to achieve 'thinking straight/clearly' (nitsahakès), which I have elaborated on in a previous chapter (Chapter 5). As I have shown previously, images that pervade the media exacerbate sentiments of social distance from Diné cultural tenets. Messages in material culture and technology contribute to colonization through the internalization of colonizing discourses, which can go unnoticed and, therefore, unchallenged, because some are very subtle (YellowBird, 2004).

The following participant, a Diné service provider, shares that those who convey knowledge are primarily White, pointing out that, in this era the focus is on acquiring material goods. Residing off the reservation and balancing demanding obligations, it is difficult to find the time and energy to react to these dominant discourses: Music was playing both in English and in Spanish, making it difficult for me to focus on our conversation with this research participant. I was glad that I had made the necessary arrangements with my equipment and that Martha graciously agreed to allow me to record the interview. Throughout our interview together she shared how her family, who lived the traditional way, taught her to accept individuals exactly as they were, without discriminating based on who people were, including those who had a disability. Pursing her lips, she drew my attention to the man sitting behind me. He had caught my attention earlier as I was waiting for her as he had been sitting alone for quite a while now listening to music and seemed undisturbed by all the commotion that was going on around him. Martha tells me that people who have been raised in traditional ways have more respect for others compared to those that haven't been exposed to that knowledge. Looking back at the gentleman with the cellphone she tells me:

> it's probably because of how we were raised, right now we have a lot of electronic stuff (…), people don't even look up. You don't even have that communication (…), where people would just talk about how we are talking? Now all people do is text. When people talk like how we're talking there's more feelings involved too.

Mary agrees. Returning to 'traditional ways of life', she says, would help individuals prioritize what is important in life:

> living on oil lamps just living in a remote area and just learning to view and experience life where nothing else, no media is, and starting from there I think that would be a type that, that you know, where we don't rely on cell phones or the need to be around people then you learn to be more um, you pay attention to other details rather than the city life. You know like, always stressing on the bills, other people, oh I need to call them or the car, you know, living just on bare necessities that's it that would be something that they could gain; that way you know all walks of life if you can live that a little bit, maybe a full year (laughs). That’s something always nice.

Being off the reservation offered advantages in particular areas, while at the same time depriving participants of other opportunities. For example, academic advancement was recognized as an important step in career growth. However, Diné participants emphasized that being off the reservation contributed to them losing their ability to maintain an awareness of Diné cultural tenets and speak their Indigenous language. Fiona clarifies:

> I grew up in the city cuz my parents wanted me to have a good education, they wanted to make sure that their kids and their offspring are going to have the best education the best house, the best bikes, equipment, and the best source of knowledge that's better than on the reservation and I hate to say (…). I know my language, every now and then, but I'm so not I can't make a sentence in Navajo. Like, I can say my name and my clans and that's about two sentences of Navajo I know.

Discussing how much she appreciates her job as a service provider, when asked about perceptions of physical disability, Martha tells me that there is a word for health in Diné language and elaborates:

> I can't think of a single word. I'm sorry I just I can't remember; I can't remember a single word for health in my own language. I can't believe it (…). I need to go back (…) have to ask my mom or my grandma (laughs) Do you remember that word? Aha, it's hard. I haven't gone back to the reservation (…) so, so some words, the longer I stay out here seems like I'm forgetting some words, hmm.

Sarah adds:

> People are leaving their reservation (…) you know for education. You know, so I would say that would be something to, something to notice I guess? (…) Where was I was going? I was going somewhere (…). Yeah, but it is becoming even more common and, actually, over getting over 60% are not living on the reservation anymore so they're coming, kinda transitioning but there are people that you know do stay on their home like they wouldn't call anywhere else home you know and I really respect that too (…). I would say even though people were raised in the city or happened to have been born in the city and say like actually how to say, I'd say there's a different attitude toward us you know? We're kinda, I, I, I take pride in knowing more about my culture then I'd say some others that that were born (…), you know cuz some don't really, they don't know anything about the culture, they don't know, they just know they're Navajo. That's literally what some people know.

Conversations with past generations and participating in events that commemorate indigenous peoples and their contributions are an important part in assisting participants in learning more about their identity as indigenous peoples. Diné participants highlighted that they resorted to connecting with relatives to retain a sense of belonging while being away from the reservation. Informal and formal social support networks included relationships and friendships developed through attendance in Native American churches, as well as events, information sessions, and conferences organized to support individuals with disabilities and their families, as well as service providers.

Creative ways to minimize the sadness and homesickness encompassed remembering culturally significant practices, such as sheep herding, weaving, gathering tea, and butchering animals, as well as preparing food for the community. Fiona explains:

> so I have blue corn mush in my fridge and that's just one of those homie things and mutton in my freezer, (participant laughs), this is one of those things that you can't really find in the city that you're kind of like I have mutton stew tonight and having that food missing home it does something it makes you feel like you're safe and it makes you feel like you're not it gets that homesick away (…) so, for me it comforts my sadness and my homesickness and I just oh I'm back home.

Conclusion

Stories and memories surrounding colonization shape everyday life. Memories about painful experiences of the past, such as boarding schools, shape interactions with past generations, while guiding responses to today’s social issues. Examples from my work show that forced removal from homelands frame how Diné participants think about disability. Reflecting upon stories from old times, they reminisce about times of the past, when relationships were not tainted by social ills that have contributed to disability. The negative outcomes of alcohol use and colonization are recognized, yet creatively redefined in narratives that express how such experiences have strengthened their relationships with their elders and have forged their belief that such mistakes must never be repeated. Examining the destructive effects of all-encompassing anger Diné participants share how the effects of colonization remind them of the need to break the cycle of contentious relationships.

Relocation from homelands certainly conjures up strong emotions of homesickness among Diné participants. Many of my conversations with them revolved around how much they missed ‘being home’, which they tried to address in creative ways, by performing tasks and engaging in activities that reminded them of family and community support available on the reservation. And yet, narratives bring to the forefront the potential of urban areas in terms of greater access to goods and services. Educational opportunities and easier access to healthcare facilities go hand in hand with more opportunities for socialization.

CHAPTER 7: INTERACTIONS IN HEALTHCARE: ACCESS, STEREOTYPES, AND THE ROLE OF CULTURE

Indigenous peoples reside in seventy (70) countries, and amount to three hundred seventy (370) million of the world population, according to 2018 reports (IWGIA, 2018, p. 6). In the last one hundred fifty (150) years, the number of indigenous nations has diminished: indicatively, “over 2,000 Indigenous peoples have gone extinct in the western hemisphere, and one nation disappears from the Amazon rainforest every year” (LaDuke, 2015, p. 1). These sobering numbers can be attributed to infringement of basic human rights, and colonizing practices that compromise diversity (LaDuke, 2015). Indigenous peoples are called to respond to acts of war, land usurpation, language loss, and restrictions to their religious and cultural beliefs, forced family separation, and labor rights violations (Paradies, 2016).

Across the world, history shows that indigenous people have experienced colonization, which continues to this day, with added fervor, primarily due the fact that new colonizing phenomena and practices are masked (DeMuth, 2012). Two interconnected factors make discussing and defining colonization difficult. The first relates to the responses people often have with regards to colonization. Some continue to view it as an essential part of expansion and economic prosperity, even a practice of ‘civilizing’ those who are being colonized. Others see it as an abhorrent aspect of the past. It is the moral questions that colonization unearths that make intellectualizing it challenging (Horvath, 1972). The second relates to the fact that colonization is widespread and varies in shape or form depending upon the context (Horvath, 1972). According to Waziyatawin and Michael Yellowbird (2005, p. 3) colonization “refers to both the formal and informal methods (behavioral, ideological, institutional, political, and economical) that maintain the subjugation and/or exploitation of Indigenous Peoples, lands, and resources”.

Thomas (1969) makes the distinction between “classic” and “ hidden” colonization (p. 37). The first, revolves around the expansionist efforts that lead to the exploitation of the natural resources, the invasion on the homelands of indigenous peoples, and the domination on economic systems. The second is much more difficult to identify and discuss because at the heart of it lies a different kind of power. It is evident in the social structures that contribute to the disempowerment of indigenous peoples. Colonization frames indigenous peoples’ engagement with the natural resources, their social position in the world, their interpersonal relationship(s), and their opportunities to enjoy peace, safety, sociopolitical equity, economic prosperity, and cultural, spiritual, physical and emotional health in everyday life (Evans-Campbell, 2008; for an overview of issues, see IWGIA, 2018).

The example of the experience of the Diné with uranium mining highlights how economic exploitation of land and natural resources can have serious effects on the physical, social, and emotional well-being of a people that span over decades. The Navajo Nation hosts more than one thousand (1,000) abandoned uranium mines and four (4) former uranium mills (Brugge et al., 2006, p. xv). Uranium was first discovered on the Navajo Nation in 1941 and rapid expansion of mining centers followed (Brugge et al., 2006). When the United States government seriously began considering exploiting nuclear energy right after the end of World War II, the Navajo Nation was struggling financially, while most young men who had fought in the war returned home to high schools that had closed due to shortage of students, and increasing pressure to secure hard-to-find employment (Brugge et al., 2006). Ninety percent (90%) of workers receiving steady income from their employment were White, employees of the Bureau of Indian Affairs (BIA) (Brugge et al., 2006, p. xvi). The introduction of new employment opportunities that did not require leaving family members behind or relocating the entire family off the reservation were welcomed by the Diné (Brugge et al., 2006). While the exact number of Diné individuals working in mines is not known, ethnographic work documenting the number of Diné miners estimates that three thousand (3,000) worked in mines in a twenty (20) year period (1940s to 1960s) (Dawson, 1992, p. 390). The Diné filled positions that were rarely occupied by their White supervisors who spent much less time in the mines, while the Diné worked as blasters, muckers, transporters and millers (Brugge & Goble, 2002, p.1411). With no appropriate protective equipment or ventilation, the men breathed contaminated air, and drank water directly from the earth they were digging. The mining companies did not provide facilities for showering or laundering contaminated work gear. Therefore, the wives and children of workers were exposed to dangerously high levels of radiation (Spieldoch, 1996). Houses were built, and utensils were made using contaminated materials. When mining on the Navajo Nation ceased in 1980s, there were more than seventy-one (71) acres of uranium tailings on the sites where the primary mining company, Kerr McGee, operated on the Navajo

Nation (Spieldoch, 1996, p. 175), while additional uranium has been left exposed and improperly disposed of on other parts of the Navajo Nation, including sacred sites (Spieldoch, 1996).

Even though the full extent of the impact of exposure to uranium had not been fully analyzed and comprehended in scientific circles, even in the 1930s, research showed serious concerns of uranium to human health. However, information was not disseminated to the Navajo workers and their families until the 1950s. Even then, teams of the United States Public Health Service (US PHS) did not disclose the detrimental effects of contact with uranium, while it is unclear whether information was widely disseminated and made available in Diné, given that many of the workers did not speak English (Brugge & Goble, 2002).

Lung cancer and other respiratory issues, as well as other illnesses are common outcomes of exposure to radiation. Indicatively, between 1965-1969 more than ninety-four percent (94%) of Diné male individuals who were admitted to two healthcare facilities (Shiprock Indian Health Service Hospital and Navajo Family Health Center) with lung cancer were miners (Gottlieb & Hussen, 1982, p. 449).

Legislative action, such as the Radiation Exposure Compensation Act of 1990 and its amendment in 2000, shows the government's willingness to acknowledge past wrong doings (Brugge & Goble, 2002). However, some miners and/or their families never received compensation, while lapses in processing complaints, lack of diagnosis, and/or misdiagnoses due to unavailability of technological means in the I.H.S. led to rejection of compensation claims (Spieldoch, 1996). The burden put on miners and their families to navigate bureaucracy and legal frameworks in order to receive compensation has had unforeseen consequences. Medical providers assisting miners and their families share that claimants have suffered physical and psychological crises that are a direct result of reliving the experience of working conditions and the additional stress of advocating for their rights for compensation in a systemically complicated and unfriendly environment (Spieldoch, 1996).

In many cases, it is the women who carry the burden of sharing the detrimental effects of mining. In making the choice to inform the public about this serious issue, those who tell their stories are aware that in doing so they are making a meaningful social and political statement not only due to the content, but also in the way that their stories are shared. In his work with the Apache, Keith Basso (2000) discusses the generative and restorative power of stories. The didactic nature of stories allows those who share this moment of exchange to think about possibilities of action and consequence based on deciphering the morale of the story. Schwarz (2001) tells us how in addition to demonstrating to the world the deep hurt that the exploitation of natural resources has caused the Diné, the emotional responses they allow us to see are an act of activism. As in any culture, the Diné have communication norms. Those who follow ‘traditional’ ways caution against the unnecessary sharing of bodily substances, as these have creative powers. Like the causative power that Witherspoon (1977) identifies with regards language, the demonstration of tears when recounting a challenging situation can increase the risk of falling ill (Schwarz, 2001). With the tears comes alive the reason for this emotional response, which can draw in the individuals present exposing them to the risk of embodying the cause of sorrow (Schwarz, 2001)[109]. In the case of mining, making manifestations of grieving public can be seen as an act of resistance against the negligence and silencing of the US government and mining companies (Schwarz, 2001).

Because of its pervasiveness, colonization contributes to constructing legal frameworks and policies (Echo-Hawk, 2010)[110], human rights agendas and responses to (self) advocacy (DeMuth, 2012) while spreading its tentacles to discourses in education (Cajete, 2012), and means of entertainment (YellowBird, 2004; Harjo, 2005), often leading to the internalization of colonizing thinking patterns and practices within Indigenous communities (Waziyatawin & YellowBird, 2012).

Indigenous peoples in North America are, therefore, asked to advocate for their rights using legal frameworks that are borne of a knowledge system that sees Native American groups as nations that are ‘dependent’ upon the United States: crimes against Native Americans are tried and decided on in courts that devalue indigenous knowledge and in which Native Americans have limited representation in leadership and/or decision-making roles (Deer, 2009). Furthermore, legal knowledge is built on a history of legal authorities that perceived Native Americans as less intelligent, weak in terms of arms, and as possessing less complex social/political systems (Williams, 2005; Deer, 2009; Echo-Hawk, 2010)[111].

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[109] There were instances throughout my fieldwork where emotions were shared. Some expressed their sadness, frustration and fear more openly than others; however, no mention was made of this social norm.

[110] Echo-Hawk is a member of the Pawnee nation.

[111] Problematic assumptions like these outlined here are evident in treaties signed between Indigenous peoples and the United States. More details will be provided in subsequent pages.

Indigenous pursuits of restoring past and current colonizing practices outside of the court system are often met with silence, denial, and/or violence (Riding In, 2005; DeMuth, 2012). For example, when Native American scholars identify remains that belong to their ancestors and are now an integral part of museum exhibitions, museums deny the damaging effects of this appropriation (for more, see Riding In, 2005). This process of denial continues in our educational practices, as Native American students and scholars often find themselves in precarious situations: on the one hand, in today's world education contributes to very tangible benefits (such as more employment opportunities); on the other, students and scholars are called to engage in an educational system that fails to acknowledge that in the name of 'advancement' this very system has condoned the eradication of indigenous languages, values and knowledge systems (Cajete, 2012)[112].

The emotions of shame, fear, anger, and sadness that may result from the hurtful, stereotypical discourses that are promoted in education, and elsewhere, often contribute to Native Americans engaging in self-blame and subconsciously perpetuating colonization (Cajete, 2012). In his work on the internalization of stereotypes, Michael YellowBird (2004) highlights how colonizing metaphors are enforced through how representation of Native Americans in everyday life: for instance, images of Native American action figures are commonly seen in attire that inaccurately portrays Native American traditions and social norms. Similar dynamics are reflected in other aspects of misrepresentation of Native American cultures. In her analysis, Harjo (2005) tells us how the use of 'Native' symbols in seemingly innocent endeavors, such as sports, is an act of

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[112] The case of boarding schools is an example of this issue. See chapter 6

cultural appropriation (Tsosie, 2002), a process which I described in previous chapter (Chapter 3). According to Harjo (2005) the concern of Native American people in cases like this lies in three areas: firstly, the commodification of symbols and practices that—for some cultures— may have sacred meaning and should only be used in specific contexts and for certain purposes; secondly, the fact that the decision-making process on how, when and why these symbols are used lays in the hands of individuals who often do not share indigenous identities. Native American counselors warn us that failure to acknowledge the emotional responses that such usurpation contributes to social ills in Indigenous communities. Finally, Harjo (2005) prompts us to consider the broader impacts of such actions. For Harjo (2005) struggles like these serve to distract indigenous individuals and communities from taking action against structural violence (Farmer, 2004) that deprives Native Americans from opportunities to equity in all aspects of life, as well as deprives them of the physical and emotional strength needed to heal as individuals and as communities.

Understanding the Historical Context of Contact Between the Diné and Non-Indigenous Populations: A Legacy of War, Oppression and Distrust

Accounts tell us that Athabascan bands came into the lands of the Pueblos sometime around 1300 AD. Ethnoarchaeological evidence and official correspondence places the Diné in present day Arizona at the beginning of the 1700s (Reed, 1941).

Relying mainly on hunting and a vegetable diet they occasionally raided the Pueblos, while developing farming techniques and perfecting beautiful weaving. Shortly after the advent of Columbus in 1492, systematic invasion by the Spaniards tried to subjugate the Athabascans. By 1540, the Spaniards had conquered most peoples (Leighton & Leighton, 1967). Seeing themselves as representatives of the Spanish crown, the Spaniards overtook most Pueblo areas, used Pueblo individuals as slaves, while their missionaries devoted their time toward converting indigenous peoples to Christianity (Denetdale, 2008). The Diné proved to be worthy opponents: raiding the Spaniards, they seized cattle, sheep and horses, and grew in size as more and more indigenous peoples ran to escape the Spaniards and were welcomed by the Diné (Leighton & Leighton, 1967). Invasions on the Diné were minimal at this time compared to other indigenous groups, as the colonizers only managed to capture a small portion of the Diné population, whom they then used as slaves (Denetdale, 2008)

In addition to the atrocities that Spaniards directly committed against the indigenous peoples of this area, their presence also contributed to creating strife between Native American groups. Accounts tell us that the Pueblo joined the Spaniards in their fights against the Diné, until 1680, when the Pueblo people decided to rebel against the Spaniards, who quickly scoured back to Spain, until their return in 1692. The Spaniards attacked the Diné with renewed vehemence and managed to increase their rule over them by the beginning of the eighteenth (18th) century (Denetdale, 2008). Throughout the eighteenth (18th) and nineteenth (19) centuries the Diné relocated more and more toward Mount Taylor and Tse’yi to protect their livestock and expand grazing zones, while warfare sporadically continued, well into the 1840s, when American forces waged systematic attacks against the Diné people (Denetdale, 2008).

A number of treaties were made between the Diné and the American invaders starting in 1846, and were broken, leading to one of the most important events in the history of the Diné people, namely their forceful relocation from their homelands; an event known as the Long Walk (Leighton & Leighton, 1967). Almost twenty (20) years later, in 1861, amid relentless expansionist efforts by the US army, James Carleton was given orders to identify an area to where indigenous peoples (Apache, Diné and others) would be relocated. He made the decision that a location close to Fort Sumner, in New Mexico, known as Bosque Redondo, would be a good choice, even though the climate was harsh, water quality was bad and the soil arid, as it would be easier for the U.S. army to control the Diné far away from familiar landscape that could serve as a good hiding place in the event of an escape (Denetdale, 2008). Carleton was particularly interested in captivating young women and children, as the former could contribute toward caring for the militia and the latter were seen as more malleable to instruction against indigenous values and ways of life (Denetdale, 2008). The overall endeavor of establishing the reservation was part of the United States agenda to subjugate peoples not only by warfare but also by superimposing cultural norms, religious beliefs and political governance systems and eradicate the way of life of indigenous peoples (Thompson, 1976). Carleton appointed Kit Carson to be in charge of bringing the Diné to Bosque Redondo. In 1863, led by Carson, militia raided Canyon de Chelly and captivated more than half (nine thousand, 9,000, to be exact) Diné (Leighton & Leighton, 1967, p. 7). They began the arduous trek covering three thousand (3,000) miles to Fort Sumner (Leighton &Leighton 1967, p.7). US army raids intensified in 1864: crops were burned, cattle were slaughtered to force the Diné to surrender due to hunger. Exhausted by a long cold winter and with the added burden of limited sustenance, more Diné were taken in captivity and placed in Fort Sumner (Denetdale, 2008; Thompson, 1976). By March 1864, approximately six thousand (6,000) Diné were held in Bosque Redondo (Denetdale, 2008, p. 43). Weakened by hunger, disease, and homesickness, Diné men were, nevertheless, put to work on the reservation where they were involved in agricultural activities and contributed to building irrigation systems, often in spite of bad weather conditions. The women who faced similar survival challenges were often taken sexually by the soldiers (Thompson, 1976).

The advent of more people over the five (5) year period of this endeavor added to existing animosity: Bosque Redondo housed not only Diné people but also individuals from other Native American groups (such as Apache). Strife began between indigenous groups about unequal distribution of rations and differential treatment on the part of Bureau of Indian Affairs agents and soldiers in favor of some indigenous groups over others (Thompson, 1976). The constant demands that Carleton placed on Congress for supplies, the escape of some Diné from Bosque Redondo, and revolts against soldiers that intensified in 1867 culminated in existing critiques on the endeavor to relocate indigenous peoples. Not trusting indigenous peoples to stay off land that the US forces saw as their own by right, Congress had already began constituting peace commissions whose responsibilities included reaching peace agreements with previously captivated indigenous peoples, determining borders that would clearly delineate federal land as opposed to portions given to indigenous groups, and relocating Indigenous peoples anew (Kessell, 1981; Tso, 1989). In the case of the Diné, peace was reached with a treaty signed on June 1 of 1868, between Diné leaders and U.S., who were represented by officers Sherman and Tappan (Kessell,1981, p. 269) ending a period that is referred to among the Diné as the *Hweldíí* (the Long Walk). Diné accounts of the traumatic event of forced relocation to Bosque Redondo have only surfaced fairly recently. Indigenous scholars attribute this silence to the desire of those who were aware of stories from their grandfathers and grandmothers about their predecessors to protect future generations (see Tohe, p. 2007). In the interest of protecting the self and interlocutors, some Diné individuals who follow 'traditional' knowledge tenets refrain from discussing difficult subjects, as Diné teachings admonish that this process may distract from focusing on prosperity in present life (Schwarz, 2001). Those who choose to share their knowledge on the Long Walk talk about great suffering, which can be used as a lesson in perseverance and can serve as a reminder of the responsibility that Dine have to their ancestors (Tohe, 2007).

The foundation of the positionality of indigenous peoples in North America today was laid during these treaty-making processes. Imbued by the doctrine of discovery, the United States government upheld that since the lands had been discovered by their forces, the territories were rightfully theirs. Indigenous Nations who happened to reside within the 'newly' discovered terrains could occupy them, as mere tenants, with whom the federal government had a 'ward like' relationship (Wilkins & Lomawaima, 2001). Treaties delineated residence and hunting boundaries for indigenous peoples, regulated trade relationships with non-indigenous peoples, determined jurisdiction of indigenous Nations, and outlined responsibilities of the federal government toward Indigenous peoples (see Wilkins, p. 2013). To an extent, the United States viewed indigenous groups as sovereign nations, in the sense that they approached them as independent entities with which commerce could be initiated. In terms of jurisdiction, treaties specified that indigenous groups would try members of their Nations for crimes that occurred on the reservation; in cases of crimes committed by an American on reservation land, federal laws applied and federal court systems held the responsibility of enforcing federal laws (Wilkins, 2013). Driven by “benevolent paternalism”, which assumed that indigenous Nations did not have equally complex and powerful governance norms (Wilkins & Lomawaima, 2001, p. 21), the federal government also enforced educational paradigms to be followed by indigenous Nations, making it mandatory for children to attend schools established by the United States. The ratification of treaties also meant that the United States entered a legally binding trust relationship pertaining to the provision of health-related services to Indigenous Nations, which continue to this day (Westmoreland & Watson, 2006; Wilkins, 2013). The federal government coupled the provision of health services with systematic oppression against indigenous medical practices. Soon after the treaty of 1868, federal government agents placed on the reservation began recording ‘problem’ areas of indigenous social life, including marriage and religious practices, the activity of medicine men and the seeming lack of concepts of personal property and ownership. In order to address social norms that it perceived as “hindrances to civilization” (Department of Interior, 1883, para 1), the Department of Interior appointed courts in each reservation, with the police chief as presiding judge to impose appropriate punishment on the offenders, either in the form of a fine, labor, or imprisonment (Department of Interior, 1883). In relation to traditional healing practices, the Court of Indian Offenses states:

> The usual practices of so-called "medicine-men" shall be considered "Indian offenses" cognizable by the Court of Indian Offenses, and whenever it shall be proven to the satisfaction of the court that the influence or practice of a so-called "medicine-man" operates as a hinderance to the civilization of a tribe, or that said "medicine-man" resorts to any artifice or device to keep the Indians under his influence, or shall adopt any means to prevent the attendance of children at the agency schools, or shall use any of the arts of a conjurer to prevent the Indians from abandoning their heathenish rites and customs, he shall be adjudged guilty of an Indian offense, and upon conviction of any one or more of these specified practices, or, any other, in the opinion of the court, of an equally anti-progressive nature, shall be confined in the agency prison for a term not less than ten days, or until such time as he shall produce evidence satisfactory to the court, and approved by the agent, that he will forever abandon all practices styled Indian offenses under this rule (Department of the Interior,1883, para 16). The Department of Interior sees no need for traditional practitioners, given the establishment of ‘capable’ physicians who provide their services to the population armed with scientific knowledge and technology that medicine men do not have, at no charge for the patient (Department of Interior, 1883).

Like other indigenous groups, the Diné initially received health-related services from military physicians as matters pertaining to Native Americans were under the jurisdiction of the War Department (Kunitz, 1983). When the Department of Interior was given jurisdiction over Native American issues, in 1849, physicians that were not affiliated with the armed forces took over the care of the Dine, and around the 1870s "half the reservations had a physician" (Kunitz, 1983, p.146).

The first hospitals opened on the Navajo reservation in the 1900s and by 1934 there was a total of three hundred sixty-seven (367) beds in hospitals and sanatoria in New Mexico, covering areas of the Navajo reservation[113] (Kunitz, 1983; Mountin & Townsend, 1936). According to the Meriam Report, issued in 1928, hospitals serving indigenous peoples on reservations were severely understaffed, lacking more than half of the staff needed to provide adequate care. More specifically, at the time of publication the report states that there were only one hundred four (104) physicians in healthcare facilities serving indigenous peoples, while vacancies were hard to fill because of the low pay and challenging working conditions (Meriam, 1928, p. 229). In addition, medical providers had training that did not match the standards of those who served in other areas of the United States, while individuals serving as nurses had little to no formal training (Meriam, 1928). Data from 1926 show that there was a one (1) to fifty-five (55) ratio of trained nurses to patients; shortage of qualified nursing staff exceeded eighty percent (80 %) (Meriam, 1928, p. 245). Among the Diné conditions in hospitals have been described as deplorable. Gregg (1965) tells us that doctors who were unfamiliar with providing

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[113] Based on author's interpretation of open facilities as reported in Mountin and Townsend 1936, p. 44)

services to the Diné were asked to work with incompetent nurses in establishments where patients were placed in crowded areas regardless of the risk of spreading disease to other patients with less severe conditions, and often were exposed to extreme cold due to failure to replace furnaces. The conditions in healthcare facilities may have strengthened existing resistance among the Diné to resort to hospitals (Kunitz, 1983). As Leighton and Leighton (1945) note the Diné thought of healthcare facilities as “a place to go to die” (1945, p. 56). Differences in social norms may also have played a role in fostering hostility toward healthcare practitioners. As opposed to traditional ceremonies, which involved spending extended periods of time with medicine men, family, and community members, patients spent little time with doctors seemed to spend much less time with a patient than medicine men, and family members were not allowed to participate in the recovery process. Diné norms of treating illness also differed from the practices employed in hospitals: patients may have struggled to grasp the benefit of consuming foods that were associated with poverty and hunger (such as broth) rather than have a family member cook foods that were traditionally perceived as fortifying to speed up the recovery process (Leighton & Leighton, 1945).

The Impact of Historical Processes on Healthcare

The expansion of medicine owes itself to a past based on of violating the bodies, minds and rights of individuals, particular those with minority status. The examples I highlight here speak to issues of physical and emotional safety, ethical questions revolving around consent, and reveal how the power dynamics involved in framing the experience of healthcare; more broadly, they reflect the values inherent in the development of medicine as a scientific field.

Much of the literature on medical transgressions against minority populations revolves around failure of medicine as a discipline to engage with minority populations in an ethnical manner. The discipline of medicine is guided by the Hippocratic oath of doing no harm. Examples of engagements of minority groups with medicine show us that the principle of doing no harm is much less straightforward than one would think and begs questions of 'how do we define harm?' and 'whose voices do we privilege in making decisions related to the risk of harm'? (Faden & Beauchamp, 1986). At the epicenter of a discussion of ethics in this context lays the broader question around whether medicine has acknowledged the humanity and agency of patients, as history has privileged doctors' decision-making power on determining harm, often in the name of scientific advancement and at the expense of minority groups (Faden & Beauchamp, 1986). For example, a literature review on the positionality of individuals with disabilities in relation to medicine shows that the discipline has involved individuals with disabilities in atrocious experiments in many countries of the world (Iacono & Carling-Jenkins, 2012). As part of the eugenics' practices during the Nazi period in Germany, healthcare professionals participated in the extermination of individuals with disabilities. An estimate of five thousand (5,000) to twenty-five thousand (25, 000) children with various disabilities were put to death throughout the timeframe of six (6) years (1939-1945), as

Hitler saw those with disabilities as a threat to his construct of the ideal State (Evans, 2004, p.15-16). After this, eugenic practices expanded to adults with all kinds of disabilities: in one-year (1940-1941) two hundred seventy-five thousand (275,000) Germans were eradicated under the auspices of the Aktion T4 euthanasia program (Evans, 2004, p.16). Half a million (500,000) others with a variety of disabilities were subjected to involuntary sterilization to promote 'purity of the race' (Evans, 2004 p. 18) and many more died painful deaths, as a result of chemical sterilizations and other inhumane experiments (Evans, 2004).

Following the Nuremberg Trials (in 1945-1946), which gave their name to the Nuremberg Code (established in 1948), ethical guidelines were formulated to address concerns in regards to interactions with research participants in clinical contexts (Faden & Beauchamp, 1986). These guidelines have informed subsequent ethical codes involving research interactions in any setting with human subjects (Iacono & Carling-Jenkins, 2012).

At a time that showcased the civil rights of minority populations, healthcare practitioners were perpetuating genocidal practices in the form of involuntary sterilization of Native American women (Ralstin-Lewis, 2005). The extent of the issue emerged in the early 1970s when a Native American doctor, Dr. Uri, made the issue public. In a piece in the Akwesasne Notes (1977), authored by Gail Jarvis, the doctor tells readers of an instance where a twenty-six (26) year old female patient shared with Dr. Uri that she had changed her mind about having children and now wanted a womb. Contrary to the provider who assured the patient that a hysterectomy is reversible, Dr. Uri had to inform the patient that contrary to what the I.H.S. physician had told the patient, a surgery to give her a womb could not be done. As the doctor further investigated I.H.S. records, she found that these procedures were performed on Native American women for a variety of conditions including headaches (Jarvis, 1977). The provider further shares that the coercive tone used by doctors to convince women to acquiesce to sterilization was coupled with threats of withholding benefits or of taking away women's other children (Jarvis, 1977). Dr. Uri joined forces with other doctors across the country who discovered other cases of sterilizations. According to their investigations only one hundred thousand (100,000) Native American women of reproductive age were not sterilized in the timeframe spanning approximately from 1972 to 1976 (Jarvis, 1977, p. 30). Following increasing pressure from medical providers and Native American activists, a full investigation began by the order of Senator Abourezk in 1975 (see Staats, 1976).

Findings revealed that from 1973 to 1976, more than three thousand (3,000) Native American women between the ages of fifteen(15) to forty-four (44) were sterilized in I.H.S. locations in Aberdeen, Oklahoma City, Phoenix and Albuquerque, while more than one thousand (1,000) were sterilized in facilities partnering with the I.H.S. (Staats, 1976, 3,4). Other sources highlight that the number of Native American women of childbearing age who were subjected to involuntary sterilization was closer to three-thousand (3,000) per year over a four-year period, namely from 1972 to 1976 (England, 1997, para 32)[114] and included Native American women as young as eleven (11) years of age (Vicenti-Carpio, 2004, p. 40). According to Temkin-Greener et al. (1981) "between

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[114] Available at http://www.dickshovel.com/IHSSterPol.html

1972 and 1978 the percentage of interval sterilizations has more than doubled from 15.1 per cent in 1972 to 30.7 per cent in 1978" (p. 406), examining the rates of bilateral tubal ligations among Diné women residing on the Navajo Nation.

The investigation led by the Department of Health, Education and Welfare (HEW) found that the I.H.S in these four (4) areas failed to follow appropriate consent practices prior to performing sterilization on Native American women. Communications with I.H.S. officials highlighted that the consent process providers followed were in violation of regulations: In 1973 a moratorium was issued on the "sterilization of individuals who were under twenty- one (21) years of age or mentally incompetent" (Staats, 1976, p. 4). Further regulations in 1974 clarified that federal funds could not be used to sterilize individuals who were not able to indicate their consent, particularly in the case of individuals who were under twenty-one (21) at the time of the procedure or legally defined as incapable of providing consent (Staats, 1976). In response to earlier District Court rulings that approved oral communication on the prohibition of withdrawal of federal funds from individuals who did not consent to sterilization, regulations of 1974 mandated that the process of obtaining informed consent for sterilization needed to include a clear explanation of the procedure, the risk and benefits to the patient, an invitation to consider other contraceptive methods given the finality of sterilization, and a statement on the continuation of renumeration by the government even in the event that consent to be sterilized is withdrawn at any time before or during the procedure (Staats, 1976). In addition, the I.H.S. and their contracted facilities failed to provide translating services to ensure that the women had a clear understanding of the content of the consent forms provided (Vicenti- Carpio, 2004).

Sterilizations of Native American women occurred within a broader framework of population control. Policies throughout the 1970s targeted the reproductive rights of women with minority status (such as Puerto Ricans, African Americans/Blacks and Chicanas): like Native American women, individuals who self-identified as members of the aforementioned groups were subjected to involuntary sterilization (Torpy, 2000). Native American women, however, faced unique barriers: unlike other groups, the contentious relationship shaped by politics in multiple agencies (such as the B.I.A and the I.H.S.) in relation to Native American peoples, as well as the trust relationship between the federal government and indigenous Nations limited women's options with regards to availability of healthcare choices (Torpy, 2000). In the 1950s the United States government engaged in an organized effort to increase the integration of Native American peoples into the wider United States social fabric. This organized effort covered all areas of social policy, including healthcare services and focused on weakening Native American social structures by promoting the relocation of the Native American population away from the reservation and on weakening the sovereignty of Native American nations by conveying more governance responsibilities to State and federal bodies (Kunitz, 1996). Widely known as the 'Termination Period', since the 1950s more and more Native American families were forced to relocate to large urban areas (Castor et al., 2006; Burhansstipanov, 2000). Thousands of Native Americans were relocated: An estimate of thirty thousand (30,000) Native Americans were relocated in the 1950s and ninety thousand more (90,000) over a period of two (2) subsequent decades (Joe, 1986, p. 164). The first to be affected by this policy were the Navajo and Hopi Nations. Under the auspices of the BIA, agents began relocating members of these nations to large urban cities where they would fill low-paid positions, while relocation of members of other Indigenous groups quickly took hold (Joe, 1986). The Relocation/Employment Assistance Program, as it was known, offered job training to Native Americans and touted that the relocation away from the reservation would help Native Americans escape poverty (Kauffman & Associates Inc, 2014). The rationale of inserting Native American peoples in remote areas of large urban centers, such as Chicago and Los Angeles, was to ensure that ties between indigenous peoples would be severed by the presence of non-Indigenous groups, while saving the government funds by having workers fill positions already available without needing to contribute to the development of reservations (Joe, 1986; Burhansstipanov, 2000).

Healthcare related legislation was passed in 1954 as PL 568 (Kunitz, 1996). In 1955 all health-related issues, including the I.H.S., were transferred from the Department of Interior to the purview of the United States Public Health Service (PHS) (Kunitz, 1996; Lawrence, 2000). The majority of healthcare providers were White, comprised primarily of personnel who had served in the military (Kunitz, 1996). The engagement of I.H.S. doctors with their patients was situated within a systemic and systematic construction, perpetuation and enforcement of State discourses in relation to Native Americans. Based on colonial underpinnings, these frameworks positioned Native American individuals, social norms, and cultures as inferior to dominant, White paradigms (Poupart, 2003). To paraphrase Volscho (2010), communications between healthcare providers and Native American women are imbued with racist assumptions about the decision-making capacities of Native American women. Healthcare workers perceive their Native American patients as irresponsible, incapable of making sound decisions about their health, bodies, and reproduction. Driven by their assumptions that women were stricken by abject poverty, alcoholism and other social ills, I.H.S. doctors performed sterilizations convinced of the legitimate grounds of genocide practices against Native Americans: in their eyes, they were contributing not only to the greater good by decreasing the numbers of families who were less valuable than their White counterparts, but also to the well-being of women whom they perceived as a priori lacking in parenting skills (Jarvis, 1977; Lawrence, 2000).

Aside from the physical and emotional repercussions of coercive sterilizations, these genocidal practices have had an impact on the performance of indigenous identity among Native American women. Vicenti and Pino (1990, as cited in Vicenti-Carpio, 2004) tell us that social norms among certain indigenous groups dictate that only women who can bear children participate in ceremonies. Coercive sterilizations, therefore, contribute to the stigmatization of women who cannot perform culturally constructed gender roles and perpetuate a cycle of internalization of negative self-perceptions and emotions of shame, fear and sadness (Vicenti-Carpio, 2004).

Access

More than two (2) million Native Americans and their descendants receive care from programs and services funded by the I.H.S. as members of the five hundred seventy-three (573) federally recognized Native American groups in North America in 37 states[115] (Weahkee, 2019, p. CJ1). There are more than six hundred (600) hospitals, clinics and facilities on or near reservations (Weakhee, 2019, p. CJ1). Services include inpatient and outpatient care, pediatrics, prenatal and dental care, rehabilitation, as well as behavioral care. Programs also provide care to elders, immunizations, diabetes management services, health education to communities, as well as physical rehabilitation services[116]. Funding constraints and location of the facility, may increase or decrease availability of services in certain areas[117]

The structure of healthcare for indigenous peoples in North America is a result of a delicate balancing act of attempts to meet legal responsibilities of the United States toward Native American peoples and to honor the sovereignty of Native American groups (see Rhoades et al., 1987; Warne, 2011). The provision of free healthcare to Native Americans is outlined in the U.S. constitution, treaties, legislative acts, court rulings and executive orders, which also outline the relationship between the federal government and facilities owned and managed by indigenous peoples (see Rhoades et al., 1987; I.H.S., 2015). Legislation —most notably the Indian Self-Determination and

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[115] Source: https://www.ihs.gov/aboutihs/

[116] Source: https://www.ihs.gov/forpatients/healthcare/

[117] https://www.ihs.gov/forpatients/faq/#q6

Education Assistance Act of 1975 (Public Law 93-638), particularly Titles I and V, its amendments in 1992 and in 2000[118], as well as the Indian Health Care Improvement Act of 1976 (Public Law 94-43), particularly Title V, which was made permanent in 2010[119]-recognizes the right to self-governance and places responsibility upon indigenous governance bodies to determine the degree of federal involvement in services rendered to their citizens, including those related to healthcare (Rhoades et al., 1987). According to (Weahkee, 2019) fifty nine percent (59%) of indigenous groups choose to receive services directly from the I.H.S. Data for the Fiscal Year (FY) 2020 show that over half of the funds allocated to the I.H.S. are administered by indigenous groups themselves through contracts (Weahkee, 2019) For those who opt to exercise the right to self-determination in healthcare services, officials within the I.H.S. regional offices, known as Contract Proposal Liaisons (CPLOs), Contracting Officers (COs), and Programmatic Officials (POs), collaborate with indigenous groups that have chosen to take over management of health-related services and provide programmatic and financial guidelines relevant to the contracting process[120].

When the Division of Indian Health (now known as the I.H.S.) transferred to the Department of Public Health Services in the mid-1950s an organized effort to decentralize healthcare services to Native Americans began, a trend which is evident

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[118] A copy of these sections can be found at https://www.ihs.gov/odsct/title1/

[119] See https://www.ihs.gov/aboutihs/legislation/ and https://www.ihs.gov/ihcia/

[120] Source: https://www.ihs.gov/odsct/title1/

when one looks at the organizational structure of the I.H.S. today (Kunitz, 1996)[121]. Small facilities were linked to larger medical and referral centers, while the burden of administration fell under the purview of area offices that, in turn, reported to headquarters in Washington DC (Kunitz, 1996, p.1466). Today, delivery of healthcare to Native American people is based on an I.H.S/Tribal/ Urban (I.T.U) system (Warne, 2011, p. 42). The I.H.S. provides care to eligible individuals in two ways: firstly, through a network of federally owned and financed medical facilities that are located in specific service areas; secondly, through facilities that are in a contractually binding relationship with the I.H.S., known as members of the Purchased/Referred Care (PRC) Program (Cunningham, 1993)[122]. The I.H.S. is involved in providing oversight and funding to facilities that are owned and managed by indigenous groups, and finally, through establishing a contract-based relationship with private providers. The mandate to provide support extends to healthcare networks in urban centers (Cunningham, 1993: 224; Sequist et al., 2011, p. 1965). Primary care services, certain specialty services, and drug prescriptions are generally provided by the federal facilities. Specialized and hospital care are available through providers contracted by the I.H.S., while I.H.S. supported not for profit organizations shoulder the responsibility of providing care to Native American individuals in urban centers, by way of Urban Indian Health Programs (Sequist et al., 2011). Availability of services and quality of care vary greatly depending upon location and allocation of Congressional funds/annum (Weahkee, 2019).

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[121] See also: https://www.ihs.gov/aboutihs/organizationalstructure/

[122] See also: https://www.ihs.gov/forpatients/faq/#q6

Documents pertaining to the FY 2020 show a budget of almost six (6) billion USD, an increase of approximately four hundred (400) million from FY 2019. Compared to other populations, a significantly lower amount of per capita expenditures occurs in Native American groups, even though there are variations in funding provisions depending on the State (Kunitz, 1996). Data that cover a sixteen-year period (2000-2016) show that IHS per capita expenditures on patients were on average up to three (3) times lower than the expenditures on a national level. While the IHS has received more funds from Congress, since 2009, the increase does not suffice to improve care, since the funds are being channeled toward addressing obligations from previous fiscal years, as well as cost inflation (NCAI, n.d) Indicatively, "in 2014, the IHS per capita expenditures for patient health services were just $3,107, compared to $8,097 per person for health care spending nationally. When looking at medical spending only, IHS per capita is only about $1,940" (NCAI, n.d, 51).

According to the Weahkee (2019) increased investments have been made toward the following areas: maintenance of current services, establishment of new facilities, direct care costs, funds toward contract based partners, toward new indigenous groups, costs for the expansion of programs (with a particular emphasis on issues like Hepatitis, HIV/AIDS, drug/alcohol use, among others), as well as funds for Community based health initiatives, for retaining current employees and attracting additional personnel, and development of electronic formats of record keeping.

Eligible members of federally recognized Native American groups can access I.H.S. care by resorting to facilities that are located within the geographical boundaries of one (1) of the twelve (12) regional offices, known as Areas, which report back to I.H.S. Headquarters[123]. The specific areas are: Alaska, Albuquerque, Bemidji, Billings, California, Great Plains, Nashville, Navajo, Oklahoma, Phoenix, Portland and Tucson[124].

Eligibility is largely dependent upon demonstrating enrollment in a federally recognized indigenous group. Individuals who are not indigenous are also eligible in some cases: children of an enrolled member until the age of nineteen (19); spouses of enrolled members who are not indigenous themselves are eligible to receive services through the I.H.S. Limitations apply to individuals who fall within certain categories: for example, women who are carrying the child of an indigenous individual who is enrolled in an indigenous group are eligible to receive prenatal care and postnatal care for six (6) weeks after the date of delivery. In addition, a non-indigenous individual residing in the household of an enrolled member has access to the I.H.S. if a medical provider determines that there is significant risk to the broader community (for example, in the case of a communicable disease). Some services are available to I.H.S. employees and populations with protected status, such as veterans[125].

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[123] Source:https://www.ihs.gov/aboutihs/organizationalstructure/

[124] Source: https://www.ihs.gov/locations/

[125] Source: https://www.ihs.gov/IHM/pc/part-2/p2c1/#2-1.2

In addition to other factors eligibility is determined by residence location. The I.H.S. distinguishes direct care from Purchased/Referred Care (PRC). The former refers to medical and dental services provided in I.H.S and/or tribal facilities. The latter relates to services provided away from an I.H.S. and/or tribal facility[126]. Formerly known as Contract Health Services (CHS), the Consolidated Appropriation Act of 2014, renamed these complementary services to Purchased/Referred Care. Strict regulations determine whether the I.H.S. covers PRC visits. The patient must meet the following criteria: firstly, enrollment in a federally recognized indigenous group. Secondly, patients using contract services must submit justification certifying the urgent nature of the health condition within a specific timeframe, i.e. seventy-two (72) hours from the beginning of treatment. The justification must also provide information on why direct care in an I.H.S. facility or alternative course of action is not a viable option. Those who are sixty-five (65) years of age or older and individuals with a disability have a grace period of thirty (30) days to fulfill their notification obligation.[127]. Finally, the patient must prove residency within –or close to—the boundaries of a reservation, and within a Purchased/Referred Care Delivery Area (PRCDA)[128]. Regulations specify: “The PRC services coverage extends 180 days

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[126] Source: https://www.ihs.gov/prc/

[127] Source: https://www.ihs.gov/prc/eligibility/requirements-notification/

[128] Per CFR at Title 42, Section 136.22: Subpart C-Contract Health Services ♦ 136.22. A PRC Delivery Area is defined as a county containing all or part of a reservation or sharing a boundary with a reservation, or in Alaska, Nevada or Oklahoma. Changes to delivery areas are made in accordance with the Administrative Procedure Act [5 U.S.C. 553]. Grounds for change of status include: user population size; the degree of involvement of eligible population living near the reservation in affairs relevant to Indigenous matters, as determined by Indigenous governance bodies. Proximity to a reservation is also a factor as is funding. Source: https://www.ihs.gov/prc/eligibility/requirements-purchased-referred-care-prc-delivery-areas/

from the date you move from your reservation/CHSDA[129]. On the 181st day, the eligibility for IHS direct care services is the only health care that continues at any IHS facility that you present yourself. PRC coverage continues when residency is established on another reservation (…) Many, or even most, people who move away from their home reservations are not eligible for PRC since they would be moving away from the PRCDA in which they have eligibility"[130].

Limited funding imposes restrictions on PRC eligibility. Data from 2011 show that in order to fully cover the healthcare needs of the user population more than eight hundred sixty million USD ($860) would need to be added to the amount allocated to PRC in 2011 (less eight hundred, 800, million). More recent data tell us that the funds allocated to PRC should amount to more than nine hundred (900) million, and DHHS budget information proposes an increase of almost five (5) million to the existing budget for PRC alone (Weahkee, 2019, p. CJ 54)[131]. As such, the I.H.S. cannot cover all PRC services rendered to patients. Effective July 5, 2007, PRC providers as well as Urban Indian programs are required to adhere to Medicare-Like rates for in-patient care[132].

Allison shared with me:

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[129] The acronym corresponds to Contract Health Service Delivery Area (CHSDA) has now been replaced by Purchased/Referred Care Delivery Area (PRCDA).

[130] Source: https://www.ihs.gov/forpatients/faq/

[131] See also https://www.ihs.gov/newsroom/directorsblog/september2011/understanding-the-purchased-referred-care-program-part-1/

[132] Source: https://www.ihs.gov/prc/medicare-like-rates-information/

> the Indian health hospitals had this, this rule that if you didn't live on the reservation for six (6) months or more that limited their ability to care for you (...). So when they told us that, I was like we can’t afford like one of us to drop our lives, move up to the reservation and live there just for 6 months (…). Like there is like a bunch of red tape, it still blows my, my mind how that works. I don't think it's fair, I think it's very biased. It almost felt like they were punishing off reservation members.

She added that the quality of services is much better off the reservation. I paraphrase: “Health services are so much better here. I am very lucky, my partner and I work very, very hard at our jobs, so that we have health insurance and we can care for our family”.

According to Zuckerman et al. (2004, p. 54) forty-nine percent (49%) of indigenous peoples in the United States have employer insurance compared to eighty-three percent (83%) of Whites; sixteen percent (16%) are covered solely by the I.H.S. Among Native Americans there were higher rates of public/state coverage compared to Whites (seventeen percent, 17%, and six percent, 6 % respectively). Almost twenty percent (20%) were not insured and did not report I.H.S. coverage.

Native Americans who reside in urban centers off the reservation heavily rely on Urban Health Programs. Borne of activist efforts in the 1960s led by Native American leaders, services targeted toward addressing the health needs of indigenous peoples residing in urban areas. They provided limited primary care, outreach and referral and were manned by volunteers. Recognized as a serious social issue, legislation provided guidelines for the ownership, management and budgetary needs of urban healthcare facilities in the mid-1970s. Subsequent legislation (PL 100-713, PL 101-630, PL 102-573) expanded the scope of urban health programs to include direct care, addiction management and mental health services[133].

According to Department of Health and Human Services reports (Weahkee, 2019) a little less than seventy-eight thousand (78,000) Native Americans who reside in urban areas utilize Urban Health Programs. Other sources indicate higher numbers: information available directly through the I.H.S. shows that the user population amounts to one hundred thousand (100,000)[134]. Users do not have access to I.H.S. direct care, PRC, or health facilities owned and operated by indigenous groups because of the lack of proximity to a reservation (Weahkee, 2019). The forty (40) organizations are located in more than forty (40) locations across a number of states (including Arizona, Colorado, New Mexico, California, and New York)[135] and provide direct medical care, outreach and referral services as well as residential and outpatient care (Weahkee, 2019). An emphasis is placed on supporting Native Americans through services like behavioral health, counselling, addiction management, prevention and treatment of Sexually Transmitted Infections (STIs), nutrition information, and health education (Weahkee 2019)[136].

There has been a history of chronically underfunding Urban Health programs, in a system that is already operating within intense funding constraints: As cited by Forquera

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[133] Source: https://www.ihs.gov/urban/history/

[134] Source: https://www.ihs.gov/urban/aboutus/

[135] Source: https://www.ihs.gov/urban/aboutus/
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[136] See also: https://www.ihs.gov/urban/aboutus/

(2001, p. 8) in 2001 only one percent (1%) of the available I.H.S resources were allocated to Urban Health, while programs and facilities owned and managed by indigenous peoples were given the majority of resources (fifty-three percent, 53%), and the rest to I.H.S. facilities. According to 2019 budget documents, Urban Health programs received a little more than forty-nine ($49) million compared to more than nine hundred sixty ($960) million allocated to PRC services (see Weahkee, 2019, pp. 118,142).

As non-profit 501 (c) (3) status organizations, facilities participating in the Urban Health program have access to a small portion of the I.H.S. budget, as shown above, but are also supported by grants, donations from private organizations and Medicare/Medicaid, or insurance, reimbursements (Forquera, 2001; Heisler, 2015). Clients cover the expenses of care they receive while enrolled in Urban Health programs, on a "sliding scale" basis (Forquera, 2001, p. 12), particularly when it comes to services that are not considered emergency care. According to Forquera (2001), clients hesitate to enroll in other than I.H.S. funded programs for which they are eligible, due to an understandable sense of entitlement to free healthcare as a result of the status. Perceived stigma and stereotypes on the part of healthcare providers also shape clients' decisions as to whether or not to resort to services (see Forquera, 2001), a topic that I will focus on in the subsequent pages.

One does not need to look too hard to find literature on the health disparities that Native American populations face; however, there is much less focus on how systemic issues and the practices of providing services in healthcare create barriers for equitable access (Sequist et al., 2005). For example, between 2001 and 2002 there were shortages in an array of vaccinations including the diphtheria and tetanus toxoids and acellular pertussis (DTaP) vaccine; varicella vaccine; measles-mumps-rubella (MMR) vaccine; and pneumococcal conjugate vaccine that affected access to vaccinations for children across the nation (Santibanez et al., 2006). Research with a comparative approach found that children who resided in certain geographical areas and sought care at public clinics were more adversely affected than children who lived in affluent locations and attended private facilities. A little over fifty-nine percent (59%) of children up to the age of nineteen (19) months seeking care at public facilities received the DTaP vaccine compared to almost sixty-eight percent (68%) for those accessing private facilities (Santibanez et al., 2006, p. 692). There were greater shortages in I.H.S. facilities compared to public clinics: Indicatively, while on a national level there was an almost two percent (2%) decline in availability of vaccines, in I.H.S. facilities the decline reached approximately fifteen percent (15%) (Santibanez et al., 2006, p. 693; Groom et al., 2006, p. 669). Clients using I.H.S. in Southwest areas experienced a decline that amounted to approximately twenty-seven percent (27%) compared to four and a half percent (4.5%) in the areas of Alaska and the Northern Plains (Groom et al., 2006, p. 699). As James tells me: “They aren’t open 24/7 (…) and they’re not always equipped with necessary things you know for certain procedures”. Fiona shares:

> They just don't have the money on the reservation to be giving you an MRI every time you ask for it they’re by now we're going to x-ray, x-ray’s cheaper you have no money we are going to bill your medical insurance but you have no money so you have no reason to get an MRI.

A common phrase I heard from individuals with disabilities, their families and services providers alike, was that healthcare services for Native American people employ a ‘band aid’ approach. I paraphrase: “You go see them and it’s, like, they slap on a band aid, cover it up and send you home; they don’t care if you are bleeding inside, just slap this on and you’re out the door”. Sarah highlights:

> They don’t have the resources (…) Like, resources like the right medicine, you know, drugs they're kind of known for, like, it's a joke like if you go to IHS you're just going to get, like, Ibuprofen, or something like that. Like, it’s kinda true.

Due to severe underfunding, the I.H.S. often does not have the resources to support optimal disease management. The burden of cost affects medication supplies. For example, long acting medication for diabetes management is not available to clients using the I.H.S.; rather, providers are forced to prescribe medication that needs to be repeated multiple times a day because it is less expensive (Warne, 2006).

The situation is further exacerbated by long wait times and staff shortages. Clients may have to face a wait time of up to four (4) hours while in a facility to see a provider (Roubideaux, 2002, p. 1401). Some Diné individuals with physical disabilities that I interviewed discussed the stress that doctors are under to see as many patients as possible in a day and associated the duress to doctors’ demeanor toward patients during interactions.

Fiona provides further details:

> doctors are rushed. I got to get to next patient, I got to get to the next patient is that it is all you need?okay thanks bye(…) and then they go cuz they booked your

> appointment you have to show up 15 minutes before your appointment and then they don't see you until 15 minutes after your appointment starts cuz the next person before you took most of that time and so then a 3 o clock appointment turns into a 4 (…) because the patients are booked back, back, back, back .

Depending upon the specialist needed, clients may need to wait six (6) weeks to four (4) months for an initial appointment and anywhere between two (2) to two (2) months for a follow up appointment (Hoeven et al., 2018, p. 22). Shortage of supplies, long wait times, and understaffing all go hand in hand to perpetuate inaccessibility to services.

Sarah explains:

> I would say there's long lines a lot of the time, no I would say all the time actually, you know, I think it's just understaffed and under like there's not enough resources, adding that, more often than not patients were given over the counter medication and sent home.

According to Warne (2006) there are intense differences in health professionals working with Native American populations compared to the United States as a whole. More specifically, while there are more than two hundred twenty (220) physicians per one hundred thousand (100,000) residents in the US, for Native Americans that number drops dramatically to less than seventy-four (74) MDs. Similar disparities exist in other specialties: there are almost eight hundred fifty (850) RNs per one hundred thousand (100,000) in the United States. In contrast, per one hundred thousand (100,000) Native

American people there are less than two hundred thirty thousand (229,000) RNs (Warne, 2006, p. 270). Covering personnel gaps is challenging for many reasons: many providers do not wish to work in environments with limited resources; facilities serving Native American people are often in rural, remote areas, while salaries are not competitive (Barrasso & Tester, 2016). The history of gaps in relation to services provided to Native American peoples can also be explained by the practices of hiring staff members, and the lack of maintaining continuity of care. Most individuals who fill provider and leadership roles do not share ties with Native American communities where they work: staff members support facilities serving Native American populations as part of their obligations to the US Public Health Service Commissioned Corps or as recipients of scholarships. At the end of their assignments and/or funding obligations they relocate to other areas (Office of Technology Assessment, U.S. Congress 1986 as cited in Cunningham & Cornelius, 1995, p. 405). Data published by the Government Accountability Office in 2016 show a twenty percent (20%) vacancy rate of primary care physicians in I.H.S. facilities (Barrasso &Tester, 2016, p. 22). In 2018, the overall vacancy rate across specialties and I.H.S. areas rose to twenty-five percent (25%), according to reports (Hoeven et al., 2018). For example, in the Navajo Area, of the sixteen hundred (1,600) provider positions more than thirty percent (30%) were vacant (Hoeven et al., 2018). A general review of the situation in I.H.S. facilities reveals that some positions remain vacant for a long period of time (approximately five, 5, years) because of lack of equipment and inadequate pay (Barrasso &Tester, 2016). One finds a similar situation in facilities that are owned and managed by Native American governance bodies. Indicatively, there is a thirty percent (30%) annual turnover rate among dentists serving in I.H.S. and facilities falling under the self-governance category (Nash & Nagel, 2005, p. 1325).

Concerns over lack of personnel were common among the Diné and non-indigenous service providers I collaborated with throughout my fieldwork. They shared that usually a service provider may be caring for three (3) or four (4) clients (depending upon the setting, sometimes at the same time) depending upon the day and other circumstances, leaving little time to do anything else other than ensure that clients' personal needs and hygiene are taken care of and that they are safe. Service providers mentioned that the burden of care under these constraints meant that they had little to no time to assist their clients with disabilities in learning new skills, or navigating challenges: Elena raises important insights:

> we have so much turnover, but it really needs to have better pay I mean you're taking care of some, you're in charge of that person's life, like you're in charge of medications, of you know, making sure they're safe, supposedly helping with their education and you know life ex, life and growing as a person, so I mean that's a big responsibility to pay someone minimum wage.

Hope highlights the implications of systemic inequities on the emotional wellbeing of clients and on their relationship with providers:

> Yeah, like I said people being paid more that would be nice but I hear a lot of, we have a high turnover rate and I feel, it saddens you because I see clients get really attached to a staff and you know as much as they want to be there if, you know,

> they can't because, I will be there to support the family, or they won't be able to support somebody so that's why; then they leave and that individual's feeling sad or you know really not much of a connection. You know, they feel like they can get attached to individual or staff and they leave. That something that's not their fault and I, maybe the communication there is like they start to think that it is their fault but really it's not as(…) you know and that's heartbreaking it's really sad to get attached to somebody 'n' one of the reasons you leave is due to money and I always found that one kind of upsetting cuz I have seen people leave and the clients feeling like it may have been their fault, but it never was.

As noted by the participants in a study published by Shah et al. (2014) providers working with Native American populations often leave after short periods of time. Every year new students and trainees enter the facilities, unfamiliar with their clients' medical histories, individual health needs and struggles. The constant flow of new faces who carry with them stereotypes about the population that they are working with, which are expressed in a discourteous manner during interactions with clients, contribute to creating an environment of understandable distrust. Shah et al (2014) are not alone in pointing out the importance of understanding the role that assumptions and stereotypes play in shaping the complexities of the dynamics in interactions between service providers and their clients. Interactions in healthcare reflect social dynamics in social contexts of everyday life and are shaped by multiple factors including: cultural and communication norms, stereotyping, as well as broader social attitudes and past experiences (Perloff et al., 2006).

The Role of Culture in Healthcare

Maupin and Ross (2012,p. 306) state that "the rising population diversity within the United States and greater recognition of the importance of culture beliefs in treatment decisions", led to the development of materials and trainings in medical programs, with a particular emphasis on reducing racial disparities and improving access of minority populations to healthcare services (Truong et al., 2014, p.1).

Now known as Cultural Competency, examining the role of culture in interactions in healthcare originated in the late 1960s as an emphasis on patient-centeredness and cross-cultural communication in healthcare. Cultural competency expanded as an approach beginning in the 1980s and throughout the 1990s. While originally focused on understanding cultural differences between immigrants and healthcare professionals in host countries, it broadened its scope to encompass all minority populations. Furthermore, it changed its scope from acknowledging cultural difference on the individual level to encompassing issues of prejudice permeating systems and affecting the community level (Saha et al., 2008, p.5). Cultural Competency focuses on providing medical providers with knowledge of 'cultural patterns present' among ethnic/racial groups and awareness of attitudes and how those connect to culture, as well as various -isms (such as sexism, racism, classism), to encourage providers to self-reflect on how their own cultural beliefs might influence interactions with patients. The goal was to provide providers with the skills to effectively communicate with patients (Betancourt, 2003).

While being culturally sensitive is undeniably an asset in social relationships, there are problems with the assumptions upon which Cultural Competency rests and the implementation of this framework in patient care (Maupin & Ross, 2012). Anthropologists have highlighted that Cultural Competency fails to acknowledge that culture is fluid and flexible. Frameworks like this have been critiqued for essentializing cultural characteristics, neglecting personal agency in performing cultural norms, and overlooking cultural variation, therefore, promoting and strengthening stereotypes. The attribution of specific behaviors to certain groups of individuals may lead to providers forgetting commonalities between themselves and their patient and to the internalization of blame on the part of patients for communication misunderstandings, as both parties of the interaction (provider and patient alike) may not be aware that biomedicine and its approach to illness and health are also products of cultural norms (Carpenter-Song et al., 2007; Maupin & Ross, 2012). Maupin and Ross (2012) also caution us that the assumption that culture alone explains behavior serves to diminish the importance of acknowledging other factors that shape individuals' behaviors, such as structural barriers. Studies on healthcare interactions have shown that the quality of care that patients receive can vary based on whether or not the facility providing services sees a large number of minorities (Mead et al., 2008). Healthcare providers attitudes toward patients vary based on the sex and race of the patient: when adjusting for other factors (such as socioeconomics, phenotype, and personality differences), findings show that medical professionals engage in prejudice against women, particularly those of minority status (Schulman et al., 1999). Gaps in the provision of healthcare services may be due to providers’ training, availability of resources in facilities, as well as disparities in opportunities to improve socioeconomic status, and geographical location, which allow for a greater or lesser degree of access to better quality healthcare services (Bach et al., 2004).

Despite the wide acknowledgement that bidirectional assumptions about culture shape how one interlocutor perceives the other, research on interactions in healthcare has focused primarily on certain minority groups, overlooking others. Much of the scholarly attention has fallen on the experiences of African American/Black individuals with healthcare providers, even though Native American peoples have a history of facing ongoing institutional discrimination and microaggressions in healthcare contexts (Perloff et al., 2006; Guadagnolo et al., 2009; Bean et al., 2014). Therefore, we know very little about interactions between Native American healthcare services’ users and service providers, who are predominantly non-indigenous, and even less about the role of cultural perceptions in these interactions. Available contributions give us differing conclusions: some state that cultural identity plays no significant role in interactions, while others tell us that Native American patients report provider bias against their cultural and religious beliefs. For example, Garroutte et al. (2008) examined how Cherokee perceived certain behaviors that are important throughout the interaction between the healthcare professional and their patients. Patients felt that their meetings with providers were overall positive and attributed this doctors’ willingness to listen to their concerns and their friendly and encouraging demeanor during treatment. Patients mentioned confusion over determining when and why their provider engaged in joking during sharing information. On the other hand, in their study involving barriers to access and healthcare service delivery among Native American/White parents and Native American/White adults, Call et al. (2006, p. 597) show that Native American adults[137] are more likely to report that medical providers do not understand their culture (7.1%) compared to Whites[138] (3.2%).

Arviso-Alford & Cohen Van Pelt (1999) note that common stressors for Diné patients during medical visits arise from providers not being aware of cultural norms pertaining to healthcare spaces and assumptions about medical procedures. As I have mentioned previously, many Diné approach healthcare facilities with apprehension due to the high rates of mortality that historically occurred in hospitals (Kunitz, 1983). Cultural beliefs of illness transmission and contagion accentuate this understandable fear. The possibility of becoming afflicted by serious illness, even death, is everywhere in hospitals: procedures that alter the patient's body, doctors who spend their days living in social and physical spaces that carry immense risk for the Diné who follow traditional ways of life (for example ERs or ORs) without taking necessary action to restore harmony after the conclusion of interaction with each patient, and technologies that remind some Diné of war and colonizers all pose a direct threat to one of the most important principles of Diné traditions: hozhó. (see Arviso-Alvord & Cohen Van Pelt, 1999; Schwarz, 2008). Exposure to medical practices is risky not only for the patient but also for the Diné provider. As Mary shared with me:

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[137] Unweighted samples ranged from 309 to 341.

[138] Unweighted samples ranged from 868 to 937.

> To be a healthcare worker means a lot to, you know, you’re going to be healing, studying about um all sorts of things and then healing, including your own healing you know cuz you’re put, opening yourself to a whole different world of chaos and in order for you to walk through that and be able to heal others, you have to heal yourself and then be able to help others again so opening yourself up and then closing again you know.

Arviso-Alford and Cohen-Van Pelt (1999) learned to approach the Operating Room (OR) as a sacred site wherein in harmony through balance (hozhó) safeguards the patient from complications or death, and herself from illness. Others highlight the risks of letting all the internalized negative emotions and situations that occur in Emergency Rooms (ERs) go untreated. Traditional medicine men perform ceremonies to bless facility spaces, purify doctors and cleanse the patient with the primary goal of restoring balance within the person and in relation to others and the physical environment that purify and cleanse the individual can help restore balance within the person and their surroundings (Arviso-Alford & Cohen Van Pelt, 1999; Schwarz, 2008).

Particular concerns arise when health problems call for medical procedures and interventions that many Diné consider invasive, such as surgery, blood transfusion, and transplantation. Likened to “butchering of sheep” (Mico, 1962, p. 16), providers have noted that because of such perceptions some Diné individuals who live by these cultural beliefs resort to surgery only when there is no alternative as, in the eyes of Diné patients and Diné medical professionals alike, the body is sacred and reflects hozhó on the individual level (Mico, 1962; Arviso-Alford & Cohen Van Pelt, 1999; Schwarz, 1997a;

Schwarz, 2008). Taking parts from her body, corn and materials from the four (4) directions that delineate the universe, Changing Woman created all Diné, who, therefore, are related with one another with strong family ties (k'é), and are connected to the sacred place here the creation of the universe took place (Schwarz 1997a, p. 62; 2008, p. 15). Natural elements such as air, heat, vibration and moisture, along with four sacred minerals (white shell, turquoise, abalone shell, and black jet) are the components of the human body (Schwarz, 1997a, p. 62; Aronilth 1990, quoted in Schwarz, 1997a). In the wisdom of the universe, all bodies encompass the number four (4) within them: the digestive system, the nervous system, the skeletal system, and the respiratory system.

Each of these brings life to the individual through the association with key figures in the Diné clan system, which defines the purpose of existence of all Diné individuals. The digestive system, which receives the sustenance a mother provides, is the person's mother; the skeletal system, represents the father's ability to support his offspring and offer them the foundations to stand strong throughout life; the respiratory system encapsulates the parental grandfather's teachings and the nervous system is the contribution of the maternal grandmother (Schwarz, 1997a, p.74).

Changes in the body (such as loss of bodily fluids or other body parts) are accepted among the Diné, as long as they occur as a result of a natural process (Schwarz, 1997a). Receiving organs or blood from others can lead to acquiring some of the donor's personality traits, propensities, and health problems. Those needing to undergo these invasive procedures attribute diseases that manifest themselves after a blood transfusion, or organ transplant, to a direct cosmic connection with the organ donor, and recipients acknowledge that the proclivity to develop addiction dramatically increases when a donor has had such challenges in their life. Equal danger exists for the blood/organ donor. If the outcome of the recipient is negative (e.g. death), the donor has to contend with possibilities that could be detrimental for their physical and emotional health: not only do they now live with an incomplete body, but also with the fact that part of their body is dead. Additional questions then arise regarding appropriate burial of the recipient. Perspectives among the Diné uphold that the introduction of foreign burial practices, which prevent direct contact with Mother Earth at the time of death, have brought about an imbalance in the reciprocal relationship with the universe:

> So, we are basically only sheep and livestock to our Creator, (…) Navajo in their burial practices traditionally, they never had any caskets, they never had any kind of embalming of the body (…). It is because we are prohibiting, we are holding back Mother Earth's partaking of the body (…) that more and more people are dying because we are not feeding Mother Earth (Schwarz 2008, p. 124).

According to some Diné participants in Schwarz's work, interfering with the way one looks can be seen as challenging the specific, sacred purpose for which all humans were brought to life:

> Every part of the body is sacred in the way that we were made. We are sacred, and that is why grandma always says ‘ Don't cut your hair…Don't cut your nails, don't paint your nails…Don't pierce your body’. We are considered sacred inside and outside (Schwarz, 2008, p. 211).

Acquired alterations to the body cause the scorn of Holy People who could choose to forsake the individuals who committed such cultural transgressions at the time of death, or worse, bring misfortune or illness to the extended family of the deceased (Schwarz, 2008). Drastic interventions to the body can disrupt the harmony through balance (hozhó) principle that ensures wellbeing within the individual, equilibrium in social relationships and in the universe. According to Mary:

> Every person, everything, is, it just, it makes that balance of the world, it balances the world out and that's just how we're still here that's how the universe sustains itself you know maybe that's the reason why it's still that's where the universe is (…) things happen for a reason there's always a reason and it's always to balance out the whole universe, so you know how like you expand a bubble and it kind of reforms itself into a round one that's just how it is, you know ”.

She concluded that no one can intervene to rectify physical disability without running the risk of altering the force of nature that guides balance in the universe. During our interview, Lisa discusses how Diné cultural beliefs can impact interactions between providers and families: certain family members were enthusiastic about practices involved in treatment, while others were hesitant to accept suggestions during treatment:

> when we were trying to with a child with physical disabilities take pictures of the child in the correct positioning in a wheelchair (…), you know some parents thought that that was just the slickest thing and all that was really great because we were doing it so professionally, other parents said I don't want pictures of my

> child (…), that is not okay. (…) They would not allow us to do it so therefore we had to ask whether or not it was okay to do that.

> The participant continued *:* "you better be respectful about that or you're going to have an irate Navajo grandmother coming in raising hell with you, okay?".

Non-indigenous service providers who participated in my research project mentioned that they felt it was unfortunate that they did not know much about Diné culture. Lack of cultural knowledge was attributed to limited interactions with the population, due to cultural norms, structural barriers and a problematic history, which shapes current relationships. As Rose shares:

I've learned they're very private people they don't share a lot you don't see a lot of them out in the communities doing… I can probably count on one hand the amount of Natives that I have seen out, you know in public so to speak. At ball games or at shopping… whether they don't have transportation whether they're there I don't know I'm not sure why they if they just kind of stick to themselves they don't want to intermingle with us or they just wanna stay with their own, their own people so to speak privacy thing. They don't wanna share everything which is sad cuz I'd love to learn their heritage, their customs, cuz they're cool people the ones that I've met so yeah I'm not sure why.

Others state that there is a cultural divide, partly due to colonization. Abigail emphasizes:

> I think in a certain way, not to say that, I'm not trying to call like every American a colonizer I'm just saying like as far as our culture goes, that's something that is a huge part of it and because that is a huge part of it, it's I don't know, I don't know,

> I, I just think that specifically in dealing with disabled persons and in my clients' case Navajo it's almost looked at as such a you versus them.

Communication Norms, Stereotypes, and their Impact in Healthcare

Studies have highlighted that social norms of appropriate communicative performance in everyday life, as well as stereotypes and biases surrounding race and identity, shape interactions in everyday life. For example, communicative practices of individuals who self-identify as African American/Black emphasize situational awareness and understanding of social settings, whereas norms of individuals who self-identify as White show an intent on establishing fixed categories in relation to classifying the individuals involved in the interaction (Rawls, 2000). Participants who self-identified as White in Rawls' (2000) research engaged in directing questions that would elicit information on the individual(s) participating in the interaction, whereas participants who self-identified as African American/Black felt that that way of communication was too invasive and insisted on knowing more about the context in which the conversation would take place so that they could adjust their communicative performance accordingly. Due to cultural norms surrounding conversation, African American/Black participants in Rawls' (2000) project reported feeling uncomfortable during interactions that were focused on eliciting information about individualized experiences.

My research revealed that communication differences can contribute to creating difficulties in participation in social life. Lisa states:

> not standing out and that's something I learned, you know, in one of my, I went to a gazillion things on cultural respect to Navajo beliefs and all that I mean I've been trained to death and that's one of the things that they definitely point out is that Americans want to excel and stand out where as it's much more important to Navajos to be part of the group and not stand out you know you, when I, I had to interview Navajos differently than White people because when I was interviewing somebody White I would say okay well then tell me good things about you why should I hire you? And somebody white will launch right in and tell you. And when you say that to a Navajo, and you know it's got to Navajo they get shy and they're afraid to brag on themselves.

D: so how would you interview a Navajo person then? how would you phrase it?

L: I would ask them are you good at this, are you good at that you know?

D: Ok.

L: Yeah, I would be specific in asking rather than making them blow their own horn. They’re not good at it.

If we conceptualize healthcare as a process that is produced by (and operating within) a broader sociopolitical context, we will realize that both patients and providers are bringing their values, behaviors and biases into institutions (Gilson, 2003). Influenced by Cultural Competency, in recent years, research has focused on gaining a deeper understanding of communication norms between patients and healthcare providers that come from diverse backgrounds; the particular focus on the complexities that arise between patients who self-identify as ethnic minorities and doctors who do not stems from the acknowledgement that communication differences and cross-cultural perceptions of those participating in interactions can have serious implications on social relationships, and levels of trust in healthcare providers (see Arviso-Alford & Cohen Van Pelt, 1999; Perloff et al., 2006; Simonds et al., 2013; J. Maupin, personal communication, October 2, 2019).

Research shows that Native Americans are concerned that their providers do not understand their indigenous language or respect their religious beliefs. Compared to Whites, less than five percent (5%) of whom state that their doctor does not understand their language, more than six percent (6%) of Native Americans report experiencing this problem. While a little over one percent (1%) of Whites report that their doctor does not respect their religious beliefs, more than six percent (6 %) of Native Americans share that they feel their religious beliefs are not being respected by their doctors. Furthermore, a higher rate of Native Americans reports no or low trust in the abilities of their own doctors or their child’s provider. More specifically, approximately twenty four percent (24%) of Native American patients worry about doctors’ trustworthiness, compared to a little over thirteen percent (13%) of Whites. I follow Simonds et al. (2013) who call for thinking about the concept of trust as a complex issue which includes confidence in a provider, but also in an institution. In their study on cultural identity and trust among Native American patients (n=219; mostly Cherokee) and White providers (n=10), they found that individuals who scored high on affinity to Native American cultural tenets scored low in institutional trust compared to those who scored low on cultural awareness(OR: 0.6; 95 % CI: 0.4, 0.9)[139]. They measured cultural identity by asking participants to rate how closely they follow Native American ways of life, religious beliefs, spiritual practices and institutional trust by examining the degree to which participants thought that tribal or clinical regulations affected decisions that providers made about patients' care (Simonds et al., 2013, p. 502).

Arviso-Alford and Cohen Van Pelt (1999) note that common stressors for Diné patients include standard practices among doctors such as asking questions that are considered personal in a fashion that is considered abrupt or discourteous (for example, while looking at the patient directly in the eye). She and her colleagues often initiate contact with Diné patients by engaging them in conversations about things that are important in Diné everyday life, such as clan membership and livestock in an effort to help the patient relax prior to the examination.

Non-indigenous providers commented on communication practices of their Diné counterparts, often sharing that they initially perceived Diné norms of communication as "stern", and "loud", particularly during instances when they felt that respect had been violated and rights needed to be re-asserted. Elena highlights: "it's just like stoic (…) so that was different and was somewhat cultural I think, but not everybody are but in general I'd say (…) it just takes a while to break the ice". Other non-indigenous service providers

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[139] See p. 505 for detailed table

identified communication differences and related them to cultural norms of performance. Abigail shares:

> We have a lot of, um, staff who are Navajo and the way that they work with clients is very much something that is like culturally acceptable work for them, the way that they talk to each other and things like that and that, when you are not from that experience that there are times where you like what what did you just say to them, but that's, that’s their, how they interact, that's what their relationships are. That’s a better way to put it, that's how they formulate their relationships, and that's how they continue to interact with each other, and I mean I have no (…) I have no comment on it because that's their joy, like that's their that's how they build relationships, that’s how they do that.

Throughout my fieldwork non-indigenous and Diné service providers discussed how important performance of kinship ties (k’é) was in creating, building, and sustaining relationships with their clients and their Indigenous colleagues, through the identification of clan relatedness. For the Diné, the primary way of identifying oneself encompasses declaring ties to the mother and father. Diné individuals will, therefore, state that they are “born to” their mother’s clan and “born for” their father’s clan (Schwarz,2008, pp. 12-13). As Lewton and Bydone (2000, p. 479) clarify: “In the narrowest sense, it informs as to who one's blood relations are”. The concept encompasses emotional responses of compassion and solidarity one feels toward family members (Lamphere, 2000, p. 600). Ideally, kinship represents the "condition in which everything is in its proper place, fulfilling its proper role and following all the cultural rules" and is “a statement of the proper order of that universe—that is, the ideal state of affairs or the way things ought to be" (Witherspoon 1975, p. 12). As a principle, k'é, therefore, reminds Diné individuals of the privilege and responsibilities that come with being closely connected not only to fellow clan members, their homeland and the physical environment, but also to the universe, and the beings that created life as we know it (Powell & Curley, 2008). Hope emphasizes how this principle relates to disability:

> I think traditionally there's such a, there's a thing in Navajo that's called k'é (…). I think that means like something maybe family or togetherness or union and that goes around for you know the people as Diné as we look out for one another and I think with that disability that doesn't exclude that either you know? it's still a union I feel and that's the way I see it.

She continues:

> you know I grew up with that again as the norm and I think I seen that tune a lot because like a family member will be talking to another Native family's child, you know, just as they would with me or somebody else and they're kind of like you know grandmotherly, is as much as I think of to another person. So that's what I bear in mind and that's why I think it is you know that k'e, what they're telling me about, that together, and just looking out for each other [140]

Kinship highlights social expectations and informs communicative practices (Witherspoon, 1975). Abigail discusses how Diné colleagues can talk to Diné clients in

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[140] Certain aspects of this narrative have been paraphrased to protect the anonymity of the participant.

ways that non-indigenous staff cannot. From her perspective, Diné clients and Diné service providers have a shared understanding of culturally appropriate ways of showing respect and setting boundaries:

> I will say like you're obviously all individuals who have personalities and things like that and not group ‘em, but there is a common thread of of how interaction in and basically what shit they will put up with is part of it (laughs) because a lot of those ladies are like no, no, no, no, this is not how this works. You’ll call me this name and this is how it is and like just very curt in ways, which is really interesting and admirable in quite a few cases, so yeah.

Some Diné participants with physical disabilities commented favorably on professionals’ engagements with them. They highlighted that the access to doctors of many specialties results in improved health, and stressed that they appreciated the fact that doctors invited their patients to ask questions. Along with Diné service providers they applauded the growing awareness of the interconnection between mental health issues and ongoing prejudice, discrimination, and self-blame in relation to disability. Diné individuals with disabilities also highlighted their appreciation for the hard work, life lessons, and close relationships they had with their providers. In addition to other aspects of care, service providers featured as key figures in advocating for their clients’ rights.

Very few Diné participants (including individuals with physical disabilities, their families and/or service providers) commented on communication differences, as the majority of narratives contain reflections on stereotypes that permeate interactions.

However, some Diné participants with a physical disability, family members, as well as Diné and non-indigenous service providers commented on how uncaring and rude certain healthcare professionals could be. I paraphrase the insight of Jane: “Physical therapists are so mean. They need to spend more time with people. Not say do this, walk away. They need to give more encouragement”. Similar sentiments are highlighted in other studies. For example, the Zuni who participated in the study led by Shah et al. (2014, p.8-9) share: “some of the employees are so rude that you just don’t want to deal with them*”*. Another participant adds: “Well probably most of the nurses over there are real mean. I don’t know what the problem is. They could at least smile or say hi or something.”

Discourses surrounding ‘appropriate’ communication go hand in hand with the social construction of stereotyping, despite the fact that research has shown that sensory engagement with the world varies within and across cultures, and there are social differences in observation practices (Kuwabara & Smith, 2012). Provided to me by Lisa, the following interview excerpt shows the complexity of dynamics, and highlights the fact that assumptions can have very real implications for Diné individuals with disabilities:

> Another thing is that, oh this is a really important, to our intelligence instruments IQ tests and in particular, they test for the kind of intelligence the White people have if you can generalize. Navajos have different kinds of intelligences is there hugely visuospatial whereas white people tend to be very verbal (…) when you only give Navajo children Anglo IQ tests they come out rather ordinary, whereas if you do visual spatial testing with Navajo children they come out gifted

Lisa elaborates:

> Navajos don't talk to their kids constantly like White people do and so therefore those kids don't if they don't have a Navajo mother who has been trained to talk to the child the children learn by observing and not by verbal things that's their cultural way of education and it worked very good you know when lives were simpler and little girls were learning how to grind corn and little boys were learning how to shoot arrows and you know butcher animals, so if that is not present in a home then that child is going to be very different as an adult simply because of how they've been treated as a child and that early training can't really be reversed by education I mean it can be made it may be ameliorated but not really changed, that early language stuff is so huge in White culture.

Based on findings provided in Call et al. (2006, p.598) racial and economic discrimination were most frequently reported by Native Americans than Whites (45.2 % compared to 43.8% for economic discrimination; 21.9% compared to 5.1% for racial/ethnic discrimination). In her work with Diné family members, Joe (1982) explores how stereotypes about race affect interactions between Diné individuals caring for family members with disabilities and healthcare workers, who are predominantly non-indigenous. Those who participated in her work share that their intelligence and credibility are continuously challenged by providers when reporting illness and discussing treatment.

Stereotypes play an integral role in navigating healthcare contexts. The presence, prevalence and effects of stereotypes in interactions in healthcare in relation to Native Americans have not received enough scholarly attention (Guadagnolo et al., 2009; Bean et al., 2014). Bean et al. (2014) highlight that common stereotypes regarding Native American patients among those training to be healthcare workers include: misperceptions regarding engagement in risky health behaviors and non-compliance.

My research revealed that perceptions of Whiteness and Indigeneity were coupled with stereotypes, and informed how the Diné participants with physical disabilities and family members I met during my fieldwork interacted with service providers; similar notions on what it means to be White/indigenous framed how professionals provided care to Diné individuals with physical disabilities. A minority of healthcare workers and service providers that participated in my research expressed that they felt that Native Americans were uneducated, lacked awareness of basic facilities, could not provide care for family, and mentioned that they were aware of the prevalence of sexual violence against women in Native American communities. As John states: "I mean (…) it just kind of scares me it feels like they' re an entirely different society from what I'm exposed to here". The overwhelming majority of professionals that I interacted with and interviewed during my fieldwork were aware of the position of privilege and responsibility that they occupied in relation to their clients, and were committed to supporting the needs of their clients, but also in addressing the 'soul wounds' (Duran, 2006) that the legacy of history perpetuates and were committed to promoting inclusion in healthcare contexts.

Abigail explains:

I think that people are, are afraid of so many different bizarre things in dealing with disabled persons especially disabled person from another culture because there’s not a lot of um… I don't know how to word this without making it a big thing but again it's specifically to American culture; we kind of don't have one as rich as other ones, okay?

D: Ok.

A: and it in the main part of it is kind of been colonizing

D: Ok.

A: so, I think that there's a lot of appropriation and not understanding those definitions of what someone's culture is and how to respect it and how to interact with it, but keep it separate without mimicking it? Um, again I just really think it boils down to, to ignorance and how people respond when they are ignorant to something.’

Diné individuals with physical disabilities shared that they felt that they had to advocate for their needs, often challenging doctors’ prejudice against Native American individuals, particularly in relation to assumptions about addiction. Situating lack of attention within a broader context of social attitudes toward Native Americans, Fiona highlights:

> whether it's Anglo hospital or IHS hospital usually IHS is a native hospital, but they hire non-native doctors cuz there's not a lot of native doctors so IHS has a scholarship that if they pay for you to become a doctor and to be a physician then you have to work at an I.H.S. For like I think it’s like 2-4 years of your doctor and serve your time, contribute back to the community that gave you your degree and then after that you can do whatever you want not Native American at all and so

> that's why I'm saying both white hospitals and Rez hospitals have both white doctors (participant laughs) and so with the white doctors in the white nurses it's very different (…) I tell them I'm in pain and even then they think I'm a drug addict.

Pain management has received an increasing amount of attention in the last two decades, despite numerous factors (such as funding shortages and lack of trained personnel) that make extensive research in that field challenging (Dubois et al., 2009). Research highlights that stereotypes that healthcare workers have about the racial and ethnic identities of the patients changes their pain management plans (Mossey, 2011). This may be due to the internalization of negative attitudes about ethnic minorities, lack of skills toward reflecting and shifting personal biases, lack of training in recognizing sensory differences with regards to pain, and unawareness of cultural variation in experiencing and talking about pain (Mossey ,2011). Studies have identified differences in prevalence and severity of pain based on racial and ethnic backgrounds. For example, drawing upon a sample of 13, 777 participants (eighty percent, 80%, non-Hispanic Whites; thirteen percent, 13%, non-Hispanic African American/Blacks; seven percent, 7%, Hispanics), Reyes-Gibby et al. (2007, p. 77) find higher rates of self-reported pain among Hispanics, as reported by patients[141]. Certain factors exacerbate experiences of acute and chronic pain: those with chronic health conditions, lower educational levels and in emotional distress were found to suffer from more frequent episodes of severe pain (Reyes-Gibby et al., 2007).

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[141] Specific rates are: 33% of Hispanics; 27% non-Hispanic Whites; 28% African American Blacks

An added difficulty in doing research on pain lies in the fact that as an experience pain is open to interpretation and depends upon many factors including differences in self-reporting, cultural norms of disclosure of personal expectations regarding the role(s) in the doctor/patient relationship (Reyes-Gibby et al., 2007; Jimenez et al., 2011). Studies have found an attitude of under-reporting pain among Native American populations as a result of social norms that emphasize the importance of living life with a mentality of accepting all experiences that occur during a lifespan. In that sense, pain can serve as starting point to practice not stressing experiences that are unpleasant (Kramer et al., 2002a). For example, participants in a study of communicative practices of arthritis pain among Native Americans in California, used general terms (such as ‘ache’, ‘discomfort’, ‘uncomfortable’) to describe their experience with arthritis, regardless of severity of pain (Kramer et al., 2002b, p. 153). The potential of language to create a situation that may physically affect not only the individual who utters the words in question, but also those around them (Witherspoon 1977), seems to have guided the narratives of the Ojibwe women who were invited to discuss their experience with pain due to cancer. Perhaps because of the generative nature of language that I have discussed in this manuscript, the research team were faced with strong sentiments against discussing that aspect of their illness, for fear that acknowledging illness would create it, making the patient even more vulnerable as it may lead to intrusive interactions with unfamiliar spaces and White doctors (Barkwell, 2005).

Interactions with healthcare professionals can alter pain level reports in patients: those who feel that their relationship with their medical provider is positive report pain relief even without any alterations to pain management plans; on the other hand, patients who experience tensions with their providers may try to demonstrate dependence on the providers' expertise to alleviate pain, which can—in turn—lead healthcare professional to think of as overemphasis of symptomatology (Miner et al., 2006). As a result, Native American patients report that their pain levels reduce at lower levels than other groups[142] (Miner et al., 2006).

In addition to stereotypes about race, assumptions about disability permeate interactions with healthcare professionals. Elaborating on the fact that doctors focus on disability instead of other relevant factors and health issues, Abigail notes:

> I have definitely seen it in a healthcare situation. The thing with that is that if you're going to a doctor's office, they know what the fuck is going on with you before you enter the room (…) Like it's irrelevant, unless they're there specifically in regards to their disability in which case they still, in my opinion, don't need to be called disabled, it's they here for X, whatever that disability may be. I just feel like it's this catch all that is so commonly used and thrown out, it's lost, I dunno it just has a connotation

The reasons for this response to disability, according to Abigail, have to do with cultural perceptions toward disability: the moment society sees disability the first instinct is to segregate those who embody it. Support systems reinforce Othering: the care of

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[142] Indicatively: Of the 1, 663 patients whose data were analyzed for this study, 45 % self-identified as African American/Black, 38% as White, 8.7% as Native American, 6.3% as Hispanic and 1.1% as Asian (Miner et al. 2006:142). Patients across all groups reported a 50% reduction of pain; only 21.4% of Native American patients reported alleviation of pain (Miner et al., 2006, p. 144).

individuals with disabilities is pervaded by the association of disability to ‘negative’ behaviors, which require medical/specialist intervention. Diné and non-indigenous service providers’ narratives emphasized that the association of disability to ‘negative’ behaviors and the expectation that emergencies or crises will occur during interactions is problematic. Rather, they pointed out that their work has provided them with new awareness that all behaviors are their clients’ mode of communication, and a way of expressing emotions (such as frustration) when all other attempts to communicate needs to providers have failed.

In the words of Abigail:

> from my experience when people use the word disabled it has a negative connotation, it’s always used as framework to prep this other person for another person. And not, I’m gonna use the term client a lot cause that’s what we use, to prep someone else for the client, it’s not to prep the client for what’s gonna happen.

The emphasis on disability as a concern during engagements with individuals with disabilities can have detrimental effects on their treatment plans as additional, immediate health needs may not be met, or preventative testing may be overlooked, while providers’ discourses can shape how an individual and/or family members perceive the disability, and interpret social positionality in relation to disability, (Martin et al., 2005; Satchidandand et al., 2012). The focus on negative connotations of disability is a practice that providers are sometimes forced to employ when advocating for their clients with disabilities, in order to successfully navigate a system that does not accept diversity.

Abigail explains:

> there are a lot of people who already being Native they're not, they don't have the same amount of advocacy as someone else, so then on top of that they’re disabled, um, some, some people are going back to the reservation to die, I mean they’re just getting pulled out, so that sucks, which you know (…) yeah I would say in the way that we medically, not medically, in the way that there are other factors to this too (…). The law, there are certain requirements for you to qualify for a funding it's not it's by no means like a free ride free ticket you have to meet these very, very specific requirements in order to get funding from the government (…) you have to be disabled enough which is a fucked up term (…), you have to be disabled enough, and not too disabled, and is a very fine line and there's only certain things that while are considered medically disabilities aren't written into the law, or aren't a part of that specific thing, are not considered disabled enough and um it's, it's frustrating because it's limiting to this person as you have this person that, that you're supposed to provide care for, but they can't be these certain things even if that is an accurate diagnosis you kind of have to make sure that they don't get that diagnosis because they might lose their funding and even though they're where they need to be there in doing what they, and they're doing everything right just being that human self who has the certain things totally disqualifies them.

Conclusion

The case of interactions in healthcare presented in this chapter shows complex dynamics that are influenced by past problematic engagements in healthcare contexts, cultural perceptions of medical practices, as well as the impact of stereotyping. Diné individuals are called to navigate a context associated to decimation of indigenous peoples, interact with professionals who, at times, react based on preconceived notions of indigenous identity. Structural constraints (in terms of time, funds and resources) affect not only Diné patients, but also providers. These issues place strain on dynamics that have a long history of contention.

There is hope, however, as Diné individuals with physical disabilities, family members, as well as their service providers form alliances with one another and identify medical practices that are effective in alleviating the strain. Recognizing the devastating effects of colonization and historical trauma, the non-indigenous service providers I interacted with expressed an urgent need and desire to learn more about their clients' culture. Though frustrated by a system that makes it challenging for an individual with a disability to express their own needs, providers, tirelessly advocated for the needs of their clients. Their actions did not go unnoticed by the Diné individuals with disabilities I spoke with. Recognizing them as important figures in their lives, Diné individuals with disabilities highlighted service providers' unwavering support, which extended to meaningful relationships.

CHAPTER 8: CONCLUSION

No matter what the ethnic or cultural background, gender/sexual identity, or social context, disability is a universal phenomenon, affecting approximately fifteen percent (15%) of the world population (WHO, 2011b, p. 7). Constraints related to systemic inequities (such as disparities in screening and access to services) preclude us from gauging the prevalence of disability among vulnerable populations in a comparable fashion that is applicable on a global scale (see Kirmayer & Brass, 2016). However, a number of studies highlight that disability disproportionately affects the everyday reality of historically marginalized populations. For example, data assessing rates of disability on a global scale show that disability of any type affects women at a higher rate than men; studies indicate a disability rate of sixty percent (60%) among women compared to less than fifty percent (50%) among men, due to a number of factors that place them at higher risk, including pregnancy and labor, as well as abuse (see WHO, 2011a; 2013)[143]. Similar trends occur among elders: in Australia, of the over three million seniors, approximately fifteen percent (15%) were affected by a disability (Australian Bureau of Statistics, 2015). According to the Federal Statistical Office (Destatis) there were almost eight (8) million individuals with severe disabilities disabilities in Germany in 2017, twenty five percent (25%) of whom were sixty-five (65) years of age or older (Destatis,

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[143] Also see http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTHEALTHNUTRITIONANDPOPULATION/EXTPRH/0,,contentMDK%3A20286128~menuPK%3A632615~pagePK%3A148956~piPK%3A216618~theSitePK%3A376855,00.html

2018). Finally, analyses stress that, globally, disability is particularly evident in contexts that experience economic hardship. Indicatively, eighty percent (80%) of individuals with disabilities reside in low-income countries (UN, 2013, as cited in WHO, 2015a).

Data from 2017 suggest that disability rates are higher among Native American populations compared to Whites. More specifically, seventeen percent (17%) of individuals who self-identify as Native American reported having a disability compared to thirteen percent (13%) of Whites. Almost forty nine percent (49%) of Native Americans who reported having a disability were seventy-five (75) years of age or older (United States Census Bureau, 2017).

Native Americans with disabilities have to contend with deeply rooted and long-lasting inequities that share the lived experience of disability in particular ways. For instance, barriers in education contribute to high rates of poverty and unemployment. Data from the NSF, for the year 2014, show that out of a total of of thirty-five thousand (35,000) research doctorate recepients, approximately 60 self identified as Native American, of whom only six (6) had a disability. (NSF, 2014). Unemployment rates among Native American individuals with disabilities are stark. Reports highlight that Native Americans with disabilities are 78% less likely to find employment than Native Americans without disabilities (Austin, 2013, p. 14). In 2000, forty- four percent (44%) of Native Americans who lived under the poverty line had a disability, while twelve percent (12%) of Native Americans with a disability resorted to public assistance programs for sustenance (Fuller-Thomson & Minkler, 2005, p. 1945-1947).

The impacts of colonization and historical trauma on the overall health of indigenous peoples (including the Diné), structural barriers that affect access to healthcare contexts and dynamics of relationships with providers coupled with cultural differences in terms of health, wellbeing and illness causation are all factors that play a role in examining concerns related to disability.

Bringing together literature from Anthropology, Disability Studies, and Indigenous scholarship, this interdisciplinary project examines cultural perceptions surrounding physical disability as they are found among Diné individuals with physical disabilities, family members who provided care for Diné individuals with physical disabilities, as well as Diné/non-indigenous service providers and healthcare workers. Furthermore, I explore the interconnectedness of cultural perceptions to constructs of personhood and identity. The final concern I address in this dissertation revolves around identifying medical practices that work well, and areas that need improvement in healthcare contexts.

Cultural Perceptions of Physical Disability

Contributions by indigenous scholars stress that disability is not recognized as a term within indigenous cultural frameworks. Joe (1997) highlights that among the Diné, the word ‘disability’ is not used; rather the performance that would be defined as ‘disability’ in non-indigenous frameworks would be discussed using descriptive terminology. For instance, the term ‘lags or falls behind others’ would be used in lieu of ‘mental retardation’ (Joe, 1997, p. 254). The work of Connors and Donnellan (1998) highlights that Diné elders attributed the adoption of ‘disability’ to contact with colonizers, whose influence extends to redefining interpretive frameworks.

Cultural interpretations of causation contribute to understandings of disability. As the axis of Diné worldview, the principle of hozhó represents an ideal: a world that was thought and sang into perfect existence by the Holy People (Witherspoon, 1977). This concept has received extensive attention and has been translated into English in various ways, including ‘walking in beauty’, ‘harmony/beauty through balance’ (see Reichard, 1950; Witherspoon, 1977). The existence of hozhó depends upon maintenance of a continuum: fostering connections and supporting others (both in terms of practical demands of everyday life, as well as emotionally), respecting the environment are practices that indicate the performance of hozhó (Lewton & Bydone, 2000).

My research somewhat corroborates these findings. A few Diné participants indicated there is no term for ‘disability’ in the Diné language. They added that cultural frameworks would emphasize difficulty performing certain tasks, or functions in lieu of characterizing the individual as having a ‘disability’. Echoing the emphasis on the impact of colonization, some Diné participants mentioned that the term disability did not exist prior to the signage of treaties with the White man.

For some Diné participants, disability is the result of practices that challenge hozhó and, therefore, produce imbalance. Exposure to natural phenomena and animal sightings were mentioned by Diné participants are circumstances that could contribute to disability. Actions performed by those who are in close connection with individuals with physical disabilities (e.g. expectant parents) also have the potential to create circumstances that could lead to disability.

Personhood, Identity, and Cultural Perceptions of Physical Disability

Academics examining disability in the United States have concentrated their efforts on questioning ableism/disablism, particularly in relation to dynamics that privilege normative ideas of identity, meritocracy, and marketability. Influenced by capitalist norms that center on productivity of a certain form (i.e. 'ideal' bodily and cognitive performance), social expectations of 'perfection' form the basis of ableism (Campbell, 2001; Goodley, 2014). Ableist idea(l)s permeate identity performance, social relationships, as well as the positionality of individuals with disabilities with regards to the State. Disablism encapsulates the differential treatment of individuals based on assumptions around disability (Campbell, 2008). Centered on misconceptions about reduced (or complete lack of) ability, disablism legitimizes stigmatization of those who self-identify or are labelled as having a disability; misconceptions which are further promulgated by systemic barriers and inaccessibility of the physical environment (Imrie & Wells, 1993; Goodley, 2014).

Proliferating in the 2000s, indigenous analyses of disability engage in a critique of ableism/disablism. Drawing our attention away from themes that are so salient in literature in Disability Studies (for example, exclusionary practices, demonization of bodily performance that does not conveniently ‘fit’ within the norm), indigenous worldviews we are told are based upon principles of respect, kindness, and collaboration (Pengra & Godfrey, 2001). Because of the centrality of these cultural values, individuals with disabilities reportedly do not experience social exclusion. Rather, their contributions are valued, regardless of the magnitude, success, or failure of the task (Connors & Donnellan, 1993; Joe, 1997). Often revered for embodying difference, individuals with disabilities fill important roles in their communities, creating the opportunity for those around them to reflect upon central cosmological concepts of acceptance, harmony, and balance (Shackel, 2008).

My research highlights that the issue is more complex. Romanticized ideas about disability and nostalgia surrounding life on the reservation, are intertwined with ableist/disablist narratives. Regardless of age, gender and the role they played in relation to disability, many Diné participants highlighted that Diné cultural tenets emphasized treating everyone equally. Individuals with disabilities, I was told, were integrated in activities, their contributions valued as would anyone else’s. These insights revealed that Diné constructs of productivity do emphasize offering (be it time, funds, manual labor, supplies for sustenance) as part of being productive. Bolstered by tight knit families who are available to provide support, not only are individuals with disabilities not excluded, they constitute an example to others: individuals with disabilities have a greater connection to cosmic spheres compared to those who do not. Their life circumstances have allowed them to reflect on what is important in life; their ability to engage in clear thinking leads to a happy life.

Other discourses offered, however, suggested that cosmological interpretations of disability do not negate ableism, and its grueling impact on self-perception. Like Sebald (1984) and Krech (1999) who critique romanticization of indigenous perspectives, Diné participants with physical disabilities that I interviewed and interacted with mentioned that they felt stigmatized because of their disability, and disclosed difficulty meeting ableist standards of performance. By the same token, Diné service providers mentioned that they felt that practices in everyday life actively contributed to the exclusion of individuals with disability.

Some Diné individuals with physical disabilities, family members who provided care for individuals with physical disabilities, as well as Diné service providers emphasized that the situation was more difficult on the reservation. Life in urban centers opened up opportunities to expand social networks, meet potential partners, identify possibilities for employment and gain access to education more readily. Negative stereotypes, lack of knowledge on how to respond to disability, were coupled with cultural norms surrounding care giving expectations that exercised extreme pressure on family members to care for individuals with physical disabilities. Finally, Diné service providers and individuals with disabilities alike identified that in the urban areas where they resided, they had access to a greater number of specialists, compared to options on the reservation, while the same applied for access to assistive devices and other necessary equipment. Diné service providers stressed that they had access to more information on how to expand their knowledge of disability etiquette in locations off the reservation, while better quality and greater availability of equipment allowed them to assist their clients with their needs more safely and comfortably.

Medical Practices That Work Well in Healthcare Contexts and Areas that Need Improvement.

Since the early 2000s, an emphasis has been placed upon reducing disparities in healthcare contexts. Driven by the assumptions an agenda to reduce health disparities, medical programs have focused their energy on the development of training sessions and materials that reflect upon the role of culture and race in terms of access to healthcare services (Smedley et al., 2003; Maupin & Ross, 2012; Truong, et al., 2014). Also known as Cultural Competence, some efforts to promote cross-cultural awareness have focused on encouraging healthcare providers to be self-reflective about their attitudes throughout their engagements with patients (Smedley et al., 2003; Betancourt, 2003). Others have operationalized it emphasizing the aspect of knowledge of cross-cultural ‘patterns’ of the intersectionality of patient beliefs and behaviors (Smedley et al., 2003; Betancourt, 2003). Yet others stress the need to provide healthcare professionals with the skills to bring together ethnographic approaches and medical interviewing identify how patients explain their illness (Smedley et. al., 2003).

Critiques of Cultural Competence have focused on how it conceptualizes culture and have questioned how it can be operationalized. Medical anthropologists have drawn attention to the fact that this model approaches ‘culture’ as a static category, which can lead to stereotyping and overlooking the similarities between individuals and groups, despite their diverse cultural background (Carpenter-Song et al., 2007; Maupin &Ross, 2012). Maupin and Ross (2012) also note that overly emphasizing the role of culture in interactions in healthcare tend to contribute to overlooking other important factors that influence dynamics in healthcare, such as structural issues.

As with other studies (see Shah et al., 2014), the men and women with physical disabilities I interviewed during my research, as well as family members, shared that they had been exposed to stereotypes in healthcare contexts. Assumptions about alcohol and drug abuse shaped how providers interacted with Diné individuals with physical disabilities and family members and affected treatment plans, particularly in relation to pain management. Family members, on the other hand, sometimes associated providers’ responses to questions as evidence of rudeness or uncaring character.

Non-indigenous providers expressed a strong desire to learn more about Diné cultural perceptions and practices surrounding disability. Vignettes from my research show that opportunities to ask questions about cultural perceptions of disability are limited. Non-indigenous providers expressed sensing a divide between themselves and their Diné clients. This dichotomy between ‘us’/’them’ was attributed to lack of knowledge surrounding cultural norms.

Aligning with literature that points to further need on structural issues, I have cited above, non-indigenous service providers fervently critiqued ableism for constructing norms that position individuals in a relentless drive to excel (Campbell, 2001; 2009; Goodley, 2014). Ableism, they told me, overlooks the web of dynamics that their clients have to navigate on a daily basis. Clients have to advocate for their rights in unwelcoming structures, under constraints that are beyond their control (such as funding), while at the same time having to perform their identities within frameworks that impose almost unattainable norms that very few, if any, can meet.

Recommendations

A note on my positionality and dynamics in the field is necessary before I delve into this section any further. I am not-indigenous. In many ways, I am privileged in relation to my participants, and –by definition— do not share the struggles they have to navigate on multiple layers, not only because of assumptions surrounding their disability identity, but also because of their identity as indigenous individuals in the United States today. However, in some ways, I share an understanding of their frustrations and joys because of my personal experience with a disability, which has been a driving force of my desire to complete an investigation of disability related issues.

Liaisons and gatekeepers cautioned me to be mindful of my tone when writing about recommendations. While not explicitly discussed in such terms, my sense is that these gatekeepers were alerting me to problematic power dynamics, where scientists often silence the voice of their participants.

For this reason, I privilege the voice of participants by providing their recommendations. Centered on addressing systemic barriers, participants from across all sample categories mentioned lack of supplies, financial constraints, as well as and transportation concerns. Individuals with disabilities and family members highlighted the need for greater access to services and continuity with medical providers. Much of their energy in interactions in healthcare, they shared, was spent on ensuring that the wide network of medical professionals they were required to see were familiar with relevant information. Diné individuals with physical disabilities and family members recognized that funding constraints affected access to resources, medical providers' remuneration and turnover rates.

Diné and non-indigenous providers' narratives linked lack of funding allocated toward supporting the needs of individuals with disabilities to disempowerment of the population they are serving: in order to ensure that clients receive the support they need, bureaucratic processes require that individuals with disabilities are pigeonholed in categories that strip them of their individual identity. A system is needed, providers told me, that focuses on giving individuals with disabilities the same rights to happiness, financial security and economic prosperity as those who are able-bodied. Often facing financial difficulties of their own, providers offered their passion for equity, the right of individuals with disabilities to a happy and safe life, and the close relationship that they have with their clients as rationale for fulfilling their professional duties. Better remuneration would lead to more manageable caseloads and improve one-on-one care and overall interaction with each of their clients.

I am in full agreement with participants recommendations. Data expanding from 2016 to 2018 highlight that healthcare facilities either under the auspices of, or contracted, by the I.H.S. are severely understaffed over extensive periods of time (Barasso & Tester, 2016; Hoeven et al., 2018), while patients also need to navigate high turnover rates among providers in healthcare facilities (Nash & Nagel, 2005). Patients often have to wait for a number of hours before seeing a provider, or a number of months for appointments, while discrepancies in allocation of specialists may cause differentiation of provider availability based on geographical location (Roubideaux 2002; Warne, 2006 Hoeven et al., 2018), and lack of medication and other supplies (Warne, 2006).

Participants and I share the same approach toward issues and possible solutions. Regardless of age, gender, or their experience with disability, participants identified failure to engage with the world in a thoughtful manner as the primary reason for social inequality. The world, they shared, is built by and for individuals without disabilities: those who may not have even contemplated disability as a possibility in the realm of human experience. Funds, politics, fear, ignorance, or purposeful exclusion were cited as motives for not changing things. The situation, they shared would be ameliorated if people with disabilities were put in leadership roles where their first-hand experience with disability would prove an invaluable asset toward identifying issues. According to some participants, in order to increase participation in leadership, access to education and employment are necessary arenas where individuals with disabilities can gain further knowledge and engage in decision-making processes that are relevant to their future.

Limitations

This study has some noteworthy limitations. Dynamics in the field and assumptions about my identity as an anthropologist precluded participant observation and interviews in healthcare facilities, even though some gatekeepers who worked within healthcare facilities disseminated information about my research to organizations they collaborated with and showed an interest in the overall process of my research. In addition, my positionality as an anthropologist undoubtedly shaped interactions with participants. While these identities were never discussed with me as an issue in a straightforward fashion, I was aware prior to initiating fieldwork that these concerns would be prevalent, particularly due to my engagement with Native American peoples, whose wounds have yet to be healed after interacting with individuals in my discipline. Concerns about the lack of protocols, as well as HIPPAA considerations, were cited as reasons for limiting the participation of healthcare facilities in my research. Finally, while I worked in diverse environments within the field (organizations and higher education institutions) my analysis would have been enriched with greater numbers of organizations and institutions.

The ethnographic nature of this research contains rich descriptions of intricacies in the field. It presents the complexities of intersections of social attitudes, interpretations of history, economic forces and policy gaps; furthermore, it offers a critical analysis of history and highlights how interpretations of events can shape current social relationships. However, as a result of access difficulties as well as the fact that I conducted fieldwork on a sensitive subject with a hard-to-access population, the sample size is fairly small. Further attention is needed on documenting the experiences of indigenous peoples with physical and other kinds of disabilities, with an emphasis on assessing variation of perspectives based on location (namely on versus off reservation areas).

Future Directions

The focus I have placed on understanding the interconnectedness of personal experiences of physical disability with social attitudes, infrastructural concerns and systemic gaps has revealed important issues: lack of funding, little time to devote full attention to clients, inadequate supplies and dissatisfaction with remuneration take a toll on the emotional well-being of service providers and healthcare workers. Narratives of physical strain of having to assist their loved ones, or clients due to inaccessible environments, complaints about equipment that has been manufactured with little regard to the physical comfort of caretaker, or mobility devices that fail to function properly on a regular basis came as no surprise. However, comments on the emotional toll of providing care were unexpected. Family members as well as providers discussed that caring for an individual with a physical disability may cause tensions at time, as the caretaker not only has to focus on ensuring the safety and well-being of the individual with the disability, but also because of what feels like an immense responsibility to make the ‘right’ decisions; miscommunications, errors in managing bureaucracy could have repercussions on important aspects of care as well as financial wellbeing of the individual with a disability. Providers highlighted that working in challenging conditions could also have indirect implications on the emotional health of clients with disabilities. For many individuals with disabilities and providers alike providing care involves forming a close relationship. Providers indicated that an enjoyable aspect of their job was helping their clients learn interpersonal skills and overcome painful life experiences. Similar narratives by individuals with disabilities revealed that their providers often occupy roles of advocates or mentors. After interacting with individuals with disabilities who were forced to regularly find new service providers, as well as colleagues who had left their duties as professional caretakers, providers who participated in my research expressed concerns over the emotional impact of sudden departures on individuals with disabilities. Recognizing that trust is a key element of this kind of relationship, providers highlighted that it could be difficult to reassure their clients that they could be counted on as a constant in their clients' life. The process of building trust was further complicated by the fact that individuals with disabilities were plagued by guilt that was hard to assuage as they engaged in self-blame after engagements with providers had been severed. Further analyses are needed to examine the complexity of these topics.

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APPENDIX A

INTERVIEW PROTOCOL

Note to reviewers: Prior to questions that examined the main research questions, I asked what term the participant preferred to use when discussing ‘disability’. This was done to ensure that I was following the participants’ wishes, and revealed interesting choices and justifications with regards to terminology.

In interactions with Diné (Navajo) participants, I asked whether they preferred use of Diné or Navajo. Diné (translated by most of my participants as Holy People) was preferred by the majority of my participants who sometimes identified that Navajo is derogatory and/or a term introduced by colonizers.

Interview prompts covered the following areas and were generally phrased in this format

-How do Diné/non-indigenous worldviews see physical disability?

-How do Diné/non-indigenous people approach/interact with people with physical disabilities?

-In what ways are they similar?

-In what ways are they different?

-What can people (with physical disabilities) do to maintain health and wellbeing?

- What areas do you think work well in the healthcare system?

-What issues do you think need improvement?

-Is there anything else you would like me to know that we haven’t talked about?

Thank you for participating in the project. Please do not hesitate to let me know if you have any additional thoughts/questions.

Note to reviewers: I engaged in semi-structured interviews. In many cases these questions served as starting points for further details offered by participants without further probing on my part. In most instances, I engaged in probing participants to encourage participants to clarify their responses further based on relevant perspectives they volunteered.

APPENDIX B

DEMOGRAPHIC INFORMATION OF PARTICIPANTS

Self-identification	*Diné with a physical disability*	*Family Member*	*Diné Service Provider*	*Diné Healthcare Worker*	*Non-Indigenous Service Provider*	*Non-Indigenous Healthcare Worker*	*Total*
Gender							
Male	5	0	2	0	0	1	8
Female	2	4	3	1	7	0	17
Age							
18-30	1	2	1	0	1	0	5
30-45	2	1	2	1	4	1	11
45-60	4	0	2	0	1	0	7
<60	0	1	0	0	1	0	2
Total	7	4	5	1	7	1	25

APPENDIX C

CODING EXAMPLES

Theme	Description	Example
Productivity	A discussion on cultural construct of participating in social obligations that ensure the livelihood of self or others	I feel like often times people who are in any way a minority group it's more impressed on them to be able to be thought of as useful (…) I often saw it as ok, you're never gonna be like them, so you need to be something so you can survive (…) but you have to survive in this idea that you have to be useful and, and useful specifically in the terminology of like able to contribute to society. From their perspective (Diné), I think they see strength (…)I think they see, I would definitely say that they see um you can offer something, everyone can offer something
Social Support	A discussion of how support networks affect a person's social life	Diné(…) we look out for one another and I think with that disability that doesn't exclude that either you know" People are very generous and kind. When they see us moving around someone is always grabbing a door. Someone takes the time to say hello(…) or If I'm getting food (…) the person making the food asked me if I want it cut a certain way so they can help (…)you know? Those are just little examples.